

**AN ANALYSIS OF THE EXPERIENCES OF  
CHILDREN WITH CEREBRAL PALSY  
IN THERAPEUTIC HORSE RIDING**

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Submitted in fulfilment of the requirements for the degree of  
Doctor of Philosophy,  
in the Graduate Programme in Psychology,  
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October 2009

## **DECLARATION**

Submitted in fulfilment of the requirements for the degree of  
Doctor of Philosophy, in the Graduate Programme in Psychology,  
University of KwaZulu-Natal, South Africa.

I declare that this dissertation is my own unaided work. All citations, references and borrowed ideas have been duly acknowledged. I confirm that an external editor was not used. It is being submitted for the degree of Doctor of Philosophy in the Faculty of Humanities, Development and Social Science, University of KwaZulu-Natal, South Africa. None of the present work has been submitted previously for any degree or examination in any other University.

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## **Acknowledgements**

Grahame Hayes, my supervisor, for facilitating the development of my critical thinking skills over the years.

Henriëtte vd Berg, for co-supervision of this thesis and motivational support.

My sister, Shamila Naidoo - this thesis is yours as much as it is mine.

My niece, Johara, for switching on the light, literally and figuratively.

Our parents, for encouraging our academic pursuits over the years, and for assisting us with the practical resources to do so.

Elder Sir, Mazzy, Agility and Inca, trusted steeds who led me to the field of therapeutic horse riding.

The children, who along with their parents, teachers and therapists, made this study possible.

Janette Stolts, the staff, and horses at the therapeutic riding school.

Joanne Folkins of Big River, B.C. and Hester Steyn of Glen Skye, whose wisdom and support has been just an e-mail away during this study and over the years of friendship.

Eline vd Merwe, Andri Henning, and Emma and Werner Booysen, for an enduring friendship and practical support of various forms during the course of this study.

Jill Bradbury, for believing in me.

Urshula Viljoen, who kindly served as a sounding board during the formulation stages of this research.

Esley and Jeannie for much appreciated assistance with transcribing the interviews.

Sonja, Lise, and Melody for their willingness to help with formatting challenges whenever the need arose.

Sureshnie Rider of 5FM, for keeping me company while I worked on my thesis.

Emmarentia McDonald, for painstakingly proofreading this document.

Rom 11:36.

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## Abstract

This study utilised a qualitative interpretive approach to investigate the subjective experiences of six children with cerebral palsy who participated in a therapeutic horse riding intervention programme over a two-year period. Data was collected through a triangulation of methods and sources of data in the form of proxy reports from teachers, parents and therapists, and participant observations on my part. Research in the field of disability and rehabilitation remains largely ungrounded with respect to formalised theorising around concepts such as strengths, capabilities, and well-being. In attempting to address this gap, the nascent sub-discipline of positive psychology was identified as a field that holds significant research utility. Arguably, its keynote contribution entails directing researchers and practitioners in the field of disability and rehabilitation to the aim of building, reinforcing and extending disabled individuals' strengths in order to optimise their functioning. Consistent with existing work, this study found that the participants' lives were characterised by experiences of difference and marginalisation in relation to non-disabled individuals. More striking, however, was the finding that they were subject to experiences of difference and othering in relation to their disabled peers. This group dynamic seemed to be accounted for in terms of a hierarchy of similarities and differences with respect to their capabilities for communication and motor functioning. Further, the findings suggested that the participants tended to utilise their bodies, the site of their impairments, to engage with their environments and social others in their own idiosyncratic and agentic ways. By virtue of the tendency to negotiate and at times *transcend* their impaired physicalities, the participants were perceived as functionally autonomous, which worked to challenge prevailing stereotypes with regard to individuals with profound forms of physical disability. Importantly, such features impacted upon the degree and quality of their engagements with their physical and psychosocial environments in significant ways. In addition, in terms of the therapeutic riding activities engaged with during the course of this study, the participants came to experience their bodies as *bodies that work*. This

seemed to have had positive implications for how they felt about their bodies and themselves. An enhanced sense of personal worth also tended to minimise their experiences of their bodies as impaired and dis-abled. In this way, their participation in therapeutic horse riding facilitated the children's experiences of themselves as *more than disabled*, thereby indicating the emancipatory potential of participating in this form of intervention. Moreover, it was noted that the limited body of existing, largely quantitatively oriented research in the field of therapeutic horse riding has often been methodologically wanting. As disconcerting was the noticeable absence of theorising around the mechanisms and processes by which therapeutic horse riding effected changes. It was therefore fitting to draw on theoretical frameworks within psychology to delineate possible mechanisms and processes by which participation in therapeutic horse riding could potentially effect subtle, meaningful shifts in the everyday functioning and psychological well-being of children with disabilities. This study contributed to existing research within the field of disability and rehabilitation through its efforts to yield "thick descriptions" and "thick interpretations" in combination with the theory-laden validation of findings around the everyday subjective experiences of children with disabilities.



## **CHAPTER ONE: INTRODUCTION**

The purpose of this chapter is to contextualise this study by relating how the idea for the study was developed and outlining the factors that motivated it. Further, an indication of how the preliminary reading of the literature led to the refinement of initial ideas and clarification of the research problem is offered. In addition, the research questions are identified. The chapter concludes by delineating the issues covered in the remaining chapters of this thesis.

### **1.1. Developing the Idea for the Thesis**

This study was based on an interest in both the psychology of the disability experience for children with disabilities, as well as the promotion of wellness via non-conventional therapeutic interventions. Being a competent horse rider, I had over time experienced first-hand the physical and psychosocial benefits associated with horse riding as a recreational activity. Reflecting on my personal experiences sparked an interest in whether such an activity could: i) be placed within a rehabilitative frame of reference, and ii) offer potentially therapeutic benefits to the population of individuals with disabilities. As a result, the purpose of this study was to utilise qualitative methods of inquiry to explore in-depth the subjective experiences of a group of 6 children with cerebral palsy, focussing in particular on what participating in a therapeutic horse riding intervention could mean for them. Moreover, in conducting a study that was qualitative in nature, a wealth of data concerning the sample of 6 participants was yielded. In analytic terms, the emphasis lay in attending to their commonalities, while privileging their nuanced and idiosyncratic subjective experiences.

### **1.2. Motivation for this Study**

The plight and needs of individuals with disabilities constitutes a compelling social concern in both international and local contexts. In South Africa, there are a vast and growing number of individuals with disabilities (Statistics SA, 2005). However, within the current health care system, services to address the multiple

needs of these individuals remain limited (Maart, Eide, Jelsma, Loeb, & Ka Toni, 2007; Soudien & Baxen, 2006). It therefore poses a challenge to psychology to play a role in contributing to both the clarification and development of theory around disability concerns. And, in the absence of definitive cures, treatment tends to entail a focus on the management and alleviation of symptoms. Interventions are utilised to maximise potential and enhance individuals' physical and psychosocial functioning. A significant contribution on the research front therefore lies in addressing the need for the development of appropriate therapeutic resources for children with disabilities. Stated differently, research endeavours are key to facilitating innovations in psychosocial rehabilitation services for individuals with disabilities.

It is common knowledge that pets and animals in general often play a positive role in our lives. Historically, animals have been utilised to enhance therapeutic outcomes in various populations including prisoners, geriatric in-patients, children in paediatric wards, and those in nursing homes and other acute care facilities (Beck, 2000; Heimlich, 2001; Strimple, 2003). Within such contexts, a variety of animals such as dogs, cats, rabbits, and birds have been utilised as therapeutic agents and associated with potential therapeutic outcomes (All, Loving, & Crane, 1999; Martin & Farnum, 2002). Moreover, the horse has also been recognised throughout history as an agent of healing for minds as well as bodies (Fitzpatrick & Tebay, 1998).

Over time, the term 'therapeutic horse riding' has been utilised to cover a variety of equine-related activities in which people with a range of disabilities participate. However, the term has caused a degree of confusion on account of the disparate definitions and interpretations of therapeutic riding that exist (Hammer et al., 2005). An early definition entailed a view of a therapeutic horse riding program as a riding program in which the primary objective is rehabilitation, rather than solely recreation or the teaching of riding skills (Biery, 1985). Similarly, Pauw (1998) defined therapeutic riding as a broad term that is used to describe a number of

different treatment strategies that utilise the horse as a therapeutic agent in physical and psychological therapy. And, more recently, Lessick, Shinaver, Post, Rivera and Lemon (2004) echoed such sentiments, stating that therapeutic riding entails “the use of the horse and equine-oriented activities to achieve a variety of therapeutic goals, including physical, emotional, social, cognitive, behavioural and educational goals” (p.48). Moreover, it was pointed out that this form of intervention encompasses various leisure and therapeutic activities (e.g., learning riding skills), while also emphasising the development of the relationship between the horse and rider (Lessick et al., 2004). The aforementioned definition of therapeutic horse riding has been utilised for the purposes of this study. Also, the terms ‘therapeutic horse riding’ and ‘therapeutic riding’ have been used here interchangeably.

Therapeutic horse riding has a rather broad scope in that it serves children and adults with visual impairments, hearing impairments, spina bifida, autism, learning disabilities and behavioural and emotional difficulties, for instance (Brickell, 2005; Britton, 1991; Lehrman & Ross, 2001; Lessick et al., 2004; Scott, 2005; Snider, Korner-Bitensky, Kammann, Warner, & Saleh, 2007). In addition, the South African Riding for the Disabled Association has maintained that this form of intervention is utilised frequently and with considerable success with children with cerebral palsy (Tredoux, 2000).

Following Rosenbaum and colleagues (2007), a diagnosis of cerebral palsy:

describes a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing foetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour, by epilepsy, and by secondary musculoskeletal problems. (p.9)

There is a growing acknowledgement amongst healthcare professionals that, for those with a positive view of animals, therapeutic horse riding can hold therapeutic utility (Bracher, 2000; Scott, 2005). However, such acknowledgement has not really translated into added impetus on the research front. At an international level, Bizub, Joy and Davidson (2003) have argued that “there has been little research or programming to determine the extent of viability of therapeutic horse riding” (p.378). And, given the limited number of studies that have been conducted locally in recent years, Grobler (2004) has made a similar declaration regarding research in the South African context.

Perhaps because of the inherently physical nature of the activity of horse riding, early research tended to emphasise the investigation of physical effects of therapeutic horse riding, often without fully considering its possible psychosocial benefits. Indeed, early findings on psychosocial effects were largely anecdotal, often serving as aggregate information to a primary investigation into the physical effects of this form of adjunctive intervention.

A preliminary reading of the existing body of research revealed that the limited corpus of South African data with respect to therapeutic riding has accorded due precedence to psychological aspects of functioning (for instance, Grobler, 2004; Helfer, 2006; Ludewig, 2006; Pauw, 1998, 1999, 2000; Rufus, 1997; Stuart, 1998; Van Dyk, Odendaal, & Botha, 1994; Von Moltke, 2002). Studies have focussed largely on constructs such as self-concept and communication. In response, this study has aimed to further develop such work through an engagement with psychosocial dimensions of functioning. As such it has addressed a broader spectrum of psychosocial factors and focussed on the psychological well-being of a group of children with cerebral palsy who participated in a therapeutic horse riding intervention over a two-year period.

In conducting this study, a number of gaps and caveats were identified within extant research. Apart from the fact that relatively few studies have been

conducted in the field, it is problematic that research to date has not yielded findings that indicate unambiguous support for or rejection of the therapeutic value of this form of intervention. However, the ways in which the research methods were utilised have gone some way toward accounting for ambivalent research findings. For instance, in their review of research that has examined the benefits of therapeutic riding, MacKinnon, Noh, Laliberte, Lariviere and Allan (1995) found that methodological problems in the majority of the quantitatively oriented studies, namely poor scientific rigour, small samples sizes and the use of non-standardised measures, tended to render reported findings inconclusive. Similarly, in her review of eight quantitatively oriented studies, Pauw (2000) concluded that small sample sizes, the lack of control groups, and the lack of control of extraneous variables tended to call into question the efficacy of the studies. Interestingly, the methodological shortfalls that these two reviews raised have continued to plague research in the therapeutic riding field. Greater attention to methodological soundness in forthcoming studies that aim to explore the potential therapeutic utility of this form of intervention is therefore warranted.

In a seminal work on the study of mental health and disability, Ryan and Thomas (1987) argued that “one of the significant effects of scientific interest in mentally handicapped people is a tendency to evaluate them in terms of clinical and behavioural symptoms and a consequent relative neglect of either their subjective experience or social existence” (p.114). Their argument is striking in that it refers to a bias that continues to befall both researchers and health care practitioners in the present day. Hence, it needs to be recognised that for individuals with disabilities shifts in functioning over time are often small and nuanced and therefore not conducive to searches for evidence of grand-scale changes in functioning. Research efforts need to be redirected to recognising and investigating the often rich personal meanings that individuals with disabilities accord to seemingly (deceptively) negligible changes that might otherwise be glossed over and summarised as data that are aggregate to the rest of a study’s findings. Accordingly, a qualitative interpretive approach to the

study of the therapeutic value of this adjunctive form of intervention has been engaged in. And, in focussing on childhood disability, the present study aimed to interpret and understand the life-worlds and subjective experiences of a group of children diagnosed with cerebral palsy.

It is also problematic that to date research has not offered us much in terms of making sense of the changes in individuals' functioning that have been yielded as findings. Thus, existing research also stands to gain from attending to theorising around what is 'therapeutic' about therapeutic horse riding as an adjunctive intervention utilised in the rehabilitation of individuals with disabilities. In early research in the field MacKinnon, Noh, Laliberte, Lariviere and Allan (1995) identified as problematic the fact that "the theoretical rationale that delineates how therapeutic riding affects psychosocial functioning has not been fully formulated" (p.9). And, a review of the literature reveals that comprehensive efforts to delineate the mechanisms and processes by which therapeutic riding effects meaningful gains with regard to psychosocial aspects of functioning have not been forthcoming. Clearly, a number of psychosocial pathways are at work in dynamic and interacting ways in the process of effecting therapeutic shifts or improvements. Thus, by proposing a theoretical relationship between interacting dynamics, mechanisms and processes particular to therapeutic horse riding that work towards effecting nuanced therapeutic shifts in individuals with disabilities, this study aimed towards resolving the broader challenge of marginal attention to theoretical groundedness within extant research.

Moreover, a review of existing work in the field of therapeutic horse riding<sup>1</sup> revealed another critical flaw that appears characteristic of much research, namely, a tendency for researchers to pay lip service to strengths-oriented thinking via a loose and cursory mention of phrases such as 'health promotion', 'quality of life', 'wellness', and 'positive health outcomes', without engaging in

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<sup>1</sup> This tendency is not only typical of work with respect to therapeutic riding, but generalises to broader trends within the field of disability and rehabilitation research.

further theorising and delineation of concepts. Yet, by neglecting to conceptually place their studies in relation to a broader understanding of optimal human functioning, many researchers have rendered the theoretical groundedness of their work vulnerable to questioning and criticism. In addressing such a limitation, this study has identified and pursued a new direction in the research agenda within the field of disability and rehabilitation by drawing on concepts and ways of thinking arising within the nascent sub-discipline of positive psychology.

While psychology has made considerable inputs into existing bodies of work, positive psychology constitutes uncharted research territory to those working in the field of disability and rehabilitation, as well as researchers examining the efficacy of interventions such as therapeutic horse riding in particular. In drawing on the principles of positive psychology (Dunn & Dougherty, 2005; Seligman & Csikszentmihalyi, 2000), this study has explored the position that therapeutic riding could serve as an adjunctive intervention that works towards optimising (rather than normalising) disabled individuals' functioning. Accordingly, an emphasis on acknowledging and building on individuals' strengths, capacities and resources, while taking into account the influence of functional limitations was adopted here.

Another significant theoretical shortcoming identified within much rehabilitation research to date - therapeutic riding work included - is the tendency to operate on taken-for-granted assumptions that neglect to declare what understandings of disability are subscribed to. Stated differently, it is problematic that there is a frequent failure to engage with the concept 'disability' in critical and meaningful ways. However, it needs to be taken into account that how we as researchers understand disability is central to how we make sense of the everyday experiences of individuals with disabilities. Hence, this study has built on the existing body of knowledge in the field of therapeutic horse riding by drawing on and subscribing to specific understandings of disability and well-being. In this

way, an attempt has been made to establish a theoretical basis for the dynamic processes of data analysis and interpretation.

In sum, this thesis has aimed to contribute to existing bodies of knowledge by suggesting new directions in the research agenda with respect to theoretical formulations around disability and optimal human functioning. Methodologically, qualitative, interpretive methods of inquiry have been deemed most suitable for the purposes of this study. In what follows, the objectives of this research undertaking are articulated through the specification of key research questions that have informed the thesis.

### **1.3. Research Questions**

The research questions had the following four aims:

- i) To explore the nature of the disability experience for children with cerebral palsy. Within a broader interpretive framework, to understand and interpret how children with cerebral palsy experience disability within their various social contexts. The first research question was thus: "What is the child with cerebral palsy's subjective experience of disability?".
- ii) To determine the potential value of a therapeutic riding intervention for a group of children with cerebral palsy. The research question here was thus "What is the potential impact of participation in a therapeutic riding intervention on the everyday functioning and psychological well-being of a group of children with cerebral palsy?".
- iii) To carry out this evaluation by assessing for, mapping out and tracking (empirically) the movement of identifiable meaningful changes with respect to the participants' functional strengths and functional limitations. In this way the assessment was individualised for each child. This study was concerned with what is 'therapeutic' about participation in a therapeutic riding intervention for a



group of children diagnosed with quite severe forms of disability. The third research question was thus: "What therapeutic effects do children with cerebral palsy derive from their participation in a therapeutic horse riding intervention?"

iv) To identify and make sense of the processes and dynamics by which therapeutic horse riding effects meaningful change in everyday functioning and psychological well-being, in a group of children with cerebral palsy. The fourth research question with which this study concerned itself was thus: "What are the dynamics and processes arising within a therapeutic horse riding intervention that promote movement toward meaningful change in everyday functioning, and psychological well-being, in a group of children with cerebral palsy?".

#### **1.4. Conclusion**

This introductory chapter has served to contextualise this study by relating how the idea for the study was developed and outlining the factors that motivated it. Further, an indication of how the preliminary reading of the literature led to the refinement of initial ideas and clarification of the research problem was offered, and the research questions specified. The remaining chapters of this thesis are structured as follows: Chapter Two (Literature Review) provides a review of research literature to date, as well as a discussion of the theoretical paradigms that inform this study. In this way, a theoretical grounding for the present study has been established. Chapter Three (Research Methodology) outlines the research methodology and research design followed during this study. In particular, the sampling techniques employed and the criteria used in the choice of the sample have been mentioned. The discussion also outlines the process of data collection including techniques and procedures used for collecting data. In addition, the process utilised for the purposes of data analysis is outlined. Chapter Four (Data Analysis and Interpretation of Findings) presents the qualitative data, and takes the form of an analysis of the research findings through interpretive themes. Chapter Five (Discussion of Findings and Reflections on the Research Process) summarises the most important research

findings and discusses them in relation to existing bodies of work. As part of this chapter, a reflexive account of my role as the researcher in shaping the research process is engaged in, and the quality of the data that was collected is discussed. Chapter Six (Conclusion: Recommendations for Further Research) raises issues and directions for future research.

## **CHAPTER TWO: LITERATURE REVIEW**

This chapter delineates the theoretical frameworks that have informed the present study. To begin with an overview of some of the key conceptualisations of disability has been conducted. This commences with a consideration of the distinctive features of a medical model, and outlines the clinical features of cerebral palsy in the process. Next, a social model of disability is discussed. This is followed by a focus on the psychological basis of disability. Indeed, this study has a particular interest in those psychological experiences of children with diagnoses of disability that entail quite severe associated physical impairments. On that basis, it is argued that the study of disability and rehabilitation may be extended and complemented by a conceptual placing of understandings of disability in relation to key issues and concepts regarding optimal human functioning. Positive psychology, a field yet to be applied comprehensively in relation to conceptualisations of disability and impairment, is regarded as a promising theoretical point of departure. In addition, therapeutic horse riding as an adjunctive intervention for use in the rehabilitation of individuals with disabilities is focussed on. In closing, the chapter theorises the potential mechanisms and processes by which therapeutic horse riding effects changes in individuals' psychosocial functioning with a view to theoretically grounding the present study.

### **2.1. Models of Disability**

Informed by a prominent line of thinking within disability research (Low, 2001; Marks, 1999a, 1999b), a fundamental premise of this study has been that conceptualisations of disability are not mutually exclusive and need not be in competition with each other. Rather, they complement one another in offering attention to alternate dimensions within the analysis and conceptualisation of disability and impairment. Indeed, Marks has described such dimensions as "different, multi-causal, multi-directional dimensions of understanding the relationship between the body, the psyche and the environment" (1999a, p.179).

Furthermore, it has been pointed out that disability and ability are not fixed states but contingent positions (Breckenridge & Volger, 2001; Marks, 1999a; Siebers, 2006). As Marks (1999a) succinctly puts it, the social construction and the psychological reproduction of disability work both to oppress those constituted as disabled and regulate those constituted as able. Bearing in mind the contingent nature of ability and disability then, it is argued that the models of disability discussed here work in interaction with each other towards elaborating a critical understanding of key issues and concepts within the field of disability research and rehabilitation practice.

### **2.1.1. A Medical Model**

The existing body of knowledge around disability may be traced to early in the 20<sup>th</sup> century when a medical model, which still dominates much thinking and practice, originated. By subscribing to a pathogenic paradigm, the emphasis in a medical model lies largely in the identification and management of the symptoms that are manifest in individuals with particular medical problems. Thus, a medical model is noted for its categorisations of people based on disability as an individual or medical problem. Disability is conceptualised as the consequence of a medical condition resulting in functional limitations that in turn restrict individuals' ability to complete expected social roles (Albrecht, 1992). In terms of early medical definitions, then, disability was equated with deficiency in the sense that a physical, psychological and/or neurological attribute was identified as deviating from an 'agreed upon' image or norm of the ideal subject (Soudien & Baxen, 2006). Hence Grönvik (2007) argued that:

ideas of the *normal body* and its *normal functions* have been the point of departure to identify disabled people; those who diverge from normal curves of IQ, faculty of vision, hearing, mobility, and other body functions create the disability population, those in need of corrections and treatments. (p.761)

Moreover, Oliver (1983) has criticised the medical model of disability for being a sub-set of a personal tragedy view. Such an understanding assumes that disability is a tragedy that befalls individuals in a random way and that disabled people cannot possibly be happy being disabled. Holt (2004) has offered the critique that in terms of a personal tragedy view, disability tends to be represented as “an essential biological ‘given’, reducible to impairment, with society’s role in disabling impaired people overlooked” (p.220). Woolfson (2004) too, has problematised a personal tragedy view, arguing that it advocates helping people to be more like non-disabled people, denying their right to be as they are. In sum, within a medical model, the body serves as the site of disability, while efforts to reduce, prohibit, and eliminate disability tend to focus on the individual (Abberley, 1999; Grönvik, 2007; Soudien & Baxen, 2006). Further, in support of the utility of a medical model, Shakespeare (2008) has argued that despite the deficiencies of medical sociology (which is dominated by the chronic illness approach) and medical ethics (which sees impairment as a problem to be avoided), the many valuable contributions to understanding disability that have been made from such perspectives cannot be ignored.

#### **2.1.1.1. Diagnosis of Cerebral Palsy as Situated within a Medical Model**

In focussing on childhood disability this study is concerned specifically with cerebral palsy. Described as the most common cause of severe physical disability in childhood (Kuban & Leviton as cited in Koman, Smith & Shilt, 2004), the prevalence of cerebral palsy has been reported to have risen to over 2.0 per 1000 live births in the past 3 decades (Odding, Roebroek & Stam, 2006). Previous definitions tended to focus exclusively on cerebral palsy as a motor disorder, and in a more recent conceptualisation, the emphasis on motor functioning has been retained. However, the likelihood that the child will also have other non-motor impairments - including communication, intellectual function, learning disabilities, epilepsy, and sensory impairment - that may be equally or more significant has been added (Rosenbaum et al., 2007).

According to Rosenbaum and colleagues:

Cerebral palsy (CP) describes a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour, by epilepsy, and by secondary musculoskeletal problems. (2007, p.9)

In addition, Raina et al. (2005) have declared that although impaired motor function remains the hallmark of the cerebral palsy syndromes, many children with this development disorder also experience sensory, communicative and intellectual impairments and could experience complex limitations in self-care functions such as bathing, feeding, dressing and mobility.

The literature indicates that except in its mildest forms, cerebral palsy can be noticed in the first 12 to 18 months of life (Odding et al., 2006; Rosenbaum, 2003). Moreover, a failure to reach motor milestones and qualitative differences in motor development such as unusual muscle stiffness or floppiness and/or asymmetric gross motor function are features that characterise the presentation of the condition (Rosenbaum, 2003). And, for a definitive diagnosis to be made, a period of observation in which no progression of symptoms is observed is a necessary precondition. In other words, any deterioration in motor functioning over time indicates that a diagnosis other than cerebral palsy should be sought (Tilton, 2006).

A review of extant research that has focussed on cerebral palsy reveals that understandings and conceptualisations of disability have been confined largely to categorisations in terms of two primary systems of classification, namely that of quality of movement and location of damage. The major subtypes of motor

deficit have been distinguished, following Best (n.d.), Matejovsky and Hoon (2007), Rosenbaum (2003), and Siebes, Wijnroks and Vermeer (2002), amongst others, in the terms discussed below. To begin with, in the most common variety, spastic cerebral palsy, limb muscles contract (tighten) abnormally, resulting in movement that is stiff and jerky; over time, these spastic muscles become shorter, exerting differential pull around an individual's joints. In contrast, dyskinetic cerebral palsy entails the distortion of purposeful movement where muscles move randomly and involuntarily, especially in the arms, hands and face - movement may range from writhing to jerking to tremors, depending on the type of dyskinesia. In addition, ataxic cerebral palsy is characterised by an abnormal pattern of posture and/or movement, accompanied by a loss of orderly muscular coordination resulting in the performance of movements with abnormal force, rhythm, and accuracy. Lastly, individuals who may have both spasticity and dyskinesia, for instance, are diagnosed with a mixed type of cerebral palsy.

The second form of categorisation that is commonly applied to diagnoses of cerebral palsy entails topographical classifications that attempt to describe what is seen clinically according to the part of the body involved. Following Best (n.d.), Finnie (2002), and Rosenbaum (2003), these classifications have been summarised as follows: Paraplegia entails the involvement of an individual's legs only, while hemiplegia entails the predominantly unilateral impairment of an arm and a leg on one side of his/her body. In addition, diplegia entails the motor impairment of primarily an individual's legs, usually with some relatively limited involvement of his/her arms. Further, triplegia consists of the involvement of three limbs, usually both legs and one arm. Finally, quadriplegia entails the involvement of all four limbs; often the trunk is also involved.

Having considered the common systems of classification, it needs to be emphasised that cerebral palsy is a collection of disorders characterised by a heterogeneous group of etiologies and a wide variety of clinical presentations (Bax et al., 2005; McCarthy, 1992). It therefore seems understandable that a

cure for cerebral palsy is neither available nor imminent (Damiano, 2006). Accordingly, the focus of treatment tends to be on the management and alleviation of symptoms and the maximisation of functioning via therapeutic interventions. Indeed, the multidimensional nature of cerebral palsy serves as a motivating factor warranting treatment within the frame of a multidisciplinary team approach (Rosenbaum, 2003; Rosenbaum et al., 2007). Such efforts may include occupational and physical therapy, speech and language therapy, orthopaedic surgery, and occasionally neurosurgery (Bjorklund, 2007; McCarthy, 1992; Murphy & Such-Niebar, 2003; Rosenbaum et al., 2007).

Having considered the features of a medical model, and paid particular attention to a diagnosis of cerebral palsy which is situated within such a model, the discussion that follows accords due consideration to a social model of disability.

### **2.1.2. A Social Model**

Some of the challenges of a deficit-oriented medical approach to conceptualising disability came to be addressed by variants of a social model of disability. A conceptualisation that has been developed over the last three decades or so by disability academics and activists, a social model serves not only to critique but also to complement and extend the existing medical model of disability. Those who advance a social argument emphasise the importance of social factors in the experience and conceptualisation of disability (e.g., Abberley, 1987, 1992; Barnes, 1996; Barton, 1996; Hughes & Paterson, 1997; Low, 2001; Maart et al., 2007; Oliver, 1983, 1990, 1996; Paterson & Hughes, 1999; Shakespeare, 1996; Soudien & Baxen, 2006; Smith & Sparkes, 2008). For instance, Oliver (1983, 1990, 1996), a key proponent of a social view, offers a structural analysis by contending that the problems of disability are societal rather than individual, and that these problems stem from oppression by society rather than the limitations of individuals. As Hughes and Paterson (1997) explain, within a social model, disability is not an outcome of bodily pathology, but rather prejudice and discrimination are seen as the real cause of disability. Hence, disability is



understood as socially produced by systematic patterns of exclusion that have been built into the social fabric of our society (Hughes & Paterson, 1997).

Furthermore, those who adopt a materialist account within a social model of disability regard disabled individuals' experiences as contextualised within a 'disablist society' (Abberley, 1992). Emphasising the importance of economic relations in the production of disability, they reason that instead of offering an enabling environment to individuals with disabilities, a capitalist society excludes and disables them precisely because of their impairments (Finkelstein, as cited in Marks, 1999a). For instance, Marks (1999a) has noted that in view of the enormous value placed on work in contemporary society for an individual's social status, exclusion from work and the reasons for this exclusion are critical to understanding disability. In contrast, Freund (2001) offered the critique that "much of the social model's materialism is confined to relating political economy to disabling or enabling material conditions" (p.691). Instead, a closer look at the material organisation of everyday life (e.g., work places) and the spaces in which life activities are carried out (e.g., in public spheres) was suggested.

In contrast to the dominant materialist view, a Foucauldian perspective on disability and impairment is distinguished by "the powerful role allocated to language and symbolism in the construction of disabled identities and disabled individuals as a population" (Hughes, 2005, p.81). Serving as an alternative critique of the medical model, Foucault's (1977,1980) work relates to the historical context of discourses. Moreover, Foucault (1977, 1980) sees power as embedded in social organisations and identifies how power and knowledge are intertwined. Concerned with measuring, classifying, examining and analysing, the languages of the sciences (and biomedicine in particular) have generated binary classifications such as normal/abnormal and ability/disability, thereby creating the potential for the othering, marginalisation and exclusion of individuals with disabilities in the service of power. In addition, Foucault (1977) refers to the control of the body through disciplinary technologies designed to shape and train

the 'docile body'. However, proponents of such a Foucauldian view have come under criticism for "the deterministic nature of their argument in which discourses are represented as subjugating human agency with little scope for resistance or acknowledgement of the 'lived experience' of the body" (Lupton, 1997, p.101).

A social model has also been criticised for offering a disembodied view of disability (Freund, 2001; Hughes & Paterson, 1997; Shakespeare & Watson, 1997, 2001). In this regard, Shakespeare and Watson (2001) have argued that a disembodied view of disability is not tenable, because "disability is a complex dialectic of biological, psychological, cultural and socio-political factors" (p.22), and because individuals are disabled both by their bodies and by social barriers. Overall, strong critique has been levelled at a social model's attempt to disregard the body, and its neglect of the experience of impairment as important to an understanding of disability (French, 1993; Freund, 2001; Hughes & Paterson, 1997; Marks, 1999a, 1999b; Shakespeare, 2005).

In response to the critique that a social model depicts the impaired body as a passive recipient of social forces, French (1993) has argued that the recognition that disability is socially produced is not, however, to deny the importance of addressing the pain or chronic illness experienced by some disabled people. Instead, the consequences of the impairment itself are viewed as distinct from the physical barriers of the built environment and the prejudices and negative attitudes of non-disabled people. These discriminatory or 'disabling' barriers and societal attitudes are seen as the focus of attention within a social model of disability.

The question of how to bring the body back into the theorising of disability without opening up a re-medicalisation of disability constitutes a main topic of debate amongst proponents of a social model. And, in their concern that a theory of disability needs to take into account the lived experience of having impairments, several theorists (e.g., Crow, 1996; Hughes & Paterson, 1997; Tremain, 2001)

have argued for the need to 'bring back' both the body and personal experience into disability. It has been their position that "instead of 'leaving' the body within the medical discourse, it would be more logical also to embrace the body and discuss the ontological questions of the body" (Grönvik, 2007, p.752). In view of the above, the present study has concerned itself with examining experiences of impairment *and* disability within the participants' everyday life worlds. Freund (2001) has raised the relevant point that despite the argument that sharp distinctions cannot, in fact, be made between an impairment and a disability, the distinction is nevertheless *analytically* useful. Bearing in mind the analytical usefulness of the distinction between impairment and disability then, this study has accorded due attention to the interaction between the body, psychological aspects of experience, and the environment.

### **2.1.3. A Psychosocial Conceptualisation of Disability**

The call more recently for due attention to '*the psychological*' within conceptualisations of disability warrants a consideration of the issues engaged with by the discipline of psychology. Indeed, psychology offers an elaborate interpretive language and conceptual toolbox with which to make sense of the life worlds and subjective experiences of individuals with disabilities. For instance, such theoretical constructs including embodiment, autonomy, self-esteem, self-concept, and identity as well as positive emotions such as interest and pride for example, are salient here. In addition, psychosocially derived concepts such as stigma, prejudice, and oppression also form part of the rich and meaningful conceptual toolbox that psychology delivers to the study of disability and impairment.

In view of a particular research interest in the psychosocial experiences of individuals with disabilities the work of Deborah Marks (1999a, 1999b) has been drawn on here for the purposes of a definition. Marks has argued for the importance of developing "a dynamic understanding of disability which recognises the importance of examining the interrelationship between embodied

subjects, and complex social and psychic relationships” (1999a, ix). Her all-encompassing, more psychosocially-oriented conceptualisation is noted for its avoidance of the usual individual/social binary that has plagued much disability theorising.

Thus, she defines disability as “the complex relationship between the environment, body and psyche, which serves to exclude certain people from becoming full participants in interpersonal, social, cultural, economic and political affairs” (1999b, p.611). Further, Marks (1999a) insists that disability does not reside in a particular body or environment, but rather is an embodied relationship. Such a conceptualisation raises the issue of the ways in which our selves are known to us through our bodies. In particular, her position brings to the fore attention to such psychological features as the implications of impairment and disability for an individual's sense of self-esteem, body image, self-image, agency and identity, for instance. These subtle and nuanced aspects of disabled individuals' experiences warrant the acknowledgement and engagement of theorists and practitioners within the disability field.

#### **2.1.4. Embodied Experiences of Disability and Impairment: Implications for Selfhood**

Moreover, in terms of a stance around embodiment and selfhood, it has been posited that as disability and impairment involve whole persons, a rejection of the Cartesian dualism of mind and body is warranted (Budgeon, 2003; Frank, 1995; Marks, 1999a). For Marks (1999a), the meaning of the term ‘embodiment’ presents a significant challenge to the mind/body dualism in that “the concept grounds perception not in a mind - as a fundamentally different substance from the material body - but in the *intentional experiencing body*” (p.129). Hence, following Marks (1999a), the position adopted here has been that the body should not be seen as matter set apart from subjectivity and the environment. Rather, the body has been seen to constitute an entity that is bound up with creative meanings and contexts in complex ways.

Shelley Budgeon (2003) has posited that bodies can be thought of “not as *objects*, upon which culture writes meanings, but as *events* that are continually in the process of becoming - as multiplicities that are never just found but are made and remade” (p.50). In Budgeon’s view, selfhood is “an embodied process involving particular experiences and engagements in certain practices which allow the body to make new, transformative connections” (2003, p.48). Her emphasis on potential transformative connections is resonant with use of the term ‘transcendence’ to signify how biology (in the form of the body) is actually *transformed* by social practice (Cornell as cited in Shilling, 2003). Such considerations call to the fore the issue of bodily agency as worthy of research attention.

Hughes and Paterson (1997; Paterson & Hughes, 1999) have criticised the failure of disability studies to adequately address the fundamental issue of bodily agency. In so doing, they have adopted the position that “disability is experienced in, on and through the body, just as impairment is experienced in terms of the personal and cultural narratives that help to constitute its meaning” (Hughes & Paterson, 1997, p.334). In Hughes and Paterson’s view, disability is therefore “experienced from the perspective of impairment” (1997, pp.334-335). Indeed, by assuming the stance that our bodies constitute our windows on the world, Hughes and Paterson (1997) conceptualise impairment as the vantage point from which disabled people perceive the world and how the world responds to them.

Further, their assertion that “the impaired body is a ‘lived body’” (Hughes & Paterson, 1997, pp.334-335), is grounded in the phenomenological position in which the body is a ‘lived body’ or a situation that provides people with their perspectives on the world (Merleau-Ponty, 1962). Thus, such a stance highlights the view that while the body does not cease to be an object with its own physical properties, it is a style of being, an intonation, a specific way of being present in

the world (Moi as cited in Hughes, 2007). In sum, Hughes and Paterson, hold that “impairment is simultaneously experienced and embodied, and so, too, is disability” (1997, p.335).

Due attention also needs to be accorded to the body images (referred to interchangeably in the literature as body schemas) of individuals with disabilities. According to Shilling (2003), the concept of body schema was developed “to address the problem of how it is we are able to coordinate our bodies to perform actions without having complete sight of them or consciously monitoring our every movement” (p.200). In terms of a conceptualisation that has informed the present study, Taleporos and McCabe (2002), have defined body image as “the combination of an individual’s psychological experiences, feelings and attitudes that relate to the form, function, appearance and desirability of one’s own body which is influenced by individual and environmental factors” (p.973). And, in terms of its functions, Grosz (as cited in Shilling, 2003) has contended that our body schema serves to unify and coordinate visual, tactile, postural, and kinaesthetic sensations so that these are experienced as the sensations of a subject coordinated into a single space. In view of such considerations, a potential link between the body images and self-images of individuals with disabilities could serve as an issue worthy of research attention.

