EVERYONE HAS THE RIGHT TO PARTICIPATE: EXPLORING THE LIVED EXPERIENCES OF ADOLESCENTS WITH CEREBRAL PALSY AND THEIR INVOLVEMENT IN PHYSICAL ACTIVITY

by
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DECLARATION

By submitting this thesis electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the sole author thereof (save to the extent explicitly otherwise stated), that reproduction and publication thereof by Stellenbosch University will not infringe any third party rights and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

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ABSTRACT

Engagement in physical activity is a basic human right and has numerous benefits for mental well-being. Persons with disabilities are often denied this right due to a number of barriers existing on physiological, psychological and structural levels. Adolescents with motor impairments may be even further marginalised due to the physical nature of their impairment as well as being at a developmental stage where their opinions may not be taken into account based on their age. Research that has been conducted in this area has mostly focused on the accounts of parents and teachers with little voice being given to adolescents.

This research aimed to explore the lived experiences of a group of adolescents with cerebral palsy (CP) and their involvement in physical activity. The sample group consisted of 15 adolescents with CP between the ages of 12 and 18 in the Western Cape. Semi-structured interviews were conducted with the participants. In addition, three staff members were interviewed in order to add a secondary layer of data to the study. The interviews were analysed using interpretative phenomenological analysis which aims to give voice to participants and to make meaning of these accounts through interpretation by the researcher. Five major themes emerged from the data, namely: (1) “When they call me cripple” – what it means to have a motor impairment, (2) My experience of physical activity – perceived benefits, facilitators and barriers to participation, (3) Protective factors and coping strategies employed by participants to overcome barriers to participation, (4) What I would like and what I recommend, and (5) Perceptions of staff members at the school. These themes were discussed through a theoretical framework focused on the psychological and social factors which influence an individual’s participation in (or avoidance of) physical activity. While this theoretical framework is based on able-bodied persons, it was interesting to compare the experiences of adolescents with CP. The findings were further discussed in comparison to the relevant literature, although the purpose of qualitative research is not to necessarily generalise findings. This discussion yielded similarities and differences in terms of experiences relating to barriers and facilitators to participation. In addition, the findings supported the notion that adolescents with disabilities know what they want and have valuable input to offer in terms of their own experiences.

Recommendations include further studies being conducted with groups of adolescents with disabilities other than CP as well as in other areas of South Africa. This could give a more rounded understanding of the experiences of adolescents with disabilities and could better inform projects that could be developed.

OPSOMMING

Betrokkenheid in fisiese aktiwiteit is ‘n basiese mensereg en het verskeie voordele vir verstandelike gesondheid. Mense wat gestremdhede het word dikwels ontken van hierdie reg, as gevolg van getalle struikelblokke wat bestaan op fisiologiese, sielkundige en strukturele vlakke. Adolessente met motoriese gestremdhede mag dalk nog meer gemarginaliseerde word as gevolg van die fisiese aard van hul gestremdheid, asook die feit dat hulle in ‘n ontwikkelings stadium is waar hulle opinie dalk nie in ag geneem word nie weens hulle ouderdom. Navorsing wat uitgevoer is in hierdie gebied het meestal gefokus op die mededeling van die ouers en onderwysers en het min stem gegee aan die adolessente self.

Hierdie navorsing het daarop gemik om die beleefde ervaringe van ‘n groep adolessente met serebrale verlamming en hulle betrokkenheid in fisiese aktiwiteit te ondersoek. Die monster groep het bestaan uit 15 adolessente met serebrale verlamming tussen die ouderdomme van 12 en 18 in die Wes-Kaap. Semi- gestruktureerde onderhoude was gedoen met die deelnemers. Bykomend is daar ook onderhoude gedoen met drie personeellede om ‘n sekondêre vlak van data aan die studie te verleen. Die onderhoude was geanaliseer deur gebruik te maak van interpreterende fenomenologiese analise, wat daarop gemik is om ‘n stem te gee aan die deelnemers en om sin te maak van hulle beskrywinge deur interpretasie van die navorser. Vyf groot temas het na vore gekom uit die data, naamliks: (1) Wanneer hulle my verlam noem – wat dit beteken om ‘n motorise gestremdheid te hê, (2) My ondervinding van fisiese aktiwiteit – waargenome voordele, fasiliteerders en struikelblokke tot deelname, (3) Beskermende faktore en hanteringsvaardighede wat gebruik word deur die deelnemers om struikelblokke tot deelname te oorkom, (4) Waarvan ek sal hou en wat ek voorstel, en (5) Persepsies van personeellede by die skool. Hierdie temas was bespreek deur ‘n teoreties raamwerk wat gefokus is op die sielkundige en sosiale faktore wat ‘n individu se deelname aan (of vermyding van) fisiese aktiwiteit beïnvloed. Alhoewel hierdie teoretiese

raamwerk gebaseer is op ongestremde persone, was dit interessant om die ondervindinge te vergelyk met adolessente met serebrale verlamming. Die bevindinge is verder bespreek in vergelyking met relevante literatuur, al is die doel van kwalitatiewe navorsing nie noodwendig om bevindinge te veralgemeen nie. Die bespreking het ooreenkomste, so wel as verskille ten opsigte van ondervindinge met betrekking tot hindernisse en fasiliteerders tot deelname opgelewer. Daarbenewens verleen die bevindinge ook ondersteuning aan die idee dat adolessente met gestremdhede weet wat hulle wil hê en dat hulle waardevolle insette het om te lewer in terme van hulle eie ervarings.

Aanbevelings sluit in dat daar verdere studies gedoen moet word met ‘n groep adolessente wat ‘n gestremdheid anders as serebrale verlamming het, asook om verdere studies te doen in ander areas van Suid-Afrika. Dit sal ‘n meer afgeronde begrip van die ondervindinge van adolessente met gestremdhede lewer en sal ook beter instaat wees om projekte in te lig wat dalk ontwikkel mag word.

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CHAPTER ONE

Introduction

"Even in the most marginalised and disempowered of lives there is always "lived experience" that lies outside the domain of the dominant stories that have marginalised and disempowered those lives."

(Freedman & Combs, 1996, p. 40)

The benefits of regular participation in sport and exercise are well established and the opportunity to participate in physical activity is understood to be a human right. Nonetheless many individuals are prevented from participating in physical activity and thus denied these benefits for a range of biological, psychological, cultural, social, economic and political reasons. Children and adolescents with CP are one such marginalised group who are sometimes prevented from equal participation in physical activity, particularly in low resource environments such as South Africa. In this dissertation I describe a study undertaken to investigate the lived experiences of a group of South African adolescents with CP and their involvement in physical activity, in order to better understand their perceptions of the factors that hinder and promote their participation. The study was undertaken with the intention of shaping subsequent projects to increase opportunities for children with disabilities to be positively engaged in regular physical activity.

Physical activity can be defined as any movement of the body involving the spending of energy and the use of skeletal muscles (WHO, 2012). Participation in regular physical activity has positive effects on physical and mental health (Crone, Smith, & Gough, 2006). Physical activity creates a space for the release of emotion through physical exertion and also promotes a sense of mental well-being (Goodwin, Thurmeier, & Gustafson, 2004).

Participating in physical activity is important for identity development and teaches children and adolescents important social and interpersonal skills (Anderson, 2009). Further, physical activity provides an opportunity for individuals with disabilities to be seen outside of the metaphor of illness (Goodwin et al., 2004).

All children and adolescents have the right to good health and the right to play, (UNICEF, n.d.) although they might be prevented from exercising this right for a host of cultural, social, political and economic reasons. Furthermore, the United Nations General Assembly has affirmed that persons with disabilities have the right to participate on an equal level with others in culture, recreation, sport and leisure activities (UN General Assembly, 2006). The United Nations Convention on the Rights of Persons with Disabilities (CRPD) asserts that persons with disability have a right to equal access and a right to full and effective enjoyment of all human rights (Schulze, 2010). South Africa is a signatory to the CRPD and is therefore bound to these requirements, nonetheless children with disabilities are still among those groups in the country who are sometimes marginalised and prevented from participating fully in physical activities of their choice.

Children and adolescents with disabilities are often unable to participate in physical activity due to the physiological restrictions placed on them by their bodies. Adapting physical activity to suit the needs of persons with disabilities may be a possible solution to this problem. Adapted physical activity is often understood to be the path to increased participation in sport and exercise for children with disabilities. The term *adapted physical activity* (APA) was first introduced in 1973 by the founders of the *Federation Internationale de l' Activite Physique Adaptee* (Hutzler & Sherrill, 2007). The term is used in many contexts with multiple meanings and connotations, which makes it difficult to offer a single definition of the term. Sherrill (1993) suggests that APA is the term used to denote the science of analysing movement and identifying problems with the psychomotor execution of these movements with the aim of developing instructional strategies to enable anyone to perform the movement. Reid (2003) has suggested that APA should be conceptualized as "adaptations that could facilitate physical activity across a wide range of individual differences" (p. 22). Broadhead (1983) has stated that the term:

> means much more than mere activities which can be adjusted to suit the needs of individuals and homogeneous groups . . . it includes education, therapy, and more, such as activities, settings, and interests which call to mind concepts like care, correction, development, learning, rehabilitation, and remediation. (p. 330)

The International Federation of Adapted Physical Activity (IFAPA) defines APA as:

> a cross-disciplinary body of knowledge directed toward the identification and solution of individual differences in physical activity. It is a service delivery profession and an academic field of study that supports an attitude of acceptance of individual differences, advocates access to active lifestyles and sport, and promotes innovation and cooperative service delivery programs and empowerment systems. Adapted physical activity includes, but is not limited to, physical education, sport, recreation, dance and creative arts, nutrition, medicine, and rehabilitation. (IFAPA, 2004)

Other terms such as *sports for the disabled*, *sport therapy*, and *psychomotor therapy* are sometimes used to denote a similar set of constructs (Hutzler & Sherrill, 2007). These definitions of APA seem to imply a focus on modifying the activity and/or equipment, and teaching individuals strategies for executing movements differently in order to increase participation. These factors can certainly facilitate participation, but there are also intra-psychological factors (such as the disabled individuals' attitudes and subjective experiences), psycho-social factors (such as ignorance, prejudices and assumptions about the nature of disability), economic factors (such as resource limitations) and political factors (such as policies and practices) which also act as obstacles to persons with disabilities participation in physical activity. The study I describe in this dissertation is an attempt to understand how these multiple factors might limit adolescents with CP from participating in physical activity. As such this study is an attempt to give voice to a group of adolescents with CP and describe their subjective experiences of participating in physical activity and their perceptions of the factors that promote and hinder this participation. Furthermore the study seeks to describe the coping strategies these adolescents employ to overcome the barriers they face to participation. The study also describes the range of physical activities that this group of adolescents would like to have access to.

In Chapter Two of this dissertation I present a summary of the relevant literature and define the key concepts. Many of the studies in the area of disability and physical activity have been conducted from the perspective of teachers and parents. This echoes a perception expressed by one of the participants in this study in relation to other people's assumptions about persons with disabilities, "*they think all disabled people are stupid and would just keep quiet".* Children and adolescents with special needs know how they feel and know what they want and want to be given the opportunity to assert their independence (Coates & Vickerman, 2008). For these reasons this study has focused on the experiences and perceptions of the adolescents themselves. Qualitative data were collected from semi-structured interviews with 15 adolescents all of whom have CP who attend a special needs school in the Western Cape. The data was analysed using interpretive phenomenological analysis. Many of the participants spoke about the physical activities they were involved in at school and this seemed to be the primary context for participation in sport and exercise programme. For this reason interviews were also conducted with three members of staff from the special needs school, who acted as key informants to describe the setting and school context in which these adolescents find themselves. In Chapter Three, I outline the research design and methodology and explain why and how the sample group, procedure and data analysis were chosen and carried out. Ethical considerations are also discussed in Chapter Three.

The data collected was rich in detail. Consequently I decided to analyse it according to five overarching themes. Namely:

(1) *"When they call me cripple" – what it means to have a motor impairment*: a description of the participants lived experiences of having a motor impairment and how they understand physical disability.

(2) *My experience of physical activity – perceived benefits, facilitators and barriers to participation:* a description of the physical activity and sports the participants are currently engaged in and their experience of participation and exclusion in physical activities.

(3) *Protective factors and coping strategies employed by participants to overcome barriers to participation:* a description of the participants' account of how they cope with and try to overcome the barriers to participation in physical activity which they experience.

(4) *What I would like and what I recommend*: an account of what physical activities the participants say they would like to have the opportunity to take part in and their recommendations about the content and format of programmes designed to increase participation.

(5) *Perceptions of staff members at the school*: a description of the context in which the participants are educated and exposed to physical activities.

Each of these themes is discussed and analysed in a chapter on its own, and thus the research findings are presented in Chapters Four through Eight.

I conclude this dissertation in Chapter Nine by comparing the findings of this study to similar studies and discussing the findings within a theoretical framework. The theoretical framework I have used draws heavily on Lutz, Linder & Greenwood's work on the psychological and social factors which influence an individual's participation in (or avoidance of) physical activity (Lutz, Linder & Greenwood, 2004). In Chapter Nine, I also discuss the limitations of this study and offer recommendations for future work in the area of promoting participation in physical activity for children and adolescents with physical impairments in South Africa.

CHAPTER TWO

Literature Review

2.1 Introduction

This research project, which explores the lived experiences of adolescents with CP and their participation in physical activity, has been positioned within the context of human rights which advocates that individuals with disabilities should have opportunities to participate in physical activities of their choice. This chapter delineates the key concepts used in this research and presents an overview of the relevant literature. It begins with a discussion on physical activity and its effects on mental health, including an explanation of the various hypotheses used to explain the positive psychological effects of physical activity. This is followed by a section defining disability and posits it within a human rights framework. The history of disability rights in South Africa is presented concluding with the current provincial framework which aims to address some of the issues still facing persons with disabilities. This is followed by an explanation of CP, including the subtypes and the means by which motor functioning is classified. The importance of physical activity is discussed early on in the chapter; however, children and adolescents with disabilities are often unable to participate in such activities. Thus the importance of adapting physical activity to accommodate the needs of children with disabilities is discussed and the benefits of participation are presented. Research which is aligned to this study is also considered and discussed. Following this, the theoretical framework is presented which is grounded in Lutz et al.’s (2004) model of the psychological and social factors that influence an individual’s participation in (or avoidance of) physical activity. The chapter concludes by illustrating the gap in qualitative research within developing countries on this topic and makes an argument for the importance of conducting work which explores the experiences and perceptions of children and adolescents.

2.2 Physical Activity and Mental Health

The World Health Organisation (2012) defines physical activity as any movement of the body involving the use of skeletal muscles and the spending of energy. Physical activity differs from exercise; exercise is a component of physical activity which is characterised by structured and repetitive activity with the aim of improving a certain aspect of fitness (WHO, 2012). Physical activity encompasses exercise as well as other forms of movement involved in working, playing, doing chores and participating in recreational pastimes (WHO, 2012).

Participation in physical activity on a regular basis has considerable positive effects on a person’s physical and mental health (Crone et al., 2006). Regular physical activity can reduce the risk of cardiovascular disease, cancer and diabetes and elevate one’s mood, create distraction from everyday concerns and reduce the risk of depression (Crone et al., 2006; Daley, 2002; WHO, 2012).

A number of hypotheses has been proposed to explain the correlation between physical activity and mental well-being (Crone et al., 2006; Donaghy, 2007). These hypotheses can be broadly divided into two sub-groups, namely, physiological hypotheses and psychological hypotheses:

2.2.1 Physiological hypotheses. These hypotheses propose that the psychological benefits of physical activity are a consequence of biological changes that occur during movement. The most popular example of this is the idea that physical activity causes a release of endorphins resulting in a “natural high” (Crone et al., 2006). This hypothesis states that the increase of blood flow to the brain during physical activity fuels the release of endorphins; mood enhancers which occur naturally in our brains (Crone et al., 2006;

Donaghy, 2007). This is, for example, evident in the elevated mood reported by marathon runners after they complete a long race (Crone et al., 2006).This hypothesis is difficult to prove as we do not know whether endorphins are able to cross the blood-brain barrier, nonetheless it still remains a widely accepted explanation for the benefits of physical activity (Daley, 2002). A number of other biological explanations of why physical activity is beneficial to mental well-being also exists. These include the release of other neurotransmitters involved in mood elevation, and the brain's adaptation to rewarding experiences (Donaghy, 2007). While it is acknowledged that these biological hypotheses exist, this study focuses only on the psychological and social benefits of participating in regular physical activity.

2.2.2 Psychological hypotheses. The psychological hypotheses attribute the mental health benefits of physical activity to psycho-social mechanisms. Examples of these hypotheses include: the distraction hypothesis, self-efficacy theory, self-esteem theory, and social interaction and belongingness (Craft, 2005; Crone et al., 2006).

2.2.2.1 The distraction hypothesis. The distraction hypothesis proposes that physical activity functions as a diversion from stressful life circumstances which can lead to psychological well-being (Daley, 2002). During physical activity, certain exercise goals are often met providing positive reinforcement (Craft, 2005). This affirmation from the self and often from others received during physical activity may provide a distraction from negative thoughts and demanding lifestyles (Craft, 2005).

2.2.2.2 Self-efficacy theory. Self-efficacy refers to how much confidence a person has in his/her ability to complete a task (Craft, 2005). This includes beliefs about one's skills as well as perceptions about whether the task can be completed successfully (Craft, 2005). The way a person feels about a stressful situation and his/her ability to handle it often influences his/her response to the situation. Physical activity, particularly exercise, creates a platform for a person to gain mastery over a certain skill and in so doing may promote his/her self-efficacy and confidence in dealing with other circumstances (Craft, 2005).

2.2.2.3 Self-esteem theory. Self-esteem is the value that is placed on certain aspects of oneself in different domains of life (Biddle & Mutrie, 2008). Participating in physical activity increases physical ability and may contribute to increased positive feelings about one's physical body (Biddle & Mutrie, 2008; Daley, 2002). Overall bodily functioning may improve as a result of engaging in physical activity which may influence physical self-worth and lead to a higher self-esteem (Daley, 2002). Improving self-esteem is important when people aim to change their behaviour (Donaghy, 2007). Physical activity allows a person to take charge of setting goals, enhancing self-confidence and creates an opportunity to build social self-esteem if participating in group activities (Donaghy, 2007).

2.2.2.4 Sense of belonging. When participating in physical activity a person may feel a sense of belongingness and social importance (Crone et al., 2006). This may create a sense of engagement and involvement and create a sense of purpose, thus increasing one's mental well-being (Crone et al., 2006).

The above propositions give a sense of how physical activity may improve one's mental health. These hypotheses suggest the mechanisms whereby participation in physical activity contributes positively to psychological and physical well-being.

2.3 Participation in Physical Activity is a Human Right

Access to services to improve one's health and well-being are basic human rights (Shelton, 2002). Given the relationship between physical activity and well-being, it is argued that all individuals should have opportunities to engage in regular physical activity of their choice. There are many groups of individuals who are marginalised in society and who consequently do not have access to opportunities to participate regularly in health promoting physical activity of their choice. These marginalised groups include the poor and individuals with disabilities (WHO, 2011). This study focuses on persons with disabilities and in particular adolescents with motor impairments.

2.4 Defining Disability

Many people are born with disabilities while some acquire them through injury or accident. Disability is a complicated phenomenon which involves a level of dysfunction in a person's physical or mental state (WHO, 2011). It also includes the structural and social barriers which restrict a person with a disability from fully participating in society (WHO, 2011).

The medical profession plays a powerful role in modern western society and their biological explanation of disability has informed a stereotype which society still adopts today (Brittain, 2004). This view states that a person's disabled state is the result of a mental or physical handicap that exists independently of the socio-political and cultural world (Brittain, 2004). In contrast, the social model of disability views society as the disabling force which through environmental, structural and cultural barriers prevents the impaired individual from fully participating in his or her community (Olive & Sapey, 2006). These two models oppose each other where the medical model focuses entirely on individual pathology, the social model rejects this and focuses solely on the flaws in the environment. However, neither model fully encompasses the complexity of having a disability. Although the social model incorporates the structural and environmental barriers into its argument, it does this by so strongly resisting the medical model that it fails to consider the individual difficulties a person may face based on his or her impairment. It presumes that only people who are oppressed because of their impairment can thus be called disabled (Shakespeare, 2006).

The International Classification of Functioning, Disability and Health (ICF) proposes a biopsychosocial model which synthesises all the factors that have an influence on the disablement of an individual and it is universally recognised as attempting to capture the complexity of disability (WHO, 2002). They propose that disability and functioning are a result of the connections between biological and contextual factors (WHO, 2002). The ICF identifies three levels at which the functioning of a human can be measured namely, the body or body part, the entire person and the entire person in social context (WHO, 2002). Thus, disablement is a dysfunction on one or more of these levels (WHO, 2002). Impairment is a problem in the functioning of the body or a part of the body (WHO, 2002). Activity limitations involve struggling to execute particular activities and participation restrictions are difficulties a person may face in terms of being involved in social situations (WHO, 2002). Due to the complexity of systems in play in every individual's life, every person has a different experience which is a function of their level of physical functioning as well as the environment in which they find themselves. Although disability has recently been understood to include the wider context in which a person exists, a certain stigmatisation of disabled people still exists, preventing them from being able to fully participate in society (WHO, 2002).

2.5 Disability in South Africa

The 2001 Census of South Africa reported that 5% (2 255 982) of the total population (44 819778) classified themselves as having some form of disability (Statistics South Africa, 2005). Persons aged 10 – 19 constitute 13,6% of the total population of persons with disabilities (Statistics South Africa, 2005). For the 2011 Census, questions on disability were restructured and based around the Washington Group (WG) questions which emphasise general health and functioning questions (Statistics South Africa, 2012). Due to this change, the disability statistics of the 1996 and 2001 Census cannot be compared to the 2011 Census (Statistics South Africa, 2012). Further, due to the misreporting on functioning and general health on persons under the age of five, the Census only profiled for persons above the age of five (Statistics South Africa, 2012). Disability was defined as “difficulties encountered in functioning due to body impairments or activity limitation, with or without assistive devices” (Statistics South Africa, 2012). It was expected that due to the inclusivity of less severe disabilities, a higher rate of disability would be reported and the census results showed that less than 10% of the population presented with difficulties or limitations in carrying out certain activities (Statistics South Africa, 2012).

In South Africa, Apartheid caused many individuals to become impaired as a result of civil unrest and violence in the country (Howell et al., 2006). Further, many people (particularly black individuals) were disabled by society during this time as they were not given equal access to resources under the oppressive former government (Department: Provincial and Local Government, 2009). Those advocating for the rights of persons with disabilities often aligned themselves with many of the anti-apartheid ideologies as they shared values of equal opportunities for all. The following table, which has been adapted from Howell et al.’s (2006) table in “A history of the disability rights movement in South Africa”, tracks the history of disability rights in South Africa from the 1970s through to the present day.

Table 2.1

A Selective History of Disability Rights in South Africa

Date	Event	Significant results
1970s and 1980s	Development of local organisations of disabled people and self-help	These groups saw the need to mobilise persons with disabilities and found

	groups in white communities and in the townships such as the Self Help Association of Paraplegics (SHAP).	practical ways to organise self-advocating disabled citizens (Howell et al., 2006).
1976	Soweto uprising occurred during which police opened fire on a large group of protesting African school children.	Many young people were disabled as a result of the violence between protesting students and the police (Howell et al., 2006).
1981	UN declared 1981 the International Year of Disabled Persons.	The Apartheid government did not recognise this event in South Africa (Howell et al., 2006).
1983	Formation of United Disability Forum and National Forum in South Africa.	Two umbrella bodies bringing together many organisations against apartheid (Howell et al., 2006).
1984	Formation of the organisation, Disabled People South Africa (DPSA).	Largest cross-disability group in South Africa which is controlled and led by disabled people. DPSA realised that the liberation of the disabled was linked to the liberation of the majority of South Africans and consequently formed connections with other anti-apartheid organisations (Howell et al., 2006).
1986	Apartheid government declared 1986 the National Year of the Disabled and created the Interdepartmental Co-ordinating	The committee failed in its role to inform the government on policy reform as it did not acknowledge the part apartheid played in the oppression of disabled persons

	Committee on Disability (ICCD).	(Howell et al., 2006).
End of 1980s	A permanent DPSA office in Soweto and a secretary general's office in East London were established.	DPSA established itself as a sound organisation with adequate membership and funding for the employment of permanent staff (Howell et al., 2006).
1990	ANC and other political organisations were unbanned and Nelson Mandela and other political prisoners were released.	Many people were disabled due to political unrest and violence in the country (Howell et al., 2006).
End 1990	Disability issues were integrated into the South African Bill of Rights.	The rights of persons with disabilities should be protected and they should be granted equal access to basic services (Howell et al., 2006).
1992	The Disability Rights Charter of South Africa was launched by DPSA and Lawyers for Human Rights.	The Charter asserts the rights of all people with disabilities to live independently, in a safe environment and in a society free from all forms of discrimination, exploitation and abuse (Disabled People South Africa, 1992).
1993	The UN document, Standard Rules on the equalisation of opportunities for persons with disabilities, was released.	The needs of every individual are equally important and persons with disabilities should have equal opportunities for participation in society. As a member of the UN South Africa is signatory to these rules. DPSA used this document as an

		important basis to the development of South Africa's White paper on an integrated national disability strategy. (Howell et al., 2006; SAHRC, 2002).
1994	Maria Rantho became the first disabled member of parliament.	Disabled persons are represented in government (Howell et al., 2006).
1995	South Africa ratified the United Nations Convention on the Rights of the Child.	Article 23:1 states that "a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community" (OHCHR, n.d.).
1996	The Constitution of the Republic of South Africa was approved in December 1996 and took effect in February 1997.	Discrimination on the basis of physical, sensory, intellectual, and mental disability is prohibited by law (Constitution of the Republic of South Africa, 1996).
1997	The Office on the Status of Disabled Persons (OSDP) was officially established.	The OSDP is involved in the development of a number of crucial disability strategies and frameworks (Howell et al., 2006; Sadek & Winai, 2003).
1997	The first provincial Disability Desk was set up.	This Disability Desk was set up in the Office of the Premier of Mpumalanga and increased the presence of persons with disabilities in government (Howell et al., 2006).