A focus on ‘the psychological’ in conceptualisations of disability is also significant in that it highlights the importance of attending to individuals’ subjective experiences within disability theorising and rehabilitation practice. Importantly, Marks has stated that “subjective and unconscious investments, identifications and the management of differences play a crucial role in the construction and experience of disability” (1999a, p.xi). And, while the scope of the present study has been psychosocial in nature, extending beyond that which is psychodynamically psychological, it is relevant to note that Marks’ work reflects an interest in *unconscious experiences* in particular. Indeed, she has submitted that due attention needs to be paid not only to the inclusion of conscious

narrative accounts, but also to unconscious experiences of disability (Marks, 1999a, 1999b).

It is also striking that emotional aspects of experiences of disability constitute a neglected area within disability theorising. Yet, while working definitions of emotions differ across researchers, consensus is emerging that both positive and negative emotions might best be conceptualised as multi-component response tendencies that unfold over relatively short time spans (Fredrickson, 2005b, 2006). According to Fredrickson (2006), emotions “typically begin with an individual’s assessment of the personal meaning of some antecedent event - what Lazarus (1991) called the *person-environment relationship*, or *adaptational encounter*” (p.87). She explains further that this appraisal process (which may be either conscious or unconscious) serves to “trigger a cascade of response tendencies that manifest across loosely coupled component systems, such as subjective experience, facial expressions, and physiological changes” (Fredrickson, 2006, p.87).

Given the goals of this study, Marks’s (1999a) assertion that a comprehensive picture of disability must necessarily take into account how impairment and disability are emotionally experienced has salience here. Support for such a view has been found in the work of Mason (as cited in Marks, 1999a), who contended that it is important to examine not just the relationships which people have with others, but also the relationships they have with themselves.

## **2.2. Considerations Regarding Health and Wellness**

### **2.2.1. Pathogenic, Salutogenic and Fortigenic Paradigms**

Moving on from the preceding exploration of the psychological aspects of disability, this study has aimed to take further the contributions from psychology through a conceptual placing of understandings of disability in relation to a prominent theoretical pathway at the moment, namely, the interdisciplinary

emphasis on human strengths and wellness. Within this approach, paradigms entailing pathogenic, salutogenic and fortigenic thinking can be distinguished.

#### **2.2.1.1. A Pathogenic Paradigm**

Typical indices of health in the Western world still focus on disease, illness, vulnerability and risks, thus indicating the pervasiveness of a pathogenic paradigm (Wissing, 2000). Further, a medical model, which subscribes to a pathogenic paradigm, still tends to dominate not only mainstream understandings, but current legislation. It provides the main criteria or symptoms for diagnoses, thereby defining categories of individuals who shall have access to services and benefits in the treatment and rehabilitation contexts (Finkelstein, 1993). Moreover, psychology in particular, and other social sciences too, have also been functioning mainly within a paradigm of pathogenic thinking (Linley & Joseph, 2004; Strümpfer, 1990; Wissing, 2000).

To the extent that there has been an engagement with issues around disability, studies to date have tended to adhere largely to descriptions in term of medically-oriented categorisations. However, researchers and practitioners need to view a medical model as representing a part of, but not the full picture with respect to disability. Hence, this study has attempted to complement existing conceptualisations (namely, the co-existing medical, social and psychological understandings), by advancing an understanding of disability in relation to wellness. Indeed, as early on as 1998 Ryff and Singer, in formulating the contours of human health, declared that scientific studies of human health have been overwhelmingly about pathogenesis rather than salutogenesis, and proposed that scientific advances were needed to explicate factors that promote optimal well-being.

#### **2.2.1.2. A Salutogenic Paradigm**

A consideration of some of the key theoretical contributions advanced by Antonovsky's (1979, 1987) salutogenic perspective provides a useful background



to the subsequent discussion of a fortigenic paradigm. To begin with, Antonovsky (1987) replaced the dichotomy of people being either diseased or healthy in favour of the health ease/dis-ease continuum, with all individuals falling somewhere between the two theoretical poles of terminal illness and total wellness. Implications are, for instance, that the focus of study changes, in the case of individuals to a person's position, at any point in time, on this continuum. Antonovsky's (1987) more holistic conceptualisation represents a valuable shift away from the normative placement of disabled individuals in the category diseased, not healthy. Rather, an individual with a disability will, depending on a number of interacting factors, occupy a position somewhere on the health ease/dis-ease continuum. Such a shift in conceptualisation serves as an indication that the origins of positive psychology (a field to be discussed shortly) entail a strong emancipatory element.

Antonovsky (1979) also maintained that stressors are omnipresent in human existence. Indeed, his salutogenic model rejects the commonly held assumption that stressors are inherently bad, in favour of the possibility that stressors may have salutary (health-enhancing) consequences (Antonovsky, 1984). Antonovsky (1984) argues, then, that it is how we respond to the omnipresent stressors in our lives that makes the difference between well-being and ill health. In contrast to the pathogenically-oriented concern with how we might eradicate this or that stressor, the salutogenic concern is with "How can we learn to live, and live well, with stressors, and possibly even turn their existence to our advantage?" (Antonovsky, 1984, p.116). Informed by Antonovsky's view, it is plausible to view disability as one of the significant stressors that are continually present in a disabled individual's life. In addition, family members and health care professionals may assist disabled individuals to live with such omnipresent stressors in as positive and as health-enhancing a manner as possible.

### **2.2.1.3. A Fortigenic Paradigm**

Arising out of a salutogenic paradigm, a fortigenic paradigm is in line with a broad interdisciplinary call for more attention, on theoretical and empirical levels, to people's strengths and resources or capacities (Wissing, 2000). Work by Wissing and Van Eeden (1994), Adams, Bezner and Steinhardt (1997), Ryff and Singer (1998, 2003), and Seligman and Csikszentmihalyi (2000) for instance, serve as examples of such emphases. Indeed, a fortigenic paradigm speaks to the bias towards deficits and pathology within much health and wellness thinking. What is emphasised instead is the identification and promotion of strengths and capacities, and (the enhancement of) wellness (Linley & Joseph, 2004; Seligman & Csikszentmihalyi, 2000; Wissing, 2000; Wissing & Van der Lingen, 2003).

### **2.2.2. Positive psychology: Features and Implications for Disability**

#### **Research and Practice**

Within a broader fortigenic paradigm we find the emerging sub-discipline of positive psychology<sup>2</sup> (also known as psychofortology). In terms of defining features, Dunn and Dougherty (2005) have succinctly declared that positive psychology is "the science of understanding human strengths and the practice of promoting these strengths to help people psychologically and physically" (p.305). Those within the field hold that treatment is not just about fixing what is broken, but instead entails nurturing what is best for the individual concerned (Seligman & Csikszentmihalyi, 2000). Applied to the context at hand, such assumptions have prompted a focus on building the qualities that help individuals with disabilities not just to endure and survive - as much useful work in the field of resilience (for instance, Masten, 2001; Masten, Best, & Garmezy, 1990; Rutter, 1987, 2007) is directed towards - but also to *flourish*.

The tendency towards a pathogenically-oriented approach dominates much of existing work - including contributions from psychology specifically - within the

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<sup>2</sup> See Strümpfer, (1995) and Seligman and Csikszentmihalyi, (2000), for instance, for a historical review of the development of positive psychology.

field of disability. Problematically, this has been largely at the expense of fully considering the repertoires of strengths and resources that are available to individuals with disabilities and their families. The present study has therefore endeavoured to move away from the tendency toward pathogenic conceptualisations primarily in terms of functional limitations and lack of ability (dis-ability), while acknowledging that such features serve as challenges for individuals with disabilities to adjust to and cope with.

These challenges may be viewed in terms of Aldwin's (1994) understanding that there are certain (ever-changing) demands with which we must cope, and that these demands in turn determine the nature and extent of the coping resources that develop in an individual. Based on Aldwin's (1994) thinking, it is plausible that over time the individual with a disability may develop certain capacities and strengths in response to the functional limitations and challenges experienced. Thus, based on a psychofortigenic view, this study has proposed a focus on individuals' capacities and strengths as a way in which to address some of the gaps in existing disability research. A move has been advocated toward assessing and promoting what it is that the individual can do, the degree (however small or large) to which the individual is able to function adaptively, as well as the resources and strengths that are available to him/her.

At this point, it is important to acknowledge that the concept of wellness constitutes a hallmark of positive psychology. Thus, based on the premise that they render the concept valuable for research, assessment and therapeutic interventions in the disability field, the discussion turns to Wissing and Van der Lingen's (2003) description of a number of core features of wellness. To begin with, wellness is not just concerned with that which is normal or adequate, or the absence of symptoms or disease (Wissing & Van der Lingen, 2003). Rather, it is about aiming for optimum health and well-being, and the maximisation of potential. This attribute of wellness as a deliberate and conscious effort to optimise rather than normalise all areas of life, and the view that enhancement of

well-being is the goal, whatever the individual's present position on the health continuum has significant implications (Wissing & Van der Lingen, 2003). For instance, such a view represents an attempt at moving beyond a pathogenic orientation toward fostering optimal functioning and well-being and has therefore held particular appeal for the present study.

It is also important to draw a distinction between the concept of wellness, and well-being. Wissing and Van der Lingen (2003) hold that well-being can be viewed as a synonym for wellness, but is more often used when reference is made to the non-physical aspects of human functioning, e.g., emotional, spiritual or psychological well-being.<sup>3</sup> Moreover, complex psychological issues cannot be understood in isolation from the social and cultural contexts in which they are embedded (Seligman & Csikszentmihalyi, 2000). Accordingly, Wissing and Van der Lingen (2003) indicate that individual well-being also depends on and interacts with environmental, contextual and cultural factors.

The authors contend further that 'being well' is a relative concept that varies from one individual or context to the next (although similarities can be found in what wellness means for different people) (Wissing & Van der Lingen, 2003). More important to note though, is that wellness is not prescriptive, or even measured by some objective standard. Rather, the criteria and goals for personal wellness need to be defined by the individual, or often in the case of children with disabilities, by families in conjunction with the therapists/health care workers who form part of a multi-disciplinary treatment team.

Another key feature of wellness discussed by Wissing and Van der Lingen (2003) entails the concept's multidimensional nature. Drawing on psychology's understanding that the different dimensions of human functioning (for instance body, mind, spirit and environment) are inter-related and inter-dependent,

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<sup>3</sup> This study has aligned itself with the latter definition, thereby promoting due attention to individuals' psychosocial experiences within the context of research and practice.

wellness has been conceptualised as referring to well-being in all spheres of life. In this regard, a number of researchers (for instance, Adams, Bezner & Steinhardt, 1997; Crose, Nicolas, Gobble, & Frank, 1992; Ryff & Singer, 1998; Seeman, 1989; Wissing & Van Eeden, 1997; Witmer & Sweeney, 1992) have conceptualised and/or measured wellness in terms of several basic dimensions, namely, emotional, physical, intellectual/cognitive, interpersonal/social, contextual/environmental, career/occupational and spiritual dimensions. And, if we consider that the concept of wellness implies inter-relatedness among the different dimensions (Wissing & Van der Lingen, 2003), then it follows that capacities, strengths and resources that an individual has access to on psychological and social levels for example, could assist that individual to optimise his/her adaptive functioning.

Having considered key features of wellness, the discussion that follows has focussed on Carol Ryff and Burton Singer's (1998) pioneering theorising around positive human health, work that has contributed significantly to the foundations of psychofortigenic thinking.

### **2.2.3. Ryff and Singer's (1998) Model of Psychological Well-being**

While assuming more of a deficit-orientation to begin with, extant research within the field of disability has variously referred to constructs such as 'positive human health', 'quality of life', and 'well-being', without grounding their discussions within a specific (strengths-oriented) model. For instance, De Chavez, Backett-Milburn, Parry and Platt (2005) have observed that although 'wellbeing' is increasingly referred to in existing bodies of work such as policy papers, this is often done so in an unreflective way. The assumption has been that the definition of 'well-being' is uncontested and that it has a shared meaning. Hence, in an attempt to address this limitation, the present study has drawn on Ryff and Singer's (1998) model of psychological well-being with a view to extending existing bodies of work in the field of disability.

The following triad of principles underlie Ryff and Singer's (1998, cf p.2) formulation of human health: Firstly, positive health is not, in the final analysis, a medical question, but is in essence rather a philosophical issue requiring an articulation of the meaning of the good life. Secondly, human wellness is at once about the mind and the body and their interconnections. Accordingly, a comprehensive assessment of positive health must take into account cognitive, psychological and physical components and the ways in which they influence each other. Thirdly, positive human health is best construed as a multidimensional dynamic process rather than a discrete state. In other words, "human-being is ultimately an issue of engagement in life, involving the expression of a broad range of human potentialities: intellectual, social, emotional and physical" (Ryff & Singer, 1998, p.2).

Undergirded by the above principles, Ryff and Singer's (1998) six-dimensional model of psychological well-being consists of the following factors:

#### 1. SELF-ACCEPTANCE

- (a) positive self-evaluation,
- (b) the ability to acknowledge multiple aspects of self, and
- (c) the ability to accept both positive and negative qualities into a balanced picture of one's abilities

#### 2. PERSONAL GROWTH

- (a) capacity to grow and develop potentials
- (b) personal changes over time that reflect growing self-knowledge and effectiveness, and
- (c) openness to new experiences

#### 3. POSITIVE RELATIONS WITH OTHER PEOPLE

- (a) close, warm, and intimate relationships with others,
- (b) a concern about the welfare of others, and

(c) empathy and affection for other people

#### 4. AUTONOMY

- (a) independent and self-determined,
- (b) ability to resist social pressures, and
- (c) ability to regulate behaviour from within

#### 5. PURPOSE IN LIFE

- (a) a sense of purpose and meaning in life, and
- (b) a sense of direction and goals in life

#### 6. ENVIRONMENTAL MASTERY

- (a) a sense of mastery and competence, and
- (b) the ability to choose situations and environments that are conducive to meeting goals.

Further, Keyes (2002) concisely summarises Ryff and Singer's (1998) model of psychological well-being in the following terms:

Individuals are functioning well when they like most parts of themselves, have warm and trusting relationships, see themselves developing into better people, have a direction in life, are able to shape their environments to satisfy their needs, and have a degree of self-determination. (pp.208-209)

Moreover, the inherent complexities attached to both the lived experience and the theoretical construct of psychological well-being need to be appreciated. Consequently, in applying Ryff and Singer's (1998) model to the present study, a consideration that was taken into account was the likelihood that the data would not be illuminated by all six dimensions of the model. Other themes around

psychological well-being that are not directly accounted for in terms of this model were also expected to emerge during the interpretive process.

Interestingly, Chesney et al. (2005) have observed that despite the preponderance of research on negative conditions and adverse health outcomes, a corollary body of work linking positive emotional states to positive health outcomes, longevity and well-being exists. In addition, the authors have declared that “pathways exist by which positive emotions may influence health and well-being, either directly through physiological changes or indirectly through health behaviours and social support” (Chesney et al., 2005, p.55). Accordingly, it has been inferred that the salutary potential of positive emotions warrants due research attention. It is significant then that a theoretical engagement with and elaboration of the health-promoting qualities associated with positive emotions is to be found in the seminal work of Barbara Fredrickson. Her broaden-and-build model (Fredrickson, 2001) forms part of the theoretical landscape that has informed this study.

#### **2.2.4. Fredrickson’s (2001) Broaden-and-build Theory of Positive Emotion**

While working definitions of emotions vary somewhat across researchers, “consensus is emerging that emotions (both positive and negative) are best conceptualised as multicomponent response tendencies that unfold over relatively short time spans” (Fredrickson, 2005b, p.219). Further, research into the adaptive functions of positive emotional states indicates that positive and negative emotions do not necessarily occupy opposite ends of a single continuum of mood (Chesney et al., 2005). Indeed, Fredrickson (2001) regards multiple, discrete positive emotions as essential elements of optimal functioning. It is her bold assertion that positive emotions serve not only as markers of flourishing or optimal well-being (as traditional perspectives within psychology suggest), but rather they also *produce* flourishing (Fredrickson, 2001, 2005b; Fredrickson & Losada, 2005).



Fredrickson's broaden-and-build theory of positive emotions contends that:

Certain discrete positive emotions - including joy, interest, contentment, pride, and love - although phenomenologically distinct, all share the ability to broaden people's momentary thought-action repertoires and build their enduring personal resources, ranging from physical and intellectual resources to social and psychological resources. (2001, p.219)

For example, Fredrickson holds that the positive emotion of joy "broadens by creating the urge to play, to push the limits, and be creative - urges evident not only in social and physical behaviour but also in intellectual and artistic behaviour" (2005b, p.221). Thus, joy can be described as broadening an individual's thought-action repertoire, widening the array of thoughts and actions that come to mind (Fredrickson, 1998, 2000a, 2000b; Fredrickson & Branigan, 2005). Furthermore, joy and related positive emotions (e.g., exhilaration and amusement) can also, over time and as a product of recurrent play, have the incidental effect of building an individual's resources (Fredrickson, 1998, 2000a, 2000b).

With respect to the thought-action tendency to play then, it is posited that while children's immediate motivations may be simply to enjoy the moment, they are simultaneously building and strengthening not only physical resources but intellectual, psychological and social resources as well (Fredrickson & Joiner, 2002; Fredrickson, 2003). Moreover, Fredrickson (2003, cf p.332) outlines the development of such resources in the following terms: Firstly, the physical activity leads to the development of co-ordination, strength and long-term improvements in cardiovascular health. Secondly, the game-playing strategies develop problem-solving skills, and serve as opportunities to learn new information. Thirdly, the camaraderie that often occurs during play creates new bonds and strengthens existing social bonds, friendships and attachments that could serve as a significant source of support at some time in the future. Fourthly, play

affords a pathway to the development of resilience and optimism as well as the development of a sense of identity and goal orientation. Importantly, Fredrickson (2000a, 2000b, 2003, 2005a, 2005b) regards these outcomes as enduring often long after the initial positive emotion has vanished. Indeed, she has stated that an increase in an individual's personal resources - which serve a protective function and are useful in promoting good health in the future - is an often incidental effect of experiencing a positive emotion (Fredrickson, 2005b).

Snyder and Lopez (2007) have aptly declared that "Fredrickson's broaden-and-build process sets a positive carousel in motion" (p.365). In this regard, her argument around the adaptive significance of positive emotions holds that "through experiences of positive emotions people *transform* themselves, becoming more creative, knowledgeable, resilient, socially integrated, and healthy individuals" (Fredrickson, 2005a, p.123). And, noting that psychological resilience is an enduring personal resource, the broaden-and-build theory makes the bolder prediction that experiences of positive emotions might also, over time, *build psychological resilience*, and not just reflect it.

For instance, Fredrickson and Joiner's (2002) study showed that the psychological broadening sparked by one positive emotion can increase an individual's receptiveness to subsequent pleasant or meaningful events, improving the likelihood that the individual will find positive meaning in these subsequent events and experience additional positive emotions. Fredrickson and Joiner's (2002) research suggests that individuals who achieve such upward spirals enjoy improved emotional well-being, while also building their coping arsenal for handling future adversities.

One way that people experience positive emotions in the face of adversity is by finding positive meaning in ordinary events and within the adversity itself (Fredrickson, 2001, 2003). Indeed, the relationship between positive meaning and positive emotions is considered reciprocal. In other words, not only does

finding positive meaning trigger positive emotion, but also positive emotions, because they broaden thinking, should increase the likelihood of finding positive meaning in subsequent events (Fredrickson, 2000a). It is significant, too, that although the active ingredient within growth and resilience may be positive emotions, the leverage point for accessing these benefits is finding positive meaning.

It is also salient that in the context of stressful circumstances, positive emotions are known to co-occur alongside negative emotions (Fredrickson, Tugade, Waugh, & Larkin, 2003). Fredrickson (2001) reasons that if negative emotions such as fear and anxiety narrow the momentary thought-action repertoire and positive emotions broaden this same repertoire, then positive emotions ought to function as efficient antidotes for the lingering effects of negative emotions. Thus, she submits the 'undoing hypothesis', positing that positive emotions might 'correct' or 'undo' the after-effects of negative emotions (Fredrickson & Levenson, 1998; Fredrickson, 2000b). Importantly, evidence for the 'undoing effect' suggests that people might improve their psychological well-being, and perhaps also their physical health, by cultivating experiences of positive emotions at opportune moments to cope with negative emotions.

In sum, the broaden-and-build theory "challenges existing paradigms because it casts positive emotions in a far more consequential role in the story of human welfare" (Fredrickson, 2005b, p.230). Positive emotions are theorised as more than important factors that *buffer* individuals against maladaptive health outcomes; rather, the broaden-and-build model suggests that they fuel human flourishing (Fredrickson, 2001, 2005b). Interestingly, recent research has indicated that finding ways to cultivate meaningful positive emotions is paramount for optimal psychological and physical functioning (Tugade, Fredrickson, & Feldman Barrett, 2004). Hence, the present study has contended that both Ryff and Singer's (1998) model of psychological well-being and Fredrickson's (2001) broaden-and-build model of positive emotion serve as

useful theoretical frameworks within which to investigate whether and by which mechanisms and processes participation in a therapeutic horse riding intervention could feed in to and perhaps foster psychological well-being in a group of children with cerebral palsy. To this end, the discussion turns to theorising potential mechanisms and processes by which therapeutic horse riding works to effect therapeutic physical and psychosocial gains.

### **2.3. Therapeutic Horse Riding: An Intervention for Individuals with Disabilities**

The discussion that follows places the activity of horse riding under conceptual analysis. In so doing, it aims to psychologically theorise a range of the potential mechanisms and processes by which a therapeutic horse riding intervention could serve to effect often nuanced, meaningful shifts in psychosocial functioning and thereby promote wellness in children with disabilities. The psychological conceptions offered here represent a move towards resolving the broader challenge of marginal attention to theoretical groundedness within extant therapeutic riding research.

By way of introduction, this theorising commences by outlining the historical background and defining features of therapeutic horse riding, and proceeds to a focus on the proposed therapeutic effects of horse riding. The discussion goes on to look at horse riding as an embodied 'self-making' activity, as well as a site for the promotion of optimal experience. In addition, consideration is given to the therapeutic nature of relationships within the context of this form of intervention. Further, a two-fold analysis of horse riding as a physical activity is conducted. At one level, the effects of exercise and sport are considered. At another level, the therapeutic effects of sensory-motor stimulation and feedback on bodily control are theorised by making particular reference to the population of children with cerebral palsy to illustrate key considerations.

### **2.3.1. Contextualising Therapeutic Horse Riding: Historical Background and Defining Features**

The horse has been recognised throughout history as an agent of healing for minds as well as bodies. Indeed, the use of horse riding as a therapeutic medium has been traced to as early as the 5<sup>th</sup> century B.C. when horses were used in the rehabilitation of wounded Greek soldiers (Mayberry, 1987). This indicates that people were aware of the benefits of horse riding early on. However, there is no isolated time in history when it was decided that individuals with disabilities could or should ride horses (Britton, 1991). The change that took place was located, rather, in people's attitudes toward horse riding for disabled individuals.

In terms of an actual event, many (for instance, Griffith, 1992; Pauw, 2000; Rolandelli & Dunst, 2003; Rufus, 1997; Scott, 2005) identify the Danish woman, Liz Hartel's accomplishment in the 1952 Olympic Games as a defining moment in the genesis of therapeutic riding. Hartel won the silver medal in the dressage trials, despite having used a wheelchair since 1943 due to paralysis from polio. In so doing, she brought the world's attention to the possibility of using horse riding as a rehabilitative therapy (Scott, 2005). Moreover, Hartel's accomplishment inspired the construction of the first therapeutic riding centres in the late 1950s in England, and then in North America. Locally, therapeutic riding was first institutionalised in the form of the South African Riding for the Disabled Association (SARDA), which was established in Cape Town in 1973. Further, in 1996, Engela Young, an occupational therapist, established the South African Therapeutic Riding Association. Both organisations offer therapeutic riding lessons to riders with a range of disabilities, as well as the training and examination of therapeutic horse riding instructors.

As mentioned in the introductory chapter, this study has aligned itself with a definition of therapeutic riding as entailing "the use of the horse and equine-oriented activities to achieve a variety of therapeutic goals, including physical, emotional, social, cognitive, behavioural and educational goals" (Lessick et al.,

2004, p.48). Another noteworthy point, following Lessick et al. (2004), is that this form of intervention not only encompasses various leisure and therapeutic activities (e.g., learning riding skills), but also places emphasis on the development of the relationship between the rider and the horse.

Within this form of intervention then, it is not only the horse but also its environment (i.e., the stables, arenas, surrounding areas, riding and play equipment, as well as instructors, leaders and side-walkers, for instance) that serves as a medium for therapeutic engagement. Moreover, children and adults with a range of diagnoses including visual impairments, hearing impairments, autism, cerebral palsy, spina bifida, Down syndrome, multiple sclerosis, learning disabilities, and behavioural and emotional difficulties, as well as cancer survivors have been reported as participants in therapeutic horse riding programmes (Brickell, 2005; Britton, 1991; Haylock & Cantril, 2006; Helfer, 2006; Lehrman & Ross, 2001; Lessick et al., 2004; Ludewig, 2006; Scott, 2005; Snider et al., 2007; Tredoux, 2000).

However, an important cautionary note is that therapeutic horse riding may not serve as an appropriate intervention for certain individuals with disabilities. For instance, it is contraindicated for children and adults who: a) indicate a lack of a desire to ride following a trial experience; b) have allergies, and bleeding disorders; c) have epileptic seizures that are uncontrolled by medication; d) have atlantoaxial instability (which entails an abnormal degree of mobility in the two uppermost cervical vertebrae of the neck; e) have any joint or bone anomalies; and f) have emotional or psychiatric difficulties that are severe to the extent that participating in horse riding may cause danger to the rider, the horse, or fellow riders (Lessick et al., 2004; Tredoux, 2000; Wood, 1990).

The literature has tended to group horse riding which has therapeutic value into different categories including hippotherapy, remedial driving and vaulting, and riding for the disabled as a sport (Britton, 1991; Grobler, 2004; Ludewig, 2006). To begin with, hippotherapy is a subtype of therapeutic horse riding that uses the

movement of a horse in a walk to promote the attainment of individualised therapeutic goals (Rolandelli & Dunst, 2003). In contrast to therapeutic horse riding where the therapeutic riding instructor is central to the intervention, in hippotherapy specially trained physical and occupational therapists use this medical treatment for clients with movement dysfunction (American Hippotherapy Association, as cited in Rolandelli & Dunst, 2003). As such, the individual is regarded as passive in hippotherapy (Hammer et al., 2005), but takes on a more active role within a therapeutic horse riding intervention. In addition, both are similar in that they support the aims of increasing balance and equilibrium responses, and increasing muscle tone to support the spine; however, therapeutic riding is distinct from hippotherapy in that it makes use of the different gaits of the horse, and has independent riding as an aim (Ludewig, 2006). Also distinct from therapeutic horse riding, remedial vaulting and riding is used in the treatment of children with particular emotional needs. By definition, vaulting involves the rider doing gymnastics on the back of the horse and aims specifically to enhance an individual's motivation and self-esteem as well as improve his/her social skills (Grobler, 2004). In contrast to this form of intervention, therapeutic riding uses goal-directed activities to facilitate perceptual-motor and sensory integration in the rider (Ludewig, 2006). Lastly, in riding for the disabled as a sport, the rider actively manoeuvres the horse, and has participation in competitive riding as an end goal (Grobler, 2004). Thus, while therapeutic riding may lead to involvement in sport, it typically entails a form of assisted riding and is not, by definition, competitive.

Having noted the distinctions between the above forms of therapeutically-oriented horse riding, in the context of the present study the intervention of choice has been therapeutic horse riding. In the South African context, this form of intervention enjoys limited but growing support (Ludewig, 2006) and is more readily practiced than hippotherapy and riding for the disabled as a sport. Consequently, therapeutic riding serves more frequently as part of the multidimensional rehabilitation of children and adults with a range of disabilities.

### **2.3.2. Therapeutic Effects of Therapeutic Horse Riding**

There is a growing acknowledgement amongst health care professionals that therapeutic riding can and often does have potential physical and psychosocial benefits for those with a positive view of animals (Bracher, 2000; Scott, 2005). These benefits constitute important components in the rehabilitation of disabled individuals.

A number of interacting factors have been theorised as contributing to the degree to which an individual with a disability may benefit from participating in the activity of horse riding. For instance, Lessick and colleagues (2004) have listed the type and severity of the disability, the motivation of the rider, as well as the match between the horse and the rider as relevant factors. In addition, the authors highlighted the importance of the riding instructor selecting a horse that best fits the individual's needs, citing the example of a person with weakened trunk control as needing a smooth, slow horse to begin with, until the individual has gained sufficient strength to be challenged more (Lessick et al., 2004). And, while riders are matched with the most appropriate horse in terms of gait, pace, size and character, Lessick and colleagues (2004) emphasise that as needs change, the riding team is modified.

A review of existing research on the efficacy of therapeutic riding reveals that the limited body of work has paid attention to adults and children with a range of diagnoses. Within this body of work, physical effects that have been studied include improvements in balance, coordination and muscular control, as well as strength, posture and joint mobility, while gross motor functioning has also received due attention (For instance, Bertoti, 1988, 1991; Biery & Kaufmann, 1989; Cherng, Liao, Leung, & Hwang, 2004; MacKay-Lyons, Conway, & Roberts, 1988; MacPhail et al., 1998; Sterba, Rogers, France & Vokes, 2002; Van Dyk, Odendaal, & Botha, 1994; Winchester et al., 2002).



Turning to psychosocial aspects of functioning, Xenophon's statement that 'the best thing for the inside of a man [sic] is the outside of the horse' (Longden, 1998) serves as an early acknowledgement of the potential psychosocial benefits of riding. However, it is only recently that interest in the psychosocial outcomes of the activity has started to be reflected quite convincingly in the research context. While in early studies findings on psychosocial effects tended to be largely anecdotal (Gatty, n.d.), often serving as aggregate information to a primary investigation into the physical benefits of therapeutic riding, key studies in the field reflect a distinct turn to investigating the psychosocial correlates of therapeutic horse riding. Highlighting intrapsychic factors, documented psychosocial benefits have included increases in motivation, self-esteem, self-efficacy beliefs and behavioural self-confidence, and improvements in concentration and attention span, while improved communication, social participation and social skills have also been reported (For instance, Bizub, Joy, & Davidson, 2003; Carlson, 1983; Crawley, Crawley, & Retter, 1994; DelGiudice & Berg, 2003; Farias-Tomaszewski, Jenkins, & Keller, 2001; Grobler, 2004; Helfer, 2006; Kaiser, Smith, Heleski, & Spence, 2006; Lehrman & Ross, 2001; Ludewig, 2006; MacKinnon & Ferreira, 2002; MacKinnon, Noh, Lariviere, McPhail, Allan, & Laliberte, 1995; Miller & Alston, 2004; Rufus, 1997; Stuart, 1998; Tredoux, 2000; Von Moltke, 2002; Wood, 1990).

While extant research has placed value on the physical and psychosocial effects of therapeutic horse riding, it is important to acknowledge that with respect to psychosocial indices in particular, studies to date have yielded somewhat ambiguous findings. It is noteworthy then that in an early review of studies on the benefits of therapeutic horse riding MacKinnon, Noh, Laliberte, Lariviere and Allen (1995) found that methodological limitations in the majority of the studies, namely, poor scientific rigour, small samples sizes and the use of non-standardised measures, tended to render reported findings inconclusive. Similarly, Pauw's (2000) review of eight studies that utilised a quantitative approach to methodology concluded that small sample sizes, the lack of control

groups, and the lack of control of extraneous variables tended to call into question the efficacy of the cited studies. The methodological shortfalls that these two reviews have raised continue to plague research in the therapeutic riding field. And, while extant research reflects a growing methodological sophistication over time, significant caveats indicate that both methodological soundness and theoretical groundedness need to be accorded due precedence in future studies that aim to investigate the therapeutic value of this form of intervention. Until this is done, the scientific foundation of therapeutic horse riding will remain under-developed.

Thus, given this study's interest in psychosocial aspects of functioning, it is problematic that studies such as those mentioned above have afforded marginal attention to theoretical groundedness in formulations of the psychosocial effects of therapeutic riding. Indeed, it is cause for concern that with respect to the body of work around the efficacy of this form of intervention, more than a decade after it was first claimed by MacKinnon and colleagues, one of the critical challenges faced by researchers continues to be that "the theoretical rationale that delineates how therapeutic riding affects psychosocial functioning has not been fully formulated" (MacKinnon, Noh, Laliberte, Lariviere & Allan, 1995, p.9). In the discussion that follows, an attempt has been made to address this specific challenge by delineating psychological conceptions of the multiple inter-related processes and mechanisms at play in therapeutic riding that could serve therapeutic effects. Essentially, an analysis has been conducted around what it is about horse riding that lends itself to its conceptualisation as a rehabilitative activity having therapeutically meaningful psychosocial effects.

In keeping with Fox's (1999) stance regarding physical activity participation, it is important to acknowledge the diverse range of environmental (e.g., physical and social context) and individual (e.g., severity of disability, strengths, needs, preferences and personal background) factors at play within a therapeutic horse riding intervention. Several mechanisms are therefore most likely to operate in

concert, with the precise combination being highly specific to the individual. The idea, then, is that different processes operate for different individuals at different points in time. Thus, in investigating the utility of a therapeutic horse riding intervention for the psychological well-being of individuals with disabilities, the diverse range of biological and psychosocial factors that could influence an individual's experiences of psychological well-being were allowed for. The isolation of a specific mechanism was not feasible, as a single mechanism cannot realistically address the vast number of psychological influences that may be experienced through the physical activity of therapeutic horse riding.

As a foreground to delineating the mechanisms and processes operating to effect psychosocial gains, Britton's (1991) assertion that therapeutic riding simply uses the recreational pleasures of horse riding to promote various social, emotional and physical benefits is worth noting. So, while therapeutic riding is by definition rehabilitative, its recreational nature distinguishes it from traditional treatment modalities. And, if one takes into account the therapeutic potential of being exposed to features of the natural environment, it is relevant that therapeutic horse riding takes place in a natural social setting, rather than a clinical environment. Also, therapeutic riding provides a novel and creative form of intervention for individuals who might have been accustomed to and become disillusioned by treatment within traditional settings (Graham, 2000). Indeed, Benda, McGibbon and Grant (2003) have viewed therapeutic horse riding as a site for nurturing and developing capabilities that may be untapped through conventional treatment. In addition, All and colleagues (1999) have proposed that horse riding, out in the fresh air and away from facilities associated with chronic illness and disability, imparts a sense of general well-being.

Moreover, Sterba and colleagues (2002) have declared that:

while similar to therapeutic devices used in clinical settings, such as the bolster swing or Swiss ball, horse riding offers more sensory-motor

stimulation and a bond between rider and horse that cannot be simulated artificially in the clinic or with an inanimate horse. (p. 306)

As opposed to engaging with an inanimate therapeutic apparatus/object, this form of intervention is unique in that it affords the rider an opportunity to interact with a powerful living animal that responds to him/her in a neutral, non-judgmental manner (Bizub et al., 2003). The rider is not passive, but rather an active agent who relates to a changing environment, and to the horse in particular, in a 'mutual interactional dialogue' (Kluwer, 1988). Hence, the question of the implications of the activity of horse riding for human agency and identity, a prominent concern within existing bodies of knowledge around disability, is brought to the fore.

#### **2.3.2.1. Implications for Identity: Horse riding as an Embodied, Self-making Activity**

The conceptual placing of therapeutic horse riding within a psychofortigenic approach to human health and wellness (as discussed in section 2.2. of this chapter) highlights the integral part that concerns with respect to psychological well-being can play in relation to human agency and identity. This study has posited that the implications of a specific intervention for an individual's sense of self are critical to an evaluation of that intervention's therapeutic efficacy. In considering human agency and identity with respect to individuals with disabilities then, the present study has aligned itself with the work of Margaret Archer (2002).

Archer (2002) challenges Harré's (1983) understanding of the self as produced discursively, where 'self' is a theoretical concept acquired in the course of social interactions. Instead, she proposes a focus on our human relations with practical reality. Underlying such a focus is the premise that "because neither our humanity, which anchors our selves, nor practical reality through which our human potentials are developed, can be dispensed with, our task is necessarily

to examine the interplay between these two irreducible components” (Archer, 2002, p.49). Thus, Archer’s (2002) conceptualisation entails the understanding that it is through practical reality that our human potentials are developed. Such an understanding yields a number of noteworthy considerations. Firstly, Archer’s (2002) specific attention to the development of potentialities may be embedded within and extended by a psychofortigenic perspective. As mentioned earlier, this approach to human health and wellness emphasises building individuals’ strengths, capacities and resources with a view to optimising rather than normalising functioning, and thereby promoting well-being. Secondly, it is significant that Archer (2002) argues for embodied practice as decisive for acquiring a sense of self. Indeed, she sees embodied practice as the *source* of a sense of self. And thirdly, given that this study examines horse riding within the context of a therapeutic riding intervention, it is salient that Archer makes specific reference to the activity of horse riding in her work. In sum, she conceptualises horse riding as an embodied, practical, ‘self-making’ activity, through which our human potentials are developed. In exploring existing bodies of knowledge with respect to disability then, the use of Archer’s (2002) view of self as created in the realm of practical activity, where horse riding constitutes such an activity, represents a previously unexplored attempt to elaborate and extend current understandings of possible mechanisms by which therapeutic riding effects psychosocial benefits.

Resonant with Archer’s view are Brandt’s (2004) assertions around the embodied nature of human-horse communication. Brandt describes communication between horse and rider as “a cyclical and dynamic process, where both species are full participants in the process” (2004, p.307). Further, she explains that when horse and rider are moving together, the rider must use his/her own body to make the horse’s body the focal point, as literally both accompany the other in a shared embodied experience. Brandt (2004) believes that without this empathic basis, horse and rider would be disjointed and in conflict, unable to have a

shared experience of each other. Such an understanding serves to compliment Archer's (2002) aforementioned conceptualisation of horse riding.

#### **2.3.2.2. The Therapeutic Nature of Relationships within the Therapeutic Riding Context**

It is also useful to examine the nature of the relationship between animals and human beings, and specifically between *horse and rider*. A significant body of evidence has indicated that the presence of animals facilitates social approach and interaction for children and adults both with and without disabilities. This suggests a relationship between interactions with animals, and our everyday functioning and well-being (Melson, 2002; Myers, 1994; Velde et al., 2005). In particular, the relationship between horses and humans has been documented historically as having therapeutic effects (Bracher, 2000). For instance, Griffith (1992) has stated that the value of horse riding is based in the relationship that develops between horse and rider. Advancing such a view, All and colleagues (1999) assert that the relationship between horse and rider is definitive or paradigmatic of the individual's improvement in any given case.

Theoretical paradigms within the psychology of child development also offer useful insights into the workings of bonds between humans and animals more broadly. Melson (2003) has argued that while a number of paradigms emphasise the importance of studying children within their naturally occurring environments, scholars of child development have paid scant attention to children's relationships with companion animals. Notwithstanding such limited engagement, a prominent line of thinking suggests that the bonds between humans and animals may be seen in terms of attachment theory, which situates human development within the context of important relationship bonds (Melson, 2003; Menzies Inc., 2003). According to attachment theory, human development takes place in the context of multiple relationships, and in particular within early relationships with caregivers who are expected to have unconditional love for us and with whom strong attachments are formed (Bowlby, 1969). Moreover, it has

been suggested that “human-animal relationships can, along with other relationships, provide opportunities for growth, the development of self-esteem, trust and understanding” (Menzies Inc., 2003, p.5).

In addition to the foregoing insights, worthwhile considerations may be drawn from psychoanalytic theory. For instance, the relationship between horse and rider has been described in the literature within a psychoanalytic framework in a number of ways. At one level, Kluwer (1988) has compared the movement dialogue between horse and rider with the preverbal movement dialogue between mother and infant. He explains that the preverbal communication between mother and child is based on the nonverbal exchange of body expressions, muscular signals of tension and release and tones. As with this mother-child communication, the movement dialogue between horse and rider is understood to be the sensory-motor equivalent of psychic trust-building activities and experiences, and is also regarded as a basis for learning and developing relations with others (Kluwer, 1988). At another level, the rhythmic experience of being carried on horseback has been described as a representation of the psychoanalytic experience of ‘being carried’ (Kluwer, 1988). Following Winnicott’s (1958) theorising, such a view alludes to the experience of being ‘contained’ within the emotional safety of a ‘holding environment’ that is realised in the relationship that is forged between horse and rider. In sum, a psychoanalytic perspective affirms that such a relationship affords the rider opportunities for unconscious experiences of well-being.

Together with the relationship between horse and rider, the interactional triad between horse, rider and *therapeutic riding instructor* needs to be taken into account. Lessick and colleagues (2004) observe that in therapeutic riding a team approach is utilised towards providing individualised treatment, with the therapeutic riding instructor playing a central role in this form of intervention. Alerting us to the therapeutic riding instructor’s role as a social facilitator is the argument that this relationship serves to facilitate interactions with other riders

and individuals within and outside of the therapeutic riding context, thereby enhancing social skills (Miller & Alston, 2004; Stuart, 1998).

Apart from serving as an opportunity to refine social skills, therapeutic riding also lends itself to providing numerous opportunities for language development when individuals are mounted and dismounted (De Gutis et al., as cited in Ludewig, 2006). Mounted on horseback, the rider participates in active listening while attempting to follow the therapeutic riding instructor's directions regarding specific activities. Goal-directed activities such as identifying and naming parts of their own and the horse's body, as well as using verbs and naming actions, for instance, afford children opportunities to increase their vocabularies as well as communication skills. Thus, the therapeutic horse riding context serves as an arena for individuals to practice and refine their expressive and receptive language skills, as they are consistently engaged in conversation with the therapeutic riding instructor, volunteers, their teacher, and each other (Von Moltke, 2002).

The above considerations regarding the facilitation of language development within the social context of a therapeutic riding setting articulate with Vygotsky's theoretical framework regarding the social nature of learning and development. Vygotsky's key theoretical construct, the zone of proximal development (ZPD), is defined as "[t]he distance between the actual developmental level as determined by independent problem solving and the level of potential development as determined through problem solving under adult guidance or in collaboration with more capable peers" (1978, p.86). According to Hedegaard (1992), the underlying assumption behind the construct of the 'zone of proximal development' is that psychological development and instruction are socially embedded. Indeed, the concept serves to highlight "the interdependence of the process of child development and the socially provided resources for that development" (Valsiner, 1988, p.145).



The therapeutic riding instructor is a key figure within the social landscape of the therapeutic riding environment (Lessick et al., 2004; Miller & Alston, 2004). In line with Vygotskian thinking, this study has posited that the therapeutic riding instructor serves as a mediator between horse and rider. The instructor communicates verbally and non-verbally with the rider (and horse), outlining clear proximal goals, offering reassurances, and providing quick and unambiguous feedback to the rider regarding the progress that he or she is making in terms of the various therapeutic horse riding tasks and activities. These functions are supported by the inputs of the leaders and side-walkers who assist the rider to perform the psychomotor tasks and activities that are outlined by the therapeutic riding instructor.

Change within the zone of proximal development is usually characterised as individual change, for Vygotsky is of the view that “what the child is able to do in collaboration today he will be able to do independently tomorrow” (1987, p.211). Thus, in Vygotsky’s terms the internalisation of socially mediated learning is demonstrated through the ability to transfer the learning to new situations. Applying the sentiments of followers of Vygotsky such as Daniels (1993) and Hedegaard (1992) to the context at hand, it is posited that riders internalise and transform the help they receive from the therapeutic riding instructors as well as leaders and side-walkers, and eventually use these same means of guidance to direct their subsequent problem-solving behaviours. In sum, it is suggested that the role of the therapeutic riding instructor, leaders and side-walkers illustrates Vygotsky’s (1994) assumption that the environment is the *source* and not the setting of learning and development.

#### **2.3.2.3. Physical Activity: The Beneficial Psychosocial Effects of Exercise and Sport**

Moving on to a consideration of the beneficial role of exercise and sport for individuals with disabilities, the description of therapeutic horse riding as an individually prescribed active or passive exercise programme performed on

horseback (Griffith, 1992) is salient here. Further, physical activity is now known to be a co-determinant of health (Pretty, 2004). Hence, therapeutic horse riding may be contextualised within the body of work which holds that exercise and physical activity have a valuable role to play in the promotion of physical and mental health and psychological well-being (Fox et al., 2000; Mutrie & Faulkner, 2004; Pretty, 2004). Indeed, Mutrie and Faulkner's (2004) declaration that "physical activity participation epitomises the principles of positive psychology" (p.159) serves as a means to solidify this study's theoretical link between issues of psychological well-being hailing from positive psychology, and what therapeutic riding has to offer towards promoting psychological well-being by virtue of it constituting a physical activity.

In terms of specific psychosocial indices, Pretty and colleagues maintain that "regular physical activity positively affects mental well-being and self-esteem" (2003, p.6). And, offering even stronger support for the link between physical activity and positive mental health, Pretty (2004) has argued that via an increase in physical activity "people would also benefit emotionally and through improved mental well-being, and *these positive mental health benefits may even outweigh the physical benefits*" [italics added] (p.76).

According to Morgan (as cited in Ryff & Singer, 1998), the literature on beneficial mental and physical health consequences of habitual physical activity has delineated multiple underlying mechanisms, tending to focus on single components of a seemingly more complex interactive system. For example, the separate role of endorphins, serotonin, norepinephrine, body temperature control systems in promoting improved mood states as a consequence of physical exercise have been examined (Ryff & Singer, 1998). In addition, exercise is well known for its beneficial effects on cardiovascular and musculoskeletal systems as well as metabolic, endocrine and immune systems (Morgan, as cited in Ryff & Singer, 1998). As Ryff and Singer (1998) contend, "the brain's release of endorphins and other neuropeptides associated with such activities as well as

social interactions engenders feelings of well-being” (p.22). It is through such mechanisms and processes, then, that habitual physical activity fosters psychosocial and physical benefits.

Moreover, exercise also helps individuals psychologically by strengthening their sense of competence and self-efficacy (Brown, 1991). Related suggestions for the positive effects of exercise include “more autonomy and personal control, and a better sense of belonging and significance” (Pretty et al., 2003, p.26). To the degree that therapeutic horse riding entails a physical activity and an exercise programme, individuals with disabilities who engage in this form of intervention stand to benefit from the associated positive physical and psychosocial effects.

Psychosocial benefits may also occur because therapeutic horse riding (while distinct from riding for the disabled as a sport in that its end goal is not competitive riding) provides disabled individuals with the opportunity to participate in an activity that is perceived as a sport. This affords the individual an opportunity to exert control over his/her environment, as well as to master new skills (Graham, 2000; MacKinnon, Noh, Lariviere, MacPhail, Allan & Laliberte, 1995). Hammer and colleagues (2005) elaborate on the argument for the acquisition and mastery of new skills, stating that apart from therapeutic gain, a positive motivational factor for the rider is added. Further, participation in therapeutic riding also allows individuals with disabilities access to experiences of competitiveness, and a challenge, along with social interactions with other riders. Indeed, Mutrie and Faulkner (2004) are of the opinion that the provision of physical activity in a supportive group environment represents one of the mechanisms by which opportunities for valuable positive social interactions may be provided.

#### **2.3.2.4. Physical Activity: The Therapeutic Effects of Sensory-motor Stimulation and Feedback on Bodily Control**

In theorising psychological conceptions of what arises during therapeutic riding that works toward effecting therapeutic improvements in disabled individuals' psychosocial functioning, an analysis of experiences at a sensory-motor level is also warranted. In the discussion that follows reference is made to the specific clinical population of children with cerebral palsy in order to illustrate broader considerations regarding the value of therapeutic riding for individuals with disabilities.

To begin with, it is important to consider that learning takes place through our sensory experiences in relationships with others and through our environment (Colby Trott, Laurel, & Windeck, 1993). Accordingly, Sterba and colleagues (2002) maintain that therapeutic horse riding is aimed at improving the individual's ability to receive and process multi-sensory information through the rhythmic multidimensional movements of the horse and activities that encompass the use of the whole body. In addition, Benda and others (2003) raise the significant point that heightened vestibular and proprioceptive stimulation, continually changing visual fields, and constant shifting of the rider's center of gravity provide important movement learning experiences that children who are not disabled acquire during play on a daily basis. Moreover, Miller and Alston (2004) observe that sequencing, patterning and motor planning help children to organise their daily activities; knowing which comes first in a sequence of events is an important part of most activities. During therapeutic riding, these and other similar skills are taught on horseback through the use of obstacle courses, pole bending, and a range of other games and activities (Miller & Alston, 2004).

As mentioned previously, cerebral palsy entails an inability to fully control motor functioning (Rosenbaum, 2003). Early on Bobath (1980), a key figure in the field of physical rehabilitation, highlighted an inability to maintain postural control due to abnormal muscle activation and ineffective movement strategies as a key

clinical feature of cerebral palsy. And, if normal movement patterns and posture are not present, it is possible that abnormal movement patterns may develop due to the child's use of other muscles more, in order to compensate for his/her muscular spasticity (Bertoti, 1988). Moreover, Stanger and Oresic (2003) have declared that children with cerebral palsy and a resultant movement disorder tend to experience limitations in functional activities such as sitting and reaching. It follows, then, that children with cerebral palsy might typically have considerable difficulties with mobility, and therefore experience their contexts and interactions in a limited manner.

Accordingly, much emphasis has been placed on addressing aspects of motor functioning within rehabilitation contexts. As Tilton (2006) pointed out, physical therapy and regular physical activity constitute the basis of every treatment programme for children with cerebral palsy. Thus, therapeutic goals have been described as commonly including improvements in the variety of movement patterns, the development of more advanced motor skills, and improvements in postural control and balance, both reactive and anticipatory (Casady & Nichols-Larsen, 2004). Moreover, on account of children with cerebral palsy's range of physical impairments, opportunities afforded by horse riding take on a particular *psychological significance*. For instance, Benda and colleagues (2003) highlight the psychological enhancement of moving freely through space on a powerful animal without the constraints of assistive devices such as wheelchairs for example. Similarly, Lessick et al. (2004) maintain that "for a person with a disability, the perception of movement and freedom on a horse can be a catalyst for therapeutic improvement" (p.49). In addition, being elevated atop a horse also affords the disabled child a unique perspective of looking from above at what is below. As an individual mounts a horse he or she leaves the safe familiarity of the ground; in this way the individual's perspective literally rises to a greater height, offering a new vantage point on his/her surroundings (Bizub et al., 2003).

Therapeutic horse riding has also been found to effect improvements in visual/spatial perception, including the rider's awareness of forms and space, and understanding relationships between forms in the environment (Miller & Alston, 2004). Through participating in therapeutic riding, the child engages in an activity that is challenging and physically and psychosocially stimulating, and that not many able-bodied children within their frame of reference might pursue. Hence Lessick et al. (2004) maintain that through horse riding, individuals with disabilities are afforded an opportunity to participate in and succeed at an activity that many able-bodied people are hesitant about or afraid to try.

If one considers that abnormal muscle tone (namely, too high, too low, or fluctuating tone) constitutes a key clinical feature of cerebral palsy, then the stimulation of the vestibular system - which is involved in the development and maintenance of normal muscle tone (Mailloux, 1993) during therapeutic horse riding is notable. In terms of mechanisms that work toward reducing abnormally high muscle tone, Hammer et al. (2005) maintain that sitting astride a horse entails a position that inhibits extension spasticity of the rider's legs and applies a long-lasting stretching of the adductor muscles of the hip. Also, the rhythmic motion of the horse serves to reduce spasticity, while simultaneously promoting bilateral symmetrical postural responses that increase tone in hypoactive muscles (Benda et al., 2003; Miller & Alston, 2004). Further, Scott (2005) has asserted that "the vertical posture required for horse riding assists the rider with low muscle tone to utilise the diaphragm, which leads to better speech" (p.158).

Perhaps the most remarkable feature setting therapeutic horse riding apart from other forms of intervention is that the sensory input that the rider receives from the rhythmic movement of the horse at a walk *cannot be reproduced in any other way* (Casady & Nichols-Larsen, 2004; Ludewig, 2006). Horse riding serves as a unique therapeutic medium in that the rhythmic, repetitive, three-dimensional movement pattern of the horse's back during a walk constitutes a simulation of movements produced by the human walk (Lessick et al., 2004). As the horse

moves, its centre of gravity is displaced three-dimensionally, and the rider is constantly thrown off-balance, requiring that his/her muscles contract and relax in an attempt to re-balance so as to stay in an upright posture on the horse; this exercise reaches deep muscles not accessible in conventional physical therapy (Brickell, 2005; Miller & Alston, 2004; Reide, 1998). Not only is the facilitation of these diagonal movement patterns and gait-specific forward movements possible solely through the modality of the horse, but the horse's diagonal movement patterns play an important role in the neurophysiological development of the motor system of the child (Ludewig, 2006).

An inability for individuals to make adjustments in their positions constitutes another key clinical feature of cerebral palsy (Finnie, 2002), and serves as an indication of problems in the functioning of individuals' proprioceptive systems. The stimulation of individuals' proprioceptive systems during therapeutic horse riding is directed at effecting improvements in functional mobility and functional independence off the horse. Thus, by stimulating proprioceptive impulses - that is, by stimulating a rider's awareness of his/her body position - as well as impacting on individuals' abilities to make adjustments in their positioning, therapeutic horse riding could serve to improve their functional mobility and functional independence off the horse. Equally important for our purposes is that these improvements could in turn serve to effect changes in psychosocial aspects of disabled individuals' functioning. And, while the tendency (not without exception) has been to discuss them separately in the literature, it is worth noting that in terms of a systems perspective, physical and psychosocial aspects of functioning are interdependent and interact with each other (Mash & Wolfe, 2007). As a result, it is plausible that the enhancement of physical skills via therapeutic interventions could necessarily impact upon the psychosocial functioning of individuals with disabilities.

It is also relevant that the experience of horse riding extends beyond stimulation of the various sensory-motor systems to providing feedback to riders on their

bodily control and functionality. Indeed, riding provides a profound bodily experience for children on horseback. And, successfully engaging in the 'bodily work' of horse riding could work to enhance the rider's self-efficacy and sense of mastery. Returning, then, to Archer's (2002) view of self as created in the realm of practical activity, it is reiterated that horse riding feeds in to the development of children's identities. The understanding presented in this study is that disabled riders 'create' their identities out of not having fallen off the horse and out of being able to stay atop the horse, which serves as evidence that the rider's body has worked. Through attention to this feature of horse riding, as well as to the sense of mastery of riding which disabled individuals may accomplish, a key issue in rehabilitation, namely, that engaging in the activity of horse riding feeds back into a conception of individuals as feeling positive about their bodies, is addressed. Furthermore, individuals feeling positive about their bodies entails a different form of psychological experience in comparison to sensory-motor stimulation and feedback. Thus, Fox (2000) has reached the relevant conclusion that exercise promotes physical self-worth and other important physical self-perceptions, such as improved body image. Mutrie and Faulkner (2004) explain this positive association by stating that gaining physical strength or capacity allows us to feel more confident in our ability to do everyday tasks, perhaps provides us with a more positive perception of our physical selves, and thus can influence our self-esteem. In sum, existing research suggests that physical competence and self-perceptions can be improved through physical activity and that this can have a positive mental health effect (Fox, as cited in Mutrie & Faulkner, 2004).

Having discussed some of the potential ways in which therapeutic horse riding serves as a catalyst for therapeutic improvement with respect to the psychosocial and motor functioning of individuals with disabilities, the present study reiterates that it is unlikely that any single theory, model or explanation will suffice. Instead, there is a strong likelihood that multiple mechanisms are effective in any one therapeutic horse riding context. These mechanisms and processes may function



not in isolation from but rather in dynamic interaction with each other towards effecting change and/or therapeutic gains in the psychosocial and motor functioning of individuals with disabilities. A further relevant point to be taken into account concerns the contingent nature of disability and ability (Breckenridge & Volger, 2001; Marks, 1999a Sebers, 2006). Also, the interaction between the body, psychological aspects of the experience, and the environment warrants due consideration. Finally, while acknowledging that functional limitations serve as challenges for individuals with disabilities to adjust to and cope with, their available strengths and resources need to be focused on when theorising the possible mechanisms and processes by which therapeutic horse riding serves as a catalyst for therapeutic improvements in their psychosocial and motor functioning.

#### **2.4. Conclusion to Literature Review**

This review of the literature commenced with a discussion of the different models of disability, and aligned itself with a social psychological model of disability, which focuses on the combination of psychological and social and environmental barriers that oppress some impaired people. Secondly, a psychofortigenic approach, which emphasises the acknowledgement and fostering of strengths, capacities, and resources in individuals with a view to facilitating optimal human functioning was delineated. Thirdly, the discussion outlined the defining features of therapeutic horse riding as an adjunctive therapeutic intervention. Further, it has responded to the challenge to delineate the mechanisms and processes by which this form of intervention could effect (often subtle) meaningful shifts and improvements in psychosocial functioning, and thereby well-being, by theorising psychological conceptions of that which arises in horse riding that has therapeutic effects. Significant implications of this theorising exist not only for rehabilitation to the degree that this form of intervention serves as a catalyst for therapeutic improvement, but also for research in terms of methodology.

## **CHAPTER THREE: RESEARCH METHODOLOGY**

To begin with, this chapter engages in an epistemological positioning of the present study within the landscape of an interpretive research paradigm. Given that it undergirds the use of a qualitative approach to methodology, the discussion of an interpretive paradigm is followed by a consideration of the basic principles of qualitative inquiry. Thereafter, the chapter provides an overview of selected qualitative methods of data collection employed in this study. Included in this overview are details regarding the selection and composition of the sample of participants. Specific techniques used in the analysis of qualitative data are also delineated.

### **3.1. An Interpretive Paradigm**

A fundamental premise of an interpretive paradigm is that social reality is not fixed and static. Rather, it is subjective and always subject to interpretation, and these interpretations are inconclusive and ongoing (Denzin, 1989; Hughes & Sharrock, 1997). In addition, an interpretive frame holds that unlike physical phenomena, social actors give meaning to themselves, to others and to the social environments in which they live; individuals can describe what they do, explain and justify it, give reasons, declare their motives, decide upon courses of action that are appropriate, and attempt to fit means to ends (Hughes & Sharrock, 1997). Thus, within an interpretive paradigm the individual is conceptualised, ontologically speaking, not as passive, but rather as an active agent (Maree, 2007). Such a stance resonates with much disability theorising that rejects the “objectification” of individuals with disabilities. As Ferguson et al. (1992) suggest, an interpretive perspective holds that disability is not only a fact or an entity, but rather an experience waiting to be described, or more precisely a social construction of multiple experiences waiting to be recognised.

A focus on subjective experience constitutes another central tenet of an interpretive paradigm. Thus, Maree (2007) has asserted that the stories,

experiences, and voices of research participants constitute the mediums through which proponents of an interpretive frame explore and understand reality. She declares further that the ultimate aim of interpretive research is to “offer a perspective of a situation and to analyse the situation under study to provide insight into the way in which a particular group of people make sense of their situation or the phenomena they encounter” (Maree, 2007, p.60). Maree’s statement underscores a related feature of this paradigm, namely that the goal of research should be interpretive understanding. In particular, interpretive work focuses on “the processes by which these meanings are created, negotiated, sustained, and modified within a specific context of human action” (Schwandt, 1994, p.120).

Thus, in terms of an interpretive perspective, meaning is not pre-given, but instead always contextually grounded (Mishler, 1986), and part of an active, ongoing social process. Consequently, in order to understand a social phenomenon, an interpretive researcher has to look in different places and at different issues with natural settings as sites allowing for the collection of substantial situational information (Henning, Van Rensburg & Smit, 2005). Another distinctive feature of an interpretive paradigm therefore entails sensitivity to the role of contextual factors.

In theorising the value of contextualised accounts of participants’ everyday experiences, Deborah Marks has pointed out that “there is very little work which looks at emotional and physical experiences within their social context or the social constitution of psychological and physical experience” (1999b, p.13). Consequently, she has proposed that in order to understand the complex and often inconsistent nature of the human condition, due precedence needs to be accorded to both strengths and challenges, while an exploration of difference also needs to be engaged in. Indeed, Marks (1999b) sees contextualised accounts of impairment as valuable in that at one level, they allow for the recognition of points of identification and difference, both within and across the

disability/ability divide. At another level, such accounts assist us in examining the context of people's intimate experiences and they might also illuminate the fact that what can appear to be a unique and particular situation might really be one that is shared collectively.

An epistemological positioning of the present study within the frame of an interpretive paradigm also warrants a consideration of the role of the researcher within the research process. In interpretive research, the assumption is that it is the researcher who is the primary instrument for the collection and analysis of data (Banister et al., 1994; Maree, 2007; Terre Blanche, Durrheim & Kelly, 2006). Furthermore, Henning et al. (2005) explain that in line with the work of Geertz (1973, 1993), the interpretive researcher constructs meaning from the data by seeing the bigger picture and by converting the "raw" empirical data (i.e., the "thin description" of the phenomenon) into what is known as a "thick description". In Geertz's (1973) terms, a "thick description" entails an account of the phenomenon that is coherent, gives more than facts and empirical content, and also interprets the data in the light of other empirical information in the same study as well as from the basis of a theoretical framework that locates the study.

And, in trying to make sense of the participants' lives interpretively, one of the key aims of this interpretive study was to provide as rich or as "thick" a descriptive account as possible of their everyday experiences of disability and impairment, as well as of the impact of participation in a therapeutic horse riding programme on their experiences. Further, qualitative methods of inquiry were deemed best suited to the project of deriving "thick" descriptive accounts from the data with a view to constructing "thick interpretations" with respect to the issues at hand. And, importantly, the ambiguous, inconsistent, often contradictory nature of everyday subjective experiences was reflected within these "thick" descriptive and interpretive accounts.

### **3.2. A Qualitative Approach to Methodology**

Hollway and Todres (2007) have suggested that as researchers conducting qualitative research, it is necessary, at the beginning of our studies, to articulate explicitly the kinds of knowledge that the specific research to be engaged in might generate. Hence, to begin with it should be noted that the present study has aimed to generate propositional knowledge (Todres, 2000) that could stimulate, add to and elaborate existing academic discourse with regard to the psychology of disability, impairment, rehabilitation, and well-being. Also, it has been posited that the role of adjunctive therapeutic interventions, and therapeutic horse riding specifically, warranted due consideration and debate. In sum, this study has intended to stimulate discourse and debate, and to be illuminative, rather than definitive in its aims.

In addition, Parker's (2004) conceptualisation of the 'principle of innovation', directing researchers to the aim of "producing work that may transform the coordinates by which a problem is usually understood" (p.104) has also been insightful here. Following Parker (2004), an important goal was to not only 'discover' or 'produce' something new, but in so doing to reflexively embed an account of what has happened in terms of, and against, usual taken-for-granted research practices.

The richness and depth of explorations and descriptions that a qualitative approach yields is regarded as one of its greatest strengths (Maree, 2007). Hence an emphasis on meaning has constituted an overarching focus of this qualitative interpretive study. And, in according precedence to meaning, Flick's (2004a) assertion that "a qualitative approach is needed to understand what this diagnosis means for the individual or what it means for a family to live with a member with this diagnosis" (p.140) underscored the utility of a qualitative approach to methodology. Moreover, her advocating the use of qualitative methods that are suitable to study social and psychological processes in fields like health and illness in a way that takes into account micro-perspectives in

order to analyse phenomena on micro-, meso-, and macro-levels has been particularly relevant here.

Borrowing from Bronfenbrenner's (1979) perspective regarding systems, attention has been directed to interactions within and between relevant systems that constitute the participants' life-worlds. At a micro-level, the focus has been on interpreting and understanding how children with cerebral palsy experience disability and impairment in their various social contexts, including home, school, and therapeutic horse riding settings. Flick (2004a) has declared that "'objective' conditions become relevant through their subjective meaning for the life-world of those who are concerned by these conditions" (p.141). Informed by such a rationale, the primary focus has been on the everyday subjective meanings that constitute the participants' experiences of being disabled.

Moreover, another important focus entailed investigating whether, and the possible ways in which participation in a therapeutic riding intervention impacted on the participants' everyday experiences. The interest lay in describing, interpreting and understanding the subjective meanings that participation in therapeutic horse riding came to hold for them. Stated differently, there was also a concern with tracking possible subtle shifts in psychosocial and physical functioning that could be derived from their participation in a therapeutic horse riding intervention.

Accordingly, the particular domain of qualitative evaluation (Clark & Dawson, 2000; Shaw, 1999) has been salient here. Working within such a frame, the possibility existed that this study could detect changes in the participants on physical and psychosocial dimensions of functioning that have not been examined previously by researchers in the field. Alternatively, such nuanced, often subtle changes might not have been reflected in the research findings of studies to date. It is also important to take into account that therapeutic shifts in physical and psychosocial aspects of functioning identified in participants in a

therapeutic horse riding intervention could be subtle and appear small or negligible, but still make a significant difference to their own lived experiences as well as those of their caregivers.

Moving on from considerations at a micro-level to an analysis at meso- and macro-levels, Flick's (2004a) observation that a qualitative approach allows researchers to look more closely at practices, institutions and lived realities is informative here. It is useful to consider the implications of subjective experiences of disability and impairment for family dynamics and functioning, as well as the practices and ideologies that constitute broader cultural and societal processes. Drawing, then, on proponents of a social model of disability (e.g., Abberley, 1987; Barton, 1996; Hughes & Patterson, 1997; Marks, 1999a, 1999b; Oliver, 1996; Shakespeare, 1994; Soudien & Baxen, 2006) due value has also been accorded to investigating the disabling physical barriers and the socially-derived prejudices and negative attitudes which children with cerebral palsy face in our culture. Thus, an understanding of disability as socially produced by systematic patterns of exclusion that have been built into the social fabric of our society (Hughes & Paterson, 1997) has been allowed for as well.

### **3.2.1. Selection of the Participants**

Children with cerebral palsy constitute a specific, limited sector of the population of children in general and children with disabilities in particular. And, in line with the sentiments of Begley (2002) and Detheridge (2002), both of whom work in the field of childhood disability, a prevailing assumption has been that the population of children who share a diagnosis of cerebral palsy cannot be considered a homogenous group. Indeed, the significant differences and idiosyncratic features of this population precludes their treatment as a group. Thus, apart from obvious differences in terms of attention span, motivation levels, cooperation levels and ages, children with cerebral palsy in general and the participants in this study in particular, constitute a *heterogeneous group* on account of features of the diagnosis. In addition to defining motor impairments,

significant communication difficulties in the form of impaired expressive and receptive language functioning are characteristic features; children with cerebral palsy are also likely to have other cognitive and perceptual difficulties which affect their freedom to respond to stimuli in their environments (Rosenbaum, 2003; Rosenbaum et al., 2007; Stanger & Oresic, 2003).

Further, as Merkens (2004) reminds us, “the accessibility of the events, activities or individuals that form the object of the investigation” (p.166) is a matter of significance. In the context at hand, a critical consideration was not only the limited availability of children who are diagnosed with cerebral palsy, but also the restricted number of individuals who tend to participate in therapeutic horse riding within the South African context more broadly, and by implication, locally as well.

Accordingly, the participants in this study<sup>4</sup> consisted of 6 girls with a primary diagnosis of cerebral palsy, ranging in age from six to eleven-years-old, who participated in therapeutic horse riding sessions at “Horses for Healing” on a weekly basis. In the group, 4 participants (Sarah, Isobel, Natalie and Joanne) were from families that were white and Afrikaans-speaking, 1 participant (Rachel) came from a white, English-speaking family, and 1 participant (Nthabiseng) was black and Sotho-speaking. Inclusion criteria entailed a diagnosis of cerebral palsy, as well as the child not being contraindicated for therapeutic horse riding. Also prerequisite was the absence of any serious or traumatic fear of animals in general, and horses specifically, as established on the basis of children’s reactions to interactions with horses during their initial visits to the therapeutic riding site.

The therapeutic horse riding program constituted a low frequency intervention in that it entailed once a week, continuous input with sessions lasting for an

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<sup>4</sup> Note that background details with respect to each participant appear in Chapter Four (Data Analysis and Interpretation of Findings) to assist the reader in contextualising the analysis that follows.



average of 30 minutes from the time of mounting to dis-mount. Notably, the children in the present study participated in the therapeutic riding intervention over a period of two years, thereby giving rise to the longitudinal nature of this research endeavour.

Participants attended Anna Fourie Primary School in Bloemfontein where learners comprise children with a range of cognitive and physically-based impairments. On Tuesday mornings during school terms the participants were transported to and from the therapeutic riding site by their class teachers. In keeping with the medium of instruction and functioning at their school, all instructions and communications at therapeutic riding sessions took place in Afrikaans.

A non-profit therapeutic development organisation situated approximately 20km to the south of Bloemfontein, "Horses for Healing," offers therapeutic riding lessons to groups of children with disabilities free of charge, and served as the site where this study was based. The facility is affiliated to the South African Riding for the Disabled Association, and as such operates within the philosophy and professional rules and regulations of the organisation.

On account of ethical considerations, the children's participation in other forms of intervention, namely occupational therapy, physiotherapy, and in certain instances speech therapy, was not suspended. Rather, the study aimed to investigate what therapeutic horse riding as an adjunctive intervention could offer as part of a multidimensional treatment team in order to avoid jeopardising possible benefits that the participants might incur from other therapies.

### **3.2.2. Methods of Data Collection**

The particular research questions as well as resources in terms of time and money available for this study were critical factors in selecting an appropriate

method of data collection. Moreover, a recognition of the inherent differences between individuals and the range of impairments and capabilities that characterise children with cerebral palsy also placed constraints on the choice of appropriate research methods.

Initially Denzin (1978) understood triangulation as a validation strategy combining data drawn from different sources and at different times, in different places or from different individuals. However, Flick (2004b) has noted that in more recent work, Denzin has transformed his understanding of triangulation to that of a strategy leading to a deeper understanding of the issues under study - "Triangulation is now seen less as a validation strategy within qualitative research and more as a strategy for justifying and underpinning knowledge by gaining additional knowledge" (Flick, 2004b, p.179). Thus, triangulation constitutes a methodological technique that aids in opening up different, sometimes inconsistent and ambiguous perspectives. In so doing, the strategy is seen to lead to broader and deeper understandings of the issues under investigation. Such research practices formed part of my efforts to enhance the rigour and quality of the derived data.

In this study, efforts at triangulation entailed the collection of data through proxy reports in the form of multiple in-depth interviews with participants' mothers, as well as teachers, therapeutic riding instructors, occupational therapists and speech therapists. Participant observations were also conducted at therapeutic riding sessions as well as at equestrian shows in which three of the six individuals participated. In the discussion that follows, key issues with respect to interviewing and participant observation as methods of data collection are outlined.

### **3.2.2.1. Interviews**

Insightfully, Harter and colleagues have declared that "narratives are an especially appropriate means of understanding disability because they wrestle

with the complexities that face people with disabilities: identity construction, (dis)order, and embodied experiences” (Harter, Scott, Noak, Leeman & Morris, 2006, p.5). Their view has served as support for utilising a narrative approach in the form of qualitative in-depth interviewing in attempting to describe, understand and interpret the lived experiences of the participants with cerebral palsy.

With regard to children with Down syndrome, Begley (2002) has proposed that it is useful to interview adults because they can provide very important factual and subjective information that children may not be able to provide. Certainly with respect to the participants in this study, feedback has been constrained by their profound difficulties in expressive and receptive language functions, as well as other cognitive and perceptual impairments. This rendered adults suitable proxies for the provision of elaborate locally produced or ‘situated’ descriptive accounts of the everyday experiences of the participants with cerebral palsy. In this study I therefore conducted a range of in-depth interviews lasting on average between 30 minutes and an hour with the participants’ occupational therapists and speech therapists as well as with the class teacher, and a private teacher who accompanied one of the participants (Rachel) to therapeutic riding lessons. Moreover, as they were the participants’ primary caregivers, I conducted interviews with each child’s mother. However, in one instance a father sat in briefly on an interview session. Interviews were scheduled at the interviewees’ convenience and took place at their homes or, in the instance of therapists, at their therapy rooms located on the school premises.

The semi-structured interviews utilised in this study were organised around areas of particular interest while also allowing flexibility in scope and depth (Greef, 2006). The participants’ histories were initially obtained in the form of documents from parents and teachers that provided me with information on each child’s medical background and the details around their skills and capabilities on different dimensions of functioning, in addition to outlining some of their strengths and challenges. Along with a review of the literature, details regarding the

participants' histories served as a guide to formulating questions for the initial interviews. However, my experiences within the interviewing context were consistent with Schostak's (2006) observation that the emergent form of the interview can be surprising and stimulating. Certainly, a more open and flexible semi-structured interview format enabled me to notice, respond to and follow up on issues raised by interviewees, including perspectives that I, as the researcher, had not anticipated or envisaged.

Banister and colleagues (1994) maintain that interviews are useful in that they permit us to explore issues that are too complex to investigate through quantitative means. Moreover, it is worth acknowledging that the topic under investigation is a sensitive one. For instance, for mothers of children with cerebral palsy, sharing histories, hopes, feelings, thoughts and concerns in relation to their children was contextualised within a society that holds stereotypical attitudes towards individuals with disabilities as deficient and lesser. My interactions with the participants' mothers (and the rest of the interviewees) as well as my approach to the data that was co-constructed as part of the research process, therefore warranted a great deal of sensitivity, empathy and respect. Moreover, taking cognisance of Banister and colleagues' (1994) point that research sets up, and is conducted within, power relationships, I hope I have conducted research 'with' rather than 'on' people.

In adopting such a stance, I found it useful to contemplate the extent to which class, 'race', gender and age relations amongst other factors interacted with interviewing relationships. Such memberships, along with my own preconceived ideas, and assumptions around ontology and epistemology played a definite role in the meanings and interpretations that arose in the process of data collection. Key aspects of my identity, including being an English-speaking Indian woman from a middle-class background, played a critical role in how the interviewees responded to me. It was my experience that they generally perceived me in positive terms, perhaps influenced to an extent by the interest I shared in the

participants. Indeed, they saw me as indirectly trying to assist the participants in this study and children with disabilities more broadly through this research endeavour. Moreover, it is likely that it was easier for interviewees to talk to me as a woman. The efforts to which I went to conduct interviews in Afrikaans, most of the interviewees' mother tongue language - except in the instance of the Sotho-speaking child, Nthabiseng, and Rachel, where interviews with their mothers were conducted in English - also seemed to go some way towards the ease with which interviewees responded to me, and aided in rapport building. Another point of commonality for most interviewees was our middle-class backgrounds. I suspect that my being employed at the local university as a lecturer also seemed to command a degree of respect and add to my credibility as a researcher who was interested in hearing about and documenting the specifics and nuances of the participants' lives.

A final consideration with respect to the interview process concerns technical aspects of interviewing. With the interviewees' permission, I tape-recorded interviews. The audio-tapes were transcribed, and the data were treated as confidential. The transcription process was informed, following Steinke (2004), by the guidelines of i) manageability, in terms of ensuring that the transcripts are easy for the transcriber to write, and ii) readability, in terms of the researcher processing the transcripts being able to interpret the data easily. With regard to transcription conventions, the use of square brackets [ ] has served to indicate words that have been omitted, thereby offering a contextual clarification. Also, capital letters served to indicate words that were spoken loudly and with emphasis. And, in presenting the data in this study, pseudonyms have been utilised to mask the identification of the individuals concerned.

### **3.2.2.2. Participant Observation**

The essence of observation is its concern with naturally occurring behaviour as it takes place in any setting (Banister et al, 1994). While I had initially approached the therapeutic riding setting with a belief that my role should be that of observer/researcher, for a number of reasons I quickly became a participant in the activities, processes and dynamics that I sought to describe and make sense of. A primary factor entailed that of human resources. The therapeutic riding setting was highly limited in terms of individuals to assist with the actual lesson as leaders and side-walkers, roles that were crucial for (safely) conducting the therapeutic riding sessions. On account of safety considerations and the children's own idiosyncratic forms of physical impairment, a great degree of assistance was necessary in terms of getting riders mounted on their horses, as well as facilitating their participation in therapeutic riding activities. Since none of this could be achieved without active engagement from all available parties, it seemed part of the natural course of events that I, too, would assist as a side-walker or a leader at times, thereby transforming my role from observer, to that of participant observer.