1997	The government produced the White Paper on an Integrated National Disability Strategy.	This document provides a framework to address political and economic inequalities that ostracise persons with disabilities from society in South Africa (Office of the President, 1997)
1998	The Employment Equity Act was implemented.	The Act states that no person may unfairly discriminate against an employee on the basis of race, gender…or disability (Employment Equity Act, 2004).
1999 to 2009	This decade was declared as the African Decade of Disabled Persons.	Promotion of "awareness, empowerment, equality and participation" for persons with disabilities living in Africa. (UN, 2003-4).
1999	Inclusion of persons with disabilities on the ANC's 1999 election list at both national and provincial levels.	The OSDP was moved to the President's office, where it is presently located (Howell et al., 2006).
2000	The Promotion of Equality and Prevention of Unfair Discrimination Act was ratified.	A person may not show prejudice towards another person based on his/her disability (The Promotion of Equality and Prevention of Unfair Discrimination Act, 2000).
2001	White Paper 6 on Special Needs Education was created and put into effect.	This policy aimed to expand the existing policy for all aspects of training and education in order to accommodate the

		broad range of learning needs in South Africa and to provide inclusive education (Department of Education, 2001).
2007	South Africa signed The United Nations Convention on the Rights of Persons with Disabilities.	All persons with disabilities should experience equal rights and freedom and have their dignity respected (UN General assembly, 2006).
2009	Disability Indaba held in South Africa.	Instrumental in the development of the Department of Public Works' Disability Policy Guideline (International Disability Indaba, 2009).
2009	The former OSDP was incorporated into the Ministry for Women, Children and Persons with Disabilities (DWCPD).	The DWCPD is responsible for "driving the government's equity, equality and empowerment agenda with regard to marginalised groups and historically disadvantaged communities in each of the three sectors" (Ministry of Women, Children and People with Disabilities, n.d).
2010	The White Paper on Sport and Recreation was developed.	The government acknowledges that sport plays an important role in uniting people across barriers created by race, religion…and disability. Thus access, development and achievement should be increased in order to improve the quality

	of life for all South Africans (Department: Sport and Recreation South Africa, 2012).

This table illustrates the progression and development of disability rights in South Africa and demonstrates some of the gains that have been made and attempts to expose the areas that are still in need of attention.

A process to review the implementation of policy by municipalities was conducted by the Social Cluster Committee of Cabinet in 2005. They found that although there was a willingness to address the needs of persons with disabilities, it was not backed by action or resource allocation (Department: Provincial and Local Government, 2009). In 2007, the Department of Provincial and Local Government conducted a study to determine the level of service delivery persons with disabilities were experiencing (Department: Provincial and Local Government, 2009). Persons who represent those with disabilities in municipalities and NGOs from all nine provinces in rural and urban settings were randomly selected to participate in the study (Department: Provincial and Local Government, 2009). A number of issues were raised including: a fragmented knowledge of disability, the employment target for people with disabilities not being reached, a lack of resources to provide accommodation, and a lack of participation from persons with disabilities in community structures and in communication about service delivery (Department: Provincial and Local Government, 2009). In society, discrimination and marginalisation are still prevalent even though laws have been passed to the contrary.

The Department of Provincial and Local Government developed a Disability Framework for Local Government for 2009 – 2014 to address some of these issues (Department: Provincial and Local Government, 2009). The Integrated National Disability Strategy and similar strategies have been instrumental in policy, but it is the responsibility of local government to ensure effective implementation (Department: Provincial and Local Government, 2009). This implementation and the delivery of services to those with disabilities is the onus of local government as they are the closest level of government to the people (Department: Provincial and Local Government, 2009). Thus, the local government should integrate disability elements into budgets and legislations; create and employ programmes which are beneficial to those with disabilities; and should establish units for disability for reporting and appraisal purposes (Department: Provincial and Local Government, 2009). The overall objective of this framework is to make sure that disability matters are incorporated into all policies and plans of local government in order to enrich the lives and increase the participation of all persons with disabilities in all aspects of life (Department: Provincial and Local Government, 2009).

2.6 Cerebral Palsy

Cerebral palsy (CP) is a non-contagious, non-hereditary and non-progressive neurological disorder of posture and movement caused by damage to the motor areas in the brain during pregnancy, birth or the first five years of life (Pakula, Van Naarden Braun, & Yeargin-Allsopp, 2009; Sherrill, 2004). This damage can be caused by lack of oxygen, toxic intake or head injuries (Sherrill, 2004). The degree of physical impairment caused by CP is highly variable; ranging from a slight limp or clumsiness to no control over motor function (Graham, 2005; Sherrill, 2004). Though figures on the prevalence of CP in resource poor settings are hard to come by, it is estimated that in high income countries the prevalence of CP is 2-2.5 cases per 1000 live births (Majnemer & Mazer, 2004). It is reported that 80% of children with disabilities live in resource poor settings, which suggests that the prevalence of CP in low and middle income countries including SA, is higher than that reported for the developed world (WHO, n.d.).

Traditionally, CP is classified according to motor type and topographical distribution of the motor symptoms (Graham, 2005). Further, the severity of a person's motor abnormality can be established with the Gross Motor Functional Classification System (GMFCS) (Graham, 2005). CP is the most common childhood motor impairment and although there are a number of ways of classifying and categorising it, the core components remain the same (Pakula et al., 2009).

2.6.1 Motor type. CP is divided into three main groups based on the nature of the motor disorder (Budden, 2005). These groups are spastic, dyskinetic and ataxic CP (Budden, 2005). Spastic CP is the most common form comprising 60 -70% of all CP cases (Budden, 2005). Spastic CP is characterised by increased muscle tone and rigidity and results in reduced motor activity (Fairhurst, 2012). This can cause weakness in the muscles and deficient selective motor control (Fairhurst, 2012). Cases of dyskinetic CP present uncontrolled and involuntary movements (Budden, 2005). Other characteristics include muscle contractions leading to abnormal posture and distorted purposeful movements (Budden, 2005). Dyskinetic CP can be divided into two subgroups namely, dystonia and choreoathetosis, however it can be difficult to distinguish between the two (Budden, 2005). The final and most rare form of CP is ataxic CP (Fairhurst, 2012). Ataxic CP is characterised by a loss of muscular coordination which results in movements of abnormal accuracy and force (Budden, 2005). People with ataxic CP typically present with disturbed balance often causing falls, tremors and low muscle tone (Budden, 2005). It is common for a person to have a mixed form of CP presenting with characteristics from more than one of the three groups (Budden, 2005). When categorising a person's motor abnormality, a main classification is usually chosen with other characteristics being listed as secondary types (Budden, 2005). CP (specifically spastic CP) is also categorised according to the localisation in the body of the motor abnormality.

2.6.2 Topographical distribution. CP can be further classified according to the parts of the body that are affected (Budden, 2005). The following figure demonstrates the anatomical aspects of hemiplegia, diplegia, quadriplegia, triplegia and monoplegia.

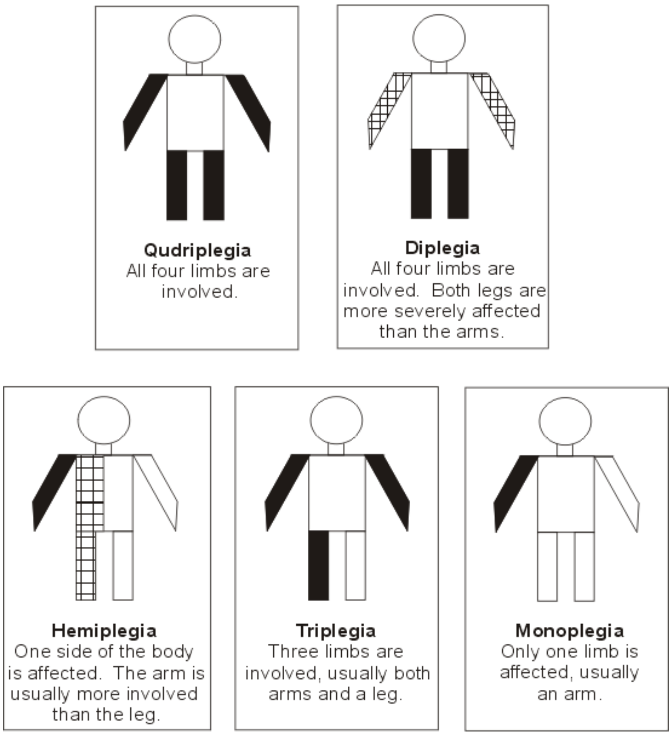

Figure 2.1. Topographical Distribution of Cerebral Palsy in the Body. Adapted from "Children with Cerebral Palsy", by PDCE Admin, Retrieved, on 8 June 2012, from http://blogs.ubc.ca/earlychildhoodintervention2/2011/02/28/children-with-cerebral palsy-cp/

2.6.3 Motor abnormalities. The Gross Motor Functional Classification System (GMFCS) is used to classify individuals with CP into five groups based on their level of mobility (Fairhurst, 2012). These distinctions are based on limitations in physical functioning and the need for mobility devices or wheelchairs (Palisano, Rosenbaum, Bartlett, & Livingston, 2007b). Level one indicates complete independence and level five is total dependence (Fairhurst, 2012). The GMFCS focuses on the level that best represents the child or adolescent’s current “abilities and limitations in gross motor function” (Palisano et al., 2007b, p. 1). Different developmental stages are expected at different ages thus five age bands have been created to classify children and adolescents with CP (Palisano, Copeland, & Galuppi, 2007a). These age bands are before the second birthday, ages 2 to 4, ages 4 to 6, ages 6 to 12 and ages 12 to 18 (Palisano et al., 2007a). Figure 2.2 illustrates each level of the Gross Motor Functional Classification System:

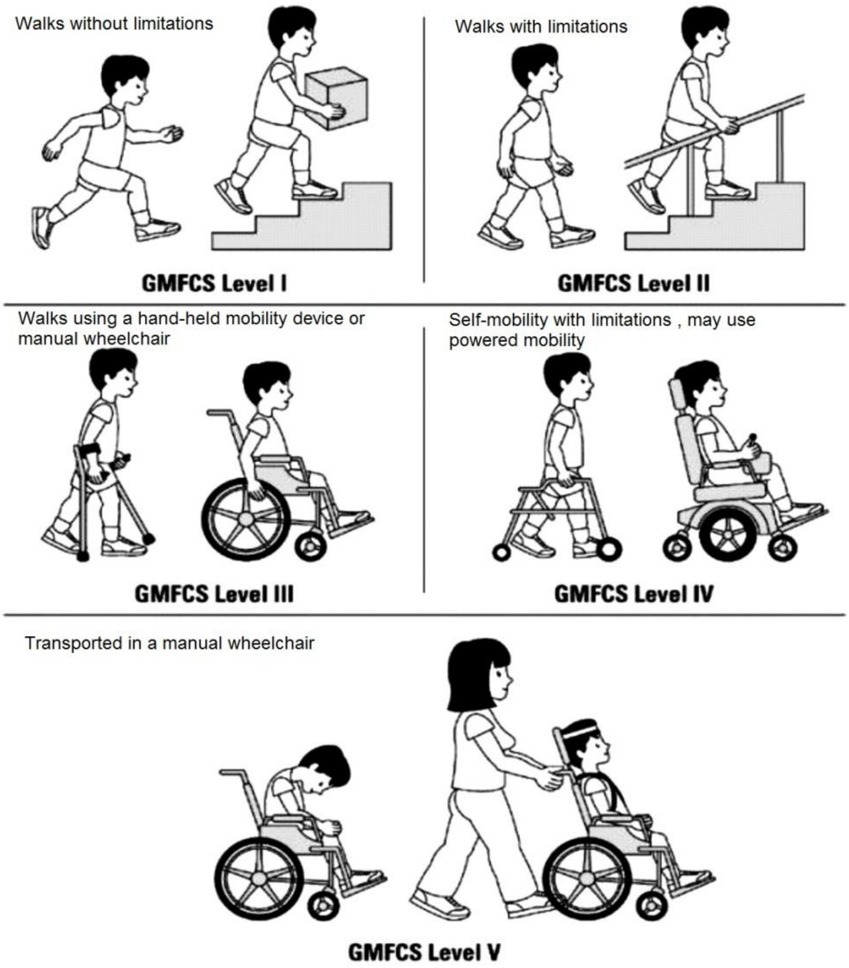

*Figure 2.2***.** The Gross Motor Functional Classification System Levels for Classifying Cerebral Palsy. Adapted from “Classifying Cerebral Palsy,” by H. K. Graham, 2005, *Childhood Disability Update,* p. 38 and “Performance of Physical Activities by Adolescents With Cerebral Palsy,” by R. J. Palisano, W. P. Copeland, and B. E. Galuppi, 2007a, *Physical Therapy,* p.80.

The motor impairments associated with CP are often coupled with epilepsy and sensory, behavioural and cognitive impairments (Pakula et al., 2009). This can cause further difficulties in functioning and participation in school and physical activity for a person with CP (Hoogsteen & Woodgate, 2010). Participation in social and physical activities is essential to a child's quality of life and children acquire skills and increase their well-being through interaction with others and performing motor tasks (Hoogsteen & Woodgate, 2010). In many situations this disability serves to be a disadvantage to their ability to participate in leisure and physical activities. It is thus important to examine ways in which effective APA can be applied.

2.7 Adapted Physical Activity

Adapted physical activity (APA) is the enhancing of physical activity through training and empowerment of individuals with movement limitations (Sherrill, 2004). APA enables individuals to embrace their physical differences and participate in physical activities according to their own specific needs (Sherrill, 2004). The focus in APA is on adapting the physical activity or the equipment used in order to enable persons with disabilities to participate. Research suggests that APA programmes exist and that they are successful in improving the mental health of children and adolescents with disabilities, however, these studies have been conducted in first world settings in countries such as the United States of America, Canada, New Zealand and Sweden.

2.7.1 The benefits of APA for persons with disabilities. A number of benefits of APA for persons with disabilities has been identified and documented. These include the negotiation of liminality and socialisation.

2.7.1.1 Negotiation of liminality. Children and adolescents with disabilities often have to take on others' feelings about their impairment (Goodwin et al., 2004). People may find it difficult to know how to react to someone with a disability and thus persons with disabilities may develop a sense of liminality through which they manage the feelings of others they meet in public (Goodwin et al., 2004). This management is often necessary in order to avoid upsetting oneself and others (Goodwin et al., 2004). Brittain (2004) found that disabled children and adolescents in a mainstream schooling system experienced positive affirmation from others when participating in physical activities. Thus physical activity may provide some resolution to the problems associated with dealing with liminality for adolescents and children. In Goodwin et al.'s (2004) study, it was found that adolescents in Canada participating in disability sports felt they did not need to manage the perceptions of others or make others feel comfortable, they could simply be themselves. They felt supported and encouraged and proud of their achievements (Goodwin et al., 2004). Adolescent girls with physical disabilities from the United States were interviewed about their experiences of physical activity and they reported that their positive experiences had enabled them to feel empowered in many other spheres of their lives (Brittain, 2004).

2.7.1.2 Socialisation. Participating in physical activity in a group setting can also foster socialisation, which is an important component of identity development (Anderson, 2009). During childhood and adolescence, peers play an important role in supporting the inclusion of people with disabilities into physical activity (Anderson, 2009). Able-bodied and disabled children and adolescents create their identity through interaction with others and sport and physical activity can create an important space for this to occur (Anderson, 2009). Anderson (2009) interviewed a number of disabled adolescent girls in the United States of America, all of whom emphasised the sense of normality, belonging and confidence that participating in physical activity provided for them. This sense of normality, belonging and confidence has a profound impact on the formation of a young person's identity.

People, particularly children and adolescents, with disabilities are often spoken for by others and the anger of feeling ignored is usually suppressed (Goodwin et al., 2004). Physical activity creates a space for the release of emotion through physical exertion and also promotes a sense of mental well-being (Goodwin et al., 2004). Further, physical activity provides an opportunity to be seen outside of the metaphor of illness (Goodwin et al., 2004). Physical activity provides children and adolescents with the opportunity to share a common experience (Goodwin et al., 2004). Participation in these activities is however often limited by a number of factors.

2.7.2 Participation in physical activities. Bult, Verschuren, Jongmans, Lindeman and Ketelaar (2011) conducted a systematic review of literature from 2001 to 2010 examining what influences disabled children to participate in leisure activities. Children over the age of twelve and those with poor motor functioning tend to participate less often in physical activity than their peers (Bult et al., 2011). Most children with disabilities are involved in rehabilitation programmes from an early age, however, they are often not able to choose what physical activities they would like to participate in (Bult et al., 2011). The level of enjoyment of engaging in a particular physical activity appears to be a mediator of the level of participation (Hagberg, Lindahl, Nyberg, & Hellénius, 2009). People who have had negative experiences with physical activity may have a ‘psychological resistance’ to participation in exercise programmes (Daley, 2002). Children and adolescents with disabilities may have been exposed to painful physical therapy and may not have been given a choice as to what leisure activities they would like to participate in.

Bult et al. (2011) identified several other factors which may influence children and adolescents participation in physical activity. For example, the ability of the family to cope with the stresses of having a disabled child facilitates participation whilst lower socio-economic status may inhibit participation (Bult et al., 2011). It appears that factors in the environment that do not support participation may limit participation in physical activity (Bult et al., 2011). These factors include lack of facilities, lack of peer support and dependence on adults for effective participation (Bult et al., 2011). These factors can be seen as social injustices towards children and adolescents with disabilities. Further, children and adolescents with CP and co-morbid learning disabilities are at a greater risk of exclusion from physical activities with peers (Bult et al., 2011).

2.8 APA and Disability in South Africa

In a developing country such as South Africa we are faced with participation limitations for disabled people on socioeconomic and cultural levels. In many cultures in South Africa, disability is believed to be a punishment from the ancestors or justice for sins they have committed and may break up families (Levin, 2006). Families may break up due to traditional beliefs but also due to the financial burden a child with a disability places on a family (Levin, 2006). For children with CP, schooling is limited to a number of specialised schools that are not accessible to most of those living with the disability and a large percentage of children and adolescents with CP do not receive any form of an education or exposure to physical activity (Levin, 2006). Children and adolescents with CP may also not be exposed to participation in the kinds of physical activities that they would like to be involved in due to limitations of finances, infrastructure and trained teachers (Levin, 2006).

2.9 Children and Adolescents with Disabilities' Experience of Physical Activity

A fair amount of research has been done in recent years giving voice to persons with disabilities, particularly in terms of engagement in physical activity. Coates and Vickerman (2008) did a systematic review of the literature on the experiences of Physical Education (PE) from the perspective of children with disabilities. They identified and reviewed seven articles published between 1990 and 2000. These sample groups included children in mainstream schools as well as those in special needs schools (Coates & Vickerman, 2008). They found that research on inclusion is often from the perspective of teachers and that there is a limited amount of research from children's perspective (Coates & Vickerman, 2008). The authors identified six key themes in the literature namely, experiences of PE, experiences of PE teachers, discrimination by others, feelings of self-doubt, barriers to inclusion, empowerment and consultation (Coates & Vickerman, 2008).

Children had good experiences of PE when they felt included in lessons and bad experiences were associated with being isolated from activities and when they felt incompetent in an activity (Coates & Vickerman, 2008). Thus it seems that successfully completing an activity is important in having a positive experience. Children identified that there were physical and psychological benefits to participating including strengthening their bodies and spending time with friends (Coates & Vickerman, 2008). Teachers often do not feel equipped to teach children with special needs and struggle with adapting the current curricula for children with special needs (Coates & Vickerman, 2008). Children with special needs may feel discriminated against due to the nature of PE programmes that exclude them as well as by bullying and rejection from others (Coates & Vickerman, 2008). As a result of this, self-doubt and a lack of self-efficacy in participating in PE may arise (Coates & Vickerman, 2008). Barriers to inclusion were identified, with structural and material barriers being most prevalent (Coates & Vickerman, 2008). Children and adolescents with special needs want to have their opinions heard and value autonomy, however this is often overshadowed by the perspectives of teachers and parents (Coates & Vickerman, 2008). When teachers make decisions about what is best for children with disabilities without being informed by the children themselves, it may lead to feelings of disempowerment (Coates &

Vickerman, 2008). The child's voice is important and should be taken into consideration when creating and assessing APA programmes and physical education curricula.

Shikako-Thomas, Majnemer, Law and Lach, (2008) conducted a systematic review to explore the factors influencing children and adolescents with CP's participation in leisure activities. They reviewed a total of ten studies, published between 1980 and 2007, five of which used qualitative methods. The researchers found that the older a child or adolescent is, the less likely he/she is to participate in activities and that interest plays a role in participation (Shikako-Thomas et al., 2008). The structural and social environments have an impact on participation as a lack of resources and equipment as well as segregation, bullying and staring serve as barriers to participation (Shikako-Thomas et al., 2008). Finally, the financial state of one's family as well as parents' willingness and preference towards certain activities can influence participation in physical activities for children and youth with CP (Shikako-Thomas et al., 2008). Shikako-Thomas et al. (2008) emphasise the importance of identifying a child's preferences to activity-involvement and their barriers to participation. Further, the researchers highlight the responsibility lying with practitioners and researchers to advocate at policy levels for greater inclusion and implementation of programmes for youth with CP (Shikako-Thomas et al., 2008). The research conducted by both Coates and Vickermann (2008), and Shikako-Thomas et al. (2008) contained reviews of studies that were conducted only in the USA and Europe. It is significant to note that limited research has emerged from developing countries on this topic.

Li and Chen (2012) conducted a qualitative study exploring the experiences of physical activity of school-aged children (11 – 16 years) with CP. This study was conducted in Hong Kong using semi-structured interviews and content analysis (Li & Chen, 2012). The researchers found that these children and adolescents engaged in minimal physical activity and preferred pastimes that required less energy expenditure such as reading and watching television (Li & Chen, 2012). Physical activity experiences were both positive and negative, with positive experiences involving enjoyment with friends and negative experiences being characterised by pain, injury and disability-related complications (Li & Chen, 2012). Facilitators to participation included management of weight, competition, improved motor functioning and encouragement from others whereas a lack of facilities, negative attitudes and overprotective parents acted as barriers (Li & Chen, 2012). The participants also commented on the social aspects of physical activity and wished to participate in activities with friends (Li & Chen, 2012).

A protocol for a study similar to the study I have undertaken has been drawn up by Claassen et al. (2011) to explore the facilitators and barriers to physical activity as experienced by adolescents. This study is located in Canada and proposed to conduct semi-structured one-on-one interviews and focus groups with adolescents with CP (Claassen et al., 2011). The parents of the participants were also interviewed (Claassen et al., 2011). The researchers sought to gain further insight into the experiences of adolescents with CP and may help in the planning of APA programmes (Claassen et al., 2011). The similarity of this protocol (which was discovered after this project had been planned) to my research indicates that there is a great need for this kind of study to be done. There is a gap in the research of the personal stories of adolescents with CP and their experiences of physical activity and it will be interesting to see what themes arise in the different contexts in comparison to my findings in a South African context. The theoretical framework through which the results are discussed will now be presented, followed by a conclusion of this chapter.

2.10 Theoretical Framework

Lutz et al. (2004) propose a theoretical framework to explain the psychological and social factors which influence an individual's participation in (or avoidance of) physical activity. The model proposes four groups of factors, namely self-presentation, social influences, social support and cohesion (Lutz et al., 2004).

Self-presentation refers to engaging in any type of behaviour that is somewhat motivated by how we want others to see us (Lutz et al., 2004). People who exercise are viewed more favourably by others than those who do not exercise and certain activities are considered more popular than others (Arbour, Latimer, Martin, Ginis, & Jung, 2007; Lutz et al., 2004). This may affect which physical activities adolescents choose to participate in (Lutz et al., 2004). Adolescents with disabilities may also be affected by the pressures of self-presentation and may make certain decisions about their bodies and participation based on how they wish to be viewed by others and may avoid participation because of how they perceive the way they might look to others when they do take part. Self-presentational benefits associated with being physically active may help to undermine the negative stereotypes associated with having a disability (Arbour et al., 2007). Self-presentation includes specific discussions on body image, eating disorders, and obsessive exercise; social physique anxiety; social facilitation and social loafing (Lutz et al., 2004). Social physique anxiety refers to how nervous a person is about their physical body when others are observing their physique and their desire to present their physique in a positive way (Lutz et al., 2004). The term social facilitation has been used to explain people's tendency to increase their level of physical performance when they feel they are being evaluated by others (Lutz et al., 2004). On the contrary, when a person feels as though his/her physical performance is not easily identifiable, he/she tends to engage in social loafing and his/her performance level decreases (Lutz et al., 2004).

Whilst people aim to promote the best possible image of themselves to others, they may also be prone to social influence to do what others want them to do (Lutz et al., 2004). Lutz et al. (2004) have based this component of the framework on the theory of planned behaviour and incorporate issues relating to social norms, attitudes and cognitive dissonance, and attitudes and persuasion. People can be influenced to engage in or avoid certain behaviours based on what their peers and society accept as norms (Lutz et al., 2004). Further, our attitudes towards physical activity are shaped by those around us and certain people may be able to persuade us to participate or not participate due to the influence they have on our lives (Lutz et al., 2004). Through exploration of cognitive dissonance in relation to attitudes, persuasive messages for engagement in physical activity may be developed as people generally want their attitudes and actions to be congruent (Luz et al., 2004). It will be interesting to examine what and who influences the attitudes of adolescents with CP and motor impairments towards physical activity.

In addition, people often exercise because they gain social support and may continue to participate in physical activity if family and friends encourage them to (Lutz et al., 2004). Positive reinforcement and confidence boosting are important components in the maintenance of exercise and when absent may cause an apprehension to participation (Lutz et al., 2004). This may be particularly relevant to adolescents with CP and motor impairments as due to their developmental stage they are more sensitive to issues of self-esteem and may also experience a further lack of confidence due to their disability.

Finally, this theoretical framework focuses on the role of social cohesion in physical activity. Cohesion within a group engaging in physical activity is important as it helps to develop and maintain goals as well as promoting a sense of belongingness (Lutz et al., 2004). It may be interesting to explore the role social cohesion has played in experiences of physical activity for the sample group as well as fostering it when developing an intervention.

Social influences are important determinants of people’s behaviour, especially during adolescence. As society tends to stigmatise those with disabilities, adolescents with CP and motor impairments will be even further affected by influences from society and may internalise them to form attitudes relating to their bodies and physical activity. This theoretical framework incorporates a broad spectrum of influences on physical activity and will thus be used to inform many of the questions in the interview schedule as well as in the analysis of the participants’ narratives. While this theory is framed around able-bodied people and the social influences on their involvement in physical activity, I think that this theory can be applied to people with disabilities as they face similar social influences in their lives as well as an added stigmatisation from society due to their disability.

2.11 Conclusion

Disability is a human rights issue because people experience inequalities such as lack of access to equal health care and participation in activities due to their disabilities (WHO, 2011). Further, people with disabilities are often denied autonomy and forced to do things against their will, such as being confined to an institution (WHO, 2011). Their dignity may be violated as they are subjected to prejudice and perhaps violence due to their disability (WHO, 2011). People often talk for people with disabilities, particularly for children and adolescents, which further subjugates and marginalises them (Goodwin et al., 2004).

In order to fully understand what participation means for a person’s mental health, we need to find out about their experiences and perceptions (Crone et al., 2006). Through discovering how adolescents with CP experience their bodies, physical activity and what physical activity they would like to participate in given their physical constraints, we can begin to break down social injustices that exist for people with disabilities. These injustices include not being given the chance to speak for oneself, not being given the opportunity to discuss what they would like to be involved in and finally to create an empowering space for their ideas to be heard (WHO, 2011).

If a child or adolescent is to effectively participate in physical activities, they must feel included in the decision-making process, have a certain amount of control over what they are participating in and be motivated through enjoyment of the activity (Biddle & Mutrie, 2008). The starting point of attaining these goals is to explore the lived experiences of the people involved, which is what I aim to achieve in this research. The following chapter will discuss the methodology used in carrying out this research.

CHAPTER THREE

Research Design and Methodology

3.1 Introduction

This study aimed to describe and analyse the way a group of adolescents with CP experience their bodies, their involvement in physical activity and how they would like to experience physical activity in the future. This chapter outlines the methodology used to achieve these aims. The research design is presented followed by a detailed description of the sample group. Next, the procedure of the study is explained including a description of the location and dates of the study, as well as of the data collection and transcription process. This is succeeded by an explanation of the data analysis procedure, information about the researcher (including how reflexivity was achieved) and comments on the validity of the study. Finally, the ethical considerations are presented.

3.2 Research Design

This study made use of a qualitative design. Data was collected in the form of semi-structured interviews. A phenomenological approach was used and the data was analysed using interpretative phenomenological analysis (IPA). The phenomenological approach argues that a person always exists within a context and that a person can only be understood as a function of his or her involvement within their meaningful world (Larkin, Watts & Clifton, 2006). Further, this world is a part of us and thus can only be understood in terms of our involvement in it (Larkin et al., 2006). Essentially, a person cannot be viewed outside of his/her context and his/her context cannot be examined objectively, but rather through his/her experiences. A central aim of phenomenology is for the subject matter to be presented in his or her own terms (Larkin et al., 2006). However, because the researcher is also a person in context with his or her own place in the world, it is near impossible to present a completely objective account of a person's experience (Larkin et al., 2006). Phenomenology is thus concerned with doing as "sensitive and responsive" a job as possible considering the researcher's own limitations (Larkin et al., 2006).

IPA aims to explore the lived experiences of participants and how they experience and make sense of their subjective and collective world (Smith & Eatough, 2007). This detailed exploration is particularly appropriate for studies in health psychology where the meanings and perceptions of participants are the focus of the study (Smith & Eatough, 2007). In IPA, semi-structured interviews are one of the most frequently used forms of data collection as they provide insight into individual experiences (Eatough & Smith, 2008). IPA requires a researcher to collect comprehensive, reflective accounts revolving around a topic that is meaningful to participants (Larkin & Thompson, 2011). Thus, this method of analysis was chosen for this particular study as I was interested in exploring the lived experiences of the participants, namely, adolescents with CP.

3.3 Sample

The sample was drawn from a school for special needs in the Western Cape. The school was originally established as a school for learners with CP. However, after the ratification of White Paper 6 on 27 July 2001, all learners with special education needs in the surrounding area were assigned to attend the school. There are currently 440 learners at the school with the majority of learners being learning disabled and only 7,1% of the learners having CP.

3.3.1 Inclusion criteria.

(a) Participants had to be between the ages of 12 and 18.

(b) Participants had to have a motor impairment.

Eighteen adolescents who met the inclusion criteria were recruited for this study. Two students did not consent to participate in the study and one student was absent during the interview process, thus 15 interviews were conducted (Refer to Addendum A for interview schedule for children and adolescents). The participants were recruited through purposive and convenience sampling from a special needs school in the Western Cape that the supervisor of the researcher had prior contact with. The principal of the school identified learners who met with the inclusion criteria and provided me and my supervisor with this list. Participants in an IPA study are typically selected purposively as the topic should centre on something that is important to them (Larkin & Thompson, 2011). This creates an opportunity for valuable and experiential understanding of the subject matter to be shared (Larkin & Thompson, 2011).

The school had expressed interest in the project and allowed me to contact the parents of the participants attending the school. Four of the participants are in the primary school and eleven are in the high school. Table 3.1 contains the demographics of the sample. Pseudonyms were created for each participant to uphold anonymity but also to maintain a sense of individuality in their accounts.

Table 3.1

Demographics of Participants

Participant*	Gender	Age	Grade at school	Length of time at the school	Assistive devices
Daisy	F	12	Grade 5	7 years	NO AD
Ed	M	12	Grade 6	2 years	WC
Bianca	F	13	Grade 8	First year	NO AD
Emma	F	13	Grade 9	8 years	NO AD
Dave	M	13	Grade 7	7 years	NO AD
Adam	M	14	Grade 7	11 years	NO AD
Cara	F	14	Grade 8	8 years	NO AD
Ben	M	14	Grade 8	First year	WC
Sofia	F	14	Grade 8	First year	NO AD
Frank	M	14	Grade 7	11 years	NO AD
Lisa	F	16	Grade 10	13 years	WC
Jane	F	16	Grade 10	Unknown	AD
Anna	F	16	Grade 10	Unknown	WC
Chris	M	18	Grade 12	15 years	NO AD
Gary	M	18	Grade 11	Unknown	NO AD

Note. NO AD = no assistive device; AD = assistive device (crutches or walking frame); WC = wheelchair.
*Pseudonyms have been given to protect the anonymity of the participants; these are in the form of names in order to give a sense of individual identity and subjective experience to each of their stories.

Eight of the participants were female and seven were male with five participants in primary school and ten in high school. Two participants were 12 years old, three were 13 years old, five were 14 years old, three were 16 years old and two were 18 years old. Currently, four of the participants use wheelchairs, one uses an assistive device and ten have no assistive devices. This gives an indication of the mobility of the participants. This being said, most of the participants have used an assistive device (crutches, a walker or a tricycle) at some point during their lives, particularly after an operation. Fourteen of the participants were born with CP or acquired it in their early years. One participant became cerebral palsied as a result of a car accident he was involved in as a child. The length of time a student has been at the school was included as it has an influence on the participant's experience of the physical activity programme offered by the school and the barriers they experience to participation. This is further explored in the discussion section.

The sample group is racially representative with participants from White, Coloured and African race groups. I have chosen not to include the participants' races in order to ensure anonymity and I feel that their racial classification did not have a large influence on my findings. I chose to provide both the grade and the age as age is not always indicative of typical grade at school and whether the child is in primary or high school may affect his or her development and responses.

Three semi-structured interviews were also conducted with staff members at the school (Refer to Addendum B for interview schedule for staff members). The headmistress of the high school, the sports teacher at the high school and a physiotherapist (who is also head of the physical therapy department) were interviewed. Their interviews were transcribed and analysed and provide a different perspective on the subject matter. It is important to note that these interviews form a secondary component to the research to contrast, support and interpolate the issues brought up by the adolescents. These interviews with staff also serve to describe the context in which the participants are educated and exposed to physical activities.

3.4 Procedure

The principal of the school was contacted and after meeting with the supervisor of the researcher, expressed her interest in the study. The principal provided us with a list of learners in the school that met with the participation criteria. Letters explaining the purpose of the study as well as consent forms addressed to the parents were sent home with these learners (Refer to Addendum C for consent to participate in research (for parents)). The contact details of both the researcher and her supervisor were provided in case any extra information was required by the parents. The parents that consented to their children participating in the study sent the signed forms back to the school. Following this, the researcher and her supervisor negotiated a time that suited the school to conduct the interviews. Upon arrival at the school, we received the parental consent forms from the secretary and proceeded to contact the learners. One-on-one interviews were conducted by me and my supervisor. The aim of the study was explained to each participant before the commencement of each interview. Issues relating to confidentiality, anonymity and the freedom to stop the interview at any time were discussed. Further, the purpose of the study was explained with time for any questions to be asked. It was explained that the interview would be recorded (if participants were comfortable with this) so that we could be sure of what they said when analysing the data and that their voices would come through. The participant could then decide if he or she would like to participate and if in agreement, was asked to sign the assent form (Refer to Addendum D for participant information leaflet and assent form).

The three staff members were also approached and informed about the study. The above-mentioned procedure was followed and if the participants agreed to take part in the study, they were asked to sign the consent form (Refer to Addendum E for consent to participate in research (for staff members)).

3.4.1 Location and dates of the study.

The semi-structured interviews were conducted at a school for special needs in the Western Cape. There are currently 440 learners at the school with the majority of learners being learning disabled and only 7,1% of the learners having CP. There are 100 staff members at the school with 50 of these being full-time professional staff members and the other 50 support and admin staff.

My supervisor and I met with the principal and went on a tour of the primary school on 6 June 2012. We were introduced to the therapists and got a good understanding of the facilities available at the primary school. The interviews with the participants took place from 18 to 21 June. The 18th of June was spent at the primary school, interviewing the participants who agreed to be part of the study. A boardroom was provided for these interviews to take place. Although the room was relatively private and mostly soundproof, being in an area that is usually reserved for staff members may have made the participants feel uncomfortable. Further, when other learners moved around outside in passing, the noise may have had an impact on the participants' concentration. We were able to complete all of the interviews at the primary school in one day.

We spent three days at the high school conducting interviews. A classroom was provided for the interviews to take place in. As this room was outside in a prefab, extraneous noise was a problem as other learners passed by on their way to class. Further, two interviews were sometimes conducted at a time in the room and while we cordoned off two separate areas to ensure privacy, a certain level of noise interference was apparent in the recordings. These interviews were conducted in a short space of time and while the researcher and supervisor often alternated in order to take breaks, it must be recognised that researcher fatigue may have played a role as a limitation to the study.

An interview with the life orientation (LO) teacher was conducted during this week too whereas the principal of the high school and the physiotherapist (PT) were interviewed about two months later. The interview with the LO teacher took place outside and although there was some wind, the quality of the audio recording was not affected. The interviews with the principal and the PT took place in their respective offices.

3.4.2 Data collection and transcription.

Data was collected in the form of semi-structured interviews. These interviews were recorded using an mp3 recording device and Moo0 VoiceRecorder 1.31 on laptops. One participant requested his interview not be recorded thus detailed notes were taken during his interview. A total of 17 interviews were recorded. Of these 17 interviews, 14 were interviews conducted with the adolescent participants and the other three with staff members. Of the 14 recordings of the adolescent participants, one of the interviews did not record and three interviews were inaudible. Of the staff interviews, the interview conducted with the principal did not record, however, substantial notes were made during the interview. Thus a total of 13 interviews were able to be transcribed.

Nine of the interviews were sent away to be transcribed by an external person. The other four interviews were transcribed by me (the researcher). This was done as three of these interviews were difficult to understand due to the participants' speech impairments or mumbling. As I had conducted the interviews, I was able to better understand what the participants were saying as opposed to an external transcriber. The fourth interview transcribed by the researcher was that of the PT, and this was done because this interview was done at a later stage in the research process and it was more expedient for me to transcribe it.

3.5 Data Analysis

The literature on IPA has not prescribed a specific method on how to analyse data, but rather lays out a set of principles and processes that should be applied (Smith, Flowers, & Larkin, 2009). IPA has a two-stage interpretation process which focuses on attempting to understand the world of the participants as well as interpreting their experiences (Smith & Eatough, 2007). IPA is phenomenological in approach as it entails an in-depth analysis of each participant's lived experience (Smith & Osborn, 2008). It aims to explore the individual's perceptions towards an occurrence and not an objective account of the occurrence itself (Smith & Osborn, 2008). In trying to understand what it is like from the participant's point of view, the researcher must also be aware of her own perspectives on the situation as well as what the participant may be choosing to omit. Thus, a second aim, one of interpretation from the researcher's perspective is present in IPA (Larkin et al., 2006). Whilst the researcher 'gives voice' to the participant, she also offers an interpretation of the first-hand accounts by expanding them with the use of psychological concepts (Larkin & Thompson, 2011). Although, there is no prescriptive method, as a researcher who is new to IPA, I chose to base my analysis on the stages of IPA analysis as laid out by Lesley Storey (2007).

3.5.1 Stage 1: Initial reading of the transcripts.

After each day of conducting interviews, my supervisor and I (the researcher) discussed the ideas and potential themes that emerged. We recorded these preliminary ideas and summarised them at the end of the interview week. This created a chance for reflexivity and began a process of detailed and continuous analysis of the interviews. After transcription of the interviews, I read and re-read each interview to get a general impression of each participant's experiences. I highlighted the parts of each interview that stood out to me and made notes in the margin detailing my ideas and interpretations.

3.5.2 Stage 2: Identifying and labelling themes.

In the second stage of analysis, I returned to the transcripts and began to group the notes I made into relevant themes. While it was important to be aware of the aim of the interviews, I was also aware of other interesting information the participants shared as part of their lived experience that I may not have expected.

3.5.3 Stage 3: Linking these and identifying thematic clusters.

Following this I began to make connections between the initial themes and created clusters of themes. This created an opportunity to look at the similarities and differences across each interview.

3.5.4 Stage 4: Organisation of themes and writing up.

Finally, I organised these into superordinate themes with their subsequent subthemes. I used illustrative quotes to identify each theme and subtheme. I then worked through each theme and expanded on my interpretations and produced a meaningful and expansive analysis of the quotes. A large proportion of the results section is comprised of extracts from transcripts in order to give voice to the participants (Smith et al., 2009). This also creates a transparent base from which my interpretations were drawn (Smith et al., 2009). I aimed to show what matters to my participants by giving examples of their responses, presenting my interpretations of their stories and examining data that does not correspond with the dominant patterns (Larkin & Thompson, 2011).

The interviews conducted with the staff members were also analysed using IPA. These results were discussed and were compared to the experiences of the children and adolescents. This information will be valuable when developing an APA intervention as it will give an idea of the experiences of those participating in APA as well as those administering it.

Table 3.2 presents the major themes and sub-themes as they will be presented in the forthcoming chapter. Due to the richness of data and the in-depth analysis characteristic of IPA, each major theme is presented in its own chapter.

Table 3.2

Themes that Emerged from the Data

Major Themes	Sub-themes
Theme 1: “When They Call Me Cripple” - What it Means to Have a Motor Impairment	A Medical View of CP
	“I am Not Disabled – I am Just Different”
	A Hierarchy of Disability
	Experience of Attending a Special Needs School
	Why it is Difficult to be an Adolescent with a Motor Impairment
Theme 2: My Experience of Physical Activity - Perceived Benefits, Facilitators and Barriers to Participation	Participation in Physical Activity
	Perceived Benefits of Participation in Physical Activity
	Factors Perceived to Promote Participation in Physical Activity
	Perceived Barriers to Participation in Physical Activity
	The Idea of Inclusivity
Theme 3: Protective Factors and Coping Strategies Employed by Participants to Overcome	Humour
	Disregarding Others

Barriers to Participation	Asserting Oneself
	Cognitive Rationalisations
	Modifying Equipment and Adapting the Physical Activity
	Religion and Purpose
	Determination and Personal Resolve
	Acceptance and Understanding
	Supportive Friends and Family
Theme 4: What I Would Like and What I Recommend	The Search for Independence
	I Want to be Able to Choose What I Participate in
	I Want There to be More Opportunities
	I Want to be Treated With Equality and Recognised For My Capabilities
	My Dreams
	Things that should be Included in a Sports Programme
Theme 5: Perceptions of Staff Members at the School	Benefits of Physical Activity
	Positive influences
	Perceived Barriers to Participation
	Potential Difficulties for Learners as a Result of these Barriers

3.6 The Researcher

I am a Masters Psychology student at Stellenbosch University. I am a 24 year old, able-bodied female with no personal experience of CP. I have grown up less than an hour away from the community in which the school is situated and thus have a good understanding of some of the cultural and social aspects relating to the sample group. My supervisor assisted with the interviews as the data collection period was limited. The supervisor is a lecturer at Stellenbosch University and is experienced in conducting qualitative research.

3.6.1 Reflexivity. As a researcher doing qualitative research, I have to be aware of my reasons for doing this study as well as my perceptions and opinions at all times. I am doing this study in pursuit of a masters degree and it falls under a project campaigning for a bid from the European Union to provide opportunities for children with CP to be involved in health promoting physical activity. Further, I have been involved in dance and physical activity throughout my life and feel that every person, able-bodied or not, has the right to and thus should be given the opportunity to experience the physical and psychological enrichment that exercise provides. Adolescents with disabilities are one of many marginalised groups who are often denied this opportunity and I think that research needs to be done in order to change this prevailing social injustice. I kept a reflective journal throughout the research process and had weekly debriefing sessions with my supervisor where we discussed the research quite extensively. An issue that arose personally for me was realising that at the start of the research an assumption had been made that the participants want to be involved in physical activity. Thus, during the interview process it was important to attempt to suspend this assumption and allow the participants to speak about their different experiences. Most importantly, I was aware that as researchers we may make the participants feel further marginalised and as a result I attempted to create a space for them to voice their opinions and ideas and not make them feel that we had already decided what was best for them.

3.7 Validity

The validity of this data was monitored through supervision. Further, I aimed to engage with the relevant literature, be sensitive towards the context of the participants, to remain committed to the data by providing in-depth analyses and to be as transparent as possible in my presentation of the results (Yardley, 2000).

3.8 Ethical Considerations

Ethical approval for this study was granted by the Departmental Ethics Screening Committee and the Stellenbosch University Committee for Human Research (Reference number: S12/05/130). Furthermore, ethical approval was granted by the Western Cape Education Department to conduct this study in a school setting (Reference number: 20120504-0048). Throughout the data collection, data analysis and in the final reporting of the results, confidentiality was upheld. No identifying information was provided to anyone except me and pseudonyms were created for the participants. Precautionary measures were taken to ensure that all interviews were stored safely and securely. The study was explained to each participant and they were told they could withdraw from the study at any time without consequence. Participation was voluntary and no participant withdrew from the study.

CHAPTER FOUR

Theme 1: "When They Call Me Cripple" – What it Means to Have a Motor Impairment

> *So if somebody says disabled, then I say, please, don't say that because it's hurtful or rude.*
>
> *(Adam, 14 year old)*

This chapter explores how participants describe their bodies and the difficulties they face as adolescents with CP. All the participants speak explicitly about what it means to them to have a motor impairment and how they understand and make sense of their disability. Implicit in the way they speak is a particular attitude towards their bodies and a view of disability which is congruent with the dominant medical discourse.

4.1 A Medical View of CP

Many of the participants speak about their disability in an open and comfortable manner without any apparent discomfort or resistance. Most participants make use of biomedical explanations to describe the nature of their disability. They locate their disability within their bodies and present themselves as the victims of biology with the medical profession positioned as having the power to cure them. Some participants describe their disability as the result of an accident at birth although they do not explicitly proportion blame for this accident. Disability is thus often spoken about as being like a disease in the sense that it is diagnosed by the medical profession and requires treatment in hospital by doctors. Some participants describe CP as a problem with their limbs (bones and muscles), while others attribute the problem to their central nervous system (particularly their brains).

> *I have cerebral palsy, and the type of cerebral palsy, it's diplegic. Your legs are normal, and my legs face in. And my bones grew skew, so when I was born they wanted to...I wouldn't be alive today if it wasn't for the doctors who saved me.* ***(Bianca, F, 13, NO AD)***

> *When I was born in 1997, a few days or months later the doctors found out that I was cerebral palsy. So my mum took me to the hospital to have x-rays done. They checked and they said, no, I've got cerebral palsy. Then they had to do an operation on my legs.* ***(Emma, F, 13, NO AD)***

> *The side of my brain for my legs and that, that was damaged at birth, so it took me a long time to develop. Ja, I was very sick as a baby. Ja, I was born premature, and we (my twin brother and I) had to be put in incubators.* ***(Adam, M, 14, NO AD)***

Two participants, Ben and Sofia, describe their disability as a failure of the brain to send messages to their muscles.

> *(When people ask why I move this way) I say it's because of cerebral palsy. There's a message in my brain that doesn't tell my legs to move like other people's.* ***(Ben, M, 14, WC)***

> *It's like your brain isn't giving the correct message to your lower body.* ***(Sofia, F, 14, NO AD)***

Sofia seems to know much more about her condition and is able to describe it in detail, although she always describes her body as being the source of her limitations.

> *Diplegia is when your muscles feel stiff when you're walking, and your brain doesn't send the correct movements down. Like your brain says go that way, and your legs will go that way. It's like yours will look up straight and normal, but my feet will go out and not do that. And I also have problems with my hip because I'm like that (gestures to indicate an oblique angle) - so not in.* ***(Sofia, F, 14, NO AD)***

Although Sofia is able to describe her form of impairment in detail, she appears not to be able to find the words to discuss the aetiology of her impairment.

> *I don't know much about it (my disability). All I know is that my feet are out - not like normal - but that's all I know. My muscles pull stiff if I walk. And when I was born, I lost oxygen, and that's what caused it also.* ***(Sofia, F, 14, NO AD)***

Some participants offer rich descriptions of the nature and causes of their impairment and seem to have made some sense of their disability. Others, such as Ben, seem to demonstrate a more superficial understanding of the biological mechanisms underlying their disability.

> *I was born like this, and I went into an incubator for nine months. I don't really know much. All I know is that I was born like this.* ***(Ben, M, 14, WC)***

It is unclear if the participants who share less about their impairments do so because they are uninformed or if they are simply less comfortable disclosing these details or if they have not made sense of their diagnosis yet.

Many participants describe being subjected to numerous medical procedures in an effort to make them look and move differently. They describe being acted upon by well-meaning doctors who are sometimes helpful and sometimes ineffective.

> *When I was three, I had an operation because I used to walk on my toes, and they gave me an operation here on my ankle to make my foot flat. And I think when I was eight, then they did another operation so that my leg can be more straight, because it was very skew. I used to wear splints when I was small. It made my legs quite nice now. It did grow much straighter now.* ***(Bianca, F, 13, NO AD)***

> *So they did an operation at the back of my foot, by the heel, they did an operation there twice. I did one in 2004, and then the other one I did in 2006. Then in 2010 the doctor said, no, my foot is not right. So then they said, okay, fine, they're going to do a totally different operation. So then they did one on the side of my foot there. They took the bone from my foot and then they put it on the side of both feet on the underside here of my foot. Ja, so then they said maybe that's going to help.* ***(Emma, F, 13, NO AD)***

Many participants position themselves as passive objects that are acted upon by surgeons who tell them what they need and what would be helpful. They often refer to the doctors as “they” or “them”; this othering suggests a lack of voice in terms of what is done to their bodies.

4.2 “I am Not Disabled – I am Just Different”

Although all participants acknowledge that their bodies have certain physical limitations, many were reluctant to identify themselves as disabled. Participants speak about the problem inherent in trying to find appropriate words to accurately describe their experience of having CP. In this context they speak of finding particular words offensive. Many participants, for example, speak of finding the word “disabled” offensive. Some participants preferred to use the word “difference” rather than “disability”. Using the concept of “difference” and “being different” seems to empower participants by allowing them to feel as capable as other people of doing things (albeit in a different way). The strong adverse reaction of many participants to the word “disabled” suggests that this word carries negative connotations for the participants. This raises important questions about the environment they live in and the discourse of disability they have been subject to.

> *I mean, that (being disabled) is not being able to do anything at all. You are just going to sit in a chair and do nothing - that's disabled. I can still get up from this chair and I can walk to my class. I can pick up my bag. I can kick a ball. I might not be able to do it as hard as an able-bodied person does, but I can do it. So I am not disabled. Yes, I am different, but I'm not disabled.* ***(Chris, M, 18, NO AD)***

> *It (my body) is normal - I just do that stuff (moving) differently. I will just say that I can't walk around and run around, or do like cross-country.* ***(Lisa, F, 16, WC)***

Some participants speak of preferring the words “physically-challenged” rather than “disabled”. This sentiment is evident in the following quotation in which Adam describes his perception of what the word “disabled” denotes:

> *The right words to use are...disabled is actually hurtful...physically-challenged means he's still mobile to move and so on. They should use the words physically-challenged, or not able to do a task as somebody else. Ja, not like mean words… People who use those words often don't know the definition of those words and how hurtful it is. So if somebody says disabled, then I say, please, don't say that because it's hurtful or rude.* ***(Adam, M, 14, NO AD)***

Some participants object to any words that focus on differences and incapacity, preferring to highlight similarities between people. This sentiment was articulated by Lisa in the following way:

> *I don't really use disabled a lot, because people are people.* ***(Lisa, F, 16, WC)***

Participants describe being referred to by others as “cripple”. The word “cripple” is experienced by most of the participants as an offensive word.

> *But I don't like it when people say cripple. I don't like that word.* ***(Lisa, F, 16, WC)***

> *The hurtful words are cripple...hey, he's a cripple.* ***(Adam, M, 14, NO AD)***

> *Like, oh, look, there goes a cripple. Oh, that boy is in a wheelchair and he's cripple. Or, oh, that girl has a crippled arm.* ***(Emma, F, 13, NO AD)***

> *I: And why is cripple not such a nice word?*
>
> *R: It sounds very ugly to say that to people.* ***(Ben, M, 14, WC)***

> *I: Are there particular words you find offensive or do not like?*
>
> *R: When they call me cripple. There's a difference between cripple and... I always say I'm disabled...cripple makes you feel like worthless - like why was I born?* ***(Sofia, F, 14, NO AD)***

Some participants acknowledge that when speaking about disability it is not so much the words that are used but rather how the words are used, by whom and in what context.

> *I: What words do you prefer to use?*
>
> *R: It doesn't really matter, as long as they are not being mean about it or just making fun, because everyone is not perfect.* ***(Lisa, F, 16, WC)***

4.3 A Hierarchy of Disability

Many participants imply that there is a hierarchy of disability with some individuals being considered more “normal” than others. This implicit hierarchy is most evident in the way participants speak of the learners in the school who have learning disorders and emotional problems. Although the school was originally established for children with CP, after White Paper 6 was passed into law, the school was open to the inclusion of children with other forms of disability. Currently, only 7,1% of the school are learners with CP with the majority of learners being able-bodied. The participants with CP refer to the learners who have learning disabilities, as normal. This distinction seems to show that, according to the participants, individuals with disabilities that are not visible are less disabled than those with visible physical disabilities.

> *Well, I'm not saying all kids are normal. I'm just saying, okay, there are some kids that have learning problems, so that's what I mean by normal. They are normal because they don't have anything physically wrong with them. Those are the people I mean by normal. Those are the people, the ones with a physical type of brain. And there are kids as well who get very emotional, and there are kids that get short-tempered - they get angry very quickly. So ja, those are the people who are normal to me.* ***(Emma, F, 13, NO AD)***

Explicit within the hierarchy is a power differential which results in those ‘on top’ subjugating those ‘below’ through bullying and other forms of verbal insults. Many participants described being subjected to bullying and discrimination by the learners in the school who do not have motor impairments. This is evident in the quote below in which Sofia talks about her experience of being made fun of and judged by other able-bodied learners.