Shipman (1997) has offered the insight that our perceptions are structured in that "we see the world through our attitudes, prejudices, values and through the models in the mind that we have learned" (p.72). Thus, my own values, attitudes, and preconceived ideas combined with the theoretical frameworks from psychology that inform my assumptions around the nature of the world and what it means to be human to impact in significant ways on my role as a participant observer.

I endeavoured to become a natural part of the lives and therapeutic riding routines of the individual participants with a view to better understanding their worlds. Thus, the most intense interaction with them took place within the therapeutic riding setting. At one level, I was interested in the participants' subjective experiences, and therefore I observed and listened to their actions,

non-verbal behaviours, and expressions. In so doing, I became a small part of their therapeutic riding context. This was motivated by the aims of coming to some sort of interpretive understanding around the meanings that they accorded to their engagements and activities at “Horses for Healing”.

At another level, I was also interested in the dynamics and repertoires that characterised their relating within the inherently social therapeutic horse riding setting. Attention was therefore paid to their interactions with each other as well as with the horses, the therapeutic riding instructor, and leaders and side-walkers. Since it seemed logical that these dynamics and processes could only be witnessed in context, I attended weekly therapeutic riding lessons, as well as the equestrian shows that children participated in, serving as a side-walker on some occasions. This entailed assisting the participants to put on safety helmets, walking with them up the mounting block and getting them mounted on their horses, and setting stirrup lengths so that riders were comfortably positioned in the saddle, and then assisting them to sit upright and centred in the saddle, while motivating and facilitating their engagement with designated psychomotor activities that formed part of the therapeutic riding experience. While taking on such a facilitating role was warranted by the profound nature of the participants' impairments, it was a profound bodily experience for me as it entailed being in close proximity to the horse and rider while both interacted with others in their environment. Such efforts proved particularly revealing in the case of Rachel and Sarah, participants who were not capable of communicating in conventional verbal terms using words and sentences. And, as the analysis that follows indicates, my participant observations allowed me to listen, observe and reflect on the participants' experiences of impairment and disability as they were lived, in complex and often messy and ambiguous ways. Such observations also constituted a source for noticing issues that had sometimes not emerged during the initial interviews. In other words, my observations at times usefully directed me to further issues to be raised and clarified within the interview context.

For interviewing purposes, I also made numerous visits to the participants' homes, another site at which I was provided with opportunities to become familiar with them and with the contexts in which day-to-day understandings of their worlds emerged. In addition, I encountered the participants on my visits to the school, and during occasions such as their annual school concert performances which I attended. Such interactions involved participant observation, and were significant in that they afforded me an insider's view into the participants' subjective everyday experiences.

At the same time however, as a researcher, it was necessary for me to be careful about that which had become familiar to me, for in immersing myself in the participants' lives, I risked ceasing to look at that which had become obvious or routine to me. I could perhaps have missed out on issues and experiences that were meaningful for the participants and significant for analytic attention. Stated differently, this form of engagement has left me open to the criticism that I could be perceived as too close to processes that I sought to examine and capture. However, my experiences echoed that of Bury (1996) in that my own engagement gave me insights which proved to be useful in the research process, and enabled me to get closer to the individuals and experiences which I was trying to analyse and make sense of.

### **3.2.3. Methods of Data Analysis**

In an interpretive study there is no clear point when data collection ends and analysis begins. Instead there is a process of phases that are not clear cut but rather feed into each other. Banister and colleagues (1994) have pointed out that meaning inheres not only in the text but also in our construction and reading of it. Clearly, my own values, prejudices, memberships, and preconceived ideas played a crucial role in the interpretive process.

The approach to the texts of data that this study has followed is based on the analytic steps outlined by Terre Blanche, Durrheim and Kelly (2006, pp.322-326),



namely (i) familiarisation and immersion; (ii) inducing themes; (iii) coding; (iv) elaboration; and (v) interpretation and checking. What follows constitutes a skeleton of the process of data analysis that was engaged in. The content or details that emerged in the course of this process are to follow in Chapter Four (Data Analysis and Interpretation of Findings).

### **Step 1: Familiarisation and Immersion**

Data collection and analysis go hand in hand. Accordingly, I approached the process of data analysis with a preliminary understanding of the meaning of the data. This was followed by a process of immersing myself in the data once again. In so doing, I got to know where particular quotations occurred in the body of transcripts, and obtained a feel for the overall meaning and the different types of meaning in the texts of data.

### **Step 2: Inducing Themes**

Induction entails inferring general rules or classes from specific instances. It therefore involved looking at the data and trying to identify or distinguish the organising principles that 'naturally' underlie the material. This process entailed moving beyond a mere summary of content. The content of the interpretive themes was influenced by the research questions, while additional issues outside of those raised as research questions was also allowed for. I looked to the data for dynamics, processes, functions, tensions and contradictions that appeared in the range of proxies' accounts of the participants' everyday experiences of impairment and disability. In addition, with notes from my participant observations as a source of data, attention was paid to whether and the ways in which such experiences were lived out within the therapeutic riding context.

### **Step 3: Coding**

While there are different ways of doing so, in this study I choose to approach the text around each participant in a case-like manner. At the same time, I looked for links to comments, issues and experiences that featured in accounts of other

participants' lives, looking at points of overlap, ambiguity, contradiction and difference within and between accounts of a single participant as well as across the participants.

What I was trying to do was to continue the sophistication of the identification of interpretive themes by coding, which entailed marking different sections of the data, including phrases, lines, sentences and paragraphs, as instances of, or relevant to, one or more of the themes under consideration. In fine tooth combing the data repeatedly, I started to see the data and themes in different ways. Thus the analysis was provided with fresh readings of the data, and new links and clarifications often emerged as well. Moreover, some of the themes emerged as excess or peripheral to the primary analysis.

#### **Step 4: Elaboration**

The purpose of elaboration was to capture the finer nuances of meaning not captured by my original coding attempts. This entailed generating and exploring with various alternative ways of structuring until I felt that a coherent illuminating account of what was going on in the data could be offered. Given that coding is an open process and interpretations themselves cannot be regarded as final or complete, the process of inducing themes and coding was repeated until it seemed to me that no significant new insights appeared to emerge at the particular point in time.

#### **Step 5: Interpretation and Checking**

In order to check my interpretations, I engaged in a form of inter-rater reliability, which was employed at three levels. Firstly, I checked my own interpretations, by standing back from the data for a period of time and then returning to them, so as to check if the material was salient to the specific themes. However, I was well aware of the dangers inherent in such a subjective process which was open to a degree of self-deception around the accuracy of the interpretations that had emerged. As a second source of establishing inter-rater reliability, I therefore

discussed the coded themes and elaborations with my research supervisors. During the supervision process, they both confirmed and queried the thematic analysis that had been yielded. Thirdly, I selected two individuals who were themselves not immersed in research in the present study's field of inquiry – one who has been involved in teaching children with disabilities, and another who is an experienced occupational therapist - to check my interpretations as well. These interactions often allowed me to consider the range of issues that emerged from the data from a fresh perspective and alerted me yet again to the open, and ongoing, never complete nature of the interpretive process.

Putting together the interpretation in the form of a written account of the issues under investigation entailed watching for, and trying to fix, weak points. On the one hand, I had to be careful about being excessively descriptive, and not offering what Geertz (1973) has referred to as “thick interpretations”. On the other hand, I had to watch for instances of over-interpretation. An important part of this process entailed reflecting on my own role in the research process, particularly with respect to collecting the data and creating the interpretation. These features appear as considerations in Chapter Five, the Discussion.

While informed by Terre Blanche and colleagues' (2006) step-wise technique, in the present study, the specific aspects around which the interpretation was framed concerned the *content* of the texts of data. As stated earlier, in an attempt to construct an image of their life-worlds and everyday experiences, particular attention was paid to consistencies and inconsistencies as well as contradictions within and between proxies' accounts of individual participants' subjective experiences. Following Ben-Ari (1995), the purpose of discussing these differences was not to detect discrepancies among the narrative accounts, but rather “to interpret and understand in terms of their respective contexts” (p.156). In the discussion that follows, these readings have been organised under thematic headings in ways that attempt to do justice both to the elements of the research questions and to the preoccupations of the interviewees in this study.

## CHAPTER FOUR: DATA ANALYSIS AND INTERPRETATION OF FINDINGS

### 4.1. Introductory Comments

Shakespeare and Watson have declared that the concept of a heterogeneity of impairment refers to the reality that different impairments “have different implications for health and individual capacity, but also generate different responses from the broader cultural and social milieu” (2001, p.15). For the group of participants in this study, points of identification and difference are lived out through not only a heterogeneity of impairments, but also a hierarchy of impairments. And, in the context at hand, such a hierarchy is stratified primarily in terms of an individual’s communicative (in)competence and motor (in)capabilities. These two dimensions of functioning entail cognitive and physical impairments specific to cerebral palsy (Rosenbaum et al., 2007; Stanger & Oresic, 2003), and have important implications, psychologically-speaking, for the participants’ experiences of self as well as for their relations with significant others within the different contexts of their life worlds.

A fundamental premise here is that the materiality of an individual’s body *does matter*. Consequently, the very real effects that impairments have on an individual’s functioning cannot be glossed over or minimised. The task at hand therefore entails an analysis of what Smith and Sparkes (2008) have described as the effects of “*having* a physical impairment and *being* a material body that is unable to do certain things” (p.228).

The identification of a hierarchy of similarities and differences in relation to communicative competence and motor capabilities may also be contextualised within Soudien and Baxen’s (2006) conceptualisation of disability as a site of difference. Certainly, the bodies of the participants in this study appear to be “relativised in a hierarchy that accords certain bodies higher value than others” (Soudien & Baxen, 2006, p.156). Thus, following Soudien and Baxen (2006), it is argued that by virtue of their disability status, the participants seem to share in

common bodies that fall short of a discursively imagined 'ideal body'. Moreover, Rabiee, Sloper and Beresford's (2005) assertion that "children who do not communicate using speech have been and continue to be defined by what they cannot do, rather than what they can" (p.385) is also salient here. And, in keeping with Vogel's (1992) thinking, it is argued that language-impaired children do indeed find it difficult to relate to and socialise with their peers; this impacts significantly on their personal relationships. Further, Paterson and Hughes (1999) have declared with regard to individuals with communicative impairments that it is not the exclusion from social space that is at issue. Rather what matters psychologically is their "ostracism from opportunities to participate in the everyday, mundane, sensate minutiae of the lifeworld" (Paterson & Hughes, 1999, p.571).

In the analysis that follows, the subjective experiences of six participants, namely Rachel, Sarah, Isobel, Natalie, Nthabiseng and Joanne, are distinguished in relation to the interpretive themes of re/negotiating communicative in/competence and deconstructing motor skills and in/capabilities. These realities are regarded as salient stratification factors that distinguish the group of participants not only from non-disabled individuals, but, importantly, from each other as well. As part of this discussion, a third interpretive theme, the role of therapeutic horse riding in relation to possible inputs into their day-to-day functioning and psychological well-being, is raised for consideration.

And, at the outset of the discussion that follows it is relevant to note that in terms of activities that belong within the framework of psychology, the focus of therapeutic horse riding sessions lay in the sensory-motor stimulation of the children. While activities were contingent on individual participants' capabilities and impairments, they typically included having leaders (who control the pace of the horse) and side-walkers (who hold on to riders' knees and heels during therapeutic riding sessions while still being least restrictive to the rider) to encourage riders on horseback to identify and name various objects in their

surroundings. Shapes, colours, comparisons of sizes of objects and the identification of their own and the horse's parts of the body also formed part of the activities. Children were also assisted to carry out various stretching exercises while on horseback while motor skills were targeted with various games entailing the use of balls of various sizes and textures and beanbags with different textures and contents that triggered visual and tactile aspects of sensory-motor stimulation in particular. A sensory forest featuring different sensory stimulation objects such as textured balls, dolls, and bells that are suspended from the branches of a tree through which the horses pass also formed part of the repertoire of activities available to the participants.

## **4.2. Rachel**

### **Biographical note**

Eleven-year-old Rachel is diagnosed with diplegic cerebral palsy which entails the motor impairment of primarily an individual's legs, usually with some relatively limited involvement of the arms (Finnie, 2002; Rosenbaum, 2003). However, while cerebral palsy is defined primarily in terms of motorically-based impairments, accompanying disturbances in communication are cited as well (Rosenbaum et al., 2007; Stanger & Oresic, 2003). In the context at hand, another salient feature that distinguishes Rachel from her peers is her inability to communicate in conventional verbal terms.

Hailing from an English-speaking upper middle-class family background, both Rachel's parents run successful businesses. In addition to Rachel, they have a daughter, Monica, who is younger by five years and not disabled. In contrast to a dearth of interactions with children in her immediate and extended family, Rachel has a wealth of support from adults at her disposal. Unlike the rest of her peers, she is home schooled by Anna, a private teacher, with lessons taking place in the family home's double garage that has been converted into a well-equipped classroom. Also, two full-time domestic helpers assist Rachel with her daily tasks. This is a necessity given that she is incapable of personal care tasks such as toileting - Rachel makes use of diapers - as well as standing up or walking independently on account of her poor postural control and ataxic limbs.

In what follows, Rachel's everyday subjective experiences are analysed in terms of the features of communicative (in)competence and motor skills and capabilities. Attention is given to the ways in which such features distinguish her not only from children in general but from her similarly disabled peers. In particular, implications of these features for Rachel's experiences of sociality and psychological well-being are highlighted. Further, the impact of her experiences of participation in therapeutic horse riding are also considered.

### **Re/negotiating communicative in/competence**

In view of Rachel's extremely limited repertoires of expressive and receptive language skills, relating with non-disabled children as well as her similarly disabled peers has proved to be inherently problematic. The discussion that follows details the impact of these language impairments on Rachel's subjective experiences.

To begin with, Rachel's communicative incompetence has tended to place a strain on her relationships with members of her family. For instance, in my first interview with her mother (Grace), conducted shortly before Rachel's 10th birthday, I enquired whether she tended to talk to her a lot. Grace responded as follows:

*G: I talk to her a lot, yes. And it's the most amazing when she lies with me on the bed at night or whenever we're having a chat, actually. She watches my mouth and she sort of tries to...She moves her mouth as well, and she's fascinated with your tongue in your mouth, and you know. And ja, she has a lot of babbling noises and sounds and that's all the start of...*

*P: Communication?*

*G: Communication. If you take...If she's still is at zero to three months with her language and that. So it should come and I believe it WILL come. If it's not sentences then words at least. Because that's our BIGGEST problem at this stage - her being nine and not being able to communicate. She's terribly frustrated. She gets VERY angry with me for not understanding. Because she KNOWS...there's a definite part of her brain that's functioning very well. But I have no understanding. I have a lot of reading in the eyes - that's how she communicates with me, and she points and shows me what she wants. But there's, there's certain things that she knows exactly what and she has no way of communicating it, you know. So if we can just work on that...I'm really quite keen to work on something that's going to help us to form some kind of a way of communicating. (Grace: Interview 1)*



Describing a form of dialogue between herself and her daughter, Grace indicates that Rachel is attentive and responsive to her communications. Indeed, she interprets Rachel's efforts at watching her mouth and trying to imitate her as she speaks as *attempts to make conversation*. In keeping with the principles of language acquisition theory (Louw & Louw, 2007), Grace interprets Rachel's "*babbling noises and sounds*" as a responsive, positive sign of the beginning of the development of language and verbal communication. Also, her daughter's current functioning at the earliest stage of the trajectory for language development - 0 to 3 months - necessarily means that there is still room for the acquisition of language skills. Further, Grace's comment "*If it's not sentences, then words at least,*" reflects a somewhat compromised expectation of, and a certain optimism around the future development of this dimension of Rachel's functioning.

Still, Grace's optimism around the potential for language acquisition does not detract from her serious concerns regarding Rachel's communicative incompetence. On the one hand, she raises as worthy of attention the very real difficulties in communication experienced by her daughter. For instance, Rachel has been credited with having attained a certain level of cognitive functioning in terms of having an awareness and sense of what she wants, and what she wants to say. However, these strengths are undermined as Rachel is not equipped with the words and expressive language skills to articulate her perceptions, needs and intentions. Consequently, it is largely through non-verbal behaviours such as eye contact and pointing that she communicates her wants and needs.

On the other hand, Grace also expresses a deep frustration with her own lack of competence in interpreting her daughter's wants and needs. Grace's guilt-ridden comments reveal a tacit assumption that in her role as a mother, she *should* assume a degree of blame or responsibility for the difficulties in communication that are experienced. The intuitive sense that she possesses as a mother is seemingly not sufficiently finely honed to enable her to 'naturally' know or

perceive Rachel's wants and wishes in the absence of a verbal exchange. Here, Grace subscribes to the culturally inscribed norm around the intuitive skills that mothers should possess as part of their parenting repertoire, and specifically the degree to which communication with their children should 'come naturally' to them. What renders this experience more complex is the fact that cultural norms around communicative exchanges between a mother and her child are based on an assumption of verbal, communicatively competent able-bodied children. It is problematic that when assessed against this gold standard, the global functioning and personhood of Rachel and other children with disabilities who share profound cognitive and language impairments tends to be found wanting.

A final salient consideration concerns Grace's resolve to engage in an intervention that is expected to facilitate *"some kind of a way of communicating"*. Such a stance is at odds with an appraisal of Rachel's current babbling and vocalisations *as her communication*.

For Rachel's parents, their younger daughter by five years, Monica, serves as a source of comparison and a sobering reminder of the profound nature of Rachel's impairments. Commenting on the relationship between her daughters, Grace asserts:

**G:** *Oh she [Rachel] of course ADORES Monica. But Monica's a little bit young, still. I think when she gets to six she'll probably be old enough to actually realise... Because I have a HUGE problem... Monica's not, doesn't mind too much going for a cuddle and a kiss from Rachel because Rachel loves it. Oh, she [Rachel] thinks the WORLD [of Monica]... And I've tried to explain to Monica - she again ADORES her cousin who's eight, Monica's only four and a half. She becomes a nuisance to Jemma often you know. But Monica absolutely IDOLISES Jemma. I said, "You know, like you think of... As much as you love Jemma, that's how much Rachel loves you". And I've tried all kinds of things, but for instance to try and get her to speak to Rachel just normally, she can't*

*understand that. She'll just say: "Hello, Rachel" and look another way, not even LOOK at her. Or she'll say exactly what I say for her to say to Rachel.*

**P:** *Okay.*

**G:** *And I said: "You can talk to her like anyone." She can't understand that. And that would make a HUGE difference to Rachel, if Monica could just communicate normally with her. (Interview 1: Grace)*

For Grace, her younger daughter's somewhat indifferent, removed approach in her interactions with Rachel is in stark contrast to her being smitten with her older cousin, Jemma. Moreover, Grace's declaration that she has "*a HUGE problem,*" indicates, at one level, that she experiences the difficulties in communication between her daughters as highly problematic. In this regard, Stalker and Connors (2004) offer the insight that "siblings are well placed to mediate difference, as they move between the outside world with its dominant views of normalcy and difference, and the family, which includes their disabled brother or sister" (p.220). It can be inferred that Monica's impartial, somewhat distant stance points to a perception of Rachel as different from herself. This position mirrors a lack of acceptance and validation that is characteristic of the broader society in which Rachel is perceived as different, and in which a negative or lesser value is accorded to the difference that she is seen to embody. Thus, Monica's failure to mediate this difference in a positive way, as she is expected to, is difficult for Grace. Yet, also implicit in her account is an acknowledgement that at such a young age, the task of negotiating the middle ground between outside and family worlds, and between normalcy and difference, is too great for her younger daughter to accomplish.

At another level, in her efforts to have Monica engage with Rachel in a real and authentic way - which would arguably accord Rachel, as the older sibling, a certain respect and dignity - Grace implicitly invokes what I would interpret as an appraisal of *ordinary human value*, stressing Rachel's personhood and inherent value as a human being. Indeed, Grace's statements indicate that she perceives

and accepts, and would prefer her younger daughter and perhaps the broader society to accept Rachel as a child like any other child that one “*can talk to like anyone,*” as she informs Monica. However, the difficulty lies in that Monica is perhaps too young to understand that for Rachel, having her affections unrequited is experienced as hurtful. Grace urgently wants to have her younger daughter communicate with Rachel in a spontaneous and real manner, and expects that, in so doing, Monica would invest emotionally in her relationship with her older sister. Indeed, Monica is intolerant of and impatient with Rachel whom she recognises to be different in the sense of not functioning on a comparable level, specifically in terms of communicative competence and independent mobility. Thus, based on the reality of the dynamics between them, it is inferred that Monica is a less than ideal conversational partner for Rachel.

Still, the degree of rejection that Rachel experiences is also quite painful for Grace. Hence, understandably, part of her response as a mother is to counteract this image of Rachel as socially isolated by appealing to a view of her as an individual who embodies a shared humanity and a shared ontological value. In so doing, Grace minimises the differences that Rachel embodies in the form of profound impairments across multiple dimensions of functioning. Notably, such efforts are in keeping with those of the mothers in a study by Goodley and Tregaskis (2006) who spoke about their children in ways that brought in the specific needs of their children while emphasising their complex humanity.

Interestingly, Grace’s validation of Rachel’s *ordinary human value* is not as clear-cut as her preceding comments would have us believe. For instance, she declares:

**G:** *She’s like any other child. She’s actually TOTALLY NORMAL. The only thing is that she can’t communicate with you. She hasn’t got the language. But all other things she’s exactly...Except now that she’s wearing a nappy. But she’s like any other child would be. There’s nothing abnormal about her [Rachel]. You*

*know she's got a disability or whatever you could call it, not even really a disability. And people are... Yet people are scared of her. They think: "Ah, what do we do with her?" or "how do we approach her?" And there is no other way. You can approach her like any other child, you know. There's no difference. I... People might say, ja but it's because I'm her mother, saying that. But there isn't....But there is no difference, she's like any other child. (Grace: Interview 1)*

Grace's ambivalence in relation to her daughter's impairments is played out in that she describes Rachel as *"totally normal"* but juxtaposes this view with the identification of her lack of verbal communication and use of diapers as what distinguishes her daughter from other 'normal' children. Clearly, Grace struggles to come to terms with the profound nature of Rachel's impairments. In so doing, she unmistakeably yet regrettably regards Rachel's impairments as a defining feature of her identity. At the same time, Grace takes issue with and pointedly rejects the label 'disability', implying that in her experience such a categorisation is invalid. Indeed, such efforts are consistent with the narratives of the mothers in Fisher and Goodley's (2007) study who tended to question conventional notions of 'normality' and were less likely to locate disability in a pathological category.

Moreover, Grace is also deeply annoyed with other people's responses to Rachel which often entail their being scared of her, or uncertain of how to interact with her. In this regard, Reeve (2006) has offered the rationale that while social encounters are usually governed by culturally 'agreed' rules of engagement, the lack of such cultural rules for the interactions between disabled and non-disabled people can lead to anxiety and confusion about how one 'ought' to behave; this in turn results in avoidance rather than engagement. Arising from stereotypical attitudes towards individuals with disabilities as deviant and deficient, other people's discomfort in relating to Rachel is experienced as painful for her mother as well. Like the parents in Rehm and Bradley's (2005) study, Gillian, too, is most concerned that her daughter is treated with dignity and respect. She does not

seem to object that people notice Rachel's differences but seems more distressed by discrimination and the inequality of treatment by others.

A large part of Rachel's daily routine entails time spent engaging in home schooling activities with Anna. Interestingly, Anna appraises Rachel's communicative capabilities in the following terms:

*A: And her vocabulary...Okay. She doesn't speak words, but the babbling sounds have increased as well. (Anna: Interview 1)*

Consistent with Grace's view, Anna acknowledges an absence of words but specifies an increase in Rachel's babbling as significant. In contrast to Grace's optimism regarding Rachel's potential for future language acquisition despite an absence of words or verbal communication in the normative linguistic sense, Anna interprets Rachel's babbling as *her vocabulary*. Along with physically taking a person's hand and leading him/her in the direction in which she wants to go for instance (as I had observed), Rachel's babbling indicates that she is trying to be agentic and responsive to her environment. In her daily life, Rachel is constantly confronted with difficulties in relating with others on account of her communicative incompetence. Thus, her babbling, vocalisations and gesturing are interpreted as Rachel's own idiosyncratic attempts to overcome such barriers to making her needs and wishes known to, and relating with, other individuals.

It is also inferred that Anna has developed her own 'literacy' in relation to reading the ways in which Rachel expresses herself. She has effectively negotiated the boundaries of communication with Rachel to arrive at a nuanced intuitively based manner of communication and social interaction that tends, on the whole, to work for the both of them. Thus, Ryan and Thomas's (1987) point that those who are in close contact with individuals with severe impairments do in fact tend to learn the barely perceptible ways in which they express their preferences and their reactions to events around them is salient here. Moreover, Anna seems to adopt

an underlying strengths-oriented perspective in which she sees Rachel in terms of her capabilities in the here and now (as opposed to a deficit orientation). While such a position could perhaps have been implicit in her mother's mention of her and Rachel *"having a chat, actually,"* it is Anna's interpretation that comes across as unreservedly validating of Rachel's capabilities.

A relevant contextual clarification is that while Rachel is home-schooled by Anna, she also attends a 'special' school, Anna Fourie, on a part-time basis. Below her mother has described this arrangement as based on a prioritisation of access to the physical therapy services that Rachel participates in on a weekly basis and the social value of being in the company of her (disabled) peers.

*G: She's a registered pupil there but we just make use of the therapies and facilities. And then a bit of social, yes, just to be with other kids, which she also enjoys. (Grace: Interview 1)*

While such motivations are undeniably laudable, Elana (with whom Rachel receives weekly occupational therapy sessions) offers a more critical perspective on the practical value of Rachel's supplementary school attendance. She declares:

*E: You know, I have told the parents MANY times: You MUST bring her to school more often. Even if she just sits in the classroom and looks at what the others do. She must get that...*

*P: How many times does she come nowadays?*

*E: She just comes to you all, to the horse riding. And then to me on a Tuesday. She doesn't come to school, or to lessons, or anything like that.*

*P: I know at home she has, she has her own classroom.*

*E: That's right. That's right. There is...it's basically a double garage that they've converted, which is wonderful. I think the fact that they took the trouble to do that and so on is really, it's a plus. But, I think she misses, she misses out a lot on*

*social contact. I think that's why she sometimes overreacts, too, when she sees other children, that she just wants to start grabbing and pinching. I think that's... She doesn't really know what to do with the little friends, ja.* (Elana: Interview 1)

Here Elana acknowledges Rachel's parents' efforts at creating a learning environment in the form of her own personalised space within which to receive home schooling. Indeed, when Grace showed me around Rachel's cheerfully decorated classroom, I noticed that the room is well-equipped with resources such as a treadmill and a Powerplate vibration machine for physical exercise, a compact disc player on which to listen to her favourite pieces of music, as well as a host of other creative, educationally oriented resources aimed at stimulating psychosocial, motor and cognitive development. Notably, during the week Rachel spends most of her time in her classroom at home. For Rachel, this space has been transformed into yet another site of therapeutic effort in relation to individually-oriented educational and therapeutic goals that are carried out in social isolation. Thus, her experience of being 'at home' is qualitatively different to that of her sister's experience, or indeed the experiences of other children (both disabled and non-disabled) within their family homes. Rachel's home has taken on an altered, rather clinical meaning far removed from the traditional value attached to the home as an environment in which she should simply be her parents' daughter, and Monica's older sister. Its primary psychological meaning as a space for the experience and expression of familial bonds and attachments, as well as a recreational space with functions in terms of rest and relaxation, has been minimised.

Moreover, Elana has also explicitly identified the prevailing scarcity of regular social contact with peers as inherently problematic, while criticising the socially isolated nature of Rachel's individually-based home schooling programme. She goes on to explain this lack of sufficient social contact with other children as a reason for what she has noticed during occupational therapy sessions to be Rachel's overreaction to and uncertainty around how to conduct herself in the



presence of her peers. And, not having been socialised into their world of norms and conventions around communication has important implications for Rachel. On account of her expressive and receptive language impairments, she is inept at communicating with other children within the frame of their linguistic and communicative conventions. In other words, without the use of language, she struggles to negotiate participation in social interactions (Hutchby, 2005). Consequently, Rachel experiences few opportunities for the practice and mastery of communicative and social skills. Also, her peers have recognised her as awkward, socially inept and different from themselves. Indeed, they appear to be put off by her lack of familiarity with the scripts for communication. And, as Rachel does not know how to approach and interact with them, her peers therefore tend to exclude her socially from shared group interactions, *just as her sister and cousins do*. By responding to her limited social competence in such a manner, her peers contribute to Rachel's subjective experiences of psychological isolation from other children.

Furthermore, Elana's view around the detrimental effects of a lack of socialisation with peers may be understood in terms of the position that along with play, interacting with other children serves as a means for enhancing cognitive development (Louw & Louw, 2007). In addition, Kaiser and colleagues (2001) have highlighted the unique role of the social context in communication development, emphasising the contributions of (input from) peers to children's language learning and use. Drawing a link between language skills and cognitive development specifically, Rutter and Sroufe (2000) have argued that "language skills become increasingly important in cognitive performance during childhood" (pp.281-282). Moreover, Yule and Rutter (1987) have contended that linguistic skills develop alongside cognitive competency, both of which simultaneously provide children with the means to make connections between their existing knowledge and that which is new to them. Indeed, it appears to be Elana's premise that social contact and social stimulation within the context of her peer group could have important salutary effects on Rachel's functioning. Overall, her

argument implicitly refers to the reality that in being home schooled Rachel is effectively missing out on important opportunities for social learning experiences to be gained from contact with her peers.

In her account, Elana cited opportunities for social contact as a critical factor that motivated her decision to place Rachel in a group of five children who attend occupational therapy sessions simultaneously. She asserts:

*E: She [Rachel] I have now asked to come specifically with a group because she never sees other children. I mean she plays like her all on her own in the house, so I saw her individually at a stage, but then I decided on account of the poor child's socialisation and to just have some contact with other children, she must come in a group. (Elana: Interview 1)*

In the extract that follows, she elaborates on how Rachel conducts herself at group-based occupational therapy sessions, stating:

*E: They're usually five [children] at a time, but hey, little Rachel is on her own planet, Pravani. I can see that she enjoys watching the other children. She's definitely VERY aware of what they are doing. And, and you know, like if they go down the scooter board then she laughs really happily and so on. But in terms of her...Otherwise regarding her participation, that's zero, you know. Actually I really, really struggle, you know. (Elana: Interview 1)*

In Elana's experience, Rachel functions at a level that is not consistent with that of her peers. She is perceived in a rather uncomplimentary way to be removed from the group and "on her own planet". Clearly, Elana experiences Rachel as not only physically and socially removed but also *psychologically removed* from the group of her peers. Further, Elana has noticed Rachel's tendency towards being a spectator rather than participating in occupational therapy activities. In tension with this image is her identification of Rachel's strong receptivity and

distinct responsiveness to what goes on in her social environment. Laughing when her peers do something that she perceives as amusing is interpreted as an expression of her unique manner of relating to and engaging with other children. This points to Rachel being social in idiosyncratic ways within the realm of her own capabilities.

However, despite an acknowledgement of Rachel's capabilities with regard to perceptual skills, it remains challenging for Elana to draw out her participation in the therapeutic activities that typically form a part of the occupational therapy regimen. An implicit assumption is therefore that on account of her profound impairments, Rachel misses out on the wealth of stimulation and salutary benefits that may be afforded by participating in therapeutic activities.

Commenting on the years of therapy, occupational therapy included, that Rachel has undergone, Elana states:

*E: And Rachel is also, hey, if I have to think how many years she's already been coming [to occupational therapy] and she just stays there [indicates a low level with her hands]. She just stays there. But unfortunately in her case, the parents still expect...*

*P: A lot?*

*E: That there should be a Dux student at the end of the day. And it is not realistic at the end of the day, and I think that they make her despondent sometimes. Because I think they set goals that she cannot reach.*

*P: I think, look, she's been for every, for any possible therapy that there is?*

*E: Everything on earth, you see. Everything on earth. And you know what's bad, Pravani, she's gone through – What can you call it? – you know if she sees someone coming closer with a ball, then she screams already. But I just think it's because she's been, from the time she was that high [shows with her hands the height of a toddler], it's what she had to do on a permanent basis. So she's got such an aversion for it, she doesn't want to do it anymore. And one can*

*understand that actually, because she's continuously been through every possible sort of therapist's hands... Actually Rachel is now at a phase where we must keep her happy. It must be nice for her to come [to therapy]. It mustn't be therapy and exercise and that sort of thing for her. It must really also be a positive. Something nice for her. (Elana: Interview 1)*

To begin with, Elana declares that Rachel has reached a plateau with respect to her functioning. This observation echoes the early insight by Banus (as cited in MacKinnon, Noh, Lariviere, MacPhail, Allan & Laliberte, 1995) that children with cerebral palsy frequently plateau despite interventions. In addition, Elana strongly condemns Rachel's parents' tendency to expect far more than she is capable of. Indeed, they are perceived as somewhat ignorant and uninformed due to the seeming lack of insight into the profound nature of their daughter's impairments. However, another plausible interpretation is that for Rachel's parents, the psychological defence of denial is at work in alleviating their distress as they struggle to reconcile the disjuncture between their expectations of Rachel and what she is realistically capable of achieving.

Arguably, the endless therapeutic regimen that Rachel is subjected to could be based on the rationale, following Koch (2005), that the greater the deviation, the more justified the intervention is. Certainly, Grace appears to subscribe to a medical conceptualisation of disability, sharing in the assumption that any deviation from the norm such as her daughter's impairments constitutes a fitting rationale for intervention. Moreover, the unrelenting nature of the interventions that are targeted at improving Rachel's functioning and facilitating her development are regarded as consistent with the profound nature of her impairments. Hence, the difference that Rachel is seen to embody is regarded as something to be worked on, removed or 'normalised'. It is argued that in keeping with the hegemonic ontological view pervasive in society, Grace also tends to associate human value/worth with ability. In other words, she, too, subscribes to an ideology of normalcy. In grappling with the profoundness of her daughter's

impairments on different dimensions of functioning, Grace resolves to get Rachel to work harder at attempts to achieve therapeutic improvements. Perhaps such efforts represent unconscious attempts to add equal human value or worth to her disabled daughter.

Moreover, Elana believes that Rachel senses intuitively that she is not living up to her parents' expectations. Indeed, it seems that her parents' failure to accord her a respectful subjectivity - played out through a tendency to deny, at a qualitative level, what she can do within her frame of reference - has not escaped Rachel's awareness either. From her parents' ongoing attempts to work on, improve, or fix those aspects of her functioning that are deemed to be deficient, Rachel appears to have internalised their projections of damage and lack, and the message that she is not acceptable as she is.

In addition, Elana unreservedly attributes a certain despondency in Rachel to the aforementioned unrealistic parental expectations. This despondency is not only expressed in a lack of participation, but has exacerbated, unsurprisingly, into a fully blown aversion for therapy. Subjecting Rachel to years of 'over-zealous' rehabilitation efforts and setting unrealistic therapeutic agendas constitute somewhat questionable efforts to manage Rachel's difference. Through a firm commitment to such rehabilitation work, her parents tend to be (perhaps unconsciously) dismissive of Rachel's relational needs and happiness in general. Ultimately, in so doing they tend to invalidate their daughter's personhood.

In her authority as an occupational therapist, then, Elana points tacitly to the fact that a succession of individually-based educational and therapeutic encounters and unrealistic parental expectations could work in concert to create and reinforce lived experiences that are psychologically damaging and 'counter-therapeutic' for Rachel. She reasons, rather, that developmentally, Rachel is at a place where any major expectations in terms of grand-scale improvements should be discarded. Instead, attention should be directed at keeping Rachel

happy, and ensuring that her experiences of the therapeutic process are transformed from the largely negative meaning that it has come to have for her. Applying Rix and Paige-Smith's (2008) ideas to the context at hand, it would appear that Elana has transformed her assessment of the effectiveness of the occupational therapy interactions with Rachel from that of the degree to which she develops in relation to therapeutic targets, to how much Rachel enjoys herself during occupational therapy sessions. Elana affirms that such an approach would be in Rachel's best interests. Perhaps implicit in her point that key members of the therapeutic team are prepared to disregard unrealistic therapeutic goals in favour of collaborating to make therapy more of a source of enjoyment for Rachel is the wish that Rachel's parents would follow suit.

However, it is not only during participation in occupational therapy activities that Rachel is more of a spectator. When I asked her teacher whether she believed that not being able to communicate verbally impacted on Rachel's relations with other children such as her peers, Anna declared:

*A: I think definitely, because she can't express herself and you know physically, she already has trouble physically. So she really does struggle. She tries to get attention but I think people also - especially some of the other children - are scared of her. Because they don't understand her. Even if they've got problems they still don't understand her. They're a bit wary about coming close to her and making contact. So I think she gets very frustrated. Because also she doesn't understand you know, if she pushes someone that maybe she's being a bit too rough. Or she pulls them. She's not too sure about the...gentle side, so people get scared. (Anna: Interview 2)*

In problematising the combination of Rachel's impairments in communication and functional mobility, a number of interesting features are brought to the fore. For instance, Anna finds it paradoxical that other children with disabilities are afraid of Rachel. This points to the group of peers as characterised not only by a

heterogeneity of impairments; an informal hierarchy of impairments operates as well. And, in terms of this hierarchy, Rachel appears to occupy the lower echelons of the group of her peers.

Interestingly, Anna also tends to externalise, to an extent, the difficulties that Rachel experiences. In particular, her peers' fears of and uncertainties around how to interact with her is interpreted as pointing to an inability to reflect on their own experiences of similarity and difference. This accounts for their failure to identify with and accept Rachel as a part of their group.

Furthermore, in accounting for the differential treatment that Rachel receives from her peers, Anna highlights her relatively restricted level of communicative competence. Such sentiments resonate with but also take further Paterson and Hughes' (1999) position that individuals with speech impairments are often ignored and made to feel inferior on account of their inability to communicate according to societally-defined norms of accepted speech standards and behaviour. Ironically, while she yearns for and seeks out social contact - stated as "*she tries to get attention*" - Rachel is subject to experiences of marginalisation and social exclusion not only by the broader society, but by the group of her disabled peers as well.

In addition, like Elana who states that:

*E: Yes, she pinches, man. She pinches so that it's very sore. So I think the children are a bit afraid of her as well, because she is also physically a lot bigger than they are* (Elana: Interview 1),

Anna also cites the risk of exposure to injury that Rachel's peers are confronted with as contributing to strained interpersonal dynamics. In her defence, Anna reasons that Rachel has yet to realise that on account of her physical strength, her physical interactions with other children are experienced as intimidating and

generally negative. Indeed, it would appear that Rachel is so starved of social interaction that when she does come into contact with other children, she expresses herself through using her physicality in the form of her rather strong hands for pinching, and her upper body for lunging forward to grab hold of others.

Yet, Rachel's physicality could also be interpreted as a resource for making contact with others. Such idiosyncratic physical expressions of sociality may be understood in the context of the absence of words or sentences with which to communicate verbally with other children. Thus, it is her body in its impaired form that embodies a certain potential and possibility by virtue of its function as a site of communication. Unfortunately, this form of communication is not experienced positively by Rachel's sibling and peers who misinterpret such behaviours as aggressive, and therefore respond to her in an avoidant manner. Here, Deal's (2003) contention that social distancing is likely to become more important when the child starts to want to 'fit in' with his or her peers serves to highlight and render intelligible Rachel's rather desperate, misread attempts to make contact with her peers, and fit in with the group.

In addition, Deborah Marks's (1999a) question around why disabled people are repeatedly constituted in popular culture as 'dangerous' or 'infantile' is salient here. The irony lies in that Rachel is perceived as 'dangerous' by the group of her (familiar) similarly disabled peers. In the context at hand, it appears that by virtue of her physical strength and imposing stature, the risks of possible injury that Rachel poses to her sister, cousins and peers at school are experienced as real. Consequently, the marginalisation and social exclusion that she is subjected to works effectively to invalidate Rachel's attempts at communication and sociality, rendering her socially and psychologically vulnerable. Indeed, negative implications for what Ryff and Singer (1998) regard as key dimensions of psychological well-being, namely her experiences of self-acceptance and positive relations with other people, are inferred.



On a more encouraging note, a year later, in our second interview, Anna indicated that Rachel has started to rely less on her physicality as a mode of communication. She asserted:

*A: She loves talking. She loves listening to people talk as well.*

*P: Okay. Does she actually like watch your mouth and that?*

*A: Ja. Sometimes when we're babbling she'll actually take my chin and look at my mouth [indicates by placing her hands on either side of her chin as Rachel would]...I just think that she is trying to find ways to do things and communicate. (Anna: Interview 2)*

Anna affirms that nowadays Rachel tends to be more explicitly attentive and responsive in interactional contexts, with such instances constituting positive psychosocial experiences for her. Also noteworthy are Rachel's active attempts to find ways to communicate. An implicit assumption here is that she has come to utilise babbling and vocalising more frequently, relying less on her physicality. At the same time, Anna is clearly responsive to Rachel's attempts to communicate with her. Indeed, she functions as an efficient conversational partner who serves a scaffolding role with regard to Rachel's efforts to use and learn language. Interestingly, Kaiser and colleagues (2001) explain children with communicative impairments' preference for initiating communicative interventions with adult partners by offering the rationale that "more competent adult speakers are more likely than peers to understand their communicative intent and can scaffold their communicative interaction" (p.147). Furthermore, scaffolding by adult conversational partners builds on the child's communication attempts, assists him/her to become a social partner and communicator, and supports the child in learning to talk by building new meanings and introducing new topics (MacDonald & Giletee as cited in Kaiser et al., 2001). In addition, being Anna's sole home schooling learner is advantageous in the sense that Rachel has her teacher's undivided attention and inputs (unlike the rest of the children in a standard classroom context).

### **De/constructing motor skills and in/capabilities**

Moving on to a consideration in terms of motor impairments, it is relevant that 11-year-old Rachel has experienced a significant developmental delay with respect to gross motor functions in that she started to walk for the first time well into her ninth year of life. Still, despite her capability for walking, Rachel is not functionally independent with respect to mobility - She continues to require the physical support of an adult in order to stand up and walk. For instance, within the therapeutic riding context I noticed that because she walks rather unsteadily, Rachel usually holds on to her teacher Anna's hands and arms to assist her to stand up, while also leaning against Anna to stabilise herself. Diagnosed with diplegic cerebral palsy<sup>5</sup>, to the observer, Rachel labours at walking in that she drags her limbs which have low muscle tone slowly and heavily. On account of her weak postural control she appears as if she could stumble and fall over at any moment. Thus, Rachel is not only much larger in stature than her peers, but she is also generally less capable motorically.

Consistent with her position around Rachel's impaired expressive and receptive language functions as considered in the foregoing discussion, here Grace identifies the disabling impact of impaired gross motor functioning on her daughter's social relations with her peers as significant. She observes:

*G: You often see her, when we are with kids and the kids are running around she would love to be part of that, you know...She can't get there, and then you put her with those kids that are playing and they're there for a second and then they run off. (Grace: Interview 1)*

In Grace's experience, Rachel yearns to share in the play activities that she sees other children engaging in. However, on account of her profound motor impairments, Rachel experiences limited autonomy as she has great difficulty in

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<sup>5</sup> Diplegic cerebral palsy entails the motor impairment of primarily the legs, usually with some relatively limited involvement of the arms (Best, n.d.; Finnie, 2002; Rosenbaum, 2003).

independently standing up, getting to where the rest of the children are playing, and following them to their successive sites of interaction. Thus, the detrimental psychosocial consequences of Rachel's limited functional mobility are highlighted. In the past, Grace attempted to address and counter Rachel's experiences of marginalisation by physically placing her amongst the group of children. However, any possible interaction with them had been fleeting, as the children tended to soon move off to another activity, leaving Rachel behind. Certainly, it is plausible that she may have internalised other children's lack of acceptance of her, which could then contribute to her negative self-perceptions and poor self-acceptance.

What would appear to frustrate Rachel even more so is that while she is incapable of standing up or walking independently like the children with whom she desperately wants to interact, she is also not really able to verbally engage with or call after them. Moreover, it is problematic that the children seem unsympathetic to and dismissive of Rachel, promptly leaving her behind. Such experiences are illustrative of Deal's (2003) contention that children's tolerance of those who are different appears to be a phenomenon that only lasts for a brief period of time.

In sum, it is argued that Rachel's lack of independent mobility, in interaction with her impaired expressive (and receptive) language skills, hinders the expression of her sociality. This contributes directly to her experiences of marginalisation, psychological isolation and social exclusion from the group. Consequently, negative implications for what Ryff and Singer (1998) conceptualise as key dimensions of psychological well-being, namely experiences of autonomy, positive relations with others and self-acceptance, are inferred.

Further, when I asked Anna to comment on whether she believes Rachel's lack of independent mobility impacts on the ways in which her peers relate to her, she stated emphatically:

*A: Definitely. Because they see her as being a bit strange, you know. They all can go and do activities [at therapeutic riding], “Why can’t she?” “Why can’t she partake the same way they can?” And that makes them question things and they look at her, and think you know, “What’s going on?” (Anna: Interview 2)*

Clearly Rachel's peers' have noticed that she is incapable of participating in therapeutic riding activities with a similar degree of involvement. Their perception of her as *“being a bit strange”* implies that they experience Rachel as different from themselves in significant, observable ways, and therefore other.

In her preceding extract, Grace had mentioned (in an outraged tone) that Rachel seems almost invisible to other children who typically exclude her from their social play activities, and express no further interest in her. It is therefore striking that, in contrast, Rachel's disabled peers do not completely disregard her. Rather, they are curious about and interested in the profound form of disability that she embodies. Clearly, Rachel's communicative incompetence and severely impaired gross motor skills constitute features of her functioning that her peers deem to be worthy of questioning and contemplation. In Anna's experience, they appear to grapple with and try to make sense of Rachel's noticeable deficits with respect to these skills and capabilities. Echoing Grace's preceding sentiments, Anna emphasises that these features distinguish Rachel from the rest of her peers.

In responding to my enquiry with regard to Rachel's communicative functioning in particular, Anna's account emphasised motor and communicative aspects of functioning as inter-related. She commented:

*A: She [Rachel] hasn't improved too much. She still points when she wants something, or else she'll just go: “Haa, haa,” and you must just try to figure it out. But she is starting to point more in the actual direction of what she wants and*

*trying to get herself there, which is a new thing. She'll try to actually REACH for the things.* (Anna: Interview 2)

To begin with, Anna declares that Rachel has not improved considerably with respect to her communicative capabilities. However, she immediately contradicts her assertion by citing as significant the ways in which Rachel has made gains in terms of the interacting features of communication and functional mobility. Here, Anna alludes to an understanding of the two dimensions of functioning as inter-related and impacting upon each other in important ways to co-constitute observable shifts in terms of Rachel's development. Moreover, her observation that nowadays Rachel tends to "*try to actually reach for the things*," indicates that an element of intentionality has featured as a recent development in her behavioural repertoire. While her attempts to reach for items that she wants of her own accord could perhaps be glossed over as a somewhat negligible gain, for Rachel such efforts are actually representative of significant developments along cognitive dimensions of functioning.

Remarkably, Rachel has also started to behave in more agentic ways. For instance, Anna reports that Rachel has discarded the expectation that caregivers promptly pass to her the items that she requires. Instead, she has grown more intrinsically motivated, utilising the capabilities that she does have to engage with her environment in more active, autonomous ways. Such efforts represent Rachel's idiosyncratic attempts at *transcending* the constraints that her impaired gross motor functioning tends to place on her daily life. Moreover, functioning in such adaptive ways is interpreted to have positive implications for her experiences of success and self-esteem. In sum, positive implications for experiences of autonomy and environmental mastery, key dimensions of Ryff and Singer's (1998) conceptualisation of psychological well-being, are highlighted here.

On account of the profound nature of her impairments, Rachel continues to be dependent on adult care to meet her daily functioning needs.<sup>6</sup> The literature indicates that dependence on adult care for daily functioning needs constitutes a significant and lifelong challenge for a large number of individuals with severe disabilities and their families (see for instance, Brandon, 2007; Button, Marvin & Pinata, 2001; Green, 2003; Landsman, 2005; Ryan & Runswick-Cole, 2008).

More so than with the rest of her disabled peers, adult care serves as an important psychosocial and practical resource for Rachel. In what follows, Anna, offers her opinion on the dynamics of care with regard to Rachel. She declares:

*A: I think people sometimes help a bit too much. If you leave her, she'll eventually try and figure a way to get to something. I mean, when was it? On Monday she was in her chair in front of the TV and she wanted a book. So she pointed and she called and stuff, and I was...[turns her head to indicate that she looked away and tried to ignore her]. So then she started to try and get there. So first she squeezed herself down so her bum was on the edge, and she was trying to get off that way and that didn't work. So she leaned over and had to go onto her hands. So she is trying to find ways of doing it. And I think if we try not to help her too much, just encourage her to try do things herself, she will do it.*  
(Anna: Interview 2)

Two interesting points emerge here. On the one hand, Anna problematises the dynamics at play with respect to Rachel's dependence on adult care. In her opinion, "people," - referring here to Rachel's parents and the two domestic helpers who are employed to assist her on a full-time basis - tend to take assisting in her daily tasks and activities to the extreme by doing things for Rachel, instead of allowing her to attempt them independently. Certainly, while such efforts might be less time-consuming for her caregivers, they also tend to

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<sup>6</sup> For instance, 11-year-old Rachel is incapable of standing up or walking independently, and she makes use of diapers for toileting purposes.

reinforce and exacerbate experiences of disempowerment. Not only is Rachel afforded few opportunities to apply and rehearse the problem-solving skills and capabilities that she does have, but she is also effectively denied opportunities to engage with her environment in active, autonomous ways. Moreover, the tendency for the domestic helpers to “*help her too much*,” may also be interpreted, following Mannoni’s (1973) thinking, as subtle efforts to ‘keep Rachel dependent’. If Rachel should become more independent of their care, their jobs could be placed at risk or even become obsolete.

On the other hand, Anna offers her subtle efforts to stimulate Rachel’s motor functions and mobility as evidence of her concerted attempts to foster independence in Rachel. Indeed, Anna experiences Rachel as *motorically capable* in that, when left to her own devices, she is able to move around her environment independently and participate in activities that require the use of her motor skills while successfully applying her problem-solving skills to the context at hand. To illustrate this point, Anna cites the example of Rachel’s efforts to get down from her chair to retrieve a book that she wanted. Subscribing to an enabling, strengths-oriented perspective, then, Anna reasons that in order to foster greater functional independence, Rachel should be presented with more frequent opportunities to actively utilise her existing cognitive and motor skills across different settings. Indeed, Anna is optimistic that Rachel is likely to flourish under caregiving relations that are facilitative, supporting and empowering.

Consistent with Anna’s sentiments, Elana criticises Rachel’s limited opportunities for engagement with her environment by stating:

**E:** *I think Rachel is anyway a lot more overprotected than little Sarah. I think Sarah is a lot more, almost given more freedom to explore and that.*

**P:** *A lot, a lot.*

*E: Whereas little Rachel is held like this [cups hands tightly indicating tightly held, suppressed]. I think that is the difference as well, you see. (Elana: Interview 1)*

Elana compares Rachel and Sarah, the next participant to be discussed, with respect to being encouraged to explore their environments. Notably, existing work often cites parental overprotection as a hindrance to individuals' social experiences (Baker & Donnelly, 2001). Here Rachel is appraised as "overprotected" by her parents and domestic helpers in that she is not afforded the necessary freedom to interact with her environment. Implicit reference is made to the reality that, as a result, she largely misses out on important learning experiences. In this regard, McKenzie and Müller (2006) remind us that there is also a risk of decreasing Rachel's intrinsic motivation to learn through spontaneous interaction with her environment. As informative is Grusec and Lytton's earlier statement that "overprotective parents undermine the development of self-efficacy because they deny children the opportunity to achieve and therefore experience success" (1988, p.19). Thus, it is also likely that Rachel could be missing out on opportunities to develop and enhance her self-efficacy beliefs by learning that her actions are effective. At the same time, however, Elana's criticisms do not take into account the motivations underlying Rachel's parents' seemingly overprotective manner. Perhaps Baker and Donnelly's (2001) insight that the protective nature of the parents in their study "was developed in response to a history of unsupportive and discriminatory experiences with doctors, therapists, teachers, friends and extended family" (p.74), is also applicable here. Certainly, I wondered whether Rachel's parents' experiences of society as largely unaccommodating and excluding of children with disabilities such as Rachel (who are stereotyped as deviant, deficient, and therefore lesser) accounts for their tendency to be overprotective.

Reinforcing her sentiments around Rachel's communicative (in)competence, Elana proposes that the goals for therapy should also necessarily be directed at maintaining her existing motor skills and capabilities.



Elana declares:

*E: And look, little Rachel as well, man, with her I think almost the same Pravani, that we must just try to maintain [functioning]. I don't think we are ever going to get her to run a marathon, or that she can do something like that. So we must try to keep the little that there is, you know, at least. (Elana: Interview 1)*

In Elana's view, grand-scale improvements in functioning do not constitute viable therapeutic goals for Rachel. Indeed, by stating rather blatantly that "*I don't think we are ever going to get her to run a marathon*" she suggests that with respect to further improvements in motor functioning, a poor prognosis is to be expected. However, adopting a strengths-oriented view, Elana believes that given the profound nature of Rachel's impairments, it would be more meaningful to accord precedence to what is within Rachel's existing repertoire of skills and capabilities, rather than assuming a deficit orientation. Consequently, intervention efforts should aptly address the goals of maintaining Rachel's current levels of functioning while preventing the further deterioration of the skills and capabilities that she has attained thus far.

### **Appraisal of participation in therapeutic horse riding**

In relation to her earlier sentiments around the maintenance of current levels of functioning as a more viable therapeutic goal, Elana declares:

*E: But little Rachel, I think she too is generally on a plateau. We are very happy about the little things that take place, but I don't think we should place terribly high expectations on her or anything, definitely not. But with her, too, I think the horse riding is extremely important, because it's also an opportunity, apart from motor functioning and balance and those things – an opportunity to get out and see other people, and another environment, and be outdoors, and you know. I think it's a wonderful opportunity for her, because otherwise she would be in that old therapy room, or whatever they call it at home, the whole day. And it's*

*[therapeutic riding is] where there is space. I think is really, at least she sees and she hears other things that are also stimulating for her. (Elana: Interview 1)*

Here Elana notices and accords precedence to the subtle yet meaningful shifts in functioning that Rachel experiences. At the same time, she cautions that in view of the plateau that has been reached, it is pointless to place unrealistically high expectations on Rachel. Against such a backdrop, Elana calls into play the unique features of the therapeutic horse riding experience. For instance, she acknowledges the opportunities for motor stimulation and improvements in balance, while singling out therapeutic riding's inputs into psychosocial dimensions of function as of particular value. Moreover, Elana prioritises the inherent value of getting out and about, seeing and being in the presence of others. Being outdoors, in a natural, social environment that is far removed from Rachel's usual home schooling and therapy environment is interpreted as therapeutic in the sense of having positive psychosocial effects on her functioning. Elana effectively juxtaposes this recreational attribute with the socially starved environment that Rachel would otherwise be confined to for the better part of her day. Thus, the physical and psychosocial space of the therapeutic riding setting is highlighted as a site of qualitatively different sources of (social and psychomotor) stimulation for Rachel.

Similarly, Anna affirms:

*A: So she [Rachel] enjoys it [the therapeutic riding] and she likes watching the other children. She ENJOYS watching them...She doesn't interact with them... but she likes to just see something different than her bedroom and the classroom [at her home]. (Anna: Interview 1)*

Across different settings, Rachel's interactions with her peers during group activities are constrained by her communicative incompetence and impaired motor skills. In contrast to moving about and engaging with them in direct and

active ways that may be more easily interpreted as social, Rachel sits aside and watches other children. However, she is clearly not oblivious to the events in her social environment. Rather, Rachel is attentive to what goes on at therapeutic riding sessions as well as responsive to her peers, albeit in an observational manner. It is plausible that Rachel's observation of other children constitutes her own unique expression of a nuanced form of interactiveness, agency and sociality. Moreover, Anna reports such experiences to be a source of enjoyment for Rachel.

Taking this further, it is argued in terms of the broaden-and-build theory of positive emotions (Fredrickson, 2001) that such positive relational experiences could serve as a psychological resource for Rachel; they could accumulate over time, and feed in to her experiences of psychological well-being. Broadly, Anna's affirmations of Rachel as being responsive to her peers in idiosyncratic ways within the therapeutic riding setting may be interpreted as typical of a more enabling perspective that takes into account and emphasises Rachel's capabilities. Such a stance is consistent with the strengths-oriented values and principles of positive psychology.

It could also be useful to frame Rachel's tendency toward observation in terms of opportunities for vicarious experiences. Following Maddux (2005), Rachel's self-efficacy beliefs could be influenced by her observations of the behaviour of her peers and the consequences of those behaviours, and this information is then utilised to form expectancies about her own behaviour and its consequences. However, it needs to be taken into account, as Maddux (2005) holds, that this process is dependent primarily on the extent to which Rachel believes that she is similar to the individual(s) that she is observing, a feature of her self-perception that is difficult to determine.

Moreover, it is significant that Anna does not simply accord precedence to the psychosocial value of therapeutic horse riding for Rachel. Rather, she goes on

to offer her views on how the sociality of the therapeutic riding context plays itself out in Rachel's subjective lived experiences. As opposed to being isolated in therapeutic interactions on a one-to-one basis with an adult, functioning in the context of a group of peers is highlighted as a source of enjoyment for Rachel. This view is reflected in Anna's declaration that Rachel *"doesn't interact with them... but she likes to just see something different than her bedroom and the classroom"*. Here attention is drawn to a telling paradox. On the one hand, the potential benefits of social interactions with her peers served as a motivating factor underlying her parents' decision to supplement Rachel's home schooling programme with part-time attendance at a school for learners with cognitive and physical impairments. On the other hand, however, the reality of Rachel's experience within the school context is that interactions with her peers tend to be strained and characterised, further, by experiences of psychological isolation and marginalisation. Such psychosocial processes place Rachel in a position of vulnerability and serve invariably to invalidate her subjective experiences and personhood.

In addition, consistent with Elana's position, Alida also alludes to the psychosocial value of a change of environment as an associated benefit of Rachel's participation in therapeutic riding lessons. Interestingly, the literature within the field of therapeutic horse riding develops this point around a change of environment further. For instance, mention is made of the salubrious properties inherent in being exposed to features of the natural social environment, as opposed to a clinical environment, for individuals who might have been accustomed to and become disillusioned by treatment within traditional settings (Graham, 2000). In particular, a decade ago All and colleagues (1999) argued that horse riding, out in the fresh air and away from facilities associated with chronic illness and disability, tends to impart a sense of general well-being. However, Anna's reference to Rachel seeing *"something different than her bedroom and the classroom"* also serves to draw attention, once again, to the remarkable irony that her home environment is structured in terms of and

consequently experienced by Rachel largely as an educational and therapeutic setting. Hence, Anna alludes to the benefits of “*something different*” in the form of a recreationally-oriented therapeutic programme that takes place outdoors as pleasurable for Rachel.

Furthermore, Anna suggests:

*A: I think the motion of the horse is very nice. She doesn't like being still. Just the sensation of being high up – it's a different view. It's a different exp... There's something different about being on a horse, it's a different view...It's peaceful there, you can look at the birds. Just the atmosphere of it.* (Anna: Interview 2)

Anna raises a feature that is well documented within the therapeutic riding literature, namely that being mounted on horseback offers significant opportunities for sensory stimulation and movement in particular (Mallon, 1992; Sterba et al., 2002). Moreover, given that Rachel has a preference for movement rather than being still, the rhythmic movement of the horse could be experienced as soothing for her. Also reflecting existing work (for instance, Casady & Nichols-Larsen, 2004; Scott, 2005) is Anna's appraisal of the elevated vantage point that Rachel assumes on horseback as an experience that serves to broaden her perspective, offering her a “different view” of reality. Another implicit assumption here is that for Rachel, participation in therapeutic riding sessions surpasses the limited appeal of a clinical environment. Thus, Anna reinforces her emphasis on the recreational value of therapeutic riding by implying that being outdoors in a natural setting facilitates an experience of a sense of calm and relaxation in Rachel.

Like Anna, I, too, noticed that within the therapeutic riding setting Rachel tended to take on the stance of an outside observer or spectator in relation to her peers. The sobering reality is that, on account of a combination of her limited

communicative competence and restricted functional mobility, Rachel is excluded from fully participating in social activities with her peers. It is however remarkable that in contrast, she appears to relate to horses and being on horseback in a spontaneous and *interactive* manner. Anna's comments below reinforce my observations. Referring to Rachel's interactions within the sensory forest<sup>7</sup> in particular, Anna declares:

*A: The first few times she was not interested. She was just sort of like: "I want to just ride, let's get the horse going". Other times then she does look at it and she does pay attention. But there was this one day when she just wanted to ride, that was it. So we stopped. And she was sitting there and she was actually taking the reins and shaking it and kicking with her legs.*

*P: So she knows that means 'Go forward'?*

*A: I mean nobody had told her that or showed her that, she just figured it out and she just wanted to go. She did not want to walk she just wanted to be on the horse. It was a day she just wanted to ride. She didn't want to get off the horse.*  
(Anna: Interview 2)

According to Anna, the rather novel sensory forest has failed to consistently capture or sustain Rachel's attention and interest. Instead she appears to have been more enthusiastic about riding a horse. Thus, it is plausible that Rachel perceives the items that comprise the sensory forest as passing distractions that delay her from proceeding with the much-loved activity of horse riding.

Moreover, at some therapeutic riding sessions I noticed that while standing at the mounting block awaiting her turn to mount a horse, Rachel tended to shift her weight from one side of her body to the other alternately, appearing to hop with excitement in anticipation of her turn to be on horseback. Her actions indicated

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<sup>7</sup> A later addition to the therapeutic riding setting, the sensory forest features different sensory stimulation objects such as textured balls, dolls, and bells that are suspended from the branches of trees through which the horses pass. Riders are then encouraged to notice, stretch, reach out for and engage with the objects while mounted on horseback with the horse at a halt.

that while she understood that it was standard practice for her to wait her turn to ride, Rachel was also in a great hurry to mount the horse and proceed with the session. Anna's account also suggests that Rachel tends, in general, to be keener on the activity of horse riding per se. The positive relating that the horse invokes in Rachel could be understood in terms of the consideration that being mounted on horseback necessitates a level of relating that taps in to her own profound physicality.

To illustrate this point, Anna cites as significant a particular instance when Rachel was standing at the sensory forest with the horse at a halt so that she could interact with the sensory stimulation items. What was striking to Anna was that Rachel asserted her enthusiasm and preference for getting on with riding the horse by taking the reins in her hands, and kicking on the horse's flanks with her legs, thereby instructing her mount with the standard command to move forward. What makes Rachel giving such a command so remarkable is that she had not been formally taught to do so at therapeutic riding sessions. It is therefore argued that due to a considerable extent to her communicative incompetence and highly limited gross motor capabilities, Rachel's deceptively passive stance veils more complex cognitive processing. Indeed, an implicit assumption is that Rachel has demonstrated a capability for making the link cognitively and motorically between the use of her perceptual skills, sensory motor processing and motor planning, and the non-verbal, bodily communication of instructing a horse to move forward. Moreover, Rachel has shown herself to be capable of appropriately drawing on and successfully applying the knowledge and skills that she has acquired to a situation in which the horse was standing at a halt while she was eager to move forward instead. A final point with regard to the preceding account is that Rachel's reluctance to dismount the horse on that particular occasion is a common feature of therapeutic riding sessions in general.

The foregoing discussion has analysed Rachel's day-to-day experiences in terms of the features of communicative (in)competence and motor skills and

capabilities. It was striking that such features distinguished her not only from children in general but also from her similarly disabled peers. In particular, implications of these features for Rachel's experiences of sociality and psychological well-being were highlighted. The foregoing discussion revealed that Rachel's impaired physicality and inability to communicate in conventional verbal terms served to render her as other, and she was consequently marginalised and socially excluded by not only able-bodied children, but her group of disabled peers as well. At the same time, however, her idiosyncratic attempts to communicate and be mobile in functionally autonomous ways were interpreted as having significant implications for her sense of self and experiences of psychological well-being. Finally, the therapeutic horse riding experience was indicated as a social arena that provided opportunities for Rachel to live out her embodied physicality in active, social ways. This was all the more meaningful given her socially isolated day-to-day existence.



### **4.3. Sarah**

#### **Biographical note**

Sarah is a noticeably petite 11-year-old who shows symptoms of diplegic cerebral palsy in that she walks with her knees pointing inwards. However, her diagnosis remains unspecified. Like Rachel, Sarah has also experienced a developmental delay along physical dimensions of functioning as she, too, only started to walk well into her ninth year of life. But, while Rachel requires adult assistance in order to stand up, and walk, Sarah has attained a greater degree of independence in this regard. Thus, a feature that distinguishes the two participants from each other is that they differ significantly in terms of how they have proceeded along the developmental trajectory for motor functioning. Another striking feature is that Sarah is also not capable of verbal communication. Instead, she engages in vocalisations and infant reflexes. Combined with her petite stature, Sarah's inability to speak tends to create an impression of her as being a much younger child. Further, her skills and capabilities are characterised by extremely low levels of cognitive functioning.

Sarah's Afrikaans-speaking middle class family - both her parents are professionals who work full-time - has a comfortable home on a spacious smallholding in a picturesque semi-rural environment just outside of the city. She has a younger brother by eight years, Alex, who is her biggest fan and rather protective of Sarah.

#### **Re/negotiating communicative in/competence**

Sarah has in common with Rachel a distinct and profound impairment with respect to expressive and receptive language skills. As a result, their everyday experiences overlap and coincide in significant ways. For Sarah, relating with others is fraught with difficulties on account of her communicative incompetence. As the discussion that follows indicates, this feature serves as a disabling barrier to the fostering of social relations with her peers, as well as her participation in classroom and therapeutic activities.

Elana, her occupational therapist, sketches an image of the profound degree of Sarah's impairments by stating that:

*E: Yes, she is just at the level of a baby. You know, the other day we again, yesterday, the day before yesterday, Pravani, I did that. I don't know if you know the Fairview scale? I had her on...It's a scale where they test global functioning, and then she tested...Then she tested at 6 months, you know. Her global functioning is at 6 months. Yes, then it is physically, cognitively, socially, emotionally. The whole tooty! You know, if you look at her in totality she is like a 6-month-old baby. Yes, that is where little Sarah is at, you know...I tested her a year ago, and then she was also just at the level of 6 months. (Elana: Interview 1)*

Elana discloses that assessments consistently reveal Sarah's functioning to be comparable to that of a 6-month-old baby. This indicates that a plateau has been reached on multiple dimensions of her functioning.

Emphasising that Sarah's speech and perceptual functioning is severely impaired, Elana offers her professional opinion on appropriate therapeutic goals for Sarah. She comments:

*E: Hey, look she's started walking now, which is wonderful. You know, for us it really is a miracle, because we didn't think it would ever happen. But with Sarah I really didn't - You know I think it would be unrealistic to have goals like for instance...*

*P: Like the standard occupational therapy goals?*

*E: Hhhmm. With speech, and with perceptual functioning, because I really don't think it's going to happen, you know. So with little Sarah I work to maintain her functioning at the level that she is now. (Elana: Interview 1)*

To begin with, Sarah eventually having started to walk for the first time well into her ninth year of life is acknowledged as unforeseen and miraculous. While in

standard practice the goals of therapy tend to be conceptualised predominantly in terms of improvements in functioning, Elana affirms instead that with respect to Sarah, the maintenance of functioning (and associated prevention of further deterioration) is a legitimate and highly sought after therapeutic goal. At the same time, the potential for therapeutic inputs to possibly or even miraculously result in improvements in Sarah's speech and perceptual functioning is explicitly rejected. An implicit assumption is therefore that Sarah's impairments on these dimensions of functioning are so profound that identifying and pursuing therapeutic goals apart from the maintenance of current levels of functioning would be unrealistic and highly inappropriate.

I was keen to discover the nature of Sarah's participation in occupational therapy sessions. When I asked whether Sarah responds when she talks to her and gives her instructions, Elana commented as follows:

**E:** *No, not at all, not at all, Pravani.*

**P:** *Also not at horse riding.*

**E:** *No, not at all. You know, everything that I do with her, I have to physically take her and do it. You know if I want her to swing in the hammock, I can't say to her "Come we're going to climb into the hammock", and even not if I put her in and say: "Put your feet in now," like I can tell another child. I have to physically put her in, take her feet, and put her feet in. So, I verbalise what I am doing to her the whole time. I say: "We're going to swing now". "We're going to put our feet in." "Sarah, hold the ball." But she can't follow the instructions herself and she can't carry them out, you know. So it's also just one of those cases where you can just guess what she really feels, you know. I accept that she hears me, but precisely what sense it is that she makes of that, you know, that's difficult to say. (Elana: Interview 1).*

In Elana's experience, the difficulties inherent in trying to determine Sarah's level of comprehension are epitomised by the fact that she cannot respond verbally to

statements, questions, or instructions. For instance, Elana indicates that while she constantly verbalises processes and instructions during occupational therapy sessions, Sarah is incapable of following through with these instructions of her own accord. Thus, in comparison to working therapeutically with children with less profound impairments, a much more physically hands-on approach is necessary with Sarah. Indeed, Elana functions as less of a facilitating therapist and more of an active agent through which Sarah is stimulated during occupational therapy sessions. For instance, Elana physically takes Sarah's hands and feet and places them where they should be. Moreover, while she acknowledges that Sarah's auditory processing is intact, she maintains that perceptually, the sense that Sarah makes of what she hears is difficult to fathom. By implication, the challenges in terms of assessing what goes on in her internal world are alluded to. Clearly, Sarah's profound impairments in expressive and receptive language functions serve as a disabling barrier not only to communication and relating socially with others, but more specifically to her ability to engage fully with and therefore receive the maximum benefits from therapeutically oriented activities. Within the therapeutic riding context as well, I have observed that not receiving feedback verbally from Sarah makes it more difficult for leaders and side-walkers to engage with and relate to her during the course of the psychomotor activities. And, when compared to her more communicatively competent peers, there is a tendency to experience her as relatively unresponsive. Thus, Hutchby's (2005) point that children who are more verbally capable and socially skilled are able to actively engage in social interactions and build social and emotional bonds with greater ease is salient here.

In view of such difficulties, I asked her mother, Maya, more pointedly about Sarah's perceptual skills and level of comprehension, enquiring:

*P: Does she understand sort of if you say: "You're not allowed to go here," "You're not allowed to go there" or "Don't do this" or "Do that"?*

**M:** *Definitely.*

**P:** *And does she sort of...*

**M:** *I think it's more the tone of your voice that she hears. And I've noticed... Because we've always said that we do, we think that she understands what's right from wrong. So if she needs a hit on the hand to not, we've done it. So and she does, when you say: "No, Sarah!" then she already pulls her hand away.*

**P:** *So she does, ja she's definitely aware...*

**M:** *No, she's aware of right and wrong, definitely, from the parents' side. (Maya: Interview 1)*

Maya states emphatically that Sarah does understand what is communicated to her verbally. She is also of the opinion that her daughter is capable of distinguishing between right and wrong. However, Maya qualifies her position, explaining that it is more to the speaker's tone of voice rather than an actual spoken instruction or comment that Sarah responds. In so doing, she concedes at an implicit level that understanding and being able to make a moral distinction between right and wrong are not within Sarah's repertoire of existing capabilities. While such features point to the profound nature of Sarah's cognitive impairments, the nuanced, idiosyncratic nature of her perceptual skills and responsiveness needs to be taken into account as well.

At the same time, Maya also indicates that she manages well with reading her daughter's emotions, wants and needs. When I enquired about how she knew what Sarah wanted or needed in the absence of verbal communication, Maya asserted:

**M:** *Ag, I just think that's a natural thing that we've got. I used to pick up her fits as well. Half an hour before she started fitting I would be at the hospital already. So, I don't know. (Maya: Interview 1).*

Maya's declaration, in a matter of fact manner, that she relies on her natural intuitive sense to interpret her daughter's wants and needs reveals a remarkable confidence in the intuitive sense that she possesses as a mother. And, to illustrate the benefits of her finely honed intuitive skills she cites the compelling example of sensing epileptic fits<sup>8</sup> 30 minutes before they occurred, and then taking Sarah to the hospital as a preventative measure. For Maya, the intuitive sense that she possesses as a mother constitutes a significant resource with which to address the demands of her parenting role. At the same time her disclaimer, "*So, I don't know,*" indicates that Maya experiences the sense of 'motherly intuition' that she has come to count on over time as elusive and difficult to make sense of.

Interestingly, Maya's experiences seem to be far removed from the pressure that Gillian reported on account of her experience of a sense of intuition as a mother as insufficient to interpret her daughter's wants and needs. We are alerted then, to the complex and ambiguous ways in which 'motherly intuition' can function as both a resource and a barrier to mothers' relationships with their children with disabilities.

Notwithstanding the benefits afforded by a reliance on 'motherly intuition', Maya still experiences Sarah's restricted communicative competence as inherently problematic and stressful. When I enquired whether she believed an inability to communicate verbally impacts on Sarah's subjective experiences, Maya declared:

***M:*** *I don't think it impacts on her.*

***P:*** *Okay...*

***M:*** *I think the impact is more on ME!*

***P:*** *Okay.*

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<sup>8</sup> Sarah experienced severe epileptic fits up until the age of 7 years.

*M: Ja now, that's, that's the WORST about, the worst thing may be that I can't...The ONLY thing maybe that I can't handle about Sarah is that if she comes home and she looks like she looks sometimes, and I don't know what [went on], WHY does she look like she looks? (Maya: Interview 2).*

In Maya's experience, Sarah does not consciously struggle with her own communicative incompetence. Instead, Sarah's inability to communicate verbally is appropriated as personally stressful to her in her role as a mother. Indeed, Maya indicates that not being able to receive a verbal account from Sarah as to why "*looks like she looks sometimes*"<sup>9</sup> is a critical concern for her. An implicit assumption here is that while her daughter is in her care, understanding and interpreting her wants and needs is unproblematic. However, Sarah's inability to account for the events of the day spent apart from her is experienced as frustrating and worrying for Maya. An impression is created of Sarah as particularly vulnerable to injury outside of her home context. In addition, Maya's experiences of vulnerability and disempowerment are exacerbated by the failure of any of the individuals into whose care Sarah is entrusted to account for the numerous serious injuries that she had incurred. Children who are disabled but have intact perceptual as well as expressive language functioning are capable of reporting back on their experiences. By implication, a 'victim' status is implicitly cast on Sarah.

Importantly, her profound impairments across multiple dimensions of functioning do not completely negate Sarah's experience of positive emotions in the context of her everyday interactions. In this regard, Elana suggests:

*E: But I think that little Sarah is very happy, you know. If she comes to me as well, she enjoys the stuff [occupational therapy activities] – so "Ha ha" – she speaks in her own way. The little hands go like so and the feet go like so*

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<sup>9</sup> Maya's concerns are based on Sarah having received numerous injuries while at school, a concussion included.

*[indicates by swinging her hands and legs vigorously]. So she does all that while we are on the red [therapy] ball, and while we are inside the drum. (Elana: Interview 1)*

Elana's confidence in her experience of Sarah as a happy child needs to be understood within the context of a history of many years of individually-based occupational therapy sessions with her. This perception of her as happy is based on the non-verbal cues that Elana has learnt to notice and read intuitively as signs of Sarah's emotional state. Unlike those of her peers who are more competent communicatively, Sarah is incapable of offering feedback on the occupational therapy experience in conventional verbal terms using words and sentences. It is therefore significant that she utilises the capabilities that she does have in idiosyncratic ways as *communicative resources*. In stating that she "*speaks in her own way*," Elana affirms that it is through her verbalisations combined with her physicality in the form of vigorously moving her hands and legs that Sarah communicates that the specific therapeutic activities that she participates in are enjoyable sensory-motor experiences. Indeed, Sarah's use of her body to communicate feelings of excitement and enjoyment is a feature that I often noticed within the therapeutic riding setting as well. Also interesting is that Sarah's communicative behaviours are experienced as non-aggressive. This contrasts starkly with Elana's earlier description of Rachel's communicative efforts as expressed in a physical manner that is generally interpreted as aggressive.