> *Yes. I think it's really silly, because they are normal, they've just got the judgment. It's nothing to be made fun of. And we are at a school like that, so I don't see why they do it. If they were so perfect, then why are they here? I don't understand people like that. That's the kind of thing I can't take, people thinking they are better than everybody. Because one day, there is going to be someone*

> *who is going to tell them what they really think, and they are not going to like it. So why do the same thing to other people?* **(Sofia, F, 14, NO AD)**

The learners in the school also appear to make fun of one other's disabilities and of the school they attend. It is hard to know if this use of humour is an adaptive way of coping or self-deprecating, but it does highlight a lack of pride in belonging to this school community.

> *Well, they make fun of each other and they make fun of the school, because they think it's like a retarded school - but it's not.* **(Lisa, F, 16, WC)**

Lisa's comment above seems to suggest that some learners feel stigmatised for attending a school specially established to cater for children with disabilities. This experience of stigmatisation and the impact it has on the self-esteem of learners with movement impairments warrants further investigation.

4.4 Experience of Attending a Special Needs School

In the context of talking about their disability some participants speak about their experience of attending a school for learners with special needs. Some participants discuss the reasons they are at the school although none of them say that they chose to be there. There seems to be a high level of ambivalence towards the school; with participants describing both advantages and disadvantages of being at a school established to meet the special needs of disabled learners.

One participant, Daisy, says that she is at the school as a result of her hand and leg although she seems reluctant to say that she has special needs:

.

Because I have... uh .... uh.... I have special needs. Ja with my hand and my leg. ***(Daisy, F, 12, NO AD)***

When Ben was asked why he attends the school, he states that it was on recommendation from the principal.

Because the principal recommended for me to come here **(Ben, M, 14, WC)**

Ben speaks as if he had no part in the decision and was told where he should go to school. Unlike Daisy, he places the decision outside of himself. It is not as a result of his impairment that he is at school but as a result of a recommendation made for him. This places the principal in a position of power; someone who has made an executive recommendation which influenced a decision possibly made by Ben's parents. This seems to have left Ben feeling as if he has no control over this aspect of his life.

While describing their experience of attending the school, some learners identified certain benefits of being at a school for children with disabilities. There does not appear to be one commonly identified advantage of being at the school; each participant has their own perception of what the personal benefit to them is. Adam, for example, finds the school to be understanding of his needs and appreciates the extra attention, time and care given to the learners to complete tasks. Adam imagines that he would not receive this attention and care in a mainstream school. His experience is of being understood and held in mind by the teachers in the school.

> *They take more care in your work and they allow you more time. You have more time here to finish something. They allow you like an extra ten or twenty minutes because they understand your needs.* ***(Adam, M, 14, NO AD)***

Chris considers the physical structure and layout of the school to be beneficial, particularly for learners in wheelchairs. Although he is not in a wheelchair he recognises that there are learners who are in need of these facilities and that they are present in the school.

> *It caters to our needs as a physically-disabled person. You know, my school has ramps. It has facilities to help us to make our lives easier at school. You know, we have wheelchairs. It's basically just the structure and infrastructure of the building that's there to support us.* ***(Chris, M, 18, NO AD)***

Chris speaks about the benefits for "us" as a collective group of learners with special needs and he is one of the few participants who talks of the school as "my school". Although he does not personally need all the structures in place he seems to feel that the school caters for the large variety of needs present and his experience is of being supported.

Emma enjoys the social aspects of the school and the variety of people she gets to meet.

> *Ja. (it's) a really fun school. You get to know a lot of people and meet a lot of people* ***(Emma, F, 13, NO AD)****.*

Although participants identify specific benefits of being at the school, none of them speak of their school with explicit pride. Very few participants convey a strong sense of belonging to a community or of having loyalty to the institution. The participants also cite a number of negative aspects of being a learner in the school. Adam, for example, describes feeling that he is infantilised and treated as being less capable than he is. Adam seems to prize being independent and sees this as a goal which needs to be achieved in order to overcome his disability. These sentiments are evident in the extract below where Adam describes feeling disempowered by being constantly reminded of what to do and where to be.

> *They remind you constantly over here to get to class, which I think is okay, but when you get to a certain grade you should be mature enough to remind yourself, oh, it's this class and this class. Because if people keep on reminding you, one day you're not going to make it in life because you're going to depend on people for reminding you.* ***(Adam, M, 14, NO AD)***

Sofia identifies negative things at school that she considers would exist in a “normal” school. These include rumours and boy problems.

> *It (being at this school) is okay. It's fine. It's just more work and more drama because the other children are older children. It's fine. It's like a normal school…Like the rumours spreading...boy problems…Like who kissed who, and who likes who.* ***(Sofia, F, 14, NO AD)***

Thus, Sofia feels that being at high school brings with it a variety of social issues which seem to be unrelated to having an impairment, and are a result of being an adolescent.

4.5 Why it is Difficult to be an Adolescent with a Motor Impairment

Participants describe facing a number of difficulties, often on a daily basis, as a result of their motor impairment. A common experience is that of being in physical pain and discomfort. Similarly many participants speak of their bodies failing them and requiring help and a range of physical and occupational therapies.

> *With my leg, ja. If I sit too long, like now, it gets a bit stiff. So I have to hold onto something, maybe with one hand or two hands. I have to give help to my leg because my foot gets very stiff.* ***(Emma, F, 13, NO AD)***

People with disabilities often have to deal with not only their own feelings and struggles relating to their impairment, but also have to manage the feelings of others. Participants describe having to manage the curiosity of others and being subjected to long stares. This seems to make the participants feel that they are under scrutiny and makes them increasingly self-conscious. More than one participant describes being stared at as intolerable. Chris describes this experience and explains that he would prefer people to satisfy their curiosity by asking him questions rather than staring. Similarly, Sofia describes how people look at her but fail to engage her in conversation.

> *The staring is...I mean, you are staring at me, and that is all you are doing. You are not actually asking me. Yes, I understand that you're curious, so ask me about it and I will explain it to you.* ***(Chris, M, 18, NO AD)***

> *It's either they make fun of me, or they check me. They never say any words.* ***(Sofia, F, 14, NO AD)***

One of the participants, Daisy, prefers people not to ask about her disability and seems to resent being an object of curiosity.

> *They first ask me … like every time they'll come and say 'how's your hand'? And looking at me and I'll be like 'It's fine'***.** *I don't like people asking questions.*
> ***(Daisy, F, 12, NO AD)***

Being the object of curiosity and the subject of people's staring is a common experience described by the participants. Some participants resent this while others seem to understand people's need to look at the unfamiliar. The oldest participant, Chris, is particularly understanding of people's fascination with the disabled body.

> *Ja, it's always been like that. It will never go away, and I don't blame them for it because as humans we have this curiosity in us. We see something strange, we are going to stare. I mean, I stare when I see people worse than me in other conditions…And it is fascinating to you, so I understand, and I don't judge you for it.* ***(Chris, M, 18, NO AD)***

One participant, Sofia, feels quite strongly about having to deal with people's generalisations and assumptions about persons with disabilities. Sofia describes her experience of feeling silenced by other people's assumption that she has cognitive impairments and lacks intellect because she has CP.

> *They think all disabled people are stupid and would just keep quiet. But I'm a different kind. My daddy always says I'm...like I didn't fall on my mouth. I will say my say when I have to, but when I must keep quiet, I'll keep quiet.* ***(Sofia, F, 14, NO AD)***

None of the participants speak of their disability as being a "blessing-in-disguise" or an advantage which gives them some special insight or talent. However, one participant, Sofia, seems to believe that having a disability has made her more empathic and better equipped to understand the difficulties others may face. Similarly, Chris believes that his experience of having a disability has left him with the capacity to consciously choose to accept differences without judgement or prejudice.

> *For me, we are all human. That is what I like about me. Actually, I'm glad because I can also see other people's flaws. I'm glad I'm different…Okay, I am normal, but if I was an able-bodied person, I would also be making fun of someone that was...so I'm glad I'm like this because I can experience it. So one day it will make...miracles do happen and I can walk normal, then I'll know what it felt like to be made fun of.* ***(Sofia, F, 14, NO AD)***

> *I just think as individuals we need to make a personal choice not to laugh at it, and just accept the people the way they are. You can't just go to people and say you need to do this and you need to do that - that is with you as an individual. You need to make a choice: I'm not going to laugh at this guy because he runs a bit differently. I'm not going to laugh at the guy because he walks a bit differently. That's an individual choice.* ***(Chris, M, 18, NO AD)***

4.6 Conclusion

The participants discuss their experience of what it means to have a motor impairment and contextualise it predominantly in the medical and physiological sense of the word. Further, they speak of "being different" as opposed to being disabled. However, some of the participants articulate that a hierarchy of disability exists, with persons with physical disabilities seen as being "worse off" than those with other disabilities. The participants also speak of attending a special needs school and what difficulties they face as adolescents with motor impairments. Although each participant presents with a unique narrative, they all appear to have experienced a certain level of discrimination as a result of their impairment. The following chapter explores these accounts with a particular focus on the participants' experiences of physical activity.

CHAPTER FIVE

Theme 2: My Experience of Physical Activity – Perceived Benefits, and Facilitators and Barriers to Participation

There is soccer but we have to watch.

(Lisa, 16 years old)

In this chapter, the participants' experience of physical activity is described and their perceptions of the perceived benefits of participation are presented. The range of physical activities participants are currently engaged in is presented along with the participants' insights into the factors they believe facilitate and hinder their participation.

5.1 Participation in Physical Activity

Many of the participants report being involved in a range of physical activities. These activities include organised sport at school, such as baseball, swimming and athletics. A number of participants also report participation in competitive sport outside of school, for example, judo, cycling and soccer. Many of the participants also describe attending physiotherapy on a weekly basis where they perform a variety of exercises such as stretching, cycling and walking on the treadmill. It appears that the decisions of these participants about what activities to engage in is influenced primarily by what is offered to them, their level of skill and competence, and what their friends chose to do. In addition to being involved in formally organised physical activity at school, a number of participants speak about taking part in activities with friends in a more informal social context.

When asked to describe the kinds of activities they participate in, a number of female participants identify informal social tasks such as spending time indoors with their friends, talking, listening to music, watching movies and playing board games. They report enjoying these activities.

> *I just hang out with my friends. I go to my friends, talk, and listen to music.* ***(Bianca, F, 13, NO AD)***

> *I: Do you guys like listening to music?*
>
> *J: Yes a lot.* ***(Daisy, F, 12, NO AD)***

> *We watch movies.* ***(Emma, F, 13, NO AD)***

> *We just like play games and do funny things…We play like um 30 seconds* ***(Daisy, F, 12, NO AD).***

It would seem that participation in these activities performs a largely social function, allowing the participants to establish, build and maintain relationships with peers. The pastime activities which female participants describe do not typically involve physical movement, although they do provide participants with an opportunity to participate in popular culture. Emma suggests that as adolescents, they have out-grown physical games and prefer to spent time taking part in more passive activities. Emma seems to consider “playing” as something that belongs in the domain of childhood.

> *I played...okay, well, we don't play anymore, but we used to play. Now we just sit and talk, have fun and listen to music…We used to play* on-on or hide-and-seek, *or we used to play board games.* ***(Emma, F, 13, NO AD)***

By contrast, the male participants describe participating in outdoor activities which have a physical component. For example, they report that they spend time with their friends engaged in activities such as playing soccer, touch rugby or just kicking a ball to one another.

> *That's basically what we do, we play touch rugby and soccer.* ***(Chris, M, 18, NO AD)***

Although there seems to be a gendered dimension to what activities participants chose to engage in socially with their peers, there are exceptions. Ben, for example, reports that he spends his free time talking to his friends.

> *We just talk and stuff. We talk about stuff that happened in the past, and movies and stuff like that.* ***(Ben, M, 14, WC)***

The difference in these activities could be a result of the level of physical impairment these two boys experience. It may be easier for Chris to be involved in sport than Kyle. While the participants engage in a variety of activities, they appear to acknowledge that physical activity is beneficial for one’s health.

5.2 Perceived Benefits of Participation in Physical Activity

Participants perceive a number of personal benefits that accrue from their participation in physical activity. They describe how physical activity promotes physical health and they identify psychological consequences and social benefits.

5.2.1 Perceived physiological health benefits.

Many of the participants consider physical activity to be health promoting and beneficial to their bodies. They report that physical activity helps them strengthen their muscles and maintain their fitness. The participants appear to understand that physical activity has general health benefits (such as reducing the risk of heart disease and controlling body weight) and particular health benefits for individuals with CP. A number of the participants report that exercise improves the strength of their muscles ad well as their agility and flexibility, which in turn enables them to move around more easily in day-to-day life.

> *Yes, you will become fit, and it's good for your body and stuff, and your heart. You won't become weaker. You'll be healthy and maybe live long.* ***(Ben, M, 14, WC)***

> *It can help to uh make your muscles strong* ***(Daisy, F, 12, NO AD)***

> *Ja, it (exercise) will help them (individuals with CP). You can't just sit around the whole day and do nothing. Like plop yourself in front of the TV the whole day, it's not going to be healthy. You will eat junk. Ja, that's not right.* ***(Emma, F, 13, NO AD)***

> *It's also healthy for you because you don't breathe in stale air; you're breathing fresh air and your lungs are good. And you also get to burn off food, and the food doesn't sit in your stomach and your stomach doesn't grow.* ***(Adam, M, 14, NO AD)***

Some participants report that they find physical activity tiring and painful and consequently they do only as much as is necessary. For many participants physical activity is associated with treatment (something prescribed) for their disability. Some participants report that they take part in sport as a way of reducing the number of physiotherapy sessions they have to attend - thus physical activity is perceived as a substitute for physical therapy. This capacity to choose a particular sport rather than attend physical therapy appears to give participants a sense of control and ownership of their bodies and the activity.

> *Because with horse-riding, when you do an hour, it's equal to doing two hours of physio.* ***(Lisa, F, 16, WC)***

Many of the participants talk of the health benefits of exercise using the pronoun “you” as opposed to “I”, “me” or “my”. This could suggest a lack of ownership of these ideas and suggests that perhaps these benefits may have been taught to them by parents or educators and they may not be fully convinced of them.

5.2.2 Perceived psychological benefits.

The participants identify many psychological benefits of physical activity, more so than with any other benefits. They report experiencing emotions such as enjoyment, excitement and a sense of achievement when taking part in physical activity which they have elected to do.

Many of the participants mention enjoyment and having fun as the primary benefit of participating in physical activities: The experience of the participants seems to be that physical exercise elevates their mood.

> *It's just fun.* ***(Bianca, F, 13, NO AD)***

> *Having fun.* ***(Daisy, F, 12, NO AD)***

> *Ja, I enjoyed it. It's really a fun sport.* ***(Emma, F, 13, NO AD)***

> *Just to play, ja, it's quite enjoyable, and the vibe or atmosphere, and obviously playing the game* ***(Chris, M, 18, NO AD)***

> *You feel happy because you know you will benefit from what you are doing.* ***(Ben, M, 14, WC)***

Participants also speak about physical movement providing them with opportunities to defy their bodies and surpass limitations. For example, Emma describes her experience of swimming as being fun because she is able to move more freely when held by the water which is in contrast to her experience when walking on land with her walking frame.

> *Like just floating in the water or swimming in the water, it's fun.* ***(Emma, F, 13, NO AD)***.

It appears that for Emma, this experience of swimming is liberating as she can experience (albeit temporarily) lightness in being and transcend the limitations of her body.

Other participants describe a feeling of relaxation in response to doing physiotherapy in warm water. They describe their experience of the water brining relief from muscular tension and reducing physical discomfort in their bodies which in turn makes them feel psychologically more relaxed. Many of the participants identify physical activity as being imperative in relieving stress and enabling relaxation.

> *It (horse riding) helped me to relax when I was stressed. If I had a bad day, then I would enjoy my riding.* ***(Lisa, F, 16, WC)***

> *Relaxed. The water is cold, but still, when you go in there, and when you've been there for a while, then it becomes warmer. Ja, so then I just float around.*
> ***(Emma, F, 13, NO AD)***

> *If I was just stressing or not feeling well, it was just something out of school for me to do.* ***(Lisa, F, 16, WC)***

It is interesting to note that these participants use the pronoun “I” when referring to these benefits. These benefits seem far more personal and attached to more emotion. They may perceive these benefits to be personally more important than the physical benefits attached to activity.

Physical activity also seems to provide participants with a distraction from the stress of everyday life. Participants describe how anger and frustration can be released physically and focus can be directed away from the stressor, when they participate in sport and exercise.

> *Golf was...I mean, it was a time when I could just space-out and just do what I needed to do* **(Chris, M, 18, NO AD)**

> *I just let go. Like all the anger I feel because I can't hit a person or be rude to them, I'll just take it out on that. That is why I like picking up weights, especially when I'm angry, because it just helps.* **(Sofia, F, 14, NO AD)**

A few participants describe how physical activity allows them to explore their identity and be creative. Their perception is that participation provides opportunities for new experiences and allows them to discover as yet unknown parts of themselves.

> *I can be myself; express myself; do different things.* **(Bianca, F, 13, NO AD)**

Physical activity thus seems to enable self-discovery and promote identity formation for some of the participants; both of which are important psychological tasks particularly during adolescence.

Participants describe participation in physical activity as bringing with it feelings of excitement and anticipation. Emma, for example, describes her experience of excitement just thinking about the prospect of being able to be active again as it will enable her to engage with her friends in a manner that she is currently unable to.

> *I feel excited because I want to run again; catch all my friends and run away from them.* **(Emma, F, 13, NO AD)**

Another participant, Chris, becomes excited about being involved in an activity he enjoys.

> *But your body goes into jitters, because there are butterflies because you are actually on the pitch. You are playing yourself.* ***(Chris, M, 18, NO AD)***

5.2.3 Perceived social benefits.

Participants describe how participation in physical activity facilitates the establishment and maintenance of peer relationships, provides a forum for socialising, and provides opportunities to offer and receive interpersonal support.

Many participants describe how participation in organised sport provides opportunities to meet new friends and build existing peer relationships.

> *You get to meet new friends.* ***(Bianca, F, 13, NO AD)***

> *Yes, and you could make good friends.* ***(Emma, F, 13, NO AD)***

Many participants describe how physical activity creates a space for them to engage with others. While some participants experience this as an opportunity for social interaction, others perceive it as obligatory to interact (an unavoidable consequence of participation):

> *Yes, you have to socialise with people* ***(Ben, M, 14, WC)***

Participation allows for the experience of being included and being part of a group or team. Many participants speak of this benefit of belonging and connection which they associate with physical activities.

> *Now I can swim with my friends.* ***(Emma, F, 13, NO AD)***

For some participants this sense of belonging also provides the experience of feeling supported, noticed and cared for. In this sense being part of organised sport is likened to being in a family.

> *But there's also a nice family feel, like everybody supports you there…Basically, like if I finish the race, the marshals and that, they clap and say well done, even though I haven't done such a great time…Yes, you can always cheer with your team mates and that. It's like a nice group feel when they're cheering you on.* ***(Adam, M, 14, NO AD)***

Thus physical activity (particularly organised sport) seems to have the potential to work against feelings of exclusion and marginalisation for some participants. This, however, is not the shared experience of all participants. Some participants, for example, describe how organised sport often entails a process of selection which brings with it the possibility of not being selected and hence feeling excluded or incompetent.

5.3 Factors Perceived to Promote Participation in Physical Activity

There appear to be a number of factors which promote and facilitate the participants’ engagement in physical activity. Chief among these are: the influence and involvement of parents; the opportunity to spend time with friends; and the experience of success and attainment of goals.

Parents seem to exert a significant influence on participants' involvement in physical activity. For example, Chris considers his interest in soccer to be the direct result of being surrounded by it in his home.

> *Well, if you ever were to meet my father and my brother, you would understand why. And if you ever go to my house, you will just see Liverpool and you'll see soccer. And just growing up in that atmosphere, I was prone to it.* ***(Chris, M, 18, NO AD)***

Chris says he was "prone" to soccer as he was constantly surrounded by it. It seems that only was Chris conditioned into the sport but that his interest and participation also allows him an avenue of connection to his brother and father; a shared interest which strengthens family bonds.

Adam describes how participation in sports seems to enable him to garner the approval of his parents and make them happy. In this instance his participation seems to have the added benefit of pleasing his parents which in turn motivates him to continue to be involved.

> *My parents think that I'm doing sport because I enjoy it, and they are happy to see me getting exercise and doing well in cycling. I wouldn't like to sit around all-day and play on the computer, because your eyes get sore and it's not that nice.*
> ***(Adam, M, 14, NO AD)***

Participants also describe how being involved in physical activities outside of school requires their parents to invest time and energy transporting them to practices and fixtures. Parents' willingness and ability to expend time and resources on physical activities can thus enable or hinder their child's participation.

Some participants report that they elect to take part in physical activities which their friends are involved in. Thus the presences and habits of peers appear to have the potential to promote participation and to influence decisions about what activities to engage in.

> *When I was in grade 4 then you had to decide on what sports you were going to take in winter and summer. My friend and I chose baseball.* ***(Daisy, F, 12, NO AD)***

Participants report that they are motivated to participate when they feel that they are making progress and achieving success. Thus the attainment of personal goals and achieving a sense of mastery appear to be factors which promote participation.

> *And also in sport, you can also try achieve stuff you want to do.* ***(Adam, M, 14, NO AD)***

> *I was good at that. Now we do it every tournament, as far as I know. I have to participate in it.* ***(Lisa, F, 16, WC)***

> *I thought that it was something I could do, unlike lots of the sports. There's something I can do, while exercising my whole body…I felt so happy. I was like, yay, I can swim!* ***(Emma, F, 13, NO AD)***

A number of participants enjoy physical activities that have a competitive component. They report that they prefer to engage in activities that are evaluated or where they have an opportunity to demonstrate their prowess, strength and skill. It appears to be important to have the opportunity to win medals and prizes for success. There seems to be two elements to the appeal of competitive sport; it provides an opportunity for domination (winning) and it provides a setting where the performance is witnessed and celebrated by spectators.

> *Well, they made me captain, because once again, the mindset, so I could tell them where to go and what to do. And we won the league back-to-back, so you got the tracksuit and you got the medal. So that was a very enjoyable part for me.* ***(Chris, M, 18, NO AD)***

> *It's just that there's a nice competition atmosphere where you can try and beat your time. And you know that if you get better, you can try and win gold and so on. You can try and get professional.* ***(Adam, M, 14, NO AD)***

> *Ja, I'm an extremely competitive person. You can ask anybody, they will tell you.* ***(Chris, M, 18, NO AD)***

> *I: What did you enjoy about it?*
> *R: Winning…I used to like it when our team was winning.* ***(Lisa, F, 16, WC)***

> *I: Does it (netball) make you happy?*
> *R: Yes, especially when I win. And if I lose, then I like to know that I've tried my*

best. ***(Bianca, F, 13, NO AD)***

I like winning. I love winning. ***(Chris, M, 18, NO AD)***

5.4 Perceived Barriers to Participation in Physical Activity

The participants identify a number of barriers to their participation in physical activity. These perceived barriers to participation occur on a variety of levels namely; structural, physiological and psychological. Issues of segregation versus integration are also raised as many participants describe their experience of feeling marginalised and excluded.

5.4.1 Structural barriers.

The term "structural barriers" is used to describe environmental structures that restrict participation in physical activity. These environmental structures include factors such as resource limitations, policies, procedures, and practices which have their origin in the socio-political and economic organisation of society and the school. Structural barriers are understood to be imposed on individuals by the macro-environment and as such are not within the direct personal control of individuals. Participants in this study identify a number of structural barriers to their participation in physical activity.

5.4.1.1 Living far away from school. Many of the participants live far away from school and are transported to and from school by bus. The school serves a wide catchment area and some learners have to leave home at 6:30am and only arrive home after school at 4:00pm (which makes for a very long school day). Because the bus departs every afternoon immediately after school, it is difficult to organise extramural activities in the afternoon (as would be the case in mainstream schools). Although there are a number of activities on offer, they are timetabled for a specific period in the school day once a week.

Bianca describes how the barrier of transport prevents her from participating in the school play and Sofia explains how it prevents her from attending any activities organised outside of normal school hours.

> *I don't really like it, because they are there on a Wednesday night and I can't go to them because I live far. It takes lots of money to go. (...) (A) High (school) was doing Anne Frank, the book, and then I couldn't go.* **(Bianca, F, 13, NO AD)**

> *I take part, but I'm not going to be in this year's play. Because there's after-school practice and I live too far.* **(Sofia, F 14, NO AD)**

It is noteworthy that Sofia still refers to herself as "taking part" even though she is not included in the final performance. This suggests that Sofia's concept of participation may include watching the rehearsals during school-time even though she does not perform in the final production. Bianca is not only concerned about living far away, but is also aware of the cost involved in travelling to and from school. Bianca seems to feel that she places a financial burden on her family as the school that suits her needs is far away from where she lives.

As a result of living far away from school, adolescents with CP are not able to fully participate in extra-mural activities. This may be difficult in creating and maintaining friendships as it will be difficult to visit school friends after school hours due to the travelling distance between them. They may also be further excluded from the communities within which they live as they do not attend school with the other adolescents in their area.

> *I: And do you see your friends after school? Do you guys hang out together?*
> *R: No. Only one. Because I live in the main road, there aren't really people that*

> *are there. But I do have friends in the church.* ***(Ben, M, 14, WC)***

> *I live too far, and my friends can't travel so far to see me.* ***(Bianca, F, 13, NO AD)***

> *I don't understand, my friends say they want to come, and then they don't come. It's just how it is* ***(Lisa, F, 16, WC)***

5.4.1.2 Staff and facility limitations. The school faces limitations in terms of a lack of facilities and staff members willing and competent to supervise physical activity programmes for learners with motor impairments. Because of these constraints, some activities are only offered to specific age groups. Thus it may be difficult for these adolescents to excel in competitive sport as their exposure to it at school may be too late or for a limited period of time. Adolescents with CP who want to participate more fully are often required to join teams and clubs outside of school, which may incur further costs for parents.

> *Well, they didn't stop baseball, but when we were in grade 6 and 7, we couldn't do it anymore because we were in the older phase. So I think only from grade 4 to 5, then you can do baseball. Then in grade 6 and 7, you can't.* ***(Emma, F, 13, NO AD)***

Adam wishes that more sports were offered and appears to be frustrated at having to wait to participate in an activity he is interested in.

> *I wish they could do more sports. They could offer soccer at the junior school so that you don't have to wait until the high school.* ***(Adam, M, 14, NO AD)***

Another participant is unable to participate in the activity of her choice due to limited space.

> *No. I wrote on the list that I want to do archery but it was full. I'm doing nothing. I'm at drama for the time being…No, I'm not doing it, I just sit here for that period because archery is full. So this is my second option.* ***(Sofia, F, 14, NO AD)***

Although Sofia says that she is in drama class during the extra-mural period, she does not appear to participate at all. Sofia appears unwilling to commit herself to the activity as it is not her choice to be there. The use of the phrase "for the time being" indicates that she does not view this activity as a permanent fixture and may hope that a spot will open for her in her activity of choice. She still considers her placement as her decision however, by referring to it as her "second option". Thus she still presents with a level of autonomy in the decision-making process, even though she cannot be accommodated in her preferred activity.