Moreover, in what follows the implications of Sarah's communicative incompetence for her experiences of sociality are considered:

**P:** *I, I thought that with her and Rachel at the horse riding, it's both of them that don't talk, that don't talk at all. And then I thought, it felt to me – but it's, perhaps just my perception – it feels to me like they really aren't part of the group, because they don't speak?*



***E:** That is the case, it's very true, Pravani. Because look, little Rachel is just on her own a lot – She doesn't have little friends. You know Sarah doesn't have an issue with not being a part of the group. Look the children are all terribly wild about her. There's permanently somebody who walks around with her...*

***P:** And talks to her, yes.*

***E:** You know, so they really love her a lot, but it doesn't bother her. Whether a person picks her up or doesn't pick her up, it's just the sa - it's just the same.*

*(Elana: Interview 1)*

Here Elana strongly concurs with my assessment (based on what I had observed at therapeutic riding lessons) of Rachel and Sarah as marginalised from the rest of the group of their peers. But, while her accounts with regard to Rachel highlighted experiences of marginalisation and social exclusion, Sarah's relations with others are appraised in a more positive light. As the extract above indicates, Sarah is much sought after by the older learners who often carry her around the school premises. However, Elana declares that perceptually, Sarah is oblivious of her popular status and appears somewhat indifferent to individuals around her. An implicit assumption here is that while Sarah does not mind being carried around by other children, such experiences are simply a source of sensory stimulation, and do not denote an engagement in meaningful interactional exchanges.

However, in contrast to Rachel's somewhat strained relationship with her younger sister, Monica, Sarah's relationship with her brother, Alex, is described in wholly positive terms. When I asked Maya how Sarah gets on with her younger sibling, she stated:

***M:** Very well. Ja no very very well. She loves him. He tickles her and he just has to talk to her and she laughs [Smiles broadly]. No, they get on very well. (Maya: Interview 1)*

Here an image is presented of Sarah as highly responsive to her brother in particular. Clearly, Alex serves as an engaging playmate and an important psychosocial resource for Rachel.

Moreover, in what follows Elana alludes to an appreciation for Sarah's exposure to sources of social contact with others as still beneficial. She asserts:

*E: With Sarah a person cannot see a need for contact at all, but Rachel definitely has it. It's perhaps also because Sarah gets exposed to other children at us [at the school] the whole time, and in the afternoons at Heleen and other children, whereas little Rachel doesn't have that. (Elana: Interview 1)*

In tension with her preceding sentiments, Elana adopts a more strengths-oriented view in the extract above, paying particular attention to Sarah's existing psychosocial resources and strengths. For instance, she suggests that the benefits of regular exposure to other children are attained through Sarah's daily school attendance, as well as the aftercare facility geared at the care of children with disabilities that she attended for a period of time. Certainly, the nature of her social relating might not seem as deep and nuanced as that of some of her more communicatively competent peers. However, based on the rationale that positive relations with others do indeed constitute an important dimension of psychological well-being (Ryff & Singer, 1998), it is argued that Sarah's ample exposure to other children takes precedence over the isolation and brevity of social contact with peers that Rachel's home schooling routine affords her. As stated earlier, while Rachel has a host of adults to interact with, she yearns for social contact with other children.

It is striking that when asked how she would describe her daughter to a person who has yet to meet her, Maya raised Sarah's affinity for others as a particular strength.

Maya proudly declared:

***M:** Ag, she's fine and she's friendly and she's actually quite an angel. She goes to anybody, she hasn't got a problem with going to anybody".* (Maya: Interview 1)

Maya's deep affection and love for her daughter is apparent in her description of Sarah as a friendly child who is well behaved and unprejudiced in her approach to others. Through such a validation of Sarah's strengths and personhood, Maya implicitly points to her daughter as embodying *an ordinary human value*. In addition, it is also plausible that Maya's mention of Sarah not having "*a problem with going to anybody*" represents an effort, at an unconscious level, to resist what she has experienced as others' often disabling attitudes towards and discomfort in responding to, and interacting socially with, profoundly disabled children such as Sarah.

And, while both concur that Sarah is agreeable to everyone within her frame of reference, Maya seems to inadvertently undermine Elana's assessment around Sarah's inability (based specifically on impairments in perceptual functioning) to recognise and distinguish between individuals. Indeed, Maya presents a complementary view of Sarah's capabilities as more sophisticated than Elana had suggested. This difference of perspective around Sarah's cognitive capabilities and their implications for her sociality indicate that across settings, the participants' subjective experiences are nuanced and often inconsistent and contradictory. Also, the way in which Elana relates to Sarah in her professional role as an occupational therapist is qualitatively different from the manner in which her mother relates to her. Parents' intimate, enduring and loving relationships with their children often tend to be in stark contrast to the professional's payment for limited hours of contact and emotional attachment (Ryan & Runswick-Cole, 2008). Hence, the agendas and dynamics inherent in each of their relationships with her tend to influence both Elana's and Maya's perceptions and experiences of Sarah.

However, in the extract below, an indication of the inconsistent, often contradictory dynamics with respect to social relations is evident. Apart from the highly positive nurturant relationship that she has with her only sibling, Alex, and the children that she comes into contact with at school, I was keen to hear if there was anyone else that Sarah played with on a regular basis. Maya responded:

*M: Me and my husband and the ousie [domestic helper]. Ja, I always say I've always been her best toy. (Maya: Interview 1)*

Speaking as a mother, Maya's response conveys the thinly veiled pain that is attached to her experience of Sarah as marginalised and socially isolated. In declaring that "*I always say I've always been her best toy,*" Maya indicates that has she tended to take on the role of a playmate, indulging Sarah with regard to play activities. However, the tone of her voice revealed strong feelings of sadness and regret in this regard. An implicit assumption here is that Maya would have preferred Sarah to have had the benefits of wider repertoire of social relations with other children upon which to draw as psychosocial resources.

### **De/constructing motor skills and in/capabilities**

While Sarah's limbs are rather spastic and her knees appear to point in an inward direction when she walks, she is still able to walk confidently and unassisted. Indeed, her relatively recently acquired capability for moving around in, and interacting with, her physical environment with ease constitutes a significant resource for her. Thus, it could be argued that being able to sit and walk independently has facilitated empowering and enabling psychological experiences for Sarah.

In this regard, her occupational therapist, Elana declares:

*E: Look, little Sarah, in that sense, she's much more independent than Rachel, you know, in terms of her moving about and so on. Whereas Rachel just only sits and looks at the world around her, Sarah will stand up and she will EXPLORE in her own manner, you know. (Elana: Interview 1).*

An image of Sarah as behaving in more agentic and autonomous ways than Rachel is presented here. In contrast to her appraisal of Rachel as more of a passive observer or spectator, Elana suggests that Sarah utilises her capacity for movement and independent mobility to explore or actively engage with her physical and social environment in idiosyncratic ways.

Interestingly, Elana interprets Sarah's emotional state as directly linked to her capabilities for independent mobility. She asserts:

*E: Pravani, I think the big thing with little Sarah is that she's really happy, you hear, I think as she is...*

*P: Her mother also says so...*

*E: I think she's a very happy child, you know. Even if it looks, even if she looks absent, I don't think she's discontent with the world or... She's happy with herself and she's just around here on and off the verandah, and she's in the classroom, and you know. I think she has peace with the world around her. Really, really. (Elana: Interview 1).*

To begin with, Elana boldly insists not only that Sarah is a happy child, but also that she is, in her opinion, content with herself and the world around her. Thus, she bestows upon Sarah a sense of acceptance of herself "as she is," implying that her subjective experiences do not appear to be dominated by emotions of deep despair or frustration on account of the profound nature of her impairments. Rather, being able to engage independently within the different contexts of her

world affords Sarah a certain psychosocial currency that feeds in to her experiences of happiness and contentment.<sup>10</sup> Further, positive implications for experiences of autonomy and self-acceptance, which constitute key dimensions of Ryff and Singer's (1998) model of psychological well-being, are inferred here.

Secondly, Elana observes that despite sometimes having what appears to be a vacant facial expression, Sarah is still highly responsive, engaging with her environment in profoundly physical ways. Moreover, she lives out her emotional states in idiosyncratic ways by utilising her physicality to engage with her environment. Thus, Elana recognises and accords value to Sarah's capacity for communication and social interaction through the use of her existing bodily capabilities to engage with her physical and social environment in a concrete manner. Sarah's perceptual functions, proprioceptive abilities and capacity for independent mobility are pointed to as significant strengths and resources. Indeed, it is plausible that if she were not capable of standing up and walking independently, or did not have an awareness of her body in space and be able to make adjustments in this regard, Sarah would not be able to actively engage with her environment with the degree of competence and skill that she displays.

A final salient point here concerns the ambiguous nature of attempts to ascertain the level of functioning of a child with profound impairments. As the nuanced, responsive nature of her independent mobility and interaction with her environment indicates, in certain respects, Sarah's functioning is far more sophisticated than a global assessment at the level of a 6-month-old baby would have us believe. We are reminded, then, that idiosyncratic features of the participants' functioning and development must necessarily be taken into account when attempting to make sense of their subjective experiences of impairment and disability.

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<sup>10</sup> This positive evaluation around Sarah's emotional state is in stark contrast to Elana's appraisal of Rachel as deeply unhappy and despondent, largely on account of the pressures around performance that her parents tend to place on her.

In view of what Elana had noticed around Sarah's bodily expressions of her emotional states, I asked Maya how her daughter expresses that she is happy. Maya declared cheerfully and with a broad smile that:

**M:** *When she's happy? Ag, she just laughs. Laughs and walks fast.*

**P:** *Ja, I've seen her walk, the... I was actually... It was a huge change for me to see her this year with the walking around, and so quickly. You look and the next moment she's sort of going where she wants to be. (Maya: Interview 1)*

Here Maya contends that characteristically, Sarah attempts to engage one socially in the form of a laugh, a feature that is universally recognised as a sign of enjoyment and positive emotion. Also consistent with Elana's observation regarding Sarah moving around within her environment, Maya interprets a tendency to walk fast as an observable indication - one that I, too, had noticed at therapeutic riding sessions - that her daughter is happy. In terms of expressive language skills, it is noteworthy that 11-year-old Sarah does not have a repertoire of words with which to verbalise her thoughts, emotions and needs. However, it is remarkable that, like Rachel, she makes explicit use of her physicality as a resource for communicating with others. Indeed, as with Rachel, Sarah's embodied expressions of physicality constitute *her (mode of) communication*.

Given that as a result of her impairments in expressive language functions, Sarah is not capable of expressing her emotions verbally, I was also curious to learn how she behaved when unhappy or irritated. Maya asserted:

**M:** *When she's cross or irritated or miserable then she normally does naughty things like banging her head against the floor and...And then you know that little pinching, she tends to, when you hold her...Her way of touching is a sort of a pinch. I don't see that as a way to say: "Listen here, you're in my space" or anything. I just think she's looking for erm sense...*

**P:** *She's looking for the sensory stim...So Sarah's looking for the sensory stimulation?*

**M:** *Hmm. And if you look at THE WAY SHE DOES IT, it's just the way she holds her fingers. If you look at the way she plays with her fingers and everything, it's basically the same. So I don't see that as aggression or crossness or anything like that. And then she used to also bite, but she hasn't done that for a long time. (Maya: Interview 1).*

In her account, Maya reinforces the idea of her daughter's physicality as a medium through which she expresses her emotions. For instance, Maya mentions Sarah's tendency to communicate her irritation or unhappiness through *"naughty things like banging her head against the floor"*. Given that Sarah could injure herself fatally by banging her head against the floor, it is striking that Maya casually mentions such *"naughty things,"* downplaying the inherent danger involved in such behaviours. At the same time, it is also interesting that Maya does not interpret Sarah's habit of pinching as a sign of aggression. Indeed, she explicitly denies any such connotation, declaring instead that Sarah's pinches are *"her way of touching"*. However, it needs to be borne in mind that Sarah's petiteness and slight frame mean that any attempts at pinching are necessarily light and painless - as I have experienced first-hand - and are therefore unlikely to be perceived as implying an aggressive intent. In support of her argument that Sarah's pinches merely represent a state of interacting with her physical and social environment, Maya likens the habit of pinching to infant reflex actions, described by her in lay terms as *"playing with her fingers"*. Also, Maya cites Sarah's habit of biting, which is less difficult to describe in non-aggressive terms, as a behaviour that her daughter had engaged in in the past, rather than an expression of aggression that she tends to indulge in currently. Clearly, Maya recognises, and is responsive to, Sarah's nuanced use of her embodied physicality as a medium for communicating her emotional states, wants and needs. Thus, in her role as her mother, Maya serves as an important psychosocial resource for Sarah.



Echoing such sentiments, Elana states:

*E: I think if her parents didn't take such good care, like they do, you know, I don't know where she would be now. That, yes, that's definitely a very positive point. I think that they also have peace with her being as she is, you know. I mean almost 90% of our parents – which a person can also understand – haven't made peace with... that the child is here and that he can only meet certain demands. Whereas I think her parents have really already travelled the road a bit, you know. That they do accept that this is how she is and know nothing is going to change that. I really think that that's definitely positive. Yes, yes. (Elana: Interview 1).*

Elana offers the insights that the vast majority of the parents of children at the school struggle to come to terms with their children having to be educated there due to the profound nature of their impairments on multiple dimensions of functioning. In contrast, Sarah's parents are regarded as atypical in their acceptance of the fact that their daughter needs to attend a school catering for her profound impairments and capabilities. Further, Elana's declaration that Sarah's parents "*accept that this is how she is and know nothing is going to change that,*" indicates that any hopes and expectations that they might have had around the possibility of finding a cure for her impairments appear to have been discarded. They have shifted their expectations over time to arrive at a strengths-oriented understanding, acceptance and validation of their daughter "*as she is*". Instead of blind optimism then, Sarah's parents are judged to have a realistic understanding of the sorts of demands and expectations that their daughter is capable of meeting within the repertoire of her existing abilities, strengths and impairments.

Based on Baumrind's (1991) definition of parental responsiveness as "the extent to which parents intentionally foster individuality, self-regulation, and self-assertion by being attuned, supportive, and acquiescent to children's special

needs and demands” (p.62), it is inferred that Sarah’s parents are responsive to her. And, in Elana’s view, such parental responsiveness is seen to constitute a resource that feeds in to positive subjective experiences for Sarah. Thus, Hewitt’s (2005, p.136) assertion that “self-esteem is in the first instance thought to be dependent upon the child’s acceptance within the social fold without regard to particular performances” is also salient here. Such an assertion is insightful in relation to the psychologically meaningful implications of Sarah’s parents’ responsiveness and unconditional acceptance of their daughter “*as she is*,” while simultaneously acknowledging and often grappling with the profound nature of her impairments. Furthermore, Elana’s account points implicitly to Sarah’s parents’ tendency to accord *an ordinary human value* to their daughter, perceiving her as sharing a basic ontological worth in common with other human beings.

When considered against her parents’ validation of Sarah “*as she is*,” the lack of acceptance and unrealistic goal setting that Rachel’s parents were criticised for is rendered more damaging, psychologically speaking. Certainly, from Elana’s insights with respect to both participants, it is plausible to infer a relationship between parental attributes such as acceptance and responsiveness, and outcomes with respect to their children’s psychological well-being.

### **Appraisal of participation in therapeutic horse riding**

In view of the inherently physical manner in which Sarah tends to relate to her environment, and given that therapeutic riding constitutes an intervention that necessarily taps in to the participants’ physicality, I was keen to discover what Elana’s assessment around possible inputs from therapeutic horse riding would point to.

When asked for her opinion about whether or not Sarah should continue with therapeutic horse riding, she responded as follows:

*E: Oh, yes, definitely, you see. A person really cannot stop it with her, you see. Because look, definitely what I mentioned just now about the stability of the trunk and things that a person needs to maintain – I think the horse riding makes a HUGE contribution to that, you see. Really, really. Look, I can just see her once a week, the physio [physiotherapist] can see her once a week, so the horse riding is at least a third form of therapy that she gets in the week, you see. No, I think if a person had to completely let go of her, then you are going to see she's going to start slumping again, and so on. So no, definitely, you see. And the other thing is, Sarah likes movement, she looks for it. She LOOKS for that INPUT, so it. I mean, I think the horse riding is wonderful, that a person can give her that, you see. No, I think she must ride for as long as she can, you see. Yes. No, definitely, you see. Definitely, yes. (Elana: Interview 1)*

Here (as she had with Rachel), Elana calls into play and prioritises efforts to maintain current levels of functioning as a legitimate therapeutic goal for Sarah. Based on the knowledge, experience and expertise that she has acquired over more than a decade of practising an occupational therapist, Elana authoritatively proposes a causal link between the hypothetical discontinuation of Sarah's participation in therapeutic riding, and a deterioration on physical dimensions of her functioning including a loss of upper body strength, weakened trunk control and poor balance, referred to as “*slumping [forward]*”. Thus, Elana reasons that therapeutic horse riding is a useful form of intervention on the grounds of its inputs into such aspects of functioning as the maintenance of upper body strength, trunk control and balance. Furthermore, by conceptualising therapeutic horse riding as constituting “*at least a third form of therapy that she [Sarah] gets in the week,*” Elana firmly and unambiguously places therapeutic horse riding alongside occupational therapy and physiotherapy within the multidimensional treatment team in terms of what it has to offer to Sarah.

Elana has also observed that Sarah enjoys engaging in movement oriented activities during occupational therapy sessions. Given her tendency to actively seek sensory-motor stimulation in the form of movement, for Elana, therapeutic riding is of significance in that it constitutes a particular intervention through which Sarah is able to receive the sought after stimulation that she enjoys. Importantly, this stimulation also happens to be critical for facilitating the maintenance of current levels of Sarah's functioning and her development. Elana's sentiments articulate with the view that therapeutic horse riding provides an opportunity for an optimal experience of a combination of sensation and movement that contributes to the maintenance, development, rehabilitation, and enhancement of physical skills in children with disabilities (Mallon, 1992).

Similarly, in what follows, the maintenance of balance and trunk control are once again prioritised as therapeutic goals. It is to Sarah's advantage as well that within the context of the multidimensional treatment team, she has a range of individuals - from occupational therapy and therapeutic horse riding included - involved with therapeutic activities that stimulate these particular skills and capabilities.

*P: We, I think for the first, for the first year at riding we let her sit across the horse's back, because her trunk was so weak.*

*E: Was so weak yes. Now she [Sarah] can really hold herself nice and upright.*

*P: Yes, very nicely.*

*E: She can really do it nicely. But you know, that's why I think it's terribly important that we maintain that, you know. Because I think if we just let her go, then she is going to lose that again, you know. So I think that's why it's, it sounds like a terribly BORING goal: to say, maintain, but with her it is very important, you know, because she easily...Our children easily lose that which they have gained. Definitely. (Elana: Interview 1)*

Here Elana agrees with my description of Sarah's trunk control as initially so poor that she could not be seated upright in the saddle at therapeutic riding sessions. And, her comment "*Now she [Sarah] can really hold herself up nice and upright,*" develops this point further as precedence is accorded to distinct improvements in terms of the development and maintenance of balance and postural control. In particular, by describing her ability to independently sit upright, assuming the correct posture in her seat as opposed to being 'floppy' and at risk of falling over or to either side, Elana presents a strengths-oriented appraisal of Sarah as *physically capable*.

Elana's observations resonate with the therapeutic riding literature in which improvements in balance and postural control are highlighted as some of the effects of participation in therapeutic horse riding. The rationale offered is that as the horse moves, its centre of gravity is displaced three-dimensionally, and the rider is constantly thrown off-balance, requiring that the rider's muscles contract and relax in an attempt to rebalance so as to stay in an upright posture on the horse (Brickell, 2005; Miller & Alston, 2004; Reide, 1998). Significantly, Casady and Nichols-Larsen (2004) have also noted that "the development of postural control is postulated to be the foundation for normal gross motor activities, and the acquisition of motor skills is proposed to be dependent on the development of postural control" (p.166).

Having established the importance of postural control for broader motor functioning then, it is interesting to note that in the preceding extract, Elana convincingly declares that maintaining Sarah's upper body strength, trunk control and balance constitute legitimate therapeutic goals. Moreover, she again alludes to the consequences of a deterioration on these aspects of functioning, should current therapeutic interventions be withdrawn. At the same time, Elana acknowledges that such goals around the maintenance of current levels of functioning might be perceived as unambitious and insignificant in comparison to grand-scale improvements. Still, the basic assumption that is foregrounded in

Elana's account is that in therapeutic terms, it is goals around the maintenance of current levels of physical functioning that are of utmost significance for Sarah.

To support her argument, Elana offers the rationale that not only Sarah but the rest of the children with disabilities with whom she works at the school consistently face the risk that the skills and levels of functioning that they have achieved thus far could deteriorate. Elana posits that it is therefore crucial to stimulate not only Sarah, but children with disabilities in general through facilitating their regular participation in therapeutic interventions. As an integrated rehabilitation approach, the triad of interventions, namely, occupational therapy, physiotherapy, and therapeutic horse riding, should ideally prioritise the maintenance of individuals' current levels of functioning.

In what follows Maya maintains that the physical effects of therapeutic riding are beneficial for Sarah. When asked to contemplate what it is about therapeutic horse riding that Sarah might benefit from, Maya asserted:

**M:** *Must be the rhythm, she likes rhythm. And I think it's a challenge for her, because she is one of those kids that don't want to be held - "Don't hold me!" She doesn't want to...*

**P:** *She pushes your hand away. We're supposed to have two people on either side, and when we actually do hold on to her she doesn't like that very much, she pushes your hand away.*

**M:** *She doesn't...She HATES it, especially here [indicates] above your, above her shoulders, she doesn't like that. And that's a...I see that as a challenge in her eyes. Because then it forces her to do the right thing. I was swinging her this morning on the swing, and it hasn't got a seat at the back, it's just a tyre. And it's actually quite...If somebody else was there they would have had a heart attack, because she knows she's got to hold on and then I swing her and she'll still take a chance and try and take her hand off. But she's SO GOOD with her balancing that she can put her hand back there. So I think that's that thing of: "I can do it on*

*my own!” and then the rhythm...That’s developed this part of her [indicates her upper body/trunk].* (Maya: Interview 1).

Here Maya echoes Elana’s point regarding the value of movement, describing this feature more finely in terms of the *rhythmic* movement that Sarah appears to be attracted to and perhaps soothed by. Thus, Maya’s view speaks to a significant feature that distinguishes therapeutic horse riding from other forms of intervention such as physiotherapy and occupational therapy. In comparison to inanimate therapeutic apparatuses such as the therapy ball, the sensory input that the rider receives from the rhythmic movement of the horse at a walk cannot be reproduced in any other way (Casady & Nichols-Larsen, 2004; Ludewig, 2006). Applying Brickell’s (2005) insights to the context at hand, it is posited that the horse’s walking action can heighten Sarah’s consciousness of her own bodily movement when riding, as well as her movement when away from the horse. In this regard, Maya keenly asserts that she has observed the effects of such proprioceptive stimulation attained during therapeutic riding to have carried over to Sarah’s positive experiences of being pushed on a makeshift swing.<sup>11</sup>

At one level, the example of Sarah intermittently removing her hands from the ropes of the swing, maintaining her balance, and then successfully replacing them on the ropes of the swing indicates that she has developed a distinct awareness of her body’s position in space, as well as an ability to make adjustments in her body’s positioning with ease. Moreover, on behalf of her daughter, Maya voices the sentiment “*I can do it on my own!*,” implicitly linking Sarah’s experiences of agency and self-efficacy to such capabilities. Indeed, for Maya, the ability to let go of the ropes of the swing, maintain her balance, and then regain her hold on the ropes constitutes a skill that Sarah has rehearsed and finely honed in the process of participating in therapeutic riding sessions.

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<sup>11</sup> In South Africa, motor vehicle tyres are often cut in half and attached to pieces of rope, with the hollow of the tyres serving as a seat, to create a makeshift swing. Like a saddle, such a swing does not have a concrete support structure to lean back against. Thus, the child on the swing is compelled to sit upright or risk losing his/her balance and falling off the swing.

At another level, Sarah's somewhat risky actions could also be interpreted as representative of a more positive perception of her physical self. Such attributes could feed in to her experiences of a positive body image as well as enhance Sarah's self-esteem. As existing research suggests, physical competence and self-perceptions can be improved through physical activity and this can have a positive mental health effect (Fox, 1997, as cited in Mutrie & Faulkner, 2004).

In comparison to Elana's exclusive focus on physical effects of therapeutic riding in terms of postural control, balance and upper body strength, the preceding extract indicates that Maya has adopted a more holistic view. In particular, she proposes that Sarah experiences horse riding as a challenge both physically and psychologically, based on her intrinsic motivation to "*do the right thing*," namely sit independently, upright in the saddle when mounted on horseback without being physically supported by an outside source such as the side-walkers.<sup>12</sup> Implicit in Maya's position is the idea that successfully engaging in the 'bodily work' of horse riding works to enhance Sarah's self-efficacy beliefs and sense of mastery.

In pointing to Sarah's experiences of self-efficacy and a sense of mastery as derived from achieving and maintaining an upright posture on horseback, Maya prompted me to mention that I had noticed that Sarah often intentionally pushes away the side-walkers' supporting hands. Thus, it is by asserting her will in unique, bodily ways that Sarah makes her wishes and intentions known. Further, while pushing others' hands away represents a resolve that Sarah is not capable of expressing in conventional verbal terms, such efforts are also psychologically significant in that they constitute an assertion of her autonomy and independence. In this regard, Maya verbalises the stance that Sarah assumes as communicating the assertion "*Don't hold me!*". Arguably, Sarah's attempts to prevent the side-walkers from holding on to her limbs in an anchoring manner are

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<sup>12</sup> As a safety precaution, side-walkers hold on to riders' knees and heels during therapeutic riding sessions thereby serving an anchoring function while still being least restrictive to the rider.



grounded in an experience of her body as *a body that works*, and that is *reliable*. Such nuanced, positive experiences of her body serve to render intelligible Sarah's blatant rejection of others' support of her body as unnecessary for maintaining an active, upright posture on horseback.

Maya also suggests that Sarah perceives sitting independently, upright in the saddle as a challenge to consistently attempt to "*do the right thing*," in maintaining such a position. Salient here is Budgeon's (2003) view of selfhood as "an embodied process involving particular experiences and engagements in certain practices which allow the body to make new, transformative connections," (p.48). Indeed, it is argued that the extract above points to Sarah's participation in therapeutic horse riding as constituting experiences and engagements that "allow the body to make new, transformative connections". Thus, skills and capabilities in terms of proprioception, postural control, and balance are called into play. Moreover, experiences of agency, self-efficacy and self-esteem are also considered to be defining features of such transformative connections. Positive implications for Sarah's experiences of psychological well-being are inferred as well.

Indeed, Maya's support of Sarah's participation in therapeutic horse riding was evident in that their family took Sarah along to participate in two horse riding shows.<sup>13</sup> She asserts:

**M:** *And the other thing that was nice for us was that it was, it was getting the outside world involved when you go to the show and so on. Because I believe that the world has not got acceptance for these kids yet. So the more you take them into the world, the better for them. So no, I see it as a total advantage.*  
(Maya: Interview 1)

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<sup>13</sup> The shows, one at the therapeutic horse riding school, and another at an agricultural show held in the city attended by riders and spectators from all over the country, included categories for disabled riders to participate in.

Maya's account is distinct in that she accords a consciousness-raising role to therapeutic horse riding. Such an attribution takes further existing bodies of work around the dynamics and processes at play in this form of intervention. Indeed, Maya's reasoning may be contextualised within social model thinking to the extent that she casts a role for therapeutic riding through disabled riders' participation in the public sporting arena of equestrian shows. Such participation is highlighted as providing tangible evidence of children with disabilities as capable, and of their impaired bodies as *bodies that work*. In this way, therapeutic riding served as a context that could address and dispel common cultural myths and stereotypes around incapability and deficit and thereby facilitate an understanding of disability as but one important facet of the children's identities.

Further, when I asked if she had any final comments to make regarding Sarah's participation in this form of intervention, Maya declared:

***M:** No, I just want her NEVER to stop!*

***P:** That's quite a big thing to say?*

***M:** No...That would be...that, that's for me her erm, her little bit of ...What can I say? That's what SHE likes. ENJOYS. Where another child might enjoy playing tennis, Sarah enjoys doing the horse riding. So I'll always make sure she does that. Ja. (Maya: Interview 2).*

Once again, therapeutic riding is accorded a privileged status as an activity that Sarah is both capable of participating in, and proficient in. Maya's statements indicate that she is convinced that in the long-term, therapeutic horse riding constitutes a significant medium through which Sarah is afforded opportunities for meaningful positive experiences. Along with emphasising therapeutic riding as enjoyable for Sarah, Maya also calls into play a conceptualisation of horse riding as a recreationally-oriented sporting activity, a description that is often cited within the therapeutic riding literature (e.g., Britton, 1991; Scott, 2005).

Moreover, she equates Sarah's participation in therapeutic riding with sporting activities such as tennis that other, typically developing children might engage in. An implicit assumption here is that Sarah's participation in horse riding, albeit in a therapeutic mode, serves as a point of commonality with other children. Her position serves to highlight Maya's ambivalent experiences of her daughter as profoundly disabled and yet simultaneously 'ordinary' in that she is like other, typically developing children who participate in and experience sporting activities as fun-filled and enjoyable. At the same time, it is ironic that, for Sarah, participating in the activity of horse riding is necessarily motivated by a therapeutic agenda. However, Maya seems to recognise the unique appeal of therapeutic riding as located in its recreational features that distinguish it from exclusively clinical forms of intervention.

In sum, the foregoing discussion illustrated that given her distinct and profound impairments with respect to expressive and receptive language skills, like Rachel, Sarah's relating with others is fraught with difficulty. This feature serves as a disabling barrier to the fostering of social relations with her peers, as well as her participation in classroom and therapeutic activities. However, she, too is able to utilise her physicality in idiosyncratic though perhaps less sophisticated ways, to communicate her wants, needs and emotions. In contrast to Rachel, however, Sarah has at her disposal the resource of independent mobility, and is able to interact with her physical and social environment with ease, and in her own idiosyncratic manner. This has served to facilitate enabling psychosocial experiences for Sarah. In addition, her experiences of therapeutic riding were described in positive terms. On the one hand, positive implications for the maintenance of balance and trunk control were reported. And, while reference was made to the social and recreational nature of this form of intervention, as well as its sporting nature, what was striking was that a feature heretofore unmentioned in existing bodies of work, namely the consciousness-raising role of therapeutic horse riding, was raised here.

#### **4.4. Isobel**

##### **Biographical note**

Isobel is a pretty 5-year-old with long blonde hair and an outgoing personality. Diagnosed with left hemiplegic cerebral palsy, her pronounced unruly motor patterns and spastic limbs are immediately noticeable and rather jarring to everyone who meets her.

Isobel's family lives in a comfortable home in a middle-class suburb in the city, in close proximity to the home of her maternal grandparents. Her parents are both employed, with her mother working on a part-time basis. Isobel has an older brother by four years, Johan, whom she gets on well with. Together with Johan, Isobel spends afternoons in the care of her grandmother, who fetches both children from their respective schools on a daily basis.

##### **Re/negotiating communicative in/competence**

The preceding discussion indicated that Rachel and Sarah's respective impairments consist, at one level, of a lack of expressive language skills and severe compromises in receptive language functions. As a result, it has been argued that both participants are lacking in competence with respect to communication in verbal terms. In contrast, based on her ability to communicate verbally with relative ease, 5-year-old Isobel's impairments with respect to such expressive language functions are appraised as working in complex and subtle ways. Moreover, in addition to being capable of verbal communication, Isobel's outgoing personality and strong social skills have meant that she has been successful in integrating herself into her group of peers.

Still, Isobel's specific diagnosis of left hemiplegic cerebral palsy has distinct consequences for her speech and language functioning. When asked to elaborate on Isobel's vocabulary and expressive language skills, Sanet, the speech therapist with whom she has therapy on a weekly basis, asserted:

*S: No, I just know that her spontaneous speech is sometimes difficult for other people to understand. But it feels to me it is not her articulation...And I wonder often, you know, like with these motor patterns as well, I say it many times to parents as well. A person just needs to remember that the disability that is in the body is...is also in the oral areas. So you must know, if this arm or this foot cannot [function], then you must expect that the tongue or the lips also cannot [function]. If there is spasticity somewhere, then it is often the case that something also happens in the oral organs. (Sanet: Interview 1)*

While cerebral palsy is defined primarily in terms of motorically-based impairments, along with impaired intellectual, behavioural and perceptual functioning, accompanying disturbances in communication are cited as well (Rosenbaum et al., 2007; Stanger & Oresic, 2003). However, existing bodies of work also indicate that oral motor impairments have been noted in the vast majority of children with cerebral palsy (Murphy & Such-Neibar, 2003). In the context at hand, too, Sanet appraises the spastic motor patterns that are characteristic features of the hemiplegic left hand side of Isobel's body as generalised to the organs for speech as well. The difficulty that others might have in understanding Isobel's speech is not attributed to underdeveloped articulation skills, but perceived instead to be grounded in her impaired physicality. Thus, along with that which is highly visible, namely Isobel's pronounced, awkward motor patterns and spastic limbs, her subtle and less obvious impaired oral motor functioning also has disabling effects on her day-to-day functioning.

For instance, within the speech therapy context, Sanet has noticed that inattention features within Isobel's repertoire of behaviours, albeit on an inconsistent basis. She stated:

*S: I really feel that at times she comes across as a bit inattentive to me. It's not...And it also doesn't feel to me like that is the case every time I see her [for speech therapy]. There are some days where it feels to me that it's going very*

*well with her, but then again there are other days when it feels to me that she is terribly inattentive. So to me it varies a bit. (Sanet: Interview 1)*

Moreover, Isobel's specific diagnosis of left hemiplegia is regarded as salient here. As Khaw, Tidemann and Stern (1994) have indicated, a diagnosis of left hemiplegia is associated with lesions involving the right hemisphere of the brain, and this hemisphere is known to play a special part in maintaining attention. As a result, a greater incidence of behavioural and school problems is to be expected in children diagnosed with left hemiplegic cerebral palsy (Khaw et al., 1994). In particular, behaviours such as inattention can serve as barriers that prolong and/or hinder Isobel's efforts to achieve everyday tasks. Consequently, a negative impact on her experiences of success, self-efficacy beliefs and sense of mastery may be inferred.

Given Sanet's comments, I was also interested to hear if Isobel's mother shared a similar assessment with respect to her communicative competence. Commenting on whether Isobel found it easy to express herself verbally, Mariette responded:

**M:** *Yes... If it becomes such a long story like now,<sup>14</sup> then I think she forgets what she really wants to say, and then she carries on and on with this thing, but she doesn't really get to the point where she actually wants to be...But in general, just communicate...to say to me "Mommy, I want this" or "Mommy, I want that" is not a problem for me. (Mariette: Interview 1)*

Here, Mariette expresses a degree of frustration with Isobel's tendency to be long-winded and sometimes forget the point of an incident that she was relating. Lived out in Isobel's expressive language functioning, such features as distractibility, a short attention span, and an inability to focus her attention are

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<sup>14</sup> Shortly after I arrived at her home for the interview, Isobel related the event of going to visit her aunt's farm at length to me, losing the point of her story along the way.

interpreted as part of the range of cognitive behavioural disturbances that constitute secondary symptoms of cerebral palsy (Khaw et al., 1994; Rosenbaum et al., 2007). However, an implicit assumption here is that Isobel's disturbances in communication would have had more severe consequences for her daily functioning were she wholly incapable of expressing herself verbally. Clearly, Mariette perceives Isobel's apparent long-windedness as a momentary source of delay in communication that requires a considerable degree of patience on the part of her audience, rather than a serious barrier to her ability to communicate verbally and interact socially with others. Thus, overall, Mariette's frustrations seem minimised in comparison to her recognition of, and appreciation for, the capability that Isobel has for verbally communicating her experiences and needs in an intelligible manner. In sum, Isobel's idiosyncratic habit or style of expressing herself has assumed an accepted and even valued status because it is functional in the contexts of her daily life.

However, in what follows, an inconsistent, more ambivalent view is revealed, as Mariette suggests that she is less satisfied with Isobel's capabilities in terms of communication than she had been in the past. She asserts:

***M:** I would really have wanted it to be a bit better, but I can understand her well enough. She will say to me: "I am very happy" or that "The shoes fit very nicely" when I bought her new shoes, or "Scooby Do [a cartoon character] did this and that". But I almost want a bit more, but it is definitely better than what it was.*  
(Mariette: Interview 2)

On the one hand, Mariette accords due precedence to Isobel's responsivity as well as her ability to verbally express her emotions and comment on her everyday experiences. On the other hand, however, Mariette's comments reveal unfulfilled hopes and expectations that her daughter should have developed further than she has to date in terms of her expressive language functioning. Perhaps a broader range of expectations with respect to a greater clarity of

expression and the more frequent expression of emotions, for instance, may be inferred here. And, it is also plausible that rather than Isobel simply reporting back, Mariette expects to have a more sophisticated conversational exchange with her. At the same time, however, the gains that Isobel has made with respect to her expressive language functioning are also acknowledged.

Interestingly, when asked to comment further on Isobel's communication while at speech therapy sessions, Sanet appraises her capabilities affirmatively. She offers the following glimpse into what a typical therapy session with Isobel is like:

**S:** *Very good. She is also one that comes in here and tells everyone what this one did and what she...She comes and tells you precisely what happened in the class.* (Sanet: Interview 1)

Here Sanet presents an image of Isobel as an engaging, chatty child who is proficient at interpreting and then spontaneously sharing her everyday experiences with enthusiasm and in detail, an attribute that affords her a certain social appeal, particularly amongst the treatment team. And, given that her relating of the day's events is unprompted, and directed at a group of adults, such tendencies point to a certain assertiveness and underlying self-confidence that sets Isobel apart from her peers. Also implicit in Sanet's comments is the assumption that (despite impairments that affect the domain of expressive and receptive language functions) Isobel is skilled in social cognitive terms in that she is perceptive of and attentive to events in her social environment.