5.4.2 Physiological barriers.

The participants experience difficulties in participation in certain physical activities due to their movement impairment. They report that a "disabled body" limits their range of movement, strength and endurance which hampers their ability to participate. Similarly they experience physical discomfort when participating in some activities, which makes the experience unpleasant.

5.4.2.1 The disabled body. Adolescents generally have heightened body awareness and those with disabilities may have an even greater focus on the way their bodies look. The adolescents in this study report not only being aware of their bodies but of feeling constrained by their bodies. This experience is evident in Sofia's words below in which she describes how she often becomes frustrated by her inability to control her weight.

> *Yes, but I get a little bit frustrated because I'm very over my body, and there are so many things I just can't do that will help me to lose weight. But my mother says I'm fine, I'm not fat any more. But I'm very over my body. I don't like being a certain...my weight mustn't be too high or too low. I must be comfortable in my body.* ***(Sofia, F, 14, NO AD)***

Sofia may feel that she has been betrayed by her body as it is unable to do things that would maintain the way she wants it to look.

One participant understands the limitations of his body and realises that it is harder for him to do certain things than it is for able-bodied persons.

> *No, like when I see other people doing it, and when I try it, it's like harder for me to do it than it is for them. So I must understand that they have more of a way of doing it because they are not as physically-challenged as I am. They've got more control over their leg muscles and that…So it took me more time than the other people to learn that sort of stuff.* ***(Adam, M, 14, NO AD)***

It seems that despite Adam's impairment, he tries to learn physical activities that he is interested in and perseveres with the acknowledgement that it may take him longer to succeed.

Another participant has stopped competing in sport as he increases with age. Chris feels that there is a more even playing field at a young age between able-bodied children and children with CP.

> *That was quite fun, because we were all small still. You know, I could function there and still be on par with the able-bodied people.* **(Chris, M, 18, NO AD)**

Chris refers to the enjoyment of it at that age which can be compared to the competitive nature sport takes on when one gets older. As children become older they may make more social comparisons with one another and become more self-aware which may cause inclusion to become more difficult. When Chris talks about his reasons for stopping, he does not locate the inability within himself, but rather identifies the strength in others. However, he later contradicts himself and claims the impairment in his left leg and increasing weakness are what caused him to stop participating.

> *Basically, I'm a huge sports fanatic…But I don't belong to a club any more or do that because, ja, I think it's just a personal choice that I made to leave that stuff. Because as I got older, I haven't got weaker, but the competition got heavier or stronger, so it became harder for me to compete. So I do it more to enjoy it rather than to compete…But as I said, as I got older it got worse, so I had to drop out because due to my left leg, I cannot jump.* **(Chris, M, 18, NO AD)**

> *That was two years ago that I played golf, but once again, I got weaker and I just dropped out.* **(Chris, M, 18, NO AD)**

Chris seems to struggle with his inability to successfully participate, and as a "sports fanatic", it must be frustrating to be physically limited. His decision to discontinue participation may be a combination between the growing strength of able-bodied players and the stagnation of his physical development; which due to his impairment is difficult to improve on. Further, children may be more accepting and resilient at a young age, but in adolescence self-confidence may drop and others may not be as accommodating of peers with physical impairments on a sports team.

5.4.2.2 Physical activity can be painful and tiring. Physical activity can be a negative experience for adolescents with CP as their muscles fatigue quickly and some movements can be painful. For example, Lisa describes how her movement and participation were restricted by physical discomfort following a surgical procedure.

> *I did some walking, but it's difficult for me because I just had an operation. They straightened my knees, and it's difficult to take weight on my leg because my knee gets sore. So I just have to take it easy.* ***(Lisa, F, 16, WC)***

Another participant, Daisy, becomes slightly flustered when talking about her difficulties. She talks about how her impairment prevents her from being able to successfully complete an activity.

> *Every time I like try to get the bat or run than I can't or like I run ...because when I run then my splint either hurts me or I fall and then I or when I hit the bat and then I can't hit the ball.* ***(Daisy, F, 12, NO AD)***

Daisy considers it painful to participate in sports and appears quite agitated when discussing her inability to perform the physical tasks. This may be because she becomes upset about not being able to fully participate, or embarrassed about not being able to move without pain or falling. Her splint appears to cause her difficulty and although she may know it will eventually help to improve her gait, at the moment it is restricting her from participating.

Physiological barriers also appear to be in constant flux. Participants may often be unable to complete activities they used to do successfully after they have had an operation or have not exercised for a while. The nature of CP is such that muscles stiffen easily if they are not frequently active. Emma talks about having to relearn how to run.

> *Yes. I can walk faster than I used to, but when my feet were sore I could run - but now I can't. I need to train, and the physio is going to teach me how to run again. Now I can't run because I haven't been running for a while.* ***(Emma, F, 13, NO AD)***

Physical activity can be painful and tiring for adolescents with CP which may discourage them from participation or may result in them becoming negative about activities that require sustained physical movement and agility. This could be due to the consistent amount of effort one has to put in just to maintain one’s physical state or rehabilitate after an operation. This may create psychological barriers as a person may become despondent over regression and a large amount of determination is required to sustain participation.

5.4.3 Psychological barriers.

The term “psychological barriers” is used in this context to refer to the self-limiting beliefs an individual holds which hinders their full participation in activities. These beliefs may for example include preconceived ideas of how they will perform or of how others will react. These beliefs are learnt through prior experience but may be elaborated by fantasies of what the individual imagines may happen.

The participants identify a number of factors which appear to act as psychological barriers towards participation in physical activity. These include embarrassment about performing in front of others as well as a fear of being teased and laughed at.

5.4.3.1 Embarrassment about performing in front of others. Some participants report feeling self-conscious and explain that they do not enjoy being watched when they are involved in physical activity.

> *I don't like it when they're watching me. They all sit on the field there and watch me. I don't like that.* **(Bianca, F, 13, NO AD)**

> *Ja, I don't like people watching me doing it.* **(Chris, M, 18, NO AD)**

> *Yes, but not with a lot of people watching. I don't like people looking at me and seeing me dance. It's just when I'm alone…No, it makes me nervous.* **(Bianca, F, 13, NO AD)**

When performing physical activity in front of others, participants feel they become subject to judgment. Thus participants may avoid participation because they may not wish to expose themselves to the negative and judgemental reactions of others. It seems that performing physical tasks in front of others, particularly able-bodied peers, creates a space where their bodies are "on-show" and this may create a feeling of alienation, embarrassment, and othering.

One participant's reason for her embarrassment is the fear that she may fall in front of her peers.

> *Just now I fall, and it's embarrassing.* ***(Bianca, F, 13, NO AD)***

Bianca seems to feel that she and her body will be ridiculed for its inability to perform. She would rather not try than risk failing in front of others. A feeling of being unsuccessful at something seems to be a psychological barrier towards participation. If a person does not feel that they can achieve at an activity, they may be unwilling to persevere. In the quotation below, it appears that Adam does not want to even claim that he "joined" a sport and he corrects himself and changes his vocabulary to "doing" the sport. He may feel that because he was not proficient in the activity, he cannot consider himself as being part of the team.

> *In 2009 I joined...I was doing swimming, but I wasn't really good at that...* ***(Adam, M, 14, NO AD)***

Adam's reasons for discontinuing with one sport were that he was not good at it and it seems that his reason for pursuing another is because of his accomplishment in it. Thus, he may wish to be involved in activities he can thrive in.

> *I recently changed to cycling. In 2010 I joined and I'm doing very well in that.* ***(Adam, M, 14, NO AD)***

Adolescents with disabilities may feel the need to be successful in a physical activity even more so than able-bodied persons as their bodies are always under scrutiny. If they do succeed in a sport they may be praised for their achievements and perseverance, but if they do not they may be embarrassed about their bodies' inability to attain certain goals.

Chris attaches shame to performance. He states that he is not ashamed of performing in front of others, but does not know why he prefers to do activities privately.

> *It's not that I'm ashamed of it. It's just...to me, it's just something that I need to do by myself. I can't really explain why, but it's for me to do it by myself.* ***(Chris, M, 18, NO AD)***

Chris may wish to first accomplish a task on his own and be certain that he will be successful in it before doing it in front of spectators. He does however identify that shame may be a reason others choose not to participate. He himself may feel this way too, but is embarrassed to say it.

> *It's hard finding players that are willing to play because a lot of them...I don't know why...but I think they are ashamed, and they choose not to play.* ***(Chris, M, 18, NO AD)***

One participant really enjoys dancing yet will not do so in front of others. Emma's shyness might not be a direct result of her impairment and it is important to realise that although it may play a part, she may be just as shy to perform in front of others if she was able-bodied.

> *R: Ja, I like to listen to pop, like hip-hop and r & b.*
>
> *I: And do you like to dance?*
>
> *R: Yes. I only do it at home.*
>
> *I: Why is that?*

> *R: Because I'm a bit too shy*
>
> *I: Do you like dancing?*
>
> *R: Yes, very much.* ***(Emma, F, 13, NO AD)***

Adolescents with CP may be ashamed of their bodies and the way they move and thus do not wish to be subjected to potential embarrassment in front of others when attempting to complete a physical activity. Further, they may be comfortable with the way they negotiate their movements but may be unsure as to how others will react.

5.4.3.2 Fear that others will tease and laugh. One participant speaks about being laughed at due to moving differently.

> *I just think when the spectators are watching them run, you know, they obviously run a bit differently. Some people are laughing at them, and they would rather hide in a corner than be exposed to that.* ***(Chris, M, 18, NO AD)***

Once again Chris does not locate these insecurities within himself, but rather as reasons why others choose not to participate. This may be a way of coping with his own insecurities. He positions "them" as others and does not seem to include himself in the category. Thus he may view people with impairments similar to his own as a separate group based on their willingness to participate.

5.4.4 Segregation versus integration.

Many participants describe their experience of marginalisation as a result of segregation between able bodies and disabled sport programmes. Some participants seem to resent this and dream of more integrated physical activities with able bodied and disabled athletes co-operating in the same teams. However this ideal of integration is not without its problems, as identified by some of the participants.

5.4.4.1 Limited number of learners with CP. There appear to be a limited number of adolescents with CP who wish to participate in certain physical activities. This makes it difficult to recruit enough individuals to populate teams or to find other teams to compete against. Disabled athletes are classified on the basis of their physical impairments and usually compete with other individuals who exhibit a similar level of impairment. This system of classification is an effort to achieve fairness but has a shadow side in that it creates segregation which leads to marginalisation. Furthermore, some individuals are not easily classified or they find themselves classified into a category where there is no one to compete against. Adam, for example, seems to acknowledge that it is difficult to classify him in competitive sport. It appears Adam is neither able-bodied nor disabled enough.

> *Honestly, no, but they couldn't really classify me because I'm not like...I am disabled, but I'm not in a wheelchair or blind...and the only judo they had was blind judo, and that is not fair because I have sight and they don't. So that wouldn't really be fair.* ***(Adam, M, 14, NO AD)***

Adam’s body does not function optimally enough to be classified within an able-bodied competitive league, yet the disabled league seems to focus on more severe physical disabilities such as blindness. Thus there seems to be a limbo in which some adolescents with CP are situated and they become marginalised from both categories. This may result in Adam feeling as though he does not belong anywhere and may further reinforce feelings of marginalisation.

> *I couldn't go with the blind judo. I'm like in between: I'm not blind, but I'm not physically normal. I'm like right in between, and they didn't have competitions for that.* ***(Adam, M, 14, NO AD)***

Adam's experience can be juxtaposed with Chris's experience of being marginalised within his own impairment classification. Although he is playing in a CP team, Chris's impairment is more severe than others so he no longer has a position on the team.

> *I'm stated as c5. That is basically the weakest player on the pitch...not necessarily the weakest...but the lowest classification. Then you get c6, c7 and c8. C8 is borderline to able-bodied. And when you want to make everything, you obviously want to bring in your strongest players, so as c5, which I am, it's the lowest classification and you get dropped. And I'm not one to be a reserve or sit on the bench the whole day in the sun. I actually want to be on the pitch, or I am not going to be there at all.* ***(Chris, M, 18, NO AD)***

This may cause Chris to feel like he does not belong anywhere as he is rejected from the physical category he has been assigned to. He responds with an "all-or-nothing" attitude and feels that if he is not actively involved, he is not part of the team.

It may be difficult to negotiate how to include adolescents in physical activity, particularly in competitive sport. However, as in all competitive sport, the best players are included in the team and by changing these rules to buffer the feelings of adolescents with CP, one may further marginalise this group as they feel they are being treated differently to others.

5.4.4.2 Marginalisation within the school. Adolescents with CP are in the minority at the school and it appears that there are not many physical activities that have been adapted to suit their needs. This can cause feelings of alienation and worthlessness. One participant seems to feel that he is less important than other learners because he is in a wheelchair and is not given the same opportunities to practice.

> *There isn't any sport really that they do. It's only the wheelchair race, but they don't worry with that. It's only when it comes close to school sports day, then they will tell you that you will be in a race. They don't practice here. They practice at home… It doesn't feel really nice, because then they leave out the wheelchairs. Like it means nothing. There are four or five wheelchair children, and most of the people are walking here, and there is no sport for them.* ***(Ben, M, 14, WC)***

It appears that Ben feels insignificant as a result of the lack of opportunities to participate. He seems to feel as if his needs (and the needs of others in wheelchairs) are being ignored.

Chris also feels that some adolescents with CP are not given the chance to achieve due to their impairment.

> *Because of them not being given a chance to excel. I mean, it's not everybody who is going to excel, but it makes it harder because you can't show your ability, because you are being outshone by a c8 that is almost an able-bodied athlete, and you are a c5 and you can't do anything.* ***(Chris, M, 18, NO AD)***

Chris considers that within the CP category there is a spectrum of impairment from almost being entirely able-bodied to not being able to do anything.

Ben and Sophia seem to justify the marginalisation that occurs when teams are selected and although they express feelings of hurt and rejection, they appear to brush it off. This may be because they do not believe that the situation could ever be changed and that they are powerless to advocate for what they want.

> *You feel really out, and upset and stuff like that. But I take it as it comes to me, because people don't really take note…It's bad, because they should really let the children practice, and we could have maybe won and whatever. But it's just a race - it doesn't really matter.* ***(Ben, M, 14, WC)***

> *On a Monday we have extramural, that's when I'm at practice. But the children who are not participating just sit and be the audience. We do that on a Monday. It's okay because some parts are funny.* ***(Sofia, F, 14, NO AD)***

The participants have different positions and experiences of marginalisation, yet many of them describe having at some point been left out and isolated from a group based on their impairment.

5.4.4.3 Activities aimed at those who are able-bodied. There are a number of physical activities that learners in the school can participate in but it appears that these activities are predominantly aimed at able-bodied learners (those with learning disabilities). One participant refers to “them” who are given the opportunity to practice yet there are no provisions made for learners in wheelchairs.

> *The children that are running, they get most of the practice here at school, and then they have to do it at home. And there's cross-country for them to practice also. There's not anything for wheelchairs.* ***(Ben, M, 14, WC)***

Ben depersonalises the group he belongs to by naming it “wheelchairs” and does not attach a concept of humanity to it. This may be because this is how he feels when he is marginalised and not given the chance to train; defined by his wheelchair and not viewed as an individual.

Participation may be facilitated through spectating, yet it does not seem that it is done willingly. Lisa mentions that they do not play, but watch while the others do. Adam explains that supporting others from the side lines for years can become tiresome.

> *Running around and swimming. At our school there is not really swimming. It's only the able-bodied people that can swim. And there is soccer, but we have to watch.* ***(Lisa, F, 16, WC)***

> *It’s like boring after a few years of cheering your team on and that. But it's exciting for the younger kids when it's like their first or their second time of doing it. So after about four or five times you cheer a bit, but you mostly sit there and watch.* ***(Adam, M, 14, NO AD)***

Spectating while others perform may make one more aware of one’s inabilities to perform certain activities and not being given the opportunity to participate in an APA may create feelings of inadequacy. With this in mind, is it possible to integrate adolescents with CP and able-bodied learners in the same activities or should we pursue different activities suited to specific needs?

5.5 The Ideal of Inclusivity

Participants seem to believe that integrated physical activities (in which able bodied and disabled athletes compete in the same team) may be unfair as adolescents with CP are not as physically capable as able-bodied adolescents. One participant, Adam, considers it fair to keep the two groups separate. Adam's discourse refers to one group as normal and the other as disabled and posits himself within the latter group. It is important to note that he is referring to competitive physical activities.

> *Well, if it was integrated it would obviously be unfair to disabled people because able-bodied people have more control and their balance is better. So I think it's okay for disabled people to compete against each other - I think that's fair - and for normal people to compete against each other. I think that's fair…There are disabled people in my race that are the same as me, or there are people who have more control and can balance on a normal bike.* ***(Adam, M, 14, NO AD)***

Adam gets particularly frustrated when the two groups are positioned against each other. He may feel that in society persons with disabilities are constantly struggling against able-bodied people.

> *Normal people. I get pretty...not upset...but angry, in a way, when it's like, hey, normal people against disabled people. That doesn't seem right.* ***(Adam, M, 14, NO AD)***

Another participant also considers it unfair to integrate the two groups as persons with disabilities are at a disadvantage. They may experience feelings of failure if they do not perform and thus should be able to compete with others of similar ability.

> *They always put able-bodied people with disability people. They always do that. I think that's a bit unfair because they are more active than the next person, so of course that person will come last.* ***(Sofia, F, 14, NO AD)***

The participants identify a large number of barriers which prevent them from participating in physical activity. These include barriers for physical activity for enjoyment and for competitive sport. Many of them seem to disagree with their exclusion but are not sure how to negotiate the current state of affairs. This disempowerment is buffered by coping mechanisms they have developed, yet these may also serve to work against them as they do not realise that they are capable of questioning the way things are.

5.6 Conclusion

Participation in physical activity for adolescents with CP appears to be influenced by a number of factors. The participants are aware of the perceived benefits of participation in physical activity but they seem to place emphasis on different benefits to those that parents may emphasise. Further, they discuss the factors that promote their participation as well as the barriers that prevent them from participating. These barriers exist on a number of levels including physiological, psychological and structural levels. In addition, the issues revolving around inclusivity are discussed. The participants express their different experiences through narratives reflecting a number of facilitators and many more barriers to their participation.

The following chapter explores the strategies the participants have employed to overcome these perceived barriers to participation.

CHAPTER SIX

Theme 3: Protective Factors and Coping Strategies Employed By Participants to Overcome Barriers to Participation

I always say that if you're going to let something like that bother you, it's going to consume you. You are going to feel, oh, I can't do that. If you join in and try, then you feel not so bad - I'm doing it and I'm trying.

(Sofia, 14 years old)

Many participants express feelings of anger and frustration when talking about the barriers they encounter to participating in physical activity and the perceived limitations of their bodies. Each participant seems to have developed their own way of making sense of these difficulties and employs strategies for dealing with the limitations imposed on them. They identify a number of strategies which they employ for dealing with the comments and reactions of others. These strategies include the use of humour, disregarding others, asserting oneself, cognitive rationalisations (such as affirming that things could be worse), adapting the activity, and appealing to their religious/spiritual beliefs. Further, the participants experience a variety of protective factors that serve as buffers to the barriers they may face. These protective factors include determination and personal resolve, acceptance and understanding, and having supportive friends and family. The coping strategies and protective factors articulated by the participants are identified and discussed in this chapter.

6.1 Humour

One participant resorts to humour to mask her embarrassment when falling in front of others.

> *I feel like a little embarrassed, but not completely embarrassed because I'm used to it. I always laugh when I fall because it shows that you're not having a fall - you are actually making a joke out of it. I always laugh when I fall, because I never almost fall, because I make sure...and I always make sure I land on my hands. I always do that.* ***(Sofia, F, 14, NO AD)***

Sofia's own laughter seems to communicate to others that it doesn't bother her, although it may still affect her personally. Through creating light of the situation, she does not have to manage other people's reactions to her falling but rather creates a comfortable space for them.

6.2 Disregarding Others

Some participants choose to ignore the comments made by others as they may feel they do not need to engage with people who do not wish to understand them beyond their disability.

One participant describes how she tends to avoid conflict and withdraws from situations where she encounters hostility or judgment.

> *No, I just left the person. I'm not a person who likes starting a fight. So I just left the person and I was like, get away. Or, I just run away...get away from that*

> *person. That's the only thing you can do. I don't do anything.* ***(Emma, M, 13, NO AD)***

Another participant resolves his conflict by not challenging the way things are and simply accepting the way society disables him. Ben may feel he does not have opinions that are worthy of being heard as he is new, or he may be waiting to assess his surroundings a little bit more before addressing issues.

> *It's fine. I take it as it comes to me for now. Because I'm new, so I don't really know how they operate here.* ***(Ben, M, 14, WC)***

A third participant displays a certain amount of resilience as she just ignores those who get in her way. Whereas Emma appears to be quite affected by the comments of others as she runs away from them, Bianca does not seem bothered. This may be denial or she may engage with enough people who accept her to counteract the negativity.

> *I enjoy myself. I don't let anybody get in my way just because I'm different.* ***(Bianca, F, 13, NO AD)***

Sophia, a participant exposed to bullying, describes how she chooses not to display her hurt as she considers it a weakness. Learning to mask pain and hurt seems to part of learning to cope for Sophia.

> *He told me that I'm worthless - things like that. And I thought, I'm never going to cry again. I don't want to feel weak, because I feel weak if I cry when people do*

> *that. I almost cried in class because a boy said, I never want to be like her. I don't know what happened, but something in my brain just said, don't cry, be strong.* ***(Sofia, F, 14, NO AD)***

6.3 Asserting Oneself

Two participants seem to reclaim their autonomy by standing up for themselves against persons who belittle them. For example, Sofia describes her response to those who make judgments about her disability as follows:

> *I told them, you think you are all that, but just get to your mirror and look at yourself and look at your faults, and then you can tell me again what you think of yourself. So stop looking at me and judging me. You don't know me. You never speak to me. So I don't even know you, but you just want to come and tell me what you think of me.* ***(Sofia, F, 14, NO AD)***

It seems that Sofia is upset by her experience of being judged on the basis of her impairment and she may feel that this doesn't define her. Due to her "fault" being so visible, she may feel that others identify her as disabled before anything else.

Similarly, Chris describes becoming angry and very defensive when others decide what he cannot do.

> *I mean, I know me, but for you to tell me that I can't, who are you? I don't tell you that you can't do this or you can't do that. So if I think I can do it, I'm going to go for it. If I can't, then I'm going to back out. Because I know what I'm capable of doing and what is hard for me to do.* ***(Chris, M, 18, NO AD)***

Chris may feel they are removing his independence by not allowing him to do certain things based on his physicality. However, he knows his own body and is aware of his own limitations and doesn’t need others to point them out to him.

6.4 Cognitive Rationalisations

Some participants contextualise their disability by placing themselves in perspective to others; they make social comparisons and acknowledge that they could be in a worse position. Doing this seems to allow them to recognise their capabilities. For example, Lisa acknowledges the difficulty she faces being in a wheelchair and notes that it limits her movement and restricts her independence. However, she puts this struggle into perspective by saying that she is not as bad off as someone who cannot talk:

> *It's difficult, you can't run around on your own and do stuff like other people. But we do get around, if you are in a wheelchair. Sometimes people can't talk.* ***(Lisa, F, 16, WC)***

It is as if Lisa reassures herself and the interviewer that while she encounters personal struggles she also has capabilities which enable her and make her more privileged than other individuals.

Participants also note that everyone struggles with something and that facing limitations is part of the human condition. Thus participants identify themselves not as disabled individuals but rather as individuals who (like everyone else) face challenges, their challenges just happen to be physical.

> *I: And do you ever feel that you want to be able to walk or run as fast as them?*
>
> *R: Ja, I feel that sometimes, but also they are having problems. I can find my own way.* ***(Emma, F, 13, NO AD)***

Another participant values his intellect and comments that although he is not physically strong, he has qualities that others may lack. While talking about the difficulties he has performing certain physical tasks, Chris hastily focuses on his strengths as opposed to his weaknesses.

> *I'm not as strong as...but I'm quite intelligent, you know. But it's things, you know...other people can't do things that I can do. It's just things we have to learn in life.* ***(Chris, M, 18, NO AD)***

Chris uses his sport acumen and interest in soccer to stay involved in the activities he enjoys by advising players on their physical performance and assuming the role of "coach".

> *With my mind I can still read the game and I can still play the game, so a lot of guys will come to me for advice because I can still see; I can create things in my mind and tell them do this or that, do this or that, just to help them out. Because they don't have the mind-set that I do, but they are physically strong and have the body that I lack.* ***(Chris, M, 18, NO AD)***

Chris acknowledges that his body is incapable of the strength and agility of his able-bodied peers and that this prevents him from taking part in competitive sport. However he reassures the interviewer (and perhaps himself) that he is able to assume a different role by virtue of his intellectual aptitude for reading the game and thus is able to fulfil a role that is not open to other physically strong athletes. He may feel that his expertise are still needed for success in a sport that he enjoys but cannot actively participate in. Thus Chris still seems to feel a sense of belonging to the team and derives satisfaction from making a meaningful and valued contribution to their success.

6.5 Modifying Equipment and Adapting the Physical Activity

Some participants describe how they are able to participate in activities and perform physical tasks by making modifications to equipment and/or adapting the tasks. For example, Adam explains how he attempts to complete things that challenge him by simplifying them.

> *I understand that I can't do that, and I must make a way around me to help me do that, but in a sort of easier way.* ***(Adam, M, 14, NO AD)***

It seems that Adam implies with the use of “I” and “me” that it is up to him to find a way to complete the task. He positions himself as the barrier that needs to be overcome as opposed to the task which could be adapted. He also positions himself as the enabler; as the one who is able to find a way around the difficulties.

Participants also describe how they have been able to modify sports equipment such as golf clubs and bicycles In order to enable their participation.

6.6 Religion and Purpose

Two participants rely on their religious/spiritual beliefs to manage their feelings about their disability. Ben believes that everyone is here for a reason, thus there must be a reason he was born with a physical impairment.

> *It's okay. I was born like this, and everybody is here on earth for a purpose. So I don't really worry with that.* **(Ben, M, 14, WC)**

Sofia also believes in her purpose on earth and instead of putting faith in medicine to mend her physically, she has put faith in God that she was born this way for a reason.

> *I used to get frustrated because none of them (operations) worked, but then I just thought, oh, well, God put us on earth for some reason, and only God can change that…This is just a phase, my disability. I also know when I die and I go to heaven, I'm going to be normal, so it's a phase to me.* **(Sofia, F, 14, NO AD)**

Sofia believes she will transcend her physical state in the afterlife and become "normal" in her next phase of life. This hope of being different one day seems to be a strategy employed by Sofia to enable her to cope better with her physical impairment.