In the extract below, her teacher, Alida, emphasises Isobel's intrapersonal attributes and strengths by commenting that:

**A:** *She [Isobel] is a lot more intrinsically motivated to achieve something or to do something correctly. That it is according to the standard that you ask. It DEFINITELY influences her perseverance because she doesn't like negative*



*comments, feedback. She waits for that praise. If there are challenges, she can communicate: "I can't" or "Help me". She uses the opportunity to ask for your help if she is uncertain, or if she really can't do something. (Alida: Interview 2)*

Alida observes that in comparison to her peers, Isobel does not have to be coaxed into attempting a novel educational task or persevering to complete a task correctly. Indeed, her intrinsic motivation to successfully perform tasks according to their given specifications implies that she sets high standards for herself. And, rather than being indifferent or apathetic, Isobel enthusiastically engages with educational tasks to the best of her abilities. However, apart from being intrinsically motivated, Alida also points, unsurprisingly, to external sources of reinforcement and reward in the form of praise (and not criticism) as a factor that underlies Isobel's performance of educational tasks according to their given specifications and high standards. It is inferred, then, that external validation is as important to Isobel, and serves to boost her self-efficacy beliefs and self-esteem. Clearly, when engaging in educational tasks, both internal and external sources of motivation are at play. A final salient point emerging here is that like Sanet, Alida accords precedence to Isobel's social cognitive strengths. For instance, she reports that Isobel is able to reflect on and make realistic judgments around what she is capable of doing. Further, should she appraise particular tasks as warranting assistance, she is able to communicate this need to others. Here again, Isobel's expressive language skills and assertiveness serve as resources that she utilises in adaptive ways, thereby fostering experiences of success and mastery.

Moreover, in what follows Isobel's distinctive sociality is highlighted as a primary psychosocial strength and resource. For instance, Alida states:

*A: She [Isobel] is also very social. "Why did something happen with her friend?" "Where is the friend today?" And she is very sensitive and attuned [to other children] in terms of emotional aspects (Alida: Interview 2).*

The preceding extract presents an image of Isobel as an affable child with an inquiring mind. Clearly, she lives out her inherent curiosity through her concern for others. And, in comparison to her peers, what is unique about Isobel is that her sociality is not based in self-interest or egotism. Rather, she is perceived to be a child with a high degree of empathy for her fellow classmates.

My observations of Isobel within the therapeutic riding context echoed Alida's sentiments. For instance, while mounted on horseback, Isobel often initiated verbal exchanges with her classmates by calling to them by name, and then commenting animatedly on some or other instance that she deemed worthy of their attention. And, in comparison to the rest of the riders, she chatted confidently and spontaneously with the leaders and side-walkers who were at first unfamiliar to her, indicating that she was not particularly shy of them.

Beyond her distinctive expressions of sociality, I also noticed that Isobel often enquired as to the whereabouts and well-being of classmates who were not present at therapeutic riding sessions. In addition, she tended to check on others who seemed to be anxious and uncertain, for instance, suggesting a genuine empathy for her peers. Such expressions of an altruistic attitude served to set her apart from the rest of the group. As Alida's comments imply, Isobel possesses a particular intuitive sense in terms of being perceptive and attuned to other children's emotional states, a characteristic not easily observed in the majority of her classmates.

It is also relevant that Isobel's experiences of sociality at school mirror the positive relations with other children that are encouraged by her family. For instance, Mariette reported that she takes Isobel with to her brother's sporting activities, where she often plays with other children. And, apart from getting on well, for the most part, with her brother who is older by four years, Isobel also has a cousin of a similar age, Heidi, whom she plays with on a regular basis.

When asked if nowadays Isobel prefers her company to that of her little friends, Mariette commented:

***M:** No, I think her friends are much more fun for her. Because for example our Care group is on Thursday evenings, then she will say “But then I don’t have a friend to play with,” so she LOOKS for a friend and is very inclined that way.*  
(Mariette: Interview 2)

Consistent with Alida’s preceding sentiments, Mariette asserts that Isobel is inclined towards being social, and is at a stage of psychosocial development where she prefers the company of other children with whom she can play to that of adults. Moreover, Isobel’s parents seem to pointedly nurture her existing strong social skills by providing her with ample opportunities for socialising with other children. Thus, in comparison to Rachel and Sarah, whose parents do not allow for or facilitate a rich exposure to relations with other children, Isobel benefits from frequent opportunities for meaningful socialisation that serve as a particular source of enjoyment to her. Drawing on a point made earlier on in the discussion, it is asserted that interactions with other children constitute an important arena for social learning experiences that are critical for Isobel’s broader development.

By living out her inherent sociality in her interactions with other children, Isobel is afforded an opportunity for further developing her psychosocial and cognitively-based strengths and resources. It is also inferred that in terms of her sociality, opportunities for experiences of a sense of mastery lead to the further expansion of skills and resources which in turn reinforces Isobel’s experiences of a sense of accomplishment. And, drawing on Ryff and Singer’s (1998) model, it is argued that her inherent sociality and the positive relations that she fosters with other children (and adults as well) - as evidenced across a range of social contexts, serve as an important psychosocial resource that feeds in to Isobel’s experiences of psychological well-being.

Moving on from a consideration of her communicative (in)competence, the discussion that follows indicates that Isobel's motor impairments also impact on her everyday functioning in disabling ways.

### **De/constructing motor skills and in/capabilities**

Like Rachel and Sarah, Isobel experienced a developmental delay along physical dimensions of functioning in that she started walking just before she was three-years-old. However, it counts as psychologically significant that, due to the shorter duration of her inability for functional mobility, the implications for Isobel's daily functioning, autonomy, independence and broader learning and development were not as chronic or as severe as that of Rachel and Sarah. Still, in looking at each participant as an individual, the discussion that follows shows that Isobel's physical impairments do indeed impact on her everyday functioning in disabling ways. It is argued that the very real consequences of her impairments on physical dimensions of functioning remain at the forefront of Isobel's subjective experiences of disability.

Given Isobel's diagnosis of left hemiplegia, what is striking is the highly noticeable expression of physical difference that she embodies. Indeed, it is almost jarring to the observer that Isobel moves, steps, and walks rather unsteadily with her left foot raised at the toes and teetering balance, while her spastic left hand tends to be raised stiffly in the form of a fist that is held in front of her trunk.<sup>15</sup>

What emerges from the description above is that the way in which Isobel presents herself is psychologically significant. For instance, drawing on Goffman's (1959) thinking, it is argued that Isobel's 'presentation of self' in her everyday life is, by virtue of her noticeably severely impaired physicality, most striking. Indeed, Isobel is often subject to socially-derived negative perceptions

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<sup>15</sup> In the literature such features have been described as typical of spastic cerebral palsy and are referred to in technical terms as arm posturing with an equinus gait and ankle plantar flexion (Goldstein & Harper, 2001; Radtka, Skinner, Dixon & Johanson, 1997).

and evaluations which conceive of her as personifying deficit and deviance. And, because of the aesthetically jarring and unappealing nature of a large part of her physical appearance, a stereotypical response is to assume that Isobel is unintelligent, unskilled with respect to social dynamics, or generally incompetent.

At the same time, what stands out here is that a presentation dominated by her impaired physicality appears incongruous with, and is seemingly exacerbated by, the otherwise perfect (genderised) image that Isobel conforms to in terms of societal norms around what a little girl should look like. In tension with her pronounced, unruly movement patterns and inflexible limbs, is Isobel's highly attractive appearance characterised by fine facial features, shiny long blonde hair that is always prettily styled with an array of fancy hairgrips, and colourful, well-coordinated attire. Furthermore, it is plausible that the presentation of a well-groomed image points to an attempt on the part of her mother to highlight and reinforce Isobel's strengths in terms of physical attributes that are appealing to others, and in so doing gloss over her impaired physicality. Together with her finely-honed social skills (which Rachel and Sarah do not possess on account of their inability to communicate in conventional verbal terms), Isobel's attractive appearance serves as a resource that she perhaps unconsciously utilises to cast doubt on the negative evaluations that others often attach to her upon noticing her awkward and peculiar movements.

Interestingly, after spending some time with Isobel at therapeutic riding sessions, I ceased to notice her spastic hand and distinctive, unruly manner of walking as strange or an oddity. Rather, her highly visible embodiment of physical difference had become assimilated into my existing perceptions of the participants as unique individuals with particular strengths and challenges. Within my own repertoire of understandings, Isobel's talkativeness, outgoing personality, and unadulterated joy in engaging socially with other children continued to stand out as definitive of her personhood.

Still, as the discussion that follows indicates, the challenges that Isobel experiences in her daily life continue to be attached largely to her impaired physicality. For instance, when asked about some of the challenges that Isobel experiences in terms of her daily functioning, her mother observed:

***M:** You know what I've noticed...She is just not agile. Where another 5-year-old already climbs stairs without holding on to a railing, and can jump down from them, she just can't do it. With undressing, she takes time, too. Tying her shoelaces, we haven't even started with trying that yet. Riding a bike is a battle. Perhaps I also don't also give her enough attention to teach her...but she battles with the stepping action of her left leg...I've compared her with other 5-year-olds...Then I would say that at this stage it is actually her balance that isn't good. That is very noticeable.* (Mariette: Interview 2)

Consistent with the literature (e.g., Finnie, 2002; Kerr, McDowell & McDonough, 2007; Stanger & Oresic, 2003), Mariette identifies a number of difficulties that Isobel experiences in performing tasks of adaptive functioning that are symptomatic of left hemiplegia and spastic cerebral palsy. Her poor balance, asymmetric weight bearing, spastic limbs, underdeveloped proprioceptive skills and impaired hand functioning have practical implications including struggling to climb up and down stairs independently, and hindering the process of dressing and undressing. In addition, Isobel is incapable of riding a bicycle because attempts to achieve an upright posture on it, and then follow through with pedalling are limited by the hemiplegic left hand side of her body. Interestingly, while it is also at times appropriate to have a sense of what behaviours are age-appropriate, Mariette systematically utilises typically developing 5-year-olds as a frame of reference. It follows, then, that the challenges that Isobel experiences as a result of her motor impairments are exacerbated and her overall functioning may be very easily evaluated as lacking or deficient. Thus, the preceding extract points to the disadvantages inherent in failing to appraise children with disabilities as individuals in their own right. In failing to utilise individual children's functioning

as the standard against which to assess for shifts and developments or gains along different dimensions of functioning, parents such as Mariette side-step achieving a fuller, more balanced picture of the disabling barriers faced by their children as well as the unique strengths and capabilities that often serve to minimise and *transcend* these challenges.

Echoing the findings of existing work around the experiences of parents with children with disabilities (e.g., Brandon, 2007; Button et al., 2001; Green, 2003; Landsman, 2005; Ryan & Runswick-Cole, 2008), Mariette assumes a degree of self-blame or responsibility for the difficulties in daily functioning that Isobel experiences. Thus, she places a question mark over her whether she is doing enough to stimulate her daughter. In Winnicott's (1958) terms, Mariette's unconscious experiences of guilt around not being responsive enough and a 'good enough mother' to Isobel are pointed to.

Remarkably, when asked to compare Isobel's present functioning with her earlier functioning during the course of the year, Mariette's account altered dramatically, assuming a more positive, strengths-oriented tone. She declared:

***M:** Yes, then there is DEFINITELY an improvement. I mean, at one stage she couldn't climb up and down stairs AT ALL. Now she will do so without holding someone's hand...to hold the railing up and climb up and down...So that has improved. At [her older brother] Johan's judo classes there are stairs. She will hold the railing and climb down, or against the wall, you know...she will always, where she can hold on on her right hand side. So that if the railings are on the right, then she will climb down on her right hand side, or if the wall is on the right hand side. (Mariette: Interview 2)*

When prompted to use Isobel herself as a frame of reference, Mariette expresses sensitivity to the improvements that have taken place in her daughter's functioning. Moreover, she draws attention to the uniquely adaptive, idiosyncratic

ways in which Isobel engages with and masters her environment by negotiating features of the physical environment that pose physical obstacles to her within different settings. The reality is that the left side of her body does not function efficiently, a clinical feature of her diagnosis of spastic left hemiplegia. It is therefore psychologically significant that Isobel makes a concerted effort to manage this critical aspect of her impaired physicality by systematically seeking out instances where she can utilise the well-functioning right hand side of her body to perform such tasks as climbing up or down a flight of stairs.

Indeed, following Budgeon's (2003) thinking, Isobel's efforts are interpreted as representative of attempts to *transcend* the constraints of her hemiplegic body. Isobel interacts with her physical environment in innovative ways that are adaptive for her. In so doing, her experiences of environmental mastery and autonomy, features that Ryff and Singer (1998) conceptualise as key dimensions of psychological well-being, are facilitated. In addition, Isobel's improved functional independence means that to a certain extent Mariette, too, has more freedom to move around physically within the different contexts of her life, given that the responsibility for her daughter has been reduced considerably on this front.

Consistent with Mariette's sentiments, when asked whether she would assess Isobel to be a relatively independent child, Erika, her occupational therapist, asserted:

**E:** Yes, for a hemi<sup>16</sup> [hemiplegic child] she is very independent. I think there her parents play a big role towards trying to get her as independent as possible. (Erika: Interview 1)

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<sup>16</sup> In terms of Foucault's (1977, 1980) understanding, professionals' interventions in the lives of disabled individuals are structured by certain discursive practices. Erika's use of medical jargon such as 'hemi' to refer to Isobel could therefore reflect a medicalised gaze based on her own occupational therapy training which tends to locate deficit and pathology in the body of the individual. As Powell and Biggs (2000) remind us, in Foucauldian terms, the identities of individuals with disabilities have been constructed, both historically and in the present day,



A diagnosis of left hemiplegic cerebral palsy is typically characterised by cognitive and motor impairments that result in a low degree of functional independence (Finnie, 2002; Kerr et al., 2007; Stanger & Oresic, 2003). It is significant, then, that Erika appraises Isobel's functioning to be highly independent relative to other children who share a similar diagnosis. Importantly, Erika also suggests a relationship between the high levels of independence that she observes in Isobel, and her parents' efforts toward facilitating such functional independence. Consequently, her parents are perceived as serving the role of an important resource for fostering psychosocial resilience in Isobel.

In addition to the difficulties in terms of gross motor skills considered in the foregoing discussion, a key physical feature which distinguishes Isobel from Rachel and Sarah is her spastic left hand. It is relevant, then, that impaired hand function has been identified as a major source of disability in children with hemiplegic cerebral palsy (Gordon, Charles & Wolfe, 2006). It follows that during the course of her daily life, Isobel's spastic left hand constitutes the target of much self-conscious awareness, and attention from others. In this regard, Mariette states:

**M:** *Now we...we actually said the wrong thing. We always spoke of the stupid hand, okay? [Laughs a bit as if embarrassed].*

**P:** *Other children's hands have names...*

**M:** *Okay [LAUGHS]. Anyway so erm and then this morning Johan said "Mommy, look at how nicely my sister's stupid hand is opened" you understand? And then she [Isobel] showed it to us, and she went to show to her Dad how opened her hand is, you know. And erm, she also never wants me to hold her hand on the left hand side. I must always take her hand on the right side.*

**P:** *Yes, I know about that as well...*

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through "expert" discourses of "abnormality" and deficit". However, as her proxy reports clearly indicate, Erika defines and engages with Isobel and the rest of the participants in ways that avoid reducing the child to a deficit or diagnosis.

*M: Now, now Erika, at the occupational therapist, also told me to tell her “No, I also want to take the clever hand that worked so hard today”.*

*P: Okay.*

*M: I did this with her, then she’s comfortable and gives you the other hand. So, so, we moved a bit from the stupid hand to the clever hand. But her brother is still on the stupid hand. (Mariette: Interview 1)*

A general point illustrated in this account is that labelling practices arising from prejudiced assumptions around impairment as rendering an individual “lesser” operate not only in the broader society but, problematically, are also at play within the theoretically safe psychological space or haven of the family context. In particular, Mariette reveals rather light-heartedly that in the past their family had referred to Isobel’s spastic left hand as her “*stupid hand*”. Such labelling practices could be interpreted in a number of ways. Firstly, the seemingly insensitive use of such a phrase may be interpreted as descriptive and realistic. In assuming the form of a spastic, tight fist, Isobel’s left hand may be regarded as ‘stupid’ or ‘unintelligent’ to the degree that it is not capable of efficiently performing the fine motor functions typically required of a human hand. Further, the use of such a phrase could also denote a reification of Isobel’s spastic left hand. Rather than being valued as a part of the human body, Isobel’s hand that does not work is accorded the almost inanimate status of a useless object. Thus, it is difficult to minimise or gloss over the fact that the use of the phrase ‘stupid hand’ is attached to meanings around deficit and *disability*, suggesting that an underlying process of devaluing Isobel’s capabilities and personhood is at work.

Secondly, given that her spastic left hand has been branded ‘stupid’ by those closest to her, negative consequences may be inferred in terms of the kinds of ideas about her body and her identity that Isobel could have internalised. In particular, Taleporos and McCabe (2002) have declared that in comparison to the experience of an individual whose difference is milder, the experience of an individual with a highly visible and obtrusive physical difference is likely to have a greater adverse impact on his/her body image. Informed by such a view, it is

posited that, in comparison to the rest of her peers, Isobel is at greater risk of developing a poor body image, given her highly pronounced, unruly movement patterns and spastic, tight-fisted left hand.

Thirdly, adopting a more subtle version of Mannoni's (1973) stance<sup>17</sup> on the pathogenic nature of relationships between parents and their children with disabilities, it could also be argued that Isobel's parents appear to maintain and enhance her experiences of disability through their use of the phrase 'stupid hand'. It is notable, however, that in their accounts, Isobel's teacher and the treatment team have implicitly contradicted any suspicions of malicious intent on the part of her family. Such a view is one that I, too, am inclined to subscribe to.

A fourth salient point arising from the preceding extract is Mariette's admission that the family was at fault in using the phrase 'stupid hand'. An implicit assumption here is that they were not fully aware of the potential negative effects of referring to Isobel's spastic left hand as her 'stupid hand'. Thus, in what is perhaps an attempt to manage any negative impressions that might have been created in the interviewing context, Mariette animatedly describes an instance in which Isobel's hand was "*nicely opened*" as a momentous occasion that warranted the attention and praise of their whole family.

In addition, Mariette reports that the occupational therapist, Erika, drew her attention to the reality that even if the phrase 'stupid hand' is used jokingly and without malicious intent, it remains attached to negative psychological meanings. It would appear that consequences in terms of reinforcing the incapacity that Isobel experiences would have been alluded to. Thus, implicit in Erika's suggestion that the label 'stupid hand' be replaced with the use of the phrase 'clever hand' was the directive that ideally, the family should shift their frame of reference to a strengths and capabilities orientation. This would mean

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<sup>17</sup> Mannoni (1973) holds, in sum, that their parents effectively 'create' and maintain disabled children's disability status

acknowledging and prioritising Isobel's efforts to make use of her left hand in her daily activities.

Based on the feelings of incapacity and deficit that she had internalised on account of her left hand being labelled 'stupid', Isobel tended, in the past, to refrain from offering it to be held on to. In so doing, an unconscious attempt was made to hide her hand, thereby shifting attention from its lack of functionality. Interestingly, then, Mariette asserts that Isobel has responded positively to the reference to her 'clever hand' by offering it to be held on to. This illustrates that implementing the change of label suggested by Erika has had immediate positive effects. Indeed, Isobel appears to have taken on an altered, more validating view of her hand as 'clever', and now perceives her hand as clever enough to offer it to hold on to. However, Mariette also admits that her son continues to use the phrase 'stupid hand', indicating that even within the family context (let alone the broader society), the process of correcting the use of devaluing naming practices is not instantly achieved.

Alida also points out that Mariette has systematically drawn Isobel's attention to the fact that her left hand does not function as well as her right hand, stating:

*A: I think for her it is something conscious. Mariette makes her AWARE that her hand is disabled. She will tell you it doesn't work as well as that [right hand] one. The [left] hand is still learning to grasp, so she is very aware of that her little hand is different to that of a normal friend's hand. But she uses it in a supporting manner, which is fantastic. (Alida: Interview 2)*

Alida reports that Isobel is acutely aware that her spastic left hand constitutes a site of difference that distinguishes her from typically developing or 'normal' children. An implicit assumption here is that, based on the fact that her left hand is spastic and functions poorly, Isobel not only experiences part of herself as *disabled*, but she has also internalised a view of herself as other in relation to

typically developing children. Further, Alida also tactfully describes Isobel's impaired left hand as "*still learning*," thereby presenting a more neutral perspective with respect to the level of dexterity that her hand could possibly attain in the future. Importantly, Isobel's awareness of her embodied difference (that is attached to experiences of devaluation) has not resulted in her disowning or neglecting to utilise her left hand in her daily life.

Such an assessment seems to lend a more positive light to Isobel's family's use of the phrase 'stupid hand'. For instance, their naming practice could also be interpreted as serving a useful function in drawing Isobel's attention to her hand as still a part of her body, albeit a poorly functioning one. In so doing, a tendency to ignore or refrain from using her involved hand - identified in existing bodies of work as a real risk facing children with spastic cerebral palsy - was avoided. Indeed, the literature indicates that in children with spastic cerebral palsy such as Isobel, the dominant hand tends to become so dextrous that the impaired hand is ignored, a condition referred to as 'conditioned disuse' or 'developmental disuse' (Gordon et al., 2006; Lin, 2003).

Thus, when asked if the use of their hemiplegic hands in a supporting manner is characteristic of all children with hemiplegic cerebral palsy, Alida declared:

*A: No, all hemi's [hemiplegic individuals] don't use the hand in a supporting manner - They must have been at least two little girls in the class already, who ignored their hands. We encourage [them to use their hands]. Sometimes it helps. Sometimes it doesn't.* (Alida, personal communication, August 24<sup>th</sup> 2008).

Clearly, Alida appraises Isobel's tendency to use her left hand to support the actions of her right hand as a highly positive attribute that is atypical of children with hemiplegia in general, and therefore distinguishes her from them. Such an appraisal is consistent with the work of Gordon and colleagues (2006) who propose that better use of the involved extremity as an assist (e.g., stabilising an

object while the non-involved hand manipulates it) would increase an individual's performance of daily living tasks and activities, thereby impacting positively on his/her quality of life. However, Alida observes that learners' use of their hemiplegic hands in a supporting manner is random as opposed to contingent on a process of external reinforcement. Thus, it is concluded that Isobel is particularly fortunate in terms of the degree of functionality that she has achieved with respect to the motor control and use of her spastic, hemiplegic left hand.

Consistent with such sentiments, Isobel's occupational therapist offers the following insights with respect to her hemiplegic hand. Erika comments:

***E:** We do a lot of fine motor coordination, but she [Isobel] is restricted by her disability. Because her hemi [hemiplegic] hand...It opens up nicely and it can be used for supporting.*

***P:** She's actually using it nicely in a supporting manner?*

***E:** She is VERY AWARE of it. She is not a hemi that ignores it. She is very aware of it and to put it down, but as soon as you expect a fine motor activity from her, then the little hand comes in [raised close to her body]. Then the muscle tone rises. Then she realises it immediately, and then she places it back on the table again...That is a cognitive process that she knows she, she must...She must use it. She can't just leave it. (Erika: Interview 1)*

Erika declares that while occupational therapy efforts are usually directed at the facilitation and rehearsal of fine motor coordination, Isobel's participation in therapeutic activities is constrained by her spastic left hand. At the same time, like Alida, Erika acknowledges it to be significant that Isobel makes an effort to keep her hand opened (that is, not closed tightly in a fist), and use it to support the actions that her right hand performs. Thus, her being attuned to the workings of her spastic hemiplegic hand is emphasised in a positive light.

Moreover, Erika also suggests that for Isobel, a cognitive process of monitoring is at work. In particular, she has learnt to monitor the reaction of her left hand to fine motor activities. This means that Isobel is capable of perceiving and responding to the heightened muscle tone that she experiences by exercising a degree of control over the motor functioning of her hemiplegic left hand. Implicit in Erika's account is the premise that Isobel's capability for using her impaired left hand to support the actions that her right hand engages in constitutes a strength and resource for coping with her impaired physicality. Also, in keeping with work by Stanger and Oresic (2003), and Kerr and colleagues (2007), for instance, it is argued that such adaptive capabilities hold significance for Isobel's functional independence and development more broadly.

Interestingly, when compared to Mariette's earlier sentiments, her comments below appear to take on more of a validating, strengths-oriented perspective in relation to Isobel's now 'clever' left hand. She asserted:

***M:** To me her little hand has improved a lot. She opens it. We were at the nursery today. She climbed on the ladder and she rode on the car and she concentrated nicely to keep the thumb open and to hold on nicely. That I can see clearly, her hand is really a lot better. (Mariette: Interview 2)*

Mariette's comments also point to Isobel having better control over the motor functioning of her left hand, and consequently being more successful at fine motor activities. At the same time, it needs to be taken into account that the recreationally-oriented physical activities that Isobel had engaged in, namely, climbing up a ladder and driving a toy car, also warranted the use of gross motor skills and motor coordination. Thus, the cited example points to improvements on gross motor levels of Isobel's functioning as well.

### **Appraisal of participation in therapeutic horse riding**

In view of the improvements in Isobel's functioning that were observed by her mother during recreationally-oriented physical activities, I was keen to hear how Isobel's participation in therapeutic riding sessions would be appraised. Mariette stated:

*M: I don't know. We don't really talk about horse riding. On Tuesdays I ask her whether they are going to ride, and whether we should fasten her pony tail low as you are going to ride and so forth. And I will ask her in the afternoon if they have ridden, and she will say yes, she rode Pilgrim or something like that. But she doesn't really talk a lot with me about it. I don't mind. I just want her to participate, do you understand? And I feel this is HER sport that she can do now...Because there isn't really another sport that she can do...I really want her to be active. I will encourage it as far as I can, even if it's not so important to her at this stage...It's important to me. I can't say it does positive things or negative things...That's difficult for me to determine, but she hasn't ever said to me that she doesn't want to ride. (Mariette: Interview 2)*

Mariette reports that while Isobel does not talk at length with her about therapeutic riding, her participation therein is systematically mentioned in their conversations on Tuesdays. Still, Mariette's insistence on Isobel being active, and her assertion that she will encourage therapeutic riding as far as she can (even though it might not be something that her young daughter considers critical at this particular point in time), is striking. Such a stance points to the *personal importance* that Isobel's participation in therapeutic horse riding has come to assume for Mariette. In particular, she constructs meaning around the value of this form of intervention for her child in terms of the necessity of being physically active. Through her perception of therapeutic riding as constituting a sport that taps in to this need that she has identified as warranting attention and importantly, intervention, Mariette accords it due value. Moreover, she goes so far as to raise the status of this form of intervention considerably by engaging in a



narrative privileging of therapeutic riding as the *only* sporting activity that is suitable for and available to her daughter to participate in. As reflected earlier on in the analysis with respect to Sarah, for example, Mariette's view is consistent with existing bodies of work that conceptualise therapeutic riding as constituting a suitable sporting activity that promotes optimal motor and psychosocial experiences in individuals with disabilities.

The literature indicates that while distinct from riding for the disabled as a sport in that its end goal is not competitive riding per se, therapeutic riding provides individuals with disabilities the opportunity to participate in an activity that the rider perceives to be a sport (Grobler, 2004; Scott, 2005). In so doing, the individual is afforded an opportunity to exert control over his/her environment, as well as to master new skills (Graham, 2000; Hammer et al., 2005; MacKinnon, Noh, Lariviere, MacPhail, Allan & Laliberte, 1995). However, the reality is that within the South African context, horse riding constitutes a single example within the limited repertoire of sporting opportunities available and easily accessible to individuals with disabilities in general and the participants with cerebral palsy in particular (Tredoux, 2000).

A final point of interest arising from the preceding extract concerns Mariette's comments with respect to the evaluation of the efficacy of Isobel's participation in therapeutic horse riding. Echoing the sentiments expressed by Erika, the occupational therapist, for instance, Mariette declares *"I can't say it does positive things or negative things...That's difficult for me to determine"*. Thus, she acknowledges the reality that it is difficult to determine the therapeutic effects of this form of intervention. And, as stated earlier, in view of the idiosyncratic, heterogeneous nature of impairments, as well as the numerous, contingent developmental, interpersonal and situational factors at play, considerable difficulties in making conclusive evaluations around the efficacy of interventions in general, and therapeutic horse riding in particular, prevail. At the same time by stating, *"but she hasn't ever said to me that she doesn't want to ride,"* Mariette

asserts that Isobel's participation in therapeutic riding is of her own free will, rather than an activity that she had selected and subsequently imposed upon her daughter.

In addition, Alida appraised Isobel's functioning within the therapeutic riding context as follows:

*A: Yes, she was almost as excited as Joanne and she just improved so beautifully in terms of her self-confidence on the horse and how she enjoyed it to actually ride and it was never necessary to convince her [to ride] it was absolutely a spontaneous love that she had for riding. She also developed beautifully in that regard, especially because she is a cerebral palsied child, it really helped with her spasticity. (Alida: Interview 2)*

Here, Alida, who had been present at therapeutic riding sessions, prioritises Isobel's experiences of enjoyment. Thus Fredrickson's (2001) ideas around the salutary effects of experiences of positive emotion are applicable here. Moreover, referring to such positive emotional experiences, Alida also draws attention to an important feature raised earlier on in the discussion and well-represented in extant research, namely the recreational value of this form of intervention. Here, too, it is argued that, for the participants with disabilities such as Isobel, opportunities for positive psychological experiences of enjoyment and relaxation are meaningful and go some way toward fostering the rider's psychological well-being. Another point that Alida raises here in relation to the value of therapeutic riding concerns the reduction of high muscle tone in children with spastic cerebral palsy such as Isobel. Her comments are consistent with the findings of existing research (e.g., Benda et al., 2003; Hammer et al., 2005; Miller & Alston, 2004) that identifies the reduction of muscle tone as a significant effect of this form of intervention. However, I had noticed that while Isobel's spastic muscles tended to relax noticeably within strides of entering the therapeutic

riding arena, but they promptly returned to their spastic state some time after she had dismounted her horse.

In sum, based on her ability to communicate verbally with relative ease, 5-year-old Isobel's impairments with respect to such expressive language functions have been appraised as working in complex and subtle ways. Moreover, in addition to being capable of verbal communication, Isobel's outgoing personality and strong social skills have meant that she has been successful in integrating herself into her group of peers. And, while gross motor and fine motor impairments associated with a diagnosis of spastic hemiplegic cerebral palsy serve as disabling barriers to Isobel's everyday functioning and independence, what is more remarkable is that she makes concerted use of the motor skills and capabilities that she does have to transcend the limitations associated with her impaired physicality. Such features serve to minimise her experiences of disability. In addition, therapeutic horse riding's sporting and recreational appeal was emphasised. Also, the psychomotor activities that therapeutic riding sessions were directed at and defined by were foregrounded by the opportunities that it provided for living out her inherent sociality, a key psychosocial resource for Isobel.

#### **4.5. Natalie**

##### **Biographical note**

Like Isobel, 4-year-old Natalie has also been diagnosed with spastic cerebral palsy that is characterised by limb muscles that tighten abnormally resulting in movement that is stiff and jerky (Best, n.d.; Matejovsky & Hoon, 2007; Rosenbaum, 2003; Siebes, Wijnroks & Vermeer, 2002). However, in terms of the parts of her body that are involved, Natalie's diagnosis is specifically one of spastic diplegia, entailing the motor impairment of her legs, with some definite though relatively limited involvement of her arms (Best, n.d.; Finnie, 2002; Rosenbaum, 2003). Thus, her motor functioning includes impairments on both gross motor and fine motor dimensions. Furthermore, in addition to a trunk with low muscle tone (otherwise referred to as 'floppy'), Natalie has asymmetric weight bearing and poor balance. And, like Rachel, she, too, is unable to achieve and maintain an upright standing position, or walk independently. However, a key feature that distinguishes Natalie from the rest of the participants discussed thus far is her use of a wheelchair for the purposes of ambulation. Remarkably, though, she does not rely exclusively on this assistive device to physically get to where she would like to be. It also counts in her favour that relative to her group of peers, Natalie has strong expressive and receptive language skills. In addition, she is chatty, and enjoys the company of adults and children alike.

Natalie's working class family lives within an extended family system on a small holding in a semi-rural area located 30kms to the west of the city. She has a younger sister by three years, Magda, and an infant brother, Adam. Their mother stays home to care for the children, while their father, the sole breadwinner, is a plumber who is consistently seeking employment on a contract basis. This means that the family's income is inconsistent, and they struggle financially.

##### **Re/negotiating communicative in/competence**

In comparison to the participants discussed thus far, Natalie shows greater competence in terms of her expressive and receptive language skills and

communicative capabilities. For instance, while Rachel and Sarah are incapable of communication in conventional verbal terms, and Isobel's affected speech and language functioning seems associated with her severe motor impairments, Natalie's everyday functioning is relatively unhindered by expressive and receptive language difficulties.

In this regard, Sanet, her speech therapist, contends:

*S: In terms of her language she is absolutely above her age level. So she really has improved a lot. So I just feel that if she was here, then it would very different.*  
(Sanet: Interview 1)

Here Sanet appraises 4-year-old Natalie's language skills as having improved to such an extent that they exceed the level of functioning of a typically developing child of her age. At the same time, Sanet maintains that Natalie's limited exposure to speech therapy implies fewer opportunities for rehearsing and facilitating the further development of her expressive and receptive language skills within a professional therapeutic setting. Moreover, in accounting for Natalie's poor attendance, implicit reference is made to her parents' inability to afford the transportation costs attached to sending her to school due to their serious financial difficulties. Thus, Sanet points to socio-economic factors as ultimately preventing Natalie from achieving the potential that she is capable of. Stated differently, Sanet suggests that a disadvantaged socio-economic status serves to hinder Natalie's attainment of optimal levels of functioning. Such a position echoes the work of Maart and colleagues (2007) who concluded that within the South African context, socio-economic factors operate as a disabling barrier to the everyday functioning and development of vast numbers of individuals with disabilities. Also, given that Natalie's working-class family lives on a smallholding located in a semi-rural area outside the city, Maart et al's (2007) contention that the unique challenges that individuals with disabilities

experience may be accounted for in terms of an urban/rural divide with respect to access to resources is also applicable here.

Further, Sanet outlines the goals of speech therapy with respect to Natalie as follows:

**S:** *Even if her [Natalie's] language is above her age level, next year I am going to work with her with, to almost maintain her language. And more specifically to work on her listening skills and auditory perception, because she still has a problem with that...And also carrying out instructions. Sometimes she will also just carry out half of the instruction. (Sanet: Interview 1)*

In the extract above, Sanet contends that the goals of Natalie's speech therapy are two-fold. On the one hand, the maintenance of current levels of expressive and receptive language functioning is identified as significant. On the other hand, however, Natalie's skills with respect to auditory perception - associated with carrying out complex instructions - are singled out as inherently problematic. A tendency to carry out only the first half of a complex instruction means that Natalie misses out on important social learning experiences within the therapy room and, by implication, across broader educational and social settings.

On a more affirming note, Alida declares:

**A:** *I think she [Natalie] really speaks very well. She has a good language structure. To me she is actually very strong in terms of auditory skills. To me it [her vocabulary] is actually relatively broad, and she can...what she sees on television, because it seems to me like she watches often... she can actually try to explain, and you can then understand what she is busy telling you. You can hold a conversation with her. (Alida: Interview 1)*

Alida identifies Natalie's expressive language skills as particularly well developed. And, in contradiction to Sanet's assessment, she appraises Natalie's auditory perceptual skills to be strong. However, the example cited (namely, Natalie offering a detailed explanation of the specifics of a television programme that she watched) also indicates a distinct reliance on visual acuties. Thus, it would appear that across contexts, Natalie's auditory perceptual capabilities are expressed in inconsistent ways.

However, what stands out most in Alida's account is her appraisal of Natalie as a fitting *conversational partner*. Complementing her strong capabilities with respect to verbal communication, Natalie is sufficiently socially skilled such that adults like Alida find an *interactional exchange* with her to be enjoyable and stimulating. This particular attribute of communicative capabilities that are not simply *competent*, but also *highly sophisticated*, serves to distinguish Natalie from her group of peers. For instance, while a conversation with Isobel might assume more of a question and answer format, Natalie is able to initiate a conversation with an adult and engage in and elaborate on aspects of a conversation in a way that entails much more than the simple sharing of information. Thus, the level of sophistication that she displays in communicative exchanges reaches far beyond the level of a typical 4-year-old. Moreover, Natalie is able to live out her sociality and zest for life with greater ease as her capability for communicative reciprocity facilitates positive interactional experiences. Thus, following Ryff and Singer's (1998) model, positive relations with other people constitutes a key dimension of Natalie's experiences psychological well-being.

Natalie's relations with her peers are described by Alida as follows:

**A:** *For me there is... more because the ones who are disabled play on the same level, like she and John... They are both on the ground while they play, therefore it is easier for them to interact with each other. But still I have to say that the little*

*girls in my class have started developing in the doll house<sup>18</sup>, that they will ask each other questions, or get more involved with each other in playing. And to me she [Natalie] is...it as if she has good relationships with everyone. And especially in the doll house, she has started to play more with the little friends, especially the other little girls. (Alida: Interview 1)*

A general point that emerges as significant in Alida's account is the reasoning that participants' capabilities for independent mobility influence their social interactions and relationships with each other in significant ways. This opinion serves as direct support for a fundamental theme within this study, namely that notwithstanding a heterogeneity of impairments, a hierarchy of mobility that informs and orders the participants' psychosocial interactions operates within the group.

In more specific terms, Alida observes, on the one hand, that Natalie's lack of ability with respect to independent ambulation serves to promote her affiliations with certain children in the group more than with others. For example, as neither she nor John (who also uses a wheelchair for ambulation purposes) are capable of standing in an upright position or walking independently, they usually find themselves occupying the same physical space at ground level. Consequently, they tend to engage with each other in social play activities more out of convenience rather than preference. In addition, being restricted (on account of their impaired physicalities) to social interactions at ground level also denotes their occupation of a recreational space that is not only lower, but also holds an implicitly 'lesser' status. Thus, Natalie's experiences of her physical and social worlds may be interpreted as inherently limited.