6.7 Determination and Personal Resolve

A number of the participants display fierce determination and describe investing much time and energy in pursuing the activities in which they participate. Some participants describe taking part in regular training, sometimes under the supervision of a coach and sometimes self-initiated. It is difficult from the interviews conducted in this study to discern the reasons for the motivation and determination displayed by some of the participants. It is possible that the determination is born of a desire to prove competence, physical prowess and resilience. It is also possible that the determination that the participants' exhibit reflects the enjoyment they take in participation and the satisfaction of achieving a sense of mastery.

There may also be a host of other reasons for the determination exhibited by some of the participants, including personality factors, the involvement of parents, and the relationship they have with the coach.

> *No, it (not playing hockey) doesn't really trouble me. But you know, I don't really think of how. Even if I can't play, it doesn't affect me. I can train myself and then maybe I'll be able to, but I don't mind.* **(Emma, F, 13, NO AD)**

Adam describes drawing inspiration from elite athletes and identifies himself with those who take part in the Olympic Games.

> *You have to finish the race, otherwise people will think there's something...you're injured and that...and then I just thought, other people like great Olympians don't give up, then why am I sitting here and sobbing my eyes out. So then I carried on. Ja, and that was basically it for my first race.* **(Adam, M, 14, NO AD)**

It is interesting that Adam labels his inspiration as coming from "Olympians" and not "Paralympians", however, this may be because he does not make a distinction between the two; just as he may not make a distinction between able-bodied and disabled athletes.

A third participant feels that she is always included as she is always willing to attempt an activity. As a result of this inclusion, Sofia seems to find acceptance and belonging which motivates her to continue trying. In this way, Sofia never feels isolated from the group as she will try to perform the task to the best of her ability. It may be easier for her to do this as her CP is not as severe as some of the other participants.

> *Yes, because I never totally feel left out. That is why I do it, because I'm determined to try.* ***(Sofia, F, 14, NO AD)***

It is difficult to establish whether this determination stems from personal willpower or from a desire to prove others wrong, but this driving force acts to buffer feelings of marginalisation and worthlessness and facilitates regular and sustained participation.

6.8 Acceptance and Understanding

Accepting and understanding one's physical limitations can be an important part of managing one's impairment. One participant acknowledges that she has difficulty accepting certain things she cannot do, but she likes who she is as a person and wouldn't change herself.

> *I feel a bit sad, but I like the way I am. I would never want to change, even though I can't do other kinds of things.* ***(Bianca, F, 13, NO AD)***

Another participant expresses her acceptance through not allowing her disability to be the sole basis of her identity. Sofia looks past it and attempts everything she can.

> *I always say that if you're going to let something like that bother you, it's going to consume you. You are going to feel, oh, I can't do that. If you join in and try, then you feel not so bad - I'm doing it and I'm trying.* ***(Sofia, F, 14, NO AD)***

6.9 Supportive Friends and Family

Support from friends and family seems to further facilitate participation and promote the resilience of the participants in this study. For example, Sofia describes how she draws strength from being with people she loves. Both Adam and Emma describe how the involvement of their parents enables their participation:

> *Being with the people I love, like being with my mother.* **(Sofia, F, 14, NO AD)**

> *My parents support me in my sport and my schoolwork, and they all say I mustn't give up. So that's basically where I find my determination from.* **(Adam, M, 14, NO AD)**

Adam seems to be attributing his sustained participation to extrinsic motivation; it appears that he may be determined to succeed to please his parents.

> *They are very supportive, especially my mum. She tells me, you will find that you can walk and run soon. Ja, you'll be fine.* **(Emma, F, 13, NO AD)**

It is interesting that Emma's mother relates being "fine" with being physically able. It seems to connote that her daughter is not currently well due to her impairment and that only once she has achieved certain physical goals, will she be "fine".

Emma also feels particularly supported by her peers at school. Due to her friendly nature, they may see past her physical impairment and as a result of the length of time she has been at the school they have become accustomed to one another.

> *People appreciate me in this school. So if I say hello to them, they say hello back. They don't say, hey, why are you saying hello to me? I talk to every single person in the school. Well, I know them very well because I've been here long enough to know. But some people are new, so I don't know them. I must still get to know them.* **(Emma, F, 13, NO AD)**

Emma seems to create a nurturing role for herself, whereby she feels she needs to get to know everyone attending the school. Her extroverted personality and confidence may overshadow the stereotype people often have of persons with disabilities.

Another participant finds comfort in a close friend who also has CP. Sofia feels that her unique difficulties are understood by her friend as opposed to the “normal” things that other individuals without CP can talk about and understand.

> *Yes, that's the one reason I can say. But with other people, they won't understand if you're sad...okay, the normal things, like because of a boy or your parents they can understand...but what you feel inside, they can't always relate to that. But I'm a person who just shrugs everything off. I always tell my friend, I'm human, I also get hurt when people make fun of me. I think they don't actually know what I'm feeling, so I don't think they actually talk about me and judging me. They don't even know me, how can they just assume that's my weak spot? It's really not my weak spot. It used to be, but I got over it.* **(Sofia, F, 14, NO AD)**

Sophia’s experience is that people think she does not have the same kinds of feelings as people who are not disabled and that due to her impairment; she is a “different kind of human”. It would seem that she is saying that she has been defined by others based on her disability yet she does not consider that to be her downfall.

6.10 Conclusion

The participants in this study seem to have each developed personal coping strategies and they demonstrate different levels of resilience and experience a variety of support. It is not possible from the data gathered in this study to determine how effective or adaptive these coping strategies are. It is nonetheless evident that the participants need to employ a range of mechanisms for dealing with adversity and negative feedback if they are going to sustain their participation in physical activities.

CHAPTER SEVEN

Theme 4: What I Would Like and What I Recommend

Because that's the worst thing to do, to just decide for me. Then I will never know what to do in life.

(Adam, 15 years old)

The participants in this study identify a number of activities that they would like the opportunity to participate in. Independence, choice and greater opportunities to participate in sport and exercise programmes appear to be of central importance to these young people. Many of the participants also speak of the importance of being challenged as they have a chance to demonstrate their capabilities and improve their skills. In this chapter, I explore these themes and describe the ideas participants have surrounding what should be included in an APA programme for young people with CP.

7.1 Independence

Many of the participants in this study seem to value independence and articulate a desire to achieve this as adults. We would expect this theme to emerge in conversation with any group of adolescents who are in the developmental stage of achieving greater autonomy and separation from their parents. However for these participants the attainment of independence seems to be more difficult and more urgent because they rely so heavily on their parents for help to overcome the limitations imposed on them by virtue of their disability. Some of the participants describe their experience of well-meaning parents who are over-protective and actively involved in aspects of their lives that they imagine would not be the case for their able-bodied peers. Further, it would seem that some participants feel they are a burden to their families and do not wish to be dependent on others for the rest of their lives. Lisa, for example, describes how she does not want others to have to look after her:

> *I don't want people to say, well, we still have to look after her and stuff…I want to be fully independent. In the future it would be better for me.* ***(Lisa, F, 16, WC)***

Similarly, Sofia also feels that she doesn't want people to have to look after her as they will not be able to do that forever. She feels she will be alone one day and therefore will need to look after herself. Both Lisa and Sofia seem to express feelings of being a burden on others and although they identify that they will be alone and it will be better for them to be independent, it appears that they are more concerned about others being free from the obligation of looking after and helping them.

> *That's another thing that I hate, when I fall, I hate people to help me up because I like to be independent. I don't like people to think that I need them to help me up…I don't want people to think that I need them always, because people are not going to be around forever. I'm going to be alone.* ***(Sofia, F, 14, NO AD)***

It seems that Sofia does not want people to think she needs them. She might not want others to pity her and she is very aware that she will be on her own one day. She seems determined to do things on her own and does not enjoy her autonomy and capability being questioned. Similarly Lisa describes her desire for independence but she also articulates a need to be able to repay her parents for looking after her, by looking after them one day.

> *I want to be able to be fully independent and my parents aren't always going to be there for me and I also have to look after them. Like when I go to university I want to get a job and stuff and then look after them just to make sure they ok and stuff.* ***(Lisa, F, 16, WC)***

Adam and Chris both clearly articulate a search for independence and autonomy in their decision-making. This is evident in the quotes below where they impassionedly express their distaste for situations in which decisions are made for them without consultation.

> *Because that's the worst thing to do, to just decide for me. Then I will never know what to do in life.* ***(Adam, M, 15, NO AD)***

> *I mean, I know me, but for you to tell me that I can't, who are you? I don't tell you that you can't do this or you can't do that. So if I think I can do it, I'm going to go for it. If I can't, then I'm going to back out. Because I know what I'm capable of doing and what is hard for me to do.* ***(Chris, M, 18, NO AD)***

7.2 A Choice

Many of the participants speak about how important it is for them to be offered options and to be able to exercise choices, particularly in the context of deciding what physical activities they would like to be engaged in. The participants feel that choosing what to participate in as opposed to being told what to do is important to them. For example, Bianca describes how she does not like being forced to play a sport she does not enjoy.

> *No. When they have the soccer inter-grade, I used to sit in the library because they would force me to play, and I don't want to.* ***(Bianca, F, 13, NO AD)***

Bianca chooses to assert herself by going to the library so that she does not have to play soccer. Bianca feels she cannot even watch the others play without being forced to participate in the inter-grade soccer match. It seems that she responds to this lack of autonomy and choice by withdrawing and refusing to be party to the activity. This response seems to suggest that some adolescents might choose to assert their autonomy by not engaging in physical activities even when these are offered because it is more important to them to have a choice than it is to participate.

Emma feels that she would like to participate in swimming, but as a leisurely activity not as a competitive sport.

> *I like swimming, but I don't really want to participate. I just want to do swimming at school and what the whole school will do, but not participating for Western Province.* ***(Emma, F, 13, NO AD)***

It appears that she feels pressured into rigorous training and competition if she chooses to participate in swimming. Thus, Emma may choose not to participate at all even though she has the opportunity to, in order to avoid competition and the pressure this brings. Emma seems to want to exercise control over her level of participation and her expressed desire to do "what the whole school will do" seems to indicate a wish to take part with her peers at school rather than be in an elite squad which separates her from them.

7.3 I Want to Participate in Activities with Friends

Daisy and Ben appear to place importance on doing certain activities because their friends do them. Daisy thinks hockey is fun, but the initial reason she gives as to why she wants to play the sport is because all of her other friends play it.

> *R: Because all of my other friends plays hockey and…and it's fun.*
>
> *I: And how does it make you feel when they play hockey and you don't get to participate?*
>
> *R: Upset.* ***(Daisy, F, 12, NO AD)***

It seems to be important to Daisy to feel like she belongs and that she can do activities with her friends. She may wish to maintain the relationships she has with her friends and may feel unable to do this when she is excluded from an activity that all of her other friends participate in. It seems that missing out on this engagement, makes her feel further isolated from her friends.

When Ben is asked what sport he would like to play, he mentions soccer. His friends play soccer and he watches them play, but it appears that he would like to be actively involved if he could be. It seems that it is not only the soccer that appeals to him but the fact that his friends play this sport and thus it provides an opportunity for him to build peer relationships.

> *I: If you had a choice, what sports would you like to take part in?*
>
> *R: Soccer.*
>
> *I: Soccer. Is it a big one? Do your friends play soccer?*
>
> *R: Yes.*

> *I: And then do you watch them play?*
>
> *R: Ja.* ***(Ben, M, 14, WC)***

7.4 Greater Opportunities

A number of participants speak about wanting to be given more opportunities to participate in activities. Adam, for example, feels marginalised as a disabled athlete and expresses his perception that persons with disabilities are ignored in South Africa.

> *I feel that in South Africa they notice normal people - and that's it. They don't really see there's another type of person that's disabled. And the cycling over here in South Africa is pretty good, but other sports for disabled people are not good…I just wish that sport in South Africa for disabled people was more recognised.* ***(Adam, M, 15, NO AD)***

It is apparent that Adam is wishing for a greater range of sports for disabled athletes to be on offer but he also seems to be asking for recognition (to be seen and taken notice of). Many of the participants identified activities that they would like to have the opportunity to participate in. Ben, for example, articulates a desire to participate in wheelchair basketball even though he knows not know anyone who plays this sport.

> *I: Are there other activities you would like to participate in?*
>
> *R: Wheelchair basketball.*
>
> *I: Do you know anybody that plays wheelchair basketball?*
>
> *R: No.*

> *I: Where have you seen it before?*
>
> *R: On the TV.* ***(Ben, M, 14, WC)***

Adam wants the opportunity to go on camps; particularly sports camps which are aimed at persons with disabilities. I understand Adam's idea of "camps" to mean a place that offers accommodation with organised recreational activities for young people to participate in, much like the American concept of a "summer camp".

> *And also camps...like I want to go on a camp, but it might be too physical for me, and there's not a camp in Cape Town or South Africa for disabled people.* ***(Adam, M, 15, NO AD)***

Spending time at a camp with other individuals and participating in focused activities may create a space to learn new skills and also have intense coaching over an extended period of time. It could also be an opportunity to spend time with other adolescents who have similar interests and may create a space that fosters friendships. Adam feels that camps are generally aimed at people who are more physically capable than him. This seems to point to some anxiety that he may not be skilled or strong enough to cope with such activities.

7.5 Challenge

Some of the participants in this study described their experience of activities designed for disabled athletes that had been over-simplified and hence not at all challenging. These participants were not only dissatisfied with the lack of challenge but also seemed to feel that such "special treatment" was insulting and incongruent with their notion of equality. Chris, for example, feels that sometimes the rules are “clipped” to benefit persons with disabilities which is both unfair and unchallenging.

> *What I don't like about the disabled league is the fact that they clip the rules to benefit the disabled people. To me, you've got to treat everyone with the same brush. Yes, okay, we are not capable...or it's more challenging and harder for us to do the things of an able-bodied person, but just keep it the same. But you know, keep us on the same level, so let all the c5s play and let all the c6s play so you are competing against people with the same body strength as you.* ***(Chris, M, 18, NO AD)***

Chris acknowledges that he and other persons with motor impairments may not be as physically capable as able-bodied athletes; but he feels that it is still important to be challenged by an activity. This may be because accomplishing a task is more meaningful when you have worked hard to complete it. Chris feels it is important to treat everyone equally regardless of their capability levels and he suggests that creating an even playing field where people of the same ability compete against one another is a possible solution. Chris seems to contradict himself as he wants everyone to be treated equally but also for everyone to compete against persons of similar body strength, that is. with the same level (or lack of) impairment. He may view this equality as a level playing field in competition in terms of competitors but with the same rules of the sport applying in spite of the group playing.

Adam seems to feel that taking away the challenge makes succeeding in it less rewarding. It appears that he has experienced things being made too easy for him due to his impairment.

> *You don't really throw a real javelin because they don't want to put the kids in danger, so it's like where you have to throw a cotton wool…I would rather throw the real material, like the real metal, and challenge myself than something that's easy, and do well.* ***(Adam, M, 15, NO AD)***

Adam says that they do not throw the real material in order not to put the kids in danger, but any person (not just a person with a disability) yielding a javelin could place people in danger. Thus, he seems to feel that he is being treated unfairly and as if he is not capable of handling equipment.

Ben appears to believe that people in wheelchairs are ignored and are thought to be incapable of doing anything. He says that they can also do something and practice and may feel that he has not been given the opportunity to do so because of other people’s impression of the capability of people in wheelchairs.

> *I would say that people in wheelchairs can also like do something. So we just have to sit around and wait for the time to go by, when we could have practiced for whatever.* ***(Ben, M, 14, WC)***

These participants convey that they are also capable of participating in activities that are challenging and should be given the chance to engage in activities suited to their abilities as opposed to being excluded.

7.6 My Dreams

When asked what they imagine for their futures and what they wish for many of the participants articulated a desire to no longer have a physical motor impairment. Daisy, for example, wishes for her hand and leg to be "right" one day.

> *To have my hand and leg be right…and…that's all.* **(Daisy, F, 12, NO AD)**

Daisy wishes that she no longer has a physical impairment. She appears to consider what other dreams she may have but ends with stating that that is all she wants. It is as if this dream is accomplished then everything else she wants could be achieved.

The first wish Ben mentions is also related to his physical impairment.

> *I want to walk, do sport, and become a radio DJ* **(Ben, M, 14, WC)**

Adam's dreams also centre on his physical state, but they are positively related to what he can do as opposed to what he can't.

> *I would like to carry on cycling for many years and hopefully one day go to the Paralympics.* **(Adam, M, 15, NO AD)**

He has goals relating to elite sport and wishes to be a Paralympic athlete one day. He does not wish to be rid of his physical impairment but rather to utilise it to his advantage. He is talented at a sport and with motivation and determination he may be very successful in it.

Chris expresses the desire to skydive and bungee-jump.

> *R: I've always wanted to skydive. I've set a goal, from 22 to 25, I want to skydive at least once…I mean, there are a lot of able-bodied people who are too scared to do it, and I just want to show them that even though I'm different, I'm still able. Many people would say you are not able to do it - you can't do it - and I just want to show them...not out of spite or whatever...I just want to show them that anything is possible. I would also like to bungee-jump.*
>
> *I: Can you tell me about that?*
>
> *R: Like I say, I just want to fly. I just want to go for it and dip. I want to experience it. I heard it's an adrenaline rush.* ***(Chris, M, 18, NO AD)***

It appears that Chris's reasons for wanting to sky-dive and bungee jump are, at least in part, to prove that despite his physical impairment he is able to accomplish a goal that frightens even those who are able-bodied. He emphasises that although he is "different", he is still "able". Chris seems to want to show that he is capable of doing anything he puts his mind to and to show others that he can do something even if they think he can't. Further, skydiving and bungee-jumping may give the sense of defying one's own body as you are flying through the sky, everyone is the same. He wants to "experience this" and it may make him feel he is able to defy his physical state and impairment.

Emma's expresses a wider array of goals, many of which do not relate to her impairment:

> *I would wish that I could get out of school. I like school, but just the work that you must do here. And then I would wish that I could get more friends. I would wish to achieve all my wishes, like with the cooking, I would wish to achieve the new recipes, or with swimming, that I could swim faster.* ***(Emma, F, 13, NO AD)***

Emma wishes to be out of school already, which may be something that many adolescents wish for as they want to be independent. Further, she speaks of wishing for something related to her physical being and her desire to swim faster. Emma may experience swimming as a leisurely activity and may enjoy the element of floating and being free from her physical state. However, she also wishes to succeed in it.

Sofia dreams of travelling and pursuing interesting careers.

> *I wish I can go to Paris. Okay, I wish for that because I want to be a singer or a journalist…Okay, I would like to have a family. Ja, just live a happy life and get old with my husband. And go to university.* ***(Sofia, F, 14, NO AD)***

The dreams expressed by the participants differ significantly from one another. These dreams highlight different aspects of their personalities, interests and capabilities, many of which are completely un-related to their disability. This is significant because it reminds us of a theme that re-occurred frequently in the interviews – the participants desire to be seen outside of the metaphor of a "disabled person".

7.7 Things That Should Be Included In a Sports Programme

The participants identify things they think are important when designing an APA programme for adolescents with motor impairments. Competition and recognition of achievement seem to be important to some of the participants. Programmes should be fair and inclusive and provide an opportunity for participants to succeed within their perceived reach. Further, participants should be actively involved and a level of enjoyment should be maintained. The participants voice these ideals yet many of them have different definitions for what constitutes these goals as is made apparent in the extracts from interviews presented below.

7.7.1 Competition.

Some of the participants express a desire to compete in activities and be recognised for their achievement. Lisa believes that the starting point for creating a programme should be to get more people to join and divide them into teams based on strength and ability. The advantage of this seems to be that it would enable people to compete with and against other individuals of the same strength.

> *To try and get more people, so that we can have different teams to see who is the strongest. Then we can take it from there.* ***(Lisa, F, 16, WC)***

7.7.2 Recognition.

Lisa also places importance on having trophies and hence being recognised for physical achievements.

> *I: What else (would be important)?*
>
> *R: And trophies and stuff* ***(Lisa, F, 16, WC)****.*

Lisa seems to value the competitive aspect of sport and wishes to be rewarded when she achieves. Adam also appears to place importance on recognition, but he feels that everyone should receive something for participation, not only those who have excelled.

> *Maybe like have a prize-giving once a year to commemorate that person and say, hey, you did well in this, you deserve something. And even the people that didn't do so well in their positions, they should also get a prize to say thank you for being in this team - so that they don't get left out.* ***(Adam, M, 15, NO AD)***

Adam seems to place high value on inclusion and making everyone feel as if they belong. His choice of the word "deserve" when somebody does well at something as opposed to saying "thank you" to someone who didn't do so well may indicate that whilst everyone should be included in a prize-giving, a hierarchy of awards should still exist based on achievement. This may reflect the participants desire to maintain fairness and not over-simplify the activities. Awards for excellence should be given to those who deserve them and whilst participation awards should be granted, a difference should exist in this recognition procedure just as it would at any prize-giving.

7.7.3 Fairness and inclusion.

Many of the participants speak about the importance of physical activity programmes being fair and inclusive. However, they seem to differ quite considerably with respect to what they consider constitutes fairness and who should be included. Lisa, for example, says that a programme should be fair and that able-bodied people should not be included.

> *I: But you think we should try and make it fair?*
>
> *R: Yes.*
>
> *I: So you shouldn't include able-bodied people?*
>
> *R: No.*
>
> *I: So how would we decide who wasn't able-bodied?*
>
> *R: I don't know, the strength of their throw.* ***(Lisa, F, 16, WC)***

It appears that Lisa feels fairness will be achieved if able-bodied persons are excluded along with those who are physically strong. Adam has a slightly different ideal and believes in a kind of inclusive-soccer that would be offered to all people who have physical impairments (including deaf and blind individuals).

> *Soccer for...not necessarily for disabled people...soccer for all the types of physical needs…I think it should be like a mix of deaf people, people who have a bit of balance and not some balance. Have some blind people on that to make it fair…So everybody would be included with physical needs, or people that weren't good would also be included, so nobody would ever be left out.* ***(Adam, M, 15, NO AD)***

Adam distinguishes between “disabled people” and people with “physical needs”. He suggests the addition of blind people to make it fair, yet mentioned a number of other physical impairments without making this consideration. He may consider blindness to be a severe physical impairment and that by including persons who are blind, one is being fair and inclusive. He says that everyone with physical needs should be included and then adds that people who “weren’t good” should also be included. He doesn’t clarify whether these “people” are able-bodied or have impairments, but his ultimate goal seems to be giving everyone a chance. It seems that he does not want anyone to be excluded or feel left out. He does not seem to be focused on achievement or winning through choosing the strongest athletes, but rather on participation and inclusion for all.

Sofia says that activities that a learner with CP can do should be incorporated into the physical education programme at school. She suggests shot-put be offered as she feels it is an activity that everyone can participate in, including learners without physical disabilities.

> *When they have PT, they should do shot-put or something that a CP learner could do. And they should have more, how do I say, more sporting activities for the disability children. They should have like a shot-put group, even with able-bodied people, and that's one thing everybody actually could do. That's what I like doing. That's the only two things I think they should do.* ***(Sofia, F, 14, NO AD)***

One of the participants, Chris, discusses how inclusion and fairness could be achieved by "disabling" able-bodied learners, for example by blindfolding sighted individuals. Chris feels that while doing this may level the playing field, it could place learners with impairments at an advantage.

> *Interviewer: Well, are you saying that we should have basketball and then put everyone in wheelchairs, and that levels the playing fields? Or play cricket, but everyone is blindfolded. I wonder what your thoughts are about that?*
>
> *Chris: I mean, I agree with that, because then it levels the playing field because we are all on the same level so it challenges you. But then again, it also makes us as disabled people stronger because we are used to that. We have been in that wheelchair for how long. You, as an able-bodied guy, you are just in the wheelchair for the first 15 minutes of your life. You are in this wheelchair, and now you need to roll, move and adjust yourself. So then again, the playing field*

> *isn't really all that even. So the only way of doing it is making the same people on the same playing field.* **(Chris, M, 18, NO AD)**

Chris seems to acknowledge that while fairness is an ideal it is not simple to achieve especially in the context of competitive sport where individuals (able-bodied and disabled) have varying levels of strength and ability. He seems to propose that athletes should be grouped together according to some characteristic although he acknowledges that this would not foster inclusivity and would in effect create a kind of segregation.

> *I: And that makes a lot of sense to me. I'm worried a little bit, and this is what I want to test out with you, is that it's a kind of form of segregation…Because you used the analogy that we all have different races and different religions, so it's like saying, okay, all the Muslim kids over there, all the Catholic kids over here and all the Jewish kids over there. So I'm worrying about that, and I wonder if you have any thoughts?*
>
> *R: I understand exactly what you mean. And, to me, that is the only variable or downfall of my way of changing the games…Because then you won't be exposed to different things, like Catholics and whatever, so then it's apartheid all over again. You know what I mean? But in the same sense, it evens up the playing field, so it cancels it out, for me, because of me getting weaker. That is why I had to drop out. But had I been on the same playing field with the c5s, I'd possibly still be playing today.* **(Chris, M, 18, NO AD)**

It appears that for Chris a fair programme would be one which centers on placing learners with the same physical impairments in teams and allowing them to compete against others with the same abilities.

Being actively involved in physical activities appears to be an important part of fostering fairness and inclusion for Adam. Adam feels that anyone who is able to go onto the field should be given an opportunity to do so.

> *People who could go onto the field, like people that can walk or at least can run a bit, but people that have no feeling in their legs, they could hand out drinks to the team or give motivation if they are losing…So they would always be included in the participation of that league or that team - they wouldn't be left out… No, it wouldn't be as fun as taking part. But, in a way, you do help because you can't just have players and no supporters. So they would still feel part of the team.*
>
> ***(Adam, M, 15, NO AD)***

Adam seems to be using a very broad definition of participation that includes both being a spectator and a supporter. He does, however, recognise that being a supporter may not provide the same level of enjoyment as actively participating, but a team cannot succeed if it does not have supporters. He seems to be acknowledging that competitive sport inevitably involves an element of selection and that consequently not everyone will be able to be on the pitch or included in a team. He also appears to value the role of spectators and supporters who witness and applaud the performance of the athletes. Similar to Chris, Adam focuses on team sports and how a programme can include as many people as possible. Whereas Chris feels participants should be grouped according to specific ability, Adam feels that everyone who is capable of participating should be able to join. Chris may be focused on physical activity in a more competitive manner whilst Adam may be more concerned about enjoyment and including everyone who is able to partake.

7.7.4 Enjoyment and excitement.

Many of the participants identify the importance of enjoyment and excitement. Adam, for example, articulates his perception that enjoyment is an important component of a physical activity programme. He also says that being well matched to your roll enables enjoyment. He draws a link between enjoyment, competence and perseverance and seems to be suggesting that in order to promote on-going participation, sports programmes should be enjoyable and should allow the athlete to feel competent.

> *And they should be put in their favourite positions, or positions that suit them, or that are right for them and that they all do well in…Because it's useless putting a lousy person as goalkeeper, and they can't persevere in that position or maybe get further in that sport one day…Because obviously they want to be in a position that they can both enjoy and persevere in.* ***(Adam, M, 15, NO AD)***

Chris articulates his perception that physical activity programmes should include a certain level of excitement. He equates excitement with activities that “make you shake” presumably with anticipation. He also associates excitement with speed and challenge, which seems to imply that an element of fear and danger are important to him.

> *The excitement. This thing (gestures to his legs) could be shaking and I should stop it, that's exciting. I mean, the pace, you have to incorporate those things. You can't just...yes, it's hard for them to do it, but you need to find ways to make it still exciting, but also helping them at the same time. Because I do find that a lot*

> *of games that are made for disabled people or clipped down for disabled people are kind of boring, and that is also part of the reason why I don't choose to do it.* ***(Chris, M, 18, NO AD)***

Chris maintains that activities that are “clipped down” for persons with disabilities are boring. Chris comments that this is one of the reasons he stopped participating. Chris seems to acknowledge that although programmes need to be modified (“clipped down”) for disabled athletes, this should not make them bland, unchallenging, unexacting and unexciting.

7.8 Conclusion

All the participants have clear (albeit different) ideas about what they would like and what they consider to be important elements of a physical activity programme for adolescents with CP. This lack of a consensus highlights the uniqueness of the individuals and the need for a diversity of programmes. It also points to some of the elements that should be included to provide options and promote and sustain participation. It would seem from the findings of this study that those who seek to design sports programmes of adolescents with CP would be well advised to make these programmes fair, challenging, and exciting. Including opportunities for computation also seems to be important along with prizes (awards), recognition and spectators/supporters. Providing athletes with a range of opportunities and allowing them to make choices and feel independent and competent would also promote sustained participation. The opportunity to participate with friends and establish and build peer relationships would also help encourage participation. Lastly the participants in this study believe that any programme should be inclusive although they acknowledge that the concept of inclusivity is incongruent with competitive sport which by necessity entails an element of selection for the team.

CHAPTER EIGHT

Theme 5: Perceptions of Staff Members at the School

The interviews conducted with the Headmistress, Life Orientation educator (LO) and the head of Physical Therapy (PT) add a secondary layer of data to the study and provide a context for the participants' stories. This chapter sets out to describe the staff members' experiences and perceptions of the benefits, facilitators and barriers to participation in physical activity for learners with motor impairments. They are offered here to augment and contextualise the findings reported from the interviews with the adolescents.

8.1 Benefits of Physical Activity

The LO educator identifies a number of benefits of physical activity that may help to buffer the difficulties faced by adolescents with CP. He seems to perceive a change in their attitudes, towards themselves and towards others, as well as an increase in confidence as a result of taking part in physical activity and gaining a sense of mastery.

> *Just the attitude itself. I mean, you have somebody that's closed off and is coming out of his shell. I mean, sport is the best. I use sport for everything…And just the attitude itself (not just towards their peers, but to themselves as well) much more confident self-image and self-confidence. Everybody is coming. They can run and they can do exercises, which is a fantastic thing for them. I'm very happy about that.* ***(LO)***

Physical activity may help to create bonds between adolescents and build self-esteem. The LO educator is "very happy" about the improvements he sees and it appears that he derives a certain level of personal satisfaction from this. Thus his motivations may be linked to his interest in the learners as well as the personal gratification he gains from seeing them develop through sport.

8.2 Positive Influences

The LO educator and PT identify a number of factors which may contribute to the successful participation and motivation of learners. These include their individual personalities as well as support from their parents.

> *I would say it very much depends on the personality, like you and I, some people are very motivated to exercise and know it's good for them and they need it and some people know that it's good for them and know all the benefits but still don't exercise…Ja and of course support from family. But I would say majority, a big percentage of that influences them is their motivation.* ***(PT)***

It is important to note that the PT considers each child's motivation as intrinsically personal and not characteristic of having a disability. She illustrates this with the use of her words like "you and I"; some people are motivated and some are not. The PT may make this observation more easily than others as she works with the learners on a one-on-one basis.

Parents also provide a strong support base. The PT views this motivation as secondary to the child's attitude, whereas the LO educator seems to place more significance on this.

> *The parents support them. The parents are very, very supportive, which is a great thing.* ***(LO)***

This perception could be because the LO educator requires parents to be more committed and involved in the success of his sport as they provide transport (where they can) and purchase sports attire. The PT on the other hand sees the learners during school time so may therefore have less interaction with parents.

Finally, the LO educator considers their attitude, as well as his own, to have an influence on their ability.

> *Because they think they can't do anything, but there is so much that they can do.* ***(LO)***

Belief in oneself can be a driving force behind participation and the PE educator may feel that his belief in and support of the learners may facilitate their belief in themselves.

8.3 Perceived Barriers to Participation

The staff members also articulate a number of barriers towards physical activity within the school. These include structural barriers such as financial constraints and competing demands, curriculum restrictions, overburdened educators, transport issues and time restrictions. Further, they speak of the marginalisation of learners with motor impairments and the hardships faced by the learners as a result of these barriers.

8.3.1 Financial constraints and competing demands.

Although the school is well resourced, the headmistress comments that there are serious financial constraints and many needs present in the school such as a need for the repair of buildings, more classrooms and more educators. Thus, money is not available for sporting equipment or specialised staff to coach sport as they are secondary needs. This issue is reinforced by the PT and LO educator. Limited financial resources are the first barrier mentioned by the PT, thus it appears that she may consider this the greatest obstacle to increasing opportunities for learners with disabilities to participate in physical activity in the school. The LO educator also considers finances to be the main barrier.

> *Money resources, financial resources and human resources are the main obstacles really.* ***(PT)***

> *I think it comes down to finances. Finances will be the problem.* ***(LO)***

Space also appears to be a resource constraint since there is a lack of sufficient physical space for sporting facilities to be placed.

> *There's no space, so they've been looking at the old garage to maybe redo and make it into like a little mini gym.* ***(PT)***

8.3.2 Life Orientation (LO) curriculum.

The curriculum that is currently in place seems to be aimed at learners in mainstream schools. LO is a compulsory subject, however, the education department does not seem to take learners with special needs into account when stipulating the content of the curriculum or when considering how the curriculum can be simultaneously offered to able-bodied and disabled learners in the same class. The headmistress states that this makes it difficult to deliver this curriculum in a school that caters for a range of disabilities (not just physical but also individuals with emotional/psychological and learning disorders). Inevitably this may result in physically disabled learners being marginalised during LO lessons.

The PT also feels that more time should be given to physical education in the school curriculum. It appears that if it is given more time during school hours, learners will be able to benefit more from physical activity.

> *Ja that would be lovely. We dream of the times when the government will decide that physical education, all types of physical education needs to be back at school. Then it's done within school hours as a school curriculum subject.* ***(PT)***

The PT seems to place the power to effect these changes within government structures and it seems that a certain level of blame is placed on the government for the current situation. While this may be (at least in part) true, it also externalises the problem and absolves educators from responsibility. Her use of the word "dream" makes it seem as though she does not believe that things can change.

The PT places further blame on the curriculum for the future of physical activity due to the CAPS system being introduced. The CAPS system will combine subjects which will result in even less time being given to physical activity.

> *Now with this new departmental CAPS something programme that there is very limited amount of time that children can spend doing something else not being in the classroom.* ***(PT)***

The LO educator seems to take a far more optimistic approach and he feels that he is able to adapt the physical activities for learners with CP. He considers education and potentially the education system as a barrier with its mainstream approach, yet he views this as a challenge he can overcome. It is important to note that the PT has been at the school for ten years and the LO educator for one year, thus she may be more attuned to the realities facing the school whereas he is enthusiastic and may have more energy to be optimistic and creative.

> *Well, obviously with regard to the different challenges that we've got with different learners, and the barriers for education on the whole and in general. We are having a mainstream approach basically, where I know what to do, but when I found that we had learners in wheelchairs and with cerebral palsy, I had to...for me, I didn't see it as an obstacle. I saw it as a challenge for me to think outside of the box, and come up with new ideas or new strategies where I could just facilitate them and help them with regard to physical activities.* ***(LO)***

The PT and LO educator have a vested interest in the physical exercise and rehabilitation of the learners and clearly support the idea that “sport is good for people”, thus they may place more importance on this aspect of schooling. In comparison other educators may think that formal schooling and the academic curriculum should take precedence in the school day. Further, learners with special needs may take longer to complete tasks and may require extra attention, thus educators may feel that time in the school day is limited. It appears that the education department does not take special needs learners (especially those with physical impairments) into consideration when creating the curriculum.

8.3.3 Educators reluctant to take on extra sporting duties.

The headmistress notes that although the educators in the school are dedicated and committed, they are overburdened with their core-business (teaching).They are reluctant to take on extra responsibilities (especially on the weekends) because these entail taking more responsibility for the learners and an additional demand on their scarce and valuable time. Further, she articulates that the responsibility of taking learners with disabilities out is greater than would be the case if the educator was taking a group of able-bodied learners out. This extra responsibility and energy is also a lot to require of educators.

The PT seems particularly concerned about their lack of training in physical activity and sports coaching. As a health care professional who is equipped with the skills and experience to work effectively with adolescents with CP, she may be concerned that educators may not know what physical activities are suitable or how to coach them correctly.

> *I find that the teachers are doing it but they certainly not equipped to do it and maybe and you need to have a motivated person that is dedicated for just that and not a teacher who is thinking about marking all the papers and everything else and let's face it, some teachers aren't sporty or not interested in sport so they can't, so that teacher's class is certainly not going to be motivated to do sport because she herself or him himself are not interested in it.* ***(PT)***

The PT may also feel that there is a lack of motivation from educators as their primary focus is on the schooling of the students and thus may not be interested in sport. She places emphasis on the importance of having a person who is interested in sport and motivated to involve learners in physical activity at the school. Due to competing needs and time, the staff currently at school may be unable to meet all of the needs of the learners and as a school, the main focus is on formal education with a secondary focus on physical education.

8.3.4 Restrictions due to transport.

The school caters for a wide catchment area and as a result many of the children are bussed to school. According to the headmistress, some learners get fetched at 6:30 am in the morning and only get dropped back at home at 4:00 pm. This is a long day with not much extra time or energy for sporting activities.

The PT also voices this concern and it has an impact on the organisation of weekend sports too. It appears that many parents do not have transport and if they do, they may not be willing to bring their children to school on a weekend.

> *Our school caters for children from many areas uhm there isn't like, if they want to do sport, they can't stay after school for very long because we've got busses going. They need to leave as the bus goes and they leave like 3 o' clock from high school every single day, so there isn't that leeway as well and if there's anything on like the Saturday or on the weekend that they would want to organise, it's also difficult from a transport point of view. Parents, not all parents have transport, and I think we've got in every school parents who are not interested, you know using a weekend day to do sport with their child.* ***(PT)***

The PT is aware that this is not a problem that is necessarily specific to their school, as in any school there may be parents who are uninterested in their children's involvement in physical activity.

The LO educator appears rather optimistic about physical activity in the school; however, when being "honest" he admits that transport is a large barrier. The school provides transport for games at other schools but the educators must wait for each learner to be picked up after.

> *(Transport) is quite a nightmare, to be honest with you. If we are playing away they are with us, so they travel with us and we'll bring them back to the high school and to the primary school. Then the parents pick them up, so we need to wait until the last, last parent comes to pick them up.* ***(LO)***

Transport seems to pose a great problem and acts as a significant barrier to greater participation in physical activity. The school provides transport and there is a rigid schedule which limits the amount of after-school activity that can take place as well as weekend activities.

8.3.5 Time limitations.

A large number of activities are on offer at the school including golf, soccer, athletics, billiards, bottcher, drama, dance, archery, and others. However, there is only one timeslot, consisting of one hour in the week for these activities. Thus, the learners have to choose between a variety of activities and may not be able to participate in their activity of choice. Learners with CP often have to attend occupational therapy or physiotherapy during this time slot, thus they are not given the opportunity to participate in physical activity.

> *It's just an hour of that sort of free sport time then I think learning disabled go into their sport during that hour and physically disabled children have to get onto the bus, be driven here and then they split. Some do sport, some do physio, some children stay and do drama. So there's definitely unequal amount of time and that, you know, spent.* ***(PT)***

The PT feels that this may be unfair and that the learners with physical disabilities have to make sacrifices due to their disability.

> *They have to, a lot of disabled children have to choose now between drama between physio and between sport which we feel we all of us sort of try to argue it and fight it and we feel that it is almost unethical to make them make that choice because they should have the access to all three but that's what we for now faced with.* ***(PT)***

The PT argues that this choice is unethical. She feels that learners with physical disabilities should be able to participate in all the activities, yet due to their impairment they are marginalised from certain activities and not given the opportunity to participate as they have to attend therapy sessions instead.

8.3.6 Marginalisation of learners with motor impairments.

In addition to the constraints of finances and time, learners with CP may be further marginalised from physical activities due to limitations in learner numbers. The PT comments that the majority of learners in the school are learning disabled and they have sporting needs different to those of learners with CP. This may result in sport being more geared towards learning disabled adolescents as they are physically more capable and may be able to participate in a greater variety of activities. Further, due to their larger numbers, they may be able to form teams and more time may be dedicated to their physical enrichment due to their majority status.

> *Definitely there is because I think we've got a majority of children are learning disabled and their sporting needs are so different to what the disabled group has…Something like that would be good. But I think because we don't have a big number of a similar disability, it's difficult to speak about a group sport.* **(PT)**

The LO educator explains the variety of sports on offer at the school, many of which seem to be aimed at learning disabled children.

> *Soccer…Swimming is quite big. Cross-country is quite big. We've got archery. We've got athletics, which is huge. We've got billiards as well. We've got table tennis as well. There's chess. There's golf…Able-bodied kids, we always start with a cardio workout. We are also doing a lot of endurance, a lot of fitness and a lot of cardio work. We are focusing a lot on cardiovascular work fitness with them. The second term is usually your winter sports. We do football...that's the dominant figure. So a lot of ball sports take place in the second term. The third term, that's where they will design a course and they will do that for me, and they will get a moderator to look after that. The fourth term would be a combination of everything, and leading up to a build-up for the following year, because we all know that in six weeks of holidays nothing happens. So usually it's a build-up we do with them.* ***(LO)***

When asked about what activities are specifically aimed at learners with physical disabilities, the LO educator responds with "what do we still have" before listing a variety of activities. This shows that perhaps the range of physical activities for physically disabled learners has become more limited over time. This may make participants feel as though they do not matter as much as learners with learning disabilities and that their needs are not as important.

> *I: Do you have any sports that's specifically geared for the relatively physically-disabled, so children in wheelchairs or on crutches?*
>
> *R: Sport for them?*
>
> *I: Ja.*
>
> *R: Athletics we have. We also have, what do we still have, there is wheelchair basketball that we're going to bring into the school system as well, into the curriculum. They are all doing different exercises like cardio workouts. We've now got punching gloves and that, where they need to punch.* ***(LO)***

The LO educator is far vaguer about the physical activities on offer for physically disabled learners. This may be because there is a greater variety on offer for learning disabled students and he may have more of an interest in the coaching of these activities. There may be more of an opportunity for learners to succeed and thus for him to attain status in competitive leagues.

When talking about the learning disabled learners, the LO educator predominantly uses the pronoun “we”. He may associate more closely with them as they are physically more similar than learners with physical disabilities. Although he probably does not purposefully make this distinction, he later refers to the physically disabled learners as “them”, thus making this discrepancy clearer. The “we” he speaks of also seems to indicate a multi-disciplinary team which is at work in the school and it seems as though the different professionals involved with the physical aspects of the learners work together to create effective programmes.

> *We've got the wheelchair learners doing exercises. I'm working in relation with the physiotherapist, so I know what areas I must go. I'm working on strengthening…The disabled ones, once again, we are just working...because you can't do a lot with them… so it will always be gradual. So we increase it all the time, and we always try and incorporate different exercises with it.* ***(LO)***

He refers to the "disabled ones" who you 'can't do a lot with'. These preconceived ideologies about what they can't do, may influence educators' willingness to create a variety of programmes for "them". While there may be learners who are very limited in their physical ability, there are learners who are more physically capable and their needs may also be ignored as they are grouped into a category of the "disabled ones". Further, it appears that the main focus of these exercises is on strengthening as opposed to enjoyment.

8.4 Potential Difficulties for Learners as a Result of these Barriers

The PT emphasises the importance of building friendships with one's school friends. Due to learners not having many opportunities to participate in activities after school, they do not have as much time to socialise with their peers and mostly only see them during the school day. They may be missing out on important physical and social skills such as learning new activities, building teamwork and solidifying friendships.

> *I think that if we study together and we do sport together and we then after school each other together it builds up that team spirit and that. Our kids are missing that because after school they are in their communities and they don't see each other outside school hours…they're not accepted in the communities where they*

> *are, it's just it's not the same. Ja their school friends are not there and we see with other with colleagues' children mostly they make friends at the school and then they carry on those relationships…they don't have those friendships in the community.* ***(PT)***

School may be a central place to facilitate these friendships and the learners (both learning disabled and physically disabled) seem to be missing out due to previously mentioned constraints. They may also not be fully accepted in their communities as they are not at school with children who live nearby. Further, it may be difficult for peers from school to visit each other after school hours due to far travelling distances and a lack of transport. Therefore the concerns the PT is expressing may relate to no place of belongingness and a difficulty in creating meaningful relationships for the learners.

The PT is aware of the specific physical difficulties learners with motor impairments experience due to their disability. Bones and bodies may grow, however, muscular strength and capability may stay stagnant. Thus, they do not necessarily become weaker as they get older but rather their muscles may reach a certain threshold.

> *As they grow, their body and bones will become like very heavy for their muscles that are, say their muscles are at level 3 power and they will stay that with training and that, they will mostly stay that but because of the bigger body it's now they appear to be weaker rather than stronger even with the therapy because they go through growth spurts, they might need surgery that all weakens them. That's why all of them, physically disabled children, need to carry on with physio for as long as possible to notice when they're going through a growth spurt and maybe give or change, alter exercise or you know carry on with exercise while*

> *they are going through the growth spurt coz during their growth spurts anything can happen, there's scoliosis and imbalance of the muscles become more apparent and they will go into more poor gait and things like that.* ***(PT)***

Adolescents with CP may find themselves struggling to perform as well as they did when they were younger in comparison to their able-bodied peers. This may cause lowered self-confidence and feelings of not wanting to participate in physical activities. The PT expresses that adolescence may be a particularly tough phase, especially for adolescents with disabilities:

> *That's a hard age period (adolescence) for anybody and for children with a disability even more so.* ***(PT)***

Participation in physical activities for enjoyment may help to improve these feelings and create a renewed sense of self-worth, competence and camaraderie.

8.5 Conclusion

The staff members identify numerous benefits of physical activity as well as positive influences which may facilitate participation in physical activity. In terms of barriers to participation, the staff members seem to place more emphasis on structural barriers than the participants. This may be because they are more involved with the managing of these resources and thus experience difficulties more directly at this level. As the PT mentions, he does not ask learners what they would like to do as often as he should. Thus, the staff members may not be aware of the vast number of limitations on multiple levels experienced by the learners as they have not asked them directly. It is important to combine the perceptions of the educators with those of the adolescents when planning an APA programme as both groups have valuable knowledge relating to their roles within the system.

CHAPTER NINE

Discussion, Recommendations and Limitations of This Study

9.1 Introduction

This study aimed to explore the lived experiences of adolescents with CP with a particular focus on their involvement in physical activity. The interviews with the participants yielded a number of different and interesting perspectives on their individual experiences. Further, I interviewed three staff members (the headmistress, the life orientation (LO) teacher and the head of physical therapy (PT)). These interviews added a secondary layer of data of factors which may influence the participation of learners with motor impairments in physical activity. The data was analysed using interpretative phenomenological analysis (IPA) which aims to give voice to participants and subsequently attempts to make meaning and provide interpretations of their voiced experiences (Larkin & Thompson, 2011). I grouped the results into five broad themes which covered in detail the variety of narratives, namely: (1) “When they call me cripple” – what it means to have a motor impairment, (2) My experience of physical activity – perceived benefits, facilitators and barriers to participation, (3) Protective factors and coping strategies employed by participants to overcome barriers to participation, (4) What I would like and what I recommend, and (5) Perceptions of staff members at the school.

While the goal of qualitative research is not to fit one’s findings into a generalisable form, it is interesting to compare the results to those of similar studies. In this chapter, the findings are discussed through the lens of the theoretical framework which aims to explain the psychological and social factors that influence an individual’s participation in (or avoidance of) physical activity (Lutz et al., 2004). This theory is based on able-bodied individuals, thus it is interesting to compare the perspectives of adolescents with disabilities to this framework. Following this, the perceived barriers and benefits of physical activity are discussed in accordance with similar studies. Finally, the recommendations, limitations and conclusive remarks of this study are presented.

9.2 Psychological and Social Influences to Participation in Physical Activity

Lutz et al.'s (2004) theoretical framework comprises four overarching components focusing on the psychological and social factors which have an influence on participation in physical activity. They are self-presentation, social influences, social support and cohesion and were presented in detail in chapter two.

9.2.1 Self-presentation.

Self-presentation refers to engaging in any type of behaviour that is somewhat motivated by how we want others to see us (Lutz et al., 2004).

9.2.1.1 Body images, eating disorders and obsessive exercise. Adolescents generally have heightened body awareness and those with disabilities may have an even greater focus on the way their bodies look. Li and Chen (2012) also found management of weight to be a facilitator of physical activity in their study with adolescents with CP in Hong Kong. However, in this study, only one participant commented on physical activity as a way to manage her weight. She became frustrated that she was unable to participate in activities that may keep her physically fit. As a young adolescent girl, she may be focused on the way her body looks, however, not all adolescents are overly conscious of their bodies. This lack of obsessing over exercise and body image from other participants may be a result of individual personalities. Further, it may be indicative of the challenges adolescents with impairments face to pursue any physical activity. The issue of weight maintenance doesn't seem to have as great an influence on their motivation to participate perhaps because factors such as just being able to participate may be more important to some of them before these factors can even be considered.

9.2.1.2 Social physique anxiety. Social physique anxiety refers to how anxious a person is about their physical body when others are observing their physique and their desire to present their physique in a positive way (Lutz et al., 2004). Social physique anxiety seems to be a psychological barrier to participation for many of the participants. Some of the participants do not enjoy being watched when performing physical activities. This may be because they are unsure of their ability to complete a task successfully and may feel judged in their failure to do so. Further they may be embarrassed about the way their bodies move and may be afraid others will tease and laugh. One participant attaches shame to performance and thinks that many of his physically impaired peers choose not to participate as they are ashamed of the way their bodies move. If the participants feel they cannot present their physiques in a positive way, they may choose not to participate at all. It appears that social physique anxiety has a large impact on the participants' decision not to participate in physical activities. Adolescents with motor impairments may feel that their bodies are under greater scrutiny than able-bodied peers because they move differently, thus the fear of being judged and not being able to present one's body in a positive way may make them choose to withdraw from physical activity. A contradiction to this appeared in the narratives of some participants as they wished to take part in an activity which is witnessed by spectators. These participants may want to be judged in activities they feel confident in performing in order to allow their bodies to be viewed in a positive and athletic way instead of as a "body-of-illness".

9.2.1.3 Social facilitation and social loafing. The term social facilitation has been used to explain people's tendency to increase their level of physical performance when they feel they are being evaluated by others (Lutz et al., 2004). In contrast, when a person feels as though their physical performance is not easily identifiable, they tend to engage in social loafing and their performance level decreases (Lutz et al., 2004). While many of the participants mentioned that they do not enjoy performing in front of others, when they do engage in sport it appears that competing and winning are crucial facilitators to participation. Four of the participants mentioned that winning is one of the things they enjoy about participating in sport and two of the participants mentioned the importance of prize-giving when planning a programme. Although they do not wish to be judged and tend to avoid participation, it appears that their physical performance may increase when they are in a space where they feel they can succeed. Thus, competing and being judged on a fair playing field may be a social facilitator for the participants. Social loafing did not appear to play a role in the participants' narratives. The participants appear to feel that their movements are always judged, regardless of where they are. Even if they are exercising on their own, they may be judging their own progress as they need to maintain a certain level of physical activity in order for their muscles not to stiffen.

9.2.2 Social influences.

People may be prone to do what others want them to do (Lutz et al., 2004). The participants mentioned a range of influences that have an impact on their attitudes towards physical activity. These include the influence and involvement of parents; the opportunity to spend time with friends; and the experience of success and attainment of goals. Further, the participants spoke of physiological and psychological barriers which may prevent them from participating.

9.2.2.1 Social norms and the theory of planned behaviour. People can be influenced to engage in or avoid certain behaviours based on what their peers and society accept as norms (Lutz et al., 2004). Different norms appear to be present for girls and boys within the group of participants. The female participants identified talking, listening to music and watching movies as activities they enjoyed doing with their friends, with one participant commenting that they used to play, but no longer do. This notion is supported by a systematic review conducted on the factors which influence adolescents with CP's participation in physical activity (Shikako-Thomas et al., 2008). The researchers found that the older a child or adolescent is, the less likely he/she is to participate in activities (Shikako-Thomas et al., 2008). While this appears to be the case amongst the female participants, some of the male participants report that they still enjoy playing physical games with their friends. However, this may also be determined by their level of physical ability, as one of the male participants in a wheelchair engages in sedentary as opposed to physical activities with his friends. Thus the social norms related to people in wheelchairs and their ability to participate in physical activities may have an influence on his decision to not participate.

The LO educator seems to reinforce these social norms as he speaks of the "disabled ones" that you can't do a lot with. Prescribing to this norm may lead him to discriminate against learners with more severe disabilities and not focus on creating activities that are adapted to their needs.

One participant in particular, Chris, seems determined to defy the norms society has placed on him as he takes on activities in order to prove that he is capable. Further, many of the participants value winning and accomplishment and this enjoyment may be linked to defying the norms and expectations peers and society have of them and other adolescents with motor impairments.

9.2.2.2 Attitudes and persuasion. The theory further states that our attitudes towards physical activity are shaped by those around us and certain people may be able to persuade us to participate or not participate due to the influence they have on our lives (Lutz et al., 2004). Many of the participants mentioned their parents as having a strong influence in their lives. Two of the male participants in particular attributed their participation in certain physical activities to parental influence. Shikako-Thomas et al. (2008) also found that parents' preference towards certain activities can influence participation in physical activities for children and youth with CP. Parents may also play a role in avoidance of certain activities and it appears that many of the participants' parents are overprotective, particularly the female participants. Li and Chen (2012) found that overprotective parents can act as barriers towards participation and this appears to be evident with some of the participants. Parents may generally be more overprotective of adolescent girls than of boys, and with the addition of an impairment, this may increase. The PT and LO educator also consider parental influence to be an important facilitator of participation and the LO educator feels his own attitude towards activities may also have an influence.

Peers also appear to influence the activities the participants choose to participate in and one participant in particular appeared to choose a specific sport on account that her friend played it.

9.2.2.3 Attitudes and cognitive dissonance. The final factor that the theorists attribute to social influence is that of attitudes and cognitive dissonance. This relates to people wanting their attitudes and actions to be congruent (Lutz et al., 2004). This did not appear to be a strong influencing factor within this group of participants. However, choosing not to participate in certain activities for fear of failure may be explained by wanting one's beliefs about oneself and one's actions to be congruent. At the same time, one's desire to prove others wrong and acting on these cognitions may also be explained by this part of the theory.

9.2.3 Social support.

The participants identified a number of support structures that facilitate their participation in physical activity. These include support from parents, friends and teammates. People often exercise because they gain social support and may continue to participate in physical activity if family and friends encourage them to (Lutz et al., 2004). One participant spoke about participating in activities with friends as making her feel like she belongs. Another participant seemed to value support and belongingness quite highly too as a motivation to continue to participate in a specific activity. When participating in physical activity a person may feel a sense of belongingness and social importance (Crone et al., 2006). This may create a sense of engagement and involvement and create a sense of purpose, thus increasing one's mental well-being (Crone et al., 2006). Feeling supported by friends and family appears to promote resilience in some of the participants, with three participants specifically commenting on how they draw strength from their parents and peers.

When the participants are excluded from an activity (i.e. spectate while others participate due to their impairment), they may feel inadequate and may further withdraw from future participation as they have not been given the opportunity or encouragement to participate. However, when given the opportunity to participate, the participants emphasised the desire for recognition of their goals attained. Positive reinforcement and confidence boosting are important components in the maintenance of exercise and when absent may cause an apprehension to participation (Lutz et al., 2004). This appears to be true of many of the participants as when they feel they have successfully accomplished a task or are recognised for an achievement they may be more encouraged to continue participating.

9.2.4 Cohesion

The final influence identified by Lutz et al. (2004) pertains to cohesion within a group engaging in physical activity. Cohesion is important as it helps to develop and maintain goals as well as promoting a sense of belongingness (Lutz et al., 2004). A sense of belongingness appeared to be very important to one person in particular and many participants discussed the importance of attaining goals. However, cohesion appears to be difficult to foster in this participant group. This could be due to a number of barriers, mainly existing on a structural level. There are a small number of learners with CP in the school, thus it may be difficult to form teams. The PT expanded on this as she comments that due to the majority of learners in the school being learning-disabled, opportunities to participate in activities seem to be aimed more at them. Further, it appears that it is difficult to classify CP learners into teams as they are either too disabled or not disabled enough. As a result, the participants may find it difficult to foster friendships and fulfil belongingness needs as they are not given the opportunity to participate as often.

There also appears to be a lack of facilities and staff members willing to take on extra responsibilities in the school. All of these factors may lead to a space where it is difficult to foster cohesion, thus making it even more difficult to facilitate participation. However, some of the participants have adapted to this and have taken on different roles in order to feel as though they belong to a team. One participant in particular uses his intellectual aptitude for sport to aide his teammates by assuming the role of coach as he cannot participate on a physical level with physically stronger peers. Thus through the identification of another strength, he is able to fulfil a role not open to other physically strong athletes and cohesion may be achieved.

In addition to this, a number of the participants had ideas as how to foster cohesion in APA programmes. These suggestions include encouraging more learners to participate and creating programmes that promote inclusion. Although the participants had different ideas as to what they would do to create an inclusive programme, the focus was on fairness and giving everyone a chance to participate whether it be in competitive leagues or in social sports.

While many of the psychological and social influences to physical activity as laid out by the theory apply to adolescents with impairments, there are definite differences as a result of the unique experiences of these participants. Some of these seem to be due to having an impairment, while others may be because they are adolescents. Finally, their individual personalities seem to have an influence on their specific experiences.

Aside from how the participants' experiences can be located in this theoretical framework, it may also be of value to compare their perceptions to what has been found in other research. The following part of this discussion will explore how the participants described their lived experiences in terms of what it means to have an impairment to them in comparison to the models that set out to explain disability. Further, the barriers and benefits to participation as identified by the participants are compared to what has been found in similar studies.

9.3 Definitions and Experiences of Disability

Most of the participants used biomedical explanations to describe the nature of their disability. They located their disability within their bodies with the medical profession as having the power to cure them. The medical profession plays a powerful role in modern western society and their biological explanation of disability has informed a stereotype which society still adopts today (Brittain, 2004). It appears that many of the participants have adopted this view and thus seem to have accepted that things are the way they are with not much room for change. While the participants medicalised their disabilities, they did identify a number of barriers in their surroundings that prevent them from being able to participate in physical activity.

A number of these barriers was placed within themselves such as the physical difficulties they experience when completing certain tasks as well as tiring easily. Further, they mentioned a number of psychological barriers such as embarrassment about performing in front of others for fear of falling or being teased and laughed at. Some of the participants seemed to place this fault within themselves whereas others focused on “other” people who judged them. In conjunction with this, most of the participants identified structural barriers such as financial and transport resources as well as a lack of facilities and opportunities in their school. Thus it appears that they feel that society has disabled them too.

The social model of disability views society as the disabling force which through environmental, structural and cultural barriers prevents the impaired individual from fully participating in his or her community (Olive & Sapey, 2006). Thus it appears that both the social model and medical model play a role in how these adolescents describe and experience their impairment. This may provide evidence of the complexity of living with an impairment and that it is a complicated human experience, unique to each individual living with an impairment who cannot be removed from his or her context nor his or her personal experience. While the ICF's biopsychosocial model may better encompass the intricacies of disability, speaking to people about their impairments and their experiences of it may give us a better idea of the reality and meaning of living with an impairment.

9.4 Barriers to Participation

Some of the barriers the participants spoke of were similar to what was found in other studies. However, some of them differed which could be due to personal experience and their specific context. Thus the aim is not to generalise the findings but rather to compare them to similar studies in order to realise what further research can be done in this field.

9.4.1 Physiological barriers.

The participants experience difficulty completing certain activities due to their impairments and one participant has stopped competing in sport as a result of this. Further, some of the participants talked about how tiring physical activity can be and that it can sometimes be painful. Li and Chen (2012) found that the participants in their study also associated negative experiences to physical activity with pain, injury and disability-related complications. The PT discussed a physical difficulty that appears to be specific to learners with CP. CP is not a progressive disorder but it can change over time and can range in severity (Sherrill, 2004). Thus muscular strength is difficult to improve upon and adolescents with CP are often “left behind” in sport as their peers may improve physically whereas they may reach a threshold. Further, one’s physical ability may be in constant flux depending on operations and amount of time spent on physical activity. A large amount of determination is required to maintain a level of physical fitness for adolescents with CP and the participants identified psychological barriers which prevent them from participating.

9.4.2 Psychological barriers.

Daley (2002) argues that people who have had negative experiences with physical activity may develop a “psychological resistance” to participation in exercise programs. The participants spoke about being embarrassed to perform in front of others for fear of falling, being teased or laughed at. This may be based on experiences they have had in the past where they have felt judged by others, particularly by able-bodied peers but also by other peers with disabilities. Thus, the hierarchy of disability the participants identify may act as a psychological barrier to participation as they may feel inadequate to perform in front of peers with learning disabilities and able bodies. Shikako-Thomas et al.’s (2008) study also identified segregation, bullying and staring as barriers to participation.

Coates and Vickerman (2008) found that children had good experiences of physical education when they felt included in lessons and bad experiences were associated with being isolated from activities and when they felt incompetent in an activity. This appears to be similar for the participants in the present study as they may feel judged if they participate and may not feel they can complete tasks successfully. Further, due to being marginalised from activities these cognitions may be reinforced by external factors. The LO educator acknowledged that he does not ask the learners often enough about what activities they would like to participate in. When teachers make decisions about what is best for children with disabilities without being informed by the children themselves, it may lead to feelings of disempowerment (Coates & Vickerman, 2008). This could make the participants feel even further marginalised and as if their opinions don't matter which could act as another psychological barrier to participation. In addition to this, structural barriers in the environment may lead to further exclusion.

9.4.3 Structural barriers.

Many of the participants spoke about living far away from school and that it is difficult to participate in activities due to transport problems. The PT, LO educator and Headmistress all spoke about these transport issues too and that most of the children are bussed to and from school. While this acts as a barrier to the participants in this study, Levin (2006) stresses that schooling for children with CP is limited to a number of specialised schools that are not accessible to most of those living with the disability and a large percentage of children and adolescents with CP do not receive any form of an education or exposure to physical activity. Although this school was originally established as a school for children with CP, the school was opened to children with other disabilities after the passing of White Paper 6. Thus while the participants are fortunate to be attending a specialised school, they appear to be marginalised within the one place that was created specifically to suit their needs as they are now in the minority.

Educational curricula have also not considered the needs of physically disabled learners in their LO syllabi as is emphasised by the LO educator and PT. The implementation and delivery of services to those with disabilities is considered to be the onus of local government as it is the closest level of government to the people, however, provincial government creates the syllabi for schools (Department: Provincial and Local Government, 2009). According to Coates and Vickerman (2008), teachers often do not feel equipped to teach children with special needs and struggle with adapting the current curricula for children with special needs.

The PT appears to place a large amount of blame for the lack of opportunity for physically disabled learners to engage in physical activity on the curriculum in place whereas the LO teacher welcomes the challenge to adapt the syllabus. The PT and the headmistress also both mention the financial constraints the school faces as well as teachers being unwilling to take on more responsibilities. While it may be a well-resourced school, there are other competing needs in the school that place physical activity lower down on the list of priorities. While only one student mentioned finances as being a constraint to participation, the Headmistress, PT and LO educator placed a large amount of importance on it as a structural barrier. Thus, the learners may not realise the financial implications of creating APA programmes and that it has an influence on many of the other barriers they face. It is argued that the local government should be privy to making some of these changes by integrating disability elements into budgets and legislations and creating and employing programmes which are beneficial to those with disabilities (Department: Provincial and Local Government, 2009).Thus, it appears that while a number of groups of people are party to the exclusion of learners with physical disabilities from participation in physical activity, they may not be communicating effectively with one another and may be shifting blame and responsibility onto one another.

9.5 Benefits of Participation

The participants spoke of a number of benefits of physical activity on a physiological, psychological and social level. They attributed the physiological benefits of exercise to strengthening their bodies and staying healthy and fit. The participants spoke quite objectively of these benefits, as if they were aware that it is good for them, but may not be the main reasons why they would choose to engage in activity. The psychological and social benefits identified by the participants appeared to be more personal to them and may act as greater facilitators to participation. The following part of the discussion will focus on these perceived benefits.

9.5.1 Psychological and social benefits.

Many of the participants felt that physical activity provided a distraction from everyday stress and was a useful tool to release anger and frustration. Children and adolescents with disabilities are often spoken for by others and the anger of feeling ignored may be suppressed (Goodwin et al., 2004). Thus, engaging in physical activity may help to release some of these feelings. This can be supported by the distraction hypothesis which proposes that physical activity acts as a diversion from stress which may lead to psychological well-being (Daley, 2002). Further, reaching goals and gaining affirmation during physical activity may provide a distraction from other negative thoughts (Craft, 2005).

Reaching goals was emphasised by a number of the participants and they expressed feelings of excitement in being able to participate in activities they previously couldn't be part of. Two participants in particular became excited about participating in activities they enjoy and are capable of completing. The LO educator also spoke of experiencing a change in attitude and an increased self-confidence in learners as a result of participating and gaining a sense of mastery in physical activities.

The self-efficacy theory states that physical activity can provide a platform for a person to gain mastery over a skill and thus promote his or her self-efficacy and self-confidence (Craft, 2005). Adolescents with CP may not often be given the chance to participate and achieve in physical activities due to previously mentioned barriers, however, the participants place a lot of value on goal attainment and feeling successful. Thus APA programmes may improve not only their physical well-being but also give them a sense of inclusion and improved self-confidence and capability. Physical activity allows a person to take charge of setting goals, enhancing self-confidence and creates an opportunity to build social self-esteem if participating in group activities (Donaghy, 2007).

Participation in group activities and with friends can facilitate a sense of belongingness. Two participants spoke about wanting to participate in activities with their friends and one participant spoke of appreciating the social support he gains from participating in an activity. When participating in physical activity a person may feel a sense of belongingness and social importance which may create a sense of engagement and purpose, thus increasing one's mental well-being (Crone et al., 2006). While this is a theoretical benefit of physical activity and was mentioned by some of the participants, other participants may not have had the opportunity to experience this as they have been excluded from physical activities. However, most of the participants spoke about promoting fair and inclusive programmes when designing an APA programme. Thus, they may wish to attain these benefits of support and social belongingness that they have potentially missed out on so far.

In addition, three participants spoke about having fun as a benefit of physical activity. The level of enjoyment of engaging in a particular physical activity appears to be a mediator of the level of participation (Hagberg et al., 2009). Finally, similar to the present study, Li and Chen (2012) found that positive experiences of physical activity were related to enjoyment with friends and that the participants in their study wished to participate in activities with friends.

Participation in physical activity can lead to improved physical and psychological well-being. The participants spoke about what they perceived to be the benefits of physical activity and it appears that some of them have not had the opportunity of being exposed to the benefits that physical activity can provide.

9.6 Recommendations

Further studies should be conducted with groups of adolescents with disabilities other than CP as well as in other areas of South Africa. This will give a more rounded understanding of the experiences of adolescents with disabilities and will better inform projects that could be developed. Further, this research can be used to inform APA programmes which could be designed for adolescents with CP. It should be kept in mind that the aim of this research was to explore the individual accounts of disability from a small number of participants in order to gain a detailed understanding of personal and unique experiences. Thus, it cannot be assumed that all adolescents with CP or other disabilities feel the same way and it is important to conduct studies with more groups in the future in order to expand our knowledge on this subject. Persons with disabilities cannot be classified as a group of people who all experience the same needs as a result of their disability because this further perpetuates othering and social injustice.

9.7 Limitations

The limitations of this study may lie in the fact that the study is not largely generalizable. Further, participants may have chosen not to divulge certain things as a result of the space limitations. A focus group may have provided the participants with a chance to express more as they may have felt more comfortable speaking with their peers around as opposed to one-on-one with an adult. This could also have provided an opportunity to create a sense of belongingness between participants as they discussed similar experiences. This could be considered for future research and may yield useful findings which could be compared to the findings of this study.

9.8 Conclusion

This research aimed to understand the experiences of a group of adolescents with CP; particularly their experiences of their bodies and their involvement in physical activity. Shikako-Thomas et al. (2008) emphasise the importance of identifying a child's preferences to activity-involvement and their barriers to participation. The participants appear to value inclusion, independence, choice and opportunity in their lives and in physical activities. Children and adolescents with special needs want to have their opinions heard and value autonomy; however this is often overshadowed by the perspectives of teachers and parents (Coates & Vickerman, 2008). While it is important to keep in mind the perceptions of teachers and parents as they do have value in terms of planning an APA programme, the needs of the children as expressed by them should also be taken into account. As expressed by one participant, people assume that she may have an intellectual impairment just because she has a physical impairment and thus may not know what she wants or needs. However, children and adolescents with special needs know how they feel and know what they want and want to be given the opportunity to assert their independence (Coates & Vickerman, 2008). In addition to this, it is the responsibility of researchers and practitioners to advocate at policy levels in order to increase support, resources and implementation of programmes for youth with CP (Shikako-Thomas et al., 2008).

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Addendum A: Interview Schedule for Children and Adolescents

1. How would you describe your relationship with your body?

2. What physical activities have you participated in?

3. Where did you participate in these physical activities?

4. What was your experience of these activities?

5. Do you enjoy participating in physical activities?

6. What kinds of physical activities would you like to participate in?

7. What barriers may stop you from participating in these activities?

8. What may support you in participating in these activities?

Addendum B: Interview Schedule for Staff Members

1. What is the range of motor impairment in the children and adolescents you work with?

2. What is the response of the children and adolescents to participation in physical activity?

3. What role does physical activity play in the lives of children and adolescents with disabilities?

4. What are the difficulties you experience when working with children and adolescents with disabilities?

5. In your opinion, what facilitates successful participation in physical activity for children and adolescents with disabilities?

6. How do you think the current physical activity programmes being offered could be improved?

7. How do you think that adapted physical activity improves the well-being of children and adolescents with disabilities?

8. How would you describe access adapted physical activity for children and adolescents with disabilities as a human rights issue?

9. Do you think adapted physical activity could serve as a transformative agent in changing attitudes towards people with disabilities?

Addendum C: Consent to Participate in Research (For Parents)

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STELLENBOSCH UNIVERSITY
CONSENT TO PARTICIPATE IN RESEARCH (FOR PARENTS)

Title of study: Everyone has the right to participate: Exploring the lived experiences of children and adolescents with motor disabilities and their involvement in adapted physical activity

You are asked to participate in a research study conducted by Lauren Conchar (MA Psychology), from the Psychology department at Stellenbosch University. These results will contribute to a masters' thesis. Your son/daughter was selected as a possible participant in this study because he/she is between the ages of 10 and 18 and has a motor impairment and/or cerebral palsy.

1. PURPOSE OF THE STUDY

This research aims to explore how children and adolescents with motor impairments and cerebral palsy experience their bodies. It includes questions about how the participant feels about his/her body and what kinds of physical activity he/she has taken part in in the past and is currently taking part in. It also aims to find out how he/she has experienced these activities and what other activities he/she would like to take part in in the future.

2. PROCEDURES

If your son/daughter agrees to volunteer to participate in this study, we would ask him/her to do the following things:

Participate in an individual interview with the researcher. Be observed by the researcher while he/she is engaging in physical activity. This interview will take approximately 40 minutes.

3. POTENTIAL RISKS AND DISCOMFORTS

Your child may become uncomfortable when talking about certain issues. Your child may end the interview whenever he/she wishes too. A counseling psychologist, Dr. Jason Bantjes, will be on-call during all the interviews if counseling is required.

4. POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY

The participant will not benefit directly from participation in this study. This research will be used to develop an adapted physical activity program suited to fit the needs of children with similar disabilities as the participants. The research will also add to the disability studies and psychology fields. Our understanding of South African children and adolescents experience of physical activity may inform future research and interventions.

5. PAYMENT FOR PARTICIPATION

The participants will not receive payment for participating in this study.

6. CONFIDENTIALITY

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law. Confidentiality will be maintained by means of restricted access to the data. Only the researcher and her supervisor will have access to the data. The data will be kept in an office space that will be inaccessible to those not involved with the research. Anonymity will be maintained in the research paper and no birth names will be used.

7. PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you don't want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise which warrant doing so.

8. IDENTIFICATION OF INVESTIGATORS

If you have any questions or concerns about the research, please feel free to contact

Principal Investigator:	Lauren Conchar Tel no: 082 884 9482 Email: lconchar@gmail.com
Supervisor:	Dr. Jason Bantjes Tel no: 021 808 2665 Email: jbantjes@sun.ac.za

9. RIGHTS OF RESEARCH SUBJECTS

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as a research subject, contact Ms Maléne Fouché [mfouche@sun.ac.za; 021 808 4622] at the Division for Research Development.

SIGNATURE OF RESEARCH SUBJECT OR LEGAL REPRESENTATIVE

The information above was described to [*me/the subject/the participant]* by [*name of relevant person]* in [*Afrikaans/English/Xhosa/other]* and [*I am/the subject is/the participant is]* in command of this language or it was satisfactorily translated to [*me/him/her*]. [*I/the participant/the subject]* was given the opportunity to ask questions and these questions were answered to *[my/his/her]* satisfaction.

[I hereby consent voluntarily to participate in this study/I hereby consent that the subject/participant may participate in this study.] I have been given a copy of this form.

____
Name of Subject/Participant

____
Name of Legal Representative (if applicable)

____ ______________
Signature of Subject/Participant or Legal Representative **Date**

SIGNATURE OF INVESTIGATOR

I declare that I explained the information given in this document to __________________ [*name of the subject/participant]* and/or [his/her] representative ____________________ [*name of the representative]. [H*e/she] was encouraged and given ample time to ask me any questions. This conversation was conducted in [*Afrikaans/*English/*Xhosa/*Other*] and [*no translator was used/this conversation was translated into* ___________ by _______________________].

____ ______________
Signature of Investigator **Date**

Addendum D: Participant Information Leaflet and Assent Form

STELLENBOSCH UNIVERSITY

FACULTY OF HEALTH SCIENCES

PARTICIPANT INFORMATION LEAFLET AND ASSENT FORM

TITLE OF THE RESEARCH PROJECT: Everyone has the right to participate: Exploring the lived experiences of children and adolescents with motor disabilities and their involvement in adapted physical activity

RESEARCHERS NAME(S): Lauren Conchar

ADDRESS: 7 Columbar street
Kleingeluk
Stellenbosch
7600

CONTACT NUMBER: 082 884 9482

What is RESEARCH?

Research is something we do to find new knowledge about the way things (and people) work. We use research projects or studies to help us find out more about disease or illness. Research also helps us to find better ways of helping, or treating children who are sick.

What is this research project all about?

This research wants to explore how children and adolescents with motor impairments and cerebral palsy experience their bodies. It includes questions about how you feel about your body and what kinds of physical activity you have taken part in in the past and are currently taking part in. It also aims to find out how you have experienced these activities and what other activities you would like to take part in in the future.

Why have I been invited to take part in this research project?

You have been invited to take part in this research because you are between the ages of 12 and 18 and you have a motor impairment and/or cerebral palsy.

Who is doing the research?

My name is Lauren and I am doing my masters degree in psychology. I am interested in finding out more about how children and adolescents with cerebral palsy and motor impairments experience their bodies and physical activity.

What will happen to me in this study?

The researcher will have a one-on-one interview with you and ask you some questions about the topics that have been mentioned above. These topics include questions about how you feel about your body; what kinds of physical activity you participate in; if you enjoy these activities; and what physical activities you would like to do.

Can anything bad happen to me?

Nothing bad can happen to you during this research. Some of the questions the researcher asks you might make you feel uncomfortable, but you are allowed to say that you do not want to answer a question.

Can anything good happen to me?

This research will be used to plan an adapted physical activity programme to suit your needs. It will use the information about what you like to do and what you to do to create something that matches your needs.

Will anyone know I am in the study?

Everything you say in the interview will stay between you and the researcher. Nobody else will know what you have said.

Who can I talk to about the study?

Dr. Jason Bantjes
Tel no: 021 808 2665

Lauren Conchar
Tel no: 082 884 9482

What if I do not want to do this?

You do not have to be interviewed if you do not want to be. Nothing bad will happen if you decide not to participate in the research. You can decide at any time during the interview to stop if you do not want to do it anymore.

Do you understand this research study and are you willing to take part in it?

YES	NO

Has the researcher answered all your questions?

YES	NO

Do you understand that you can pull out of the study at any time?

YES	NO

________________________________ ________________________

Signature of Child Date

Addendum E: Consent to Participate in Research (For Staff Members)

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STELLENBOSCH UNIVERSITY
CONSENT TO PARTICIPATE IN RESEARCH (FOR STAFF MEMBERS)

Title of study: Everyone has the right to participate: Exploring the lived experiences of children and adolescents with motor disabilities and their involvement in adapted physical activity

You are asked to participate in a research study conducted by Lauren Conchar (MA Psychology), from the Psychology department at Stellenbosch University. These results will contribute to a masters' thesis. You were selected as a potential participant because you interact with children and adolescents with cerebral palsy and motor impairments through physical activity.

1. PURPOSE OF THE STUDY

This research aims to explore how children and adolescents with motor impairments and cerebral palsy experience their bodies. It includes questions about how the participant feels about his/her body and what kinds of physical activity he/she has taken part in in the past and is currently taking part in. It also aims to find out how he/she has experienced these activities and what other activities he/she would like to take part in in the future. The research further aims to describe the insights which teachers have developed through offering adapted physical activity programmes to children with disabilities.

2. PROCEDURES

If you agree to volunteer to participate in this study, we would ask you to do the following things:

Participate in an hour-long individual interview with the researcher.

3. POTENTIAL RISKS AND DISCOMFORTS

You may become uncomfortable when talking about certain issues. You may end the interview whenever you wish too. A counseling psychologist, Dr. Jason Bantjes, will be on-call during all the interviews if counseling is required.

4. POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY

The participant will not benefit directly from participation in this study. This research will be used to develop an adapted physical activity program suited to fit the needs of children with similar disabilities as the participants. The research will also add to the disability studies and psychology fields. Our understanding of South African children and adolescents experience of physical activity may inform future research and interventions.

5. PAYMENT FOR PARTICIPATION

The participants will not receive payment for participating in this study.

6. CONFIDENTIALITY

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law. Confidentiality will be maintained by means of restricted access to the data. Only the researcher and her supervisor will have access to the data. The data will be kept in an office space that will be inaccessible to those not involved with the research. Anonymity will be maintained in the research paper and no birth names will be used.

7. PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you don't want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise which warrant doing so.

8. IDENTIFICATION OF INVESTIGATORS

If you have any questions or concerns about the research, please feel free to contact

Principal Investigator:	Lauren Conchar Tel no: 082 884 9482 Email: lconchar@gmail.com
Supervisor:	Dr. Jason Bantjes Tel no: 021 808 2665 Email: jbantjes@sun.ac.za

9. RIGHTS OF RESEARCH SUBJECTS

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as a research subject, contact Ms Maléne Fouché [mfouche@sun.ac.za; 021 808 4622] at the Division for Research Development.

SIGNATURE OF RESEARCH SUBJECT OR LEGAL REPRESENTATIVE

The information above was described to [*me/the subject/the participant]* by [*name of relevant person]* in [*Afrikaans/English/Xhosa/other]* and [*I am/the subject is/the participant is]* in command of this language or it was satisfactorily translated to [*me/him/her*]. [*I/the participant/the subject]* was given the opportunity to ask questions and these questions were answered to *[my/his/her]* satisfaction.

[I hereby consent voluntarily to participate in this study/I hereby consent that the subject/participant may participate in this study.] I have been given a copy of this form.

____

Name of Subject/Participant

____

Name of Legal Representative (if applicable)

____ _______________

Signature of Subject/Participant or Legal Representative **Date**

SIGNATURE OF INVESTIGATOR

I declare that I explained the information given in this document to ___________________ [*name of the subject/participant]* and/or [his/her] representative ______________________ [*name of the representative]. [H*e/she] was encouraged and given ample time to ask me any questions. This conversation was conducted in [*Afrikaans/*English/*Xhosa/*Other*] and [*no translator was used/this conversation was translated into* ____________ by _________________________].

____ _______________

Signature of Investigator **Date**