On the other hand, however, Alida declares that Natalie's sociality is not only limited to mutually exclusive relations with those peers whose profound motor

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<sup>18</sup> Located at the far end of their classroom, the doll house corner serves as a site that prompts and facilitates participation in gendered play activities within a group context. It has dolls, teddy bears, prams, kitchen items etc.



impairments also necessitate the utilisation of a wheelchair. Rather, on a regular basis, she interacts socially with other classmates, and the girls within the group in particular, especially during their play activities in the dolls' house. In terms of the value of such interactions, Fredrickson (2003, 2006) has indicated that the camaraderie that often occurs during play creates new bonds and strengthens existing social bonds, friendships and attachments that could serve as a significant source of support at some time in the future. Indeed, she boldly asserts that play affords a pathway to the development of resilience and optimism as well as the development of a sense of identity and goal orientation (Fredrickson, 2003).

Overall, in the preceding extract, Natalie is appraised as an individual who gets on well with all her classmates. In effect, Alida's account places her in a privileged social position - she is able to draw on and benefit from (the opportunity for) social relations with a range of unique individuals within the group of her peers. It is inferred, then, that Natalie's wealth of interpersonal resources has positive implications for her experiences of psychological well-being. Moreover, it seems plausible that other individuals could find relating with Natalie to be meaningful psychosocial experiences. In other words, Natalie is also capable of serving as an interpersonal resource for her peers.

### **De/constructing motor skills and in/capabilities**

While taking into account Natalie's capabilities with respect to communicating with others, it is also useful to consider the challenges that she experiences as a consequence of her motor impairments. In this regard, her teacher, Alida, commented:

*A: The only way that she [Natalie] can move herself forward is to almost bunny hop, and she must also be taught to cross with her alternating feet, and not to bunny hop. So even her manner of moving is to crawl at this stage. It places her in a position of being able to participate on a lot fewer gross motor apparatuses.*

*Then, what is positive for me is that she will still move and she can get herself to a place where she wants to be...And then there is, another thing with her is she tries to be independent. Especially to help herself up onto her wheelchair independently. They are teaching her that at occupational therapy. She really tries. I think she does want to be independent as far as possible. (Alida: Interview 1)*

Alida reveals that while Natalie generally uses a wheelchair to assist her to move around from one point to another within her environment, she is not completely immobile without it. Rather, she is capable of propelling herself forward by crawling on her hands and knees or bunny hopping. In so doing, Natalie actively *transcends* the disabling effects that her severely impaired physicality has on her day-to-day functioning. Clearly, such efforts are qualitatively different from Isobel's adaptive utilisation of the uninvolved right hand side of her body to interact with her physical environment. In particular, as Natalie's inability to achieve and maintain an upright standing position and use of a wheelchair for the purposes of ambulation indicates, her motor impairments are appraised to be of a more severe nature. Consequently, it is argued here that Natalie's efforts at crawling and bunny hopping have a more profound *transformative impact* on her body, as well as on her daily functioning and sense of self.

Interestingly, Alida adopts a strengths-oriented view, framing Natalie's particular adaptive mode of mobility in terms of an understanding that developmentally she still has to learn, and therefore needs to be taught, the precise motor patterns and coordination that walking entails. Implicit in Alida's stance is the rather optimistic prognostic assumption that the achievement of independent mobility is not completely beyond the realm of Natalie's capabilities.

Furthermore, a critical feature that sets Natalie apart from her group of peers is that she is highly motivated to function independently. Remarkably, she translates this intrinsic motivation into interacting with her physical environment in

idiosyncratic, agentic ways. Thus, while generally poor motor control and an inability to achieve an automatic righting posture means that she is not capable of walking, Natalie still determinedly gets herself to where she wants to be. Based on the foregoing account, then, it is argued that Natalie's intrinsic motivation and perseverance constitute psychosocial resources that are instrumental in driving her efforts at unassisted, independent mobility. Positive implications in relation to her experiences of autonomy, regarded by Ryff and Singer (1998) as a key dimension of psychological well-being, are also inferred here. Through such influences as her intrinsic motivation, tendency to act autonomously, and perseverance, then, the challenges that Natalie faces on account of her profoundly impaired physicality are effectively minimised.

In the preceding extract, Alida presented an ambivalent view of bunny hopping as a mode of mobility that is discouraged, yet also still positively viewed as a resource for Natalie. Interestingly, when asked whether she continues to bunny hop, her mother, Carien, asserted:

**C:** *Yes. When she does so, she says she is running.* (Carien: Interview 2)

Here, Carien's comment points to Natalie's assertion that bunny hopping represents her personalised, distinctive mode of moving fast. In other words, to Natalie, bunny hopping *is* running. This holds psychological significance in that Natalie's "running" represents her own active, idiosyncratic efforts at *transcending* the limitations imposed by her severely impaired physicality. Remarkably, rather than passively remaining in her wheelchair, Natalie gets herself out of it and independently moves around her environment by bunny hopping with what I had observed to be a remarkable degree of speed and agility. Indeed, Natalie's capability for her own mode of running is a unique strength and resource that she is proud of, and that serves as a boost to her self-esteem.

In addition, with regard to Natalie's fine motor functioning, her occupational therapist places particular emphasis on the challenges that she faces. Sumari declares:

**S:** *It is actually poor. Especially, she is sometimes shaky if she has to do things...As soon as you really present her with actual demands, then it [the spasticity] starts getting worse. She battles with the fine motor control. I think at this stage it is actually her BIGGEST problem. (Sumari: Interview 2)*

Here Sumari observes, as she had with Isobel, that when demands to make use of her existing fine motor capabilities are placed on Natalie, the stiffness muscle tone of her arms and hands is exacerbated. Based on her professional authority as an occupational therapist then, Sumari prioritises such spasticity and the resulting difficulties experienced with fine motor control as a highly debilitating barrier to Natalie's performance of, and participation in, daily tasks and activities.

Further, when asked to comment on what her daughter battles with, given her diagnosis of spastic diplegia, Carien, stated:

**C:** *She [Natalie] really wants to...If we have finished eating she wants to take the plates to the kitchen...to the kitchen, or the cups or the tumblers. But she cannot, because if she crawls then she smashes them if she places her hand in front and then the glass breaks, so she cannot take it to the kitchen. But she takes plastic things to the kitchen. Um, then, I think it's a bit difficult for her to see her cousins and sister and everyone running around and playing outside, and being able to do everything themselves, and she cannot...Because at a stage she asked if her sister can walk, is it still her sister...Then I said "Yes, it's still your sister". Then she said...erm...if she cannot walk, am I still going to love her?*

**P:** *So she actually thinks about that?*

**C:** *Yes...she does, A LOT. I think it's just a bit heavy for her. (Carien: Interview 1)*

A number of interesting points emerge here. To begin with, Carien indicates that Natalie is highly enthusiastic about participating in domestic activities such as clearing the dining table after meals. However, because Natalie usually crawls on her hands and knees, performing such tasks places her at risk for injury. It is remarkable, then, that Carien recognises Natalie's need to assist her in this particular domestic task as *valid*. Consequently, she has made a concerted effort to facilitate Natalie's participation in clearing the dining table by replacing items of crockery that are made of glass with unbreakable plastic items. Thus, by virtue of her mother's initiative, Natalie is empowered to utilise the capabilities that she does have in effective ways. In this manner, she is included in, and feels that she contributes to, a seemingly mundane domestic task that is meaningful for her. Further, heightened self-efficacy beliefs and experiences of autonomy are inferred here. In addition, making do with the motor skills that she does have to master the task of clearing the dining table points to positive implications for Natalie's experiences of a sense of mastery. Drawing on Ryff and Singer's (1998) model, it is argued that such positive experiences within the context of her home feed in to Natalie's experiences of psychological well-being.

In addition, Carien also reveals that Natalie pointedly reflects on and struggles to make sense of her disabled status. While her cousins and siblings are undeniably a valued source of social interaction and play, none of them are similarly disabled. Natalie therefore experiences herself as marginalised to a certain extent, and seems to occupy a position of an other in her everyday interactions with them. Indeed, she is consistently aware of and self-conscious about the negative form of difference and lack of ability that her impaired body and use of a wheelchair signifies. Such concerns appear to be based on Natalie's observations of and awareness that her siblings and cousins interact more easily and with greater agility in the physical spaces that she, too, shares. For them, moving between bodily postures or positions and physical spaces while playing is not really subject to constraints imposed by their physicalities. Thus, notwithstanding her use of a wheelchair, as well as her adaptive mode of

mobility in the form of crawling or bunny hopping, Natalie still finds her limited participation difficult to accept, and emotionally heavy. Further, negative implications for her experiences of self-acceptance, a key dimension of Ryff and Singer's (1998) model of psychological well-being, are inferred.

Indeed, Natalie contemplates and explicitly questions the basis upon which individuals qualify to be members of the same family. In calling into play issues of identity, she seems to experience self-doubt with regard to her own humanity and ontological worth. In particular, Natalie she has noticed that Magda, her younger sister by three years, has achieved the developmental milestone of independent ambulation, while she continues to crawl, bunny hop, and utilise a wheelchair instead. Thus, Natalie is self-conscious about and troubled by the reality that Magda and other typically developing children of a similar age can walk independently, while she cannot. Perhaps partly on account of the stigmatised image of individuals who utilise wheelchairs as signifying deviance, deficiency and incapability, the message which Natalie seems to have internalised is that she is devalued and that she occupies a lesser status in relation to her able-bodied sister and society at large.

It is also striking that Natalie's competence in verbally communicating her thoughts, feelings and experiences serves as a resource that she uses to seek clarification on and make sense of the otherness that she feels on account of her impairments. Natalie pointedly verbalises her own fragile self-perceptions and faltering self-acceptance to her mother. It is plausible that such self-doubt is attached to deficit-oriented socially derived ideas that she has internalised around being disabled and therefore unlovable. In wondering out loud whether Carien shares such a view, Natalie seems to be seeking affirmation and validation that her mother's love for her is unconditional, and untainted by her particular embodied form of difference or *disability*. And, while Carien does not say so explicitly, it is inferred that in response, Natalie received the necessary reassurance and validation of herself as valued in her own right, and as a

member of their family. Thus, Carien seems to have fulfilled that aspect of her role as a parent that warrants assisting Natalie towards self-acceptance and fostering a healthy sense of self-esteem.

However, I suspected that despite such assurances, Natalie continued to be plagued by feelings of being other and less valued in relation to typically developing children (including her younger siblings). Alida's comments below reflect similar sentiments. She asserted:

*A: I think she [Natalie] is unfortunate in terms of her self-image. I think sometimes it is not nice for her to be a child who uses a wheelchair. Especially because she can move nicely. She can carry [her] weight on her arms and she can bunny hop to a place, but I think, though, that she is actually one of the children who almost would have preferred not to have been disabled. (Alida: Interview 2)*

Alida clearly assesses Natalie's self image as poor, and inherently tied to her use of a wheelchair on account of her impaired physicality. The negative meanings that Natalie attaches to her use of a wheelchair may be interpreted against an appreciation that this particular assistive device constitutes a universally recognised symbol of disability and deviance. Thus, to the observer, the stigmatised form of difference that Natalie embodies is immediately striking and easily identifiable. And, when she is seated in her wheelchair, Natalie is vulnerable to value-laden social meanings around *having* and *being* a body that is less capable and deficient. It is inferred, then, that in utilising a wheelchair, Natalie appears to be self-conscious about, and somewhat embarrassed by, the stereotypical image of being incapable and therefore 'lesser' that she portrays.

Furthermore, in social interactions with Natalie, others necessarily have to gaze down at her, while she is compelled to look up at them from a lowered, seemingly passive vantage point. Occupying a lowered position relative to the rest of her

physical and social environment may be interpreted as contributing to Natalie's experiences of a sense of disempowerment. In practical terms, too, it is inferred that Natalie struggles with limited interaction with her environment as she cannot join in the activities that her playmates participate in with a comparable degree of competence, agility and confidence.

However, here Natalie's idiosyncratic efforts to move from one place to another are raised as pointing to a distinctive strength – She makes use of the bodily capabilities that she does have to *transcend* the limiting effects of her physical impairments in active, adaptive ways. Still, while implying that such attributes count as impressive, Alida points out that Natalie utilises her capabilities for cognitive reflection - resource that sets her apart from the participants discussed thus far - towards recognising the possibilities inherent in being able-bodied. And, in realising that she is effectively missing out on a range of positive experiences as a result of her impairments, Natalie is obviously distressed. As Alida suggests, Natalie would have preferred to have discarded her disability status and instead lived out her motor capabilities in more interactive and fulfilling ways. She experiences not being in a position to do so as emotionally painful, and damaging to her self-esteem and sense of self.

Moreover, when I asked Alida to comment specifically on Carien's observation that Natalie compares herself a lot with her younger sister and is very aware of her limitations, she declared:

*A: I think it is normal when a child starts to realise. Like Isobel as well, has realised...And how her mother then explained to her is the truth. Her little hand cannot open as much as her sister's hand, ag, I mean her brother's hand. So she [Natalie] realises her limitations, and her mother tells her that she is not a child who can walk. Her little legs are not strong enough. So I think she has started becoming aware of that for the first time now when her sister started to walk. So I think it, for them it makes a disabled class a nice environment to be in and to live*



*because now they realise as well, there are other children with other disabilities as well. But in the class itself she [Natalie] is, in spite of her disability, she lives her life, and she functions and she plays, and she is active...So I think if they come to a school for children with disabilities where there are also other playmates with other disabilities, it makes it for them, that they feel more accepting of themselves. (Alida: Interview 1)*

Alida's account raises a few significant points. Firstly, she describes the process of Natalie developing a sense of awareness of her own difference and then reflecting on that difference as nothing out of the ordinary for children with disabilities who have reached a certain level of cognitive capability. In Natalie's case, such reflexive processes were influenced by her observation that her younger sister had already reached the developmental milestone of independent mobility. Thus, Alida appraises mothers like Carien (and Isobel's mother, Mariette) as having done what is best for their children (given the reality of their severe and chronic impairments), by explaining to them that they are disabled. As participants such as Natalie struggle to make sense of the severe effects of their impairments on a day-to-day basis, such painful confirmations of their irreversible disability statuses seem to be unavoidable and inevitable.

Secondly, Alida regards it as useful that children make sense of and embrace being disabled as a significant but not all-consuming aspect of their identities. Further, she submits that the practice of inclusive education - described by Soudien and Baxen as "essentially recognising and respecting the differences among learners and building on their similarities" (2006, p.152) - facilitates such a goal. Indeed, Alida suggests that in attending a school geared exclusively towards individuals with severe physical and cognitive impairments, participants such as Natalie are exposed to and can forge a sense of group membership and shared identity with others who are similar by virtue of their impairments. As she contends, interacting and affiliating with other children with disabilities on a consistent basis could serve to gloss over feelings of difference and deficit in

relation to societal norms<sup>19</sup>. Positive self-perceptions and an increase in self-acceptance could be fostered as well. Thus, for children with disabilities, interactions with and support from their disabled peers serve as critical psychosocial resources. Also implicit in Alida's account is an understanding that when functioning in the context of individuals who are similar in that they are disabled, participants are afforded an opportunity to look beyond the challenges that they experience on account of their impairments. Instead, they are able to express themselves as children first and foremost, thus allowing for other important aspects of their identities to come to the fore, and be lived out and nurtured.

Thirdly, Alida reaffirms that Natalie *transcends* the limitations of her impaired body by being active and well integrated into her group of peers. And, it is not only her motivation and zest for life that distinguishes Natalie from the rest of her group of peers. Rather, by translating these particular attributes into interacting with her physical and social environments in autonomous, meaningful ways, she also achieves a remarkable degree of functionality. It is suggested, then, that such features may be interpreted as evidence of her efforts at transformational coping (Aldwin, 1994). Moreover, these strengths serve to foster Natalie's experiences of psychological well-being, as well as contribute to her capacity for psychosocial resilience.

### **Appraisal of participation in therapeutic horse riding**

Given the profound nature of her motor impairments, I was keen to discover how Natalie's participation in psychomotorically-oriented therapeutic riding sessions would be appraised.

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<sup>19</sup> Notably, Alida's appraisal is in tension with sentiments expressed within the special education literature (for instance, Brodin & Lindstand, 2007; Kliwer & Raschke, 2002) which caution that individuals with disabilities who are segregated from non-disabled learners suffer from feelings of inadequacy and are deprived of opportunities for social experiences that stimulate further development.

Her mother, Carien, highlighted the following gains as attributable to horse riding in particular:

*C: Erm I have seen that nowadays she has that way of, that you, if you stand like so on your knees, then she always stood like so [Demonstrates]...what she does nowadays...she stands and then she lets go and then she falls forward. She has now got it right to stand [in an upright position] for longer on her knees like so [standing on knees with an imaginary side plate in her hand]...than what she could do. Yes...from the time that she has been there [at therapeutic riding]... if she is there then she has to stand like this [Demonstrates]. (Carien: Interview 1)*

Implicit in Carien's account is the premise that Natalie's poor postural control and underdeveloped righting responses are influenced by her participation in therapeutic horse riding in positive ways. Carien suggests that by impacting on her postural control responses, Natalie's experience of the modality of horse riding has meant steadier balance. In turn, this has allowed her the functional benefit of being able to adaptively "stand" on her knees in an upright position more comfortably and for a longer time-frame than was previously possible.

Importantly, Natalie's new steadier balance has been instrumental in affording her new opportunities to engage in the domestic activities that she enjoys such as helping with clearing the dining table. In contrast to her previous tendency to break plates while crawling on her hands and knees, nowadays Natalie is able to execute this action with greater ease and confidence by "walking" on her knees. In this way, she is able to carry items of crockery from the dining table to the kitchen without breaking them or hurting herself. Moreover, such competencies illustrate Casady and Nichols-Larsen's (2004) point that "any motor skill or active postural control achieved while on the horse has the potential to influence functional tasks off the horse" (p.166). Clearly, Natalie experiences her body as reliable and capable of relating with her environment in concrete, successful ways. Conceptualised by Ryff and Singer (1998) as a core dimension of

psychological well-being, experiences of environmental mastery are interpreted as impacting positively on Natalie's self-esteem in particular.

Echoing her preceding sentiments Carien declares:

*C: I think actually if she stands on her knees, she can already stand up straight for a short time [C : Show the Aunty quickly. P: Wow, that's really good, Natalie. And for so long.]. And I can see with the walking frame as well that she uses that she now walks with it more that you can see it [horse riding] helped alot. (Carien: Interview 1)*

At one level, Carien reinforces Natalie's capability for standing on her knees for longer periods of time as a newfound strength and resource. Indeed, when Natalie keenly demonstrated this idiosyncratic form of motor skill to me during a visit to her home, it was obvious that "standing" on her knees is a capability that she is very proud of. Indeed, she takes pleasure in showing off this particular skill to others. Importantly, such demonstrations are generally met with affirming responses that serve to reinforce Natalie's sense of achievement.

At another level, Carien also relates Natalie's more proficient utilisation of her walking frame to the stimulation that she has gained from engaging in psychomotor activities at therapeutic horse riding. Identified as serving an adjunctive function, then, Natalie's participation in this form of intervention is appraised as feeding in to what other assistive devices attempt to rehearse and foster with respect to her motor control and broader motor functioning.

Offering a complimentary view, Alida appraises Natalie's participation in therapeutic horse riding in the following terms:

*A: To me she is, like I've said already, a lot more willing to participate [in therapeutic riding activities]...She has more self-confidence and she probably*

*feels that she can ride on the horse's back. I don't have to walk with her...And motorically she has also improved a lot as well. I wouldn't say that she doesn't bunny hop anymore, because she bunny hops all the way, but she has more than enough self-confidence to move around in the class on her own. Even outside she will start to attempt to go to an area where she really wants to play.*  
(Alida: Interview 1)

Here, Alida acknowledges that large-scale gains across different dimensions of Natalie's functioning are not evident. However, she affirms that what counts as psychologically significant are the subtle yet noticeable shifts that impact in important ways on Natalie's daily life. For instance, Natalie's improved self-confidence - an important psychosocial resource - seems related to her no longer feeling uncertain. Rather she feels supported and grounded, both physically and psychologically, as she rides on the back of a rather large animal. Indeed, Alida describes Natalie as comfortable enough in and with her body to be able to move around in her school environment more actively. Thus, implicit reference is made to her more concerted expressions of autonomy and increased independence, as well as enhanced self-acceptance.

The relationship between Natalie's participation in therapeutic horse riding and her increasingly confident engagement with her physical (and social) environment may also be accounted for in terms of Mutrie and Faulkner's (2004) argument that gaining physical strength or capacity allows us to feel more confident in our ability to do everyday tasks, perhaps providing us with a more positive perception of our physical selves. In this way, our self-esteem is influenced positively. Identified by Ryff and Singer (1998) as two of the key dimensions in their model, it is inferred here that Natalie's expressions of autonomy and enhanced self-acceptance feed in to her experiences of psychological well-being.

Unsurprisingly, Natalie's strong sense of affiliation for her classmates is also reflected within the therapeutic riding context. What is remarkable about Natalie in particular is that the sociality afforded by the therapeutic riding experience is called into play and lived out well before she arrives at therapeutic riding lessons. Thus, Alida asserts:

*A: She [Natalie] enjoys the therapeutic riding a lot. For her it is a lot of fun to drive there in the bus. She knows our routines and rituals from school onwards. She participates in them. But she is just very quiet [with her classmates]. If she sits in front with me, she talks continuously. She shows me all sorts of road signs, and she tells me she sees a red lamppost, or whatever she sees. So she is better...and she knows she has an audience with whom to speak. (Alida: Interview 1)*

A number of points emerge as interesting here. Firstly, Alida alludes to a view of therapeutic riding as an outing and a recreational experience that Natalie finds enjoyable even prior to reaching the therapeutic riding site. It is also relevant that transport to and from school, which constitutes a necessity, is problematic for her parents. Thus, it is inferred that the scope of Natalie's recreational experiences and outings away from her home is also extremely limited. Perhaps an outing to therapeutic horse riding is particularly savoured as she does not seem to visit elsewhere much. Clearly, Natalie's subjective experiences differ significantly from that of the participants discussed thus far in that socio-economic factors operate as a distinct barrier that hinders her exposure to a broader repertoire of stimulating psychosocial experiences.

Secondly, Alida observes that Natalie's preference for adult company and interactional exchanges is brought to the fore when they are seated at the front of

the bus alongside each other<sup>20</sup> while travelling to and from the therapeutic riding site. For the duration of the trip, Natalie savours the stimulation of conversation with an adult as opposed to her peers. The bus trip also constitutes an opportunity for her to be cognisant of the changing surroundings. Remarkably, Natalie is not only perceptive of what is going on in the changing external environment, but she also tends to express her communicative competence and sociality by talking continuously to Alida, commenting and reflecting on what is striking to her. Perhaps because Alida is the class teacher and perceived to be a highly respected (though approachable) authority figure, Natalie values the audience she has in her. Clearly, Natalie recognises Alida as an individual who is validating of her experiences and her personhood in that she is responsive to and interested in what she has to say.

A final point arising from the preceding extract is that such an interactional exchange could be all the more meaningful for Natalie, given the elevated vantage position that she occupies for the duration of the bus trip. When seated at the front of the bus, Natalie is far removed from the lowered, disempowered position that she usually assumes when seated in her wheelchair. On the bus, she engages in looking down from high up. Significantly, this elevated experience sets a precedent that is followed through within the therapeutic riding context where, when seated on horseback, Natalie is once again able to temporarily discard the lowered position and status that she otherwise occupies. In this regard, Benda and colleagues (2003) have usefully pointed to the experience of moving freely through space on a powerful animal without the constraints of assistive devices as psychologically meaningful and empowering.

Given that in the preceding extract, Alida had described Natalie as communicative and quite chatty when in her (adult) company, I asked her to

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<sup>20</sup> It was an established ritual that, when travelling to and from therapeutic riding lessons, the children took turns at sitting in what they regarded as a privileged seat at the front of the minibus alongside Alida.

comment on whether Natalie tended to initiate conversations with her playmates while at therapeutic riding as well. In response, Alida declared:

*A: Yes, she [Natalie] definitely does that. Yes, she is a special one. She will listen to what the students say to her and she will talk back. She will carry out the instructions, and it is definitely good for her. Like physiotherapy is good for her spasticity, this is also very very good. She enjoys the horses and she knows his name. (Alida: Interview 2)*

A general point emerging from Alida's account is the prioritisation of therapeutic riding as a context in which Natalie can live out her sociality. While she agrees that Natalie does initiate conversations with her playmates at therapeutic horse riding sessions, it is her contact with adults in this setting that Alida finds more striking. Indeed, Natalie is cited as cognitively capable of listening and responding to the therapeutic riding instructors, leaders and side-walkers who encourage and facilitate her efforts at performing the designated psychomotor tasks. Clearly, contact with members of the therapeutic riding team comprises another important source of social interaction and an interpersonal resource for Natalie. Moreover, I have observed that along with her bubbly enthusiasm, Natalie's warm disposition often tends to elicit positive feedback from them. Arguably, such positive appraisals then feed in to her positive self-perceptions, as well as her experiences of mastery and self-esteem.

In addition, consistent with extant research (e.g., Benda et al., 2003; Bertoti, 1988; Hammer et al., 2005; Miller & Alston, 2004), Alida seems convinced that therapeutic horse riding makes an input into the reduction of the spasticity and limited range of movement that Natalie experiences. Significantly, she equates this unique mode of psychomotor stimulation with the stimulation that Natalie receives during physiotherapy sessions. However, by subsequently mentioning Natalie's enjoyment of horses, Alida highlights the opportunities for social relating that are inherent to and definitive of the therapeutic riding experience. In this



regard, Sterba and colleagues (2002) point out that while this form of intervention is similar to therapeutic devices used in clinical settings, the activity of horse riding offers more sensory–motor stimulation and a bond between rider and horse that cannot be simulated artificially in a clinic or with an inanimate therapeutic apparatus. In comparison to standard physiotherapy sessions then, therapeutic horse riding is a truly *social* form of intervention that entails interactions with a multiplicity of individuals (human and animal). A final point arising from the preceding extract is that Alida privileges the familiarity that Natalie experiences in terms of a more personalised *relationship* with a particular horse.

Like Alida, Natalie's mother also singles out her daughter's bond with a particular horse as significant. Carien states:

**C:** *She likes it [therapeutic riding] a lot, especially PILGRIM just as if it is her horse.* (Carien: Interview 2)

Here Carien asserts that Natalie experiences therapeutic riding as enjoyable. Remarkably, she accounts for such positive experiences of therapeutic riding in terms of an important relational aspect inherent in this form of intervention. Specific mention is made of Natalie's relationship with Pilgrim, the horse that she usually rides. Indeed, her mother asserts that Natalie has assumed a heart-felt affinity for Pilgrim, almost as if the horse were a pet that belonged to her. Thus, Carien calls into play a well-theorised feature within existing bodies of work, namely that the relationship between the horse and rider holds therapeutic value (All et al., 1999; Bizub et al., 2003; Brandt, 2004; Kluwer, 1988). For instance, drawing on attachment theory, it has been suggested that "human-animal relationships can, along with other relationships, provide opportunities for growth, the development of self-esteem, trust and understanding" (Menziés Inc., 2003, p.5). Moreover, Natalie's relationship with the horse is regarded as empowering in that it serves as a validating, secure base from which she is afforded

opportunities for experiences of success and mastery. This then serves to boost her self-efficacy beliefs and self-esteem.

In addition, Alida offers the following comments:

*A: I think everything that happens here at school has a terribly positive influence on her life. And I also think the horse riding has a very good influence on her self-confidence and that introversion, and the complete expressionlessness and lack of response to anything. It helped to get her out, to crawl out of her shell a bit and to give her self-confidence. (Alida: Interview 2)*

In the extract above, Alida situates therapeutic riding as one of a range of positive inputs that are afforded to Natalie by the school. Further, she explicitly appraises Natalie's participation in therapeutic riding as a *catalyst* for the stimulation and development of psychosocial aspects of her functioning. Dramatically, Alida describes Natalie's experiences at therapeutic horse riding as having helped her "to crawl out of her shell a bit". Thus, a fitting inference is that in the process of her participating in this form of intervention, Natalie's experiential world has expanded and her sense of self has been affirmed and strengthened. While she had previously been perceived as introverted, despondent and apathetic, Natalie's participation in the inherently social activity of therapeutic riding seems to have awakened in her a certain responsiveness, self-confidence and autonomy. Positive implications for her experiences of psychological well-being are therefore inferred from Alida's appraisal.

An emphasis on therapeutic riding's input into psychosocial aspects of Natalie's functioning is also reflected in Sumari's assertion that:

*S: It [Therapeutic riding] actually does a lot for them to discover emotional wellbeing. It lets them feel good a bit, and especially...their physical state. I think because there is so little for their age group that does something like this, they*

*think it's wonderful...that they have something targeting their age group which they can master. And I think that she [Natalie] likes animals and she also likes to be outside, so I think for her it's wonderful. (Sumari: Interview 2)*

Here Sumari (Natalie's occupational therapist) notices and prioritises overarching inputs into "*emotional well-being*". Through her use of this phrase, the 'feel good' effects of Natalie's participation in therapeutic horse riding are raised for attention. In this regard, existing bodies of work indicate that exercise and physical activity have mood-enhancing properties (Fox, 1999; Mutrie & Faulkner, 2004; Pretty et al., 2003; Scully et al., 1998). Thus, to the degree that it constitutes a form of exercise and physical activity then, a positive influence on individuals' mood states may be also be regarded as true of therapeutic horse riding.

In considering the salutary potential of positive emotions, it is argued that Fredrickson's (2001) broaden-and-build theory of positive emotions is informative here. The theory boldly asserts that positive emotions serve not only as markers of flourishing or optimal well-being - as traditional perspectives within psychology suggest - but rather they also *fuel* human flourishing (Fredrickson, 2001, 2005b, 2006, italics added). Accordingly, it is argued that in serving as an arena within which positive emotions are fostered, therapeutic horse riding contributes to the participants' flourishing.

Also informative is the 'undo hypothesis' which posits that positive emotions might 'correct' or 'undo' the after-effects of negative emotions (Fredrickson & Levenson, 1998; Fredrickson, Mancuso, Branigan, & Tugade, 2000). Evidence for the 'undoing effect' suggests that individuals might improve their psychological well-being, and perhaps also their physical health, by cultivating experiences of positive emotions at opportune moments to cope with negative emotions (Fredrickson, 2000a, 2000b). Following Fredrickson (2001), it is argued

that for participants such as Natalie who enjoy good physical health<sup>21</sup> but have poor psychomotor functioning on account of their profoundly impaired physicalities, attempts to promote positive emotions within the therapeutic riding context have yet another distinctive significance - positive emotions could potentially 'undo' the effect of negative emotions that often accompany the participants' subjective experiences of impairment and disability.

Moreover, in the preceding extract, Sumari also brings to the fore a point raised earlier on in this discussion, namely that part of the unique value of this form of intervention lies in that for young children with disabilities (including the participants in this study, and disabled individuals more generally), the range of appropriate and accessible therapeutic resources is extremely limited. Generalising her comments regarding Natalie, Sumari argues, in her role as an occupational therapist, that in participating in therapeutic riding, children with disabilities are provided with the appropriate sensory motor stimulation. Such stimulation renders them capable of mastering psychomotor activities, and provides them with opportunities for experiences of success. These sentiments echo the findings of existing research within the field of therapeutic riding (for instance, Bizub et al., 2003; Miller & Alston, 2004).

Interestingly, Sumari comments that *"they think it's wonderful,"* thereby appropriating a positive appraisal of the opportunities for stimulation and recreation provided by this form of intervention to the participants themselves. A final point of interest that emerges from the preceding extract is that its psychosocial and recreational aspects are also singled out as contributing to the particular appeal that therapeutic riding holds for Natalie.

In sum, the preceding discussion has described Natalie as distinct from the participants considered before her in that she makes use of a wheelchair for the

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<sup>21</sup> Notably, all the children were in good physical health for the duration of their participation in therapeutic horse riding, and this study.

purposes of ambulation. It has also yielded a view of Natalie as an individual whose captivating personality and significant communicative strengths combine with her adaptive modes of mobility (in the form of crawling and bunny hopping) to *transcend* the disabling barriers to relating with others posed by her profound physical impairments. Furthermore, in terms of inputs from therapeutic riding, participation in this form of intervention has been broadly appraised as having subtle though distinct improvements on Natalie's physical functioning. Importantly, these gains are then generalised to her performance of functional tasks and activities in other contexts. In turn, their more proficient performance is interpreted as having a positive influence on psychosocial dimensions of Natalie's functioning. Importantly, the inherent sociality that characterises her personhood appears to be stimulated in the context of, and enhanced by, her participation in therapeutic riding. It is argued that the preceding features render Natalie's experience of therapeutic riding to be 'therapeutic' in that positive implications for her experiences of self-confidence, acceptance and a sense of self have been inferred.

#### **4.6. Nthabiseng**

##### **Biographical note**

A petite, dimpled child, 5-year-old Nthabiseng stood out from her peers at therapeutic riding sessions based on her initial very real fear of animals. Like Natalie, Nthabiseng has been diagnosed with diplegic cerebral palsy. However, in contrast, her motor impairments seem negligible. Instead, it is more her cognitively-based impairments, and socially-derived communicative impairments that influence Nthabiseng's day-to-day functioning in significant ways.

Hailing from a middle-class family who live in a comfortable home within five kilometres of the school, Nthabiseng has a younger brother by three and a half years, Kgotso. The family is Sotho-speaking, with English as a second language. This renders communicating in Afrikaans, the language medium of the school, a particular challenge for Nthabiseng.

##### **Re/negotiating communicative in/competence**

Diagnosed with diplegic cerebral palsy, 5-year-old Nthabiseng's communicative functioning is characterised by extremely under-developed expressive *and* receptive language skills. However, it is the largely socially-derived basis of such impairments - namely, her lack of proficiency in the normative medium of communication within the school context - which distinguishes Nthabiseng's experiences of communicative incompetence from that of the participants discussed thus far. Indeed, it is inherently problematic that while Nthabiseng is a mother-tongue speaker of Sotho, the language of instruction and functioning at Anna Fourie School is Afrikaans<sup>22</sup>.

As a point of departure, it is useful to unpack her parents' decision to enrol Nthabiseng at Anna Fourie School, particularly as it entailed knowingly exposing her to ongoing challenges with respect to communication. Given that their

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<sup>22</sup>The school's population consists predominantly of white, Afrikaans-speaking learners with disabilities from pre-primary to matric levels.

family's home is located in a middle-class suburb less than five kilometres away from the school, the issue of accessibility needs to be taken into account. However, drawing on some of the basic assumptions of a social model of disability, the discussion that follows argues that in making sense of her parents' choice of a school for Nthabiseng, critical socially-derived factors take precedence.

Soudien and Baxen (2006) emphasise that within the South African context, differences within the population of individuals with disabilities - which is heterogeneous in terms of age, social class, 'race', ethnicity, and capabilities more broadly - have yet to be taken into account in the provision of education and rehabilitation services<sup>23</sup>. A remnant of the apartheid era, a segregation of educational services based on ethnicity and an accompanying inequitable allocation of resources is identified as a *disabling barrier* in the lives of black learners with disabilities. Indeed, a salient feature of South Africa's political history is that for black children who comprise a significant sector of the population of learners with disabilities, access to quality education that is conducted in their mother-tongue languages is scarce (Maart et al., 2007; Soudien & Baxen, 2006).

Nthabiseng's predicament with respect to language resonates with the abovementioned wider imbalances within the South African context. Apart from Anna Fourie School, Lethaba and Mbali schools are other educational institutions in Bloemfontein (located some distance away from her home) that she might have registered at. Attended by black, Sotho-speaking learners, the latter schools cater specifically for individuals with extremely low levels of cognitive functioning and poor general functional ability.<sup>24</sup> Moreover, in contrast to Anna

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<sup>23</sup> Soudien and Baxen (2006) suggest that this feature is also characteristic of other third world countries.

<sup>24</sup> Both Sotho-medium schools, Mbali School caters for learners with severe mental retardation while Lethaba School caters for learners with physical disabilities and learning disabilities. In addition, as opposed to a standard academic curriculum, both schools offer skills and craft subjects to learners.

Fourie School, they are widely perceived as poorly equipped, and offering an inferior quality of education.

Florian and colleagues (2006) assert that while classification and categorisation may be necessary for accountability in determining eligibility and the appropriate provision of educational services, history has shown that the unintended consequences of such processes need to be carefully considered. For instance, due to their status as educational institutions for disabled learners who are incapable of pursuing a standard academic curriculum (and are therefore compelled to be educated through a special education curriculum), a strong social stigma is attached to individuals who attend Mbali and Lethaba schools. Learners tend to be stereotyped as “second class citizens” who are deviant and deficient on account of their profound impairments across multiple domains of functioning. Hence, for parents in general, admission to Anna Fourie School is often accompanied by a sense of relief around their children’s capabilities for pursuing an academic career. Stated differently, many parents interpret admission to the school as an external, authoritative source of confirmation that their children are as “educable” as they had hoped.<sup>25</sup> It is therefore relevant that Nthabiseng’s parents are middle-class professionals who prioritise access to a high quality of education. An implicit assumption then, is that they too attach significance to affirming yet prejudiced perceptions of their child as “not as retarded” as the more deficient and deviant learners at Mbali and Lethaba schools, and they would therefore have been disappointed if Nthabiseng had not met the admission criteria for attending Anna Fourie School.

However, in this regard, Mariaan, the speech therapist with whom Nthabiseng has therapy twice weekly, has rather sobering reservations. She disclosed:

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<sup>25</sup> Importantly, its high matric pass rates serve as evidence that such potential is frequently realised by the majority of the learners who pursue a standard academic curriculum –as opposed to a special education curriculum- at Anna Fourie School (Alida: personal communication, September 28<sup>th</sup>, 2008).



*M: Yes, you know, we are keeping her here for a year to begin with. But further on, I don't think she is cognitively very well endowed. It is a problem, and we are an academic school. So, in the future a decision is going to have to be made.* (Mariaan: Interview 1)

In her professional opinion, Mariaan suggests that while Nthabiseng has been admitted to Anna Fourie School to begin with, her low level of cognitive functioning places a question mark over her prospects for continuing with a standard academic education. Indeed, Mariaan implies that Nthabiseng's parents have false hopes with respect to their daughter's intellectual capabilities. Thus, an underlying idea here is that Mariaan expects Nthabiseng's education at Anna Fourie School to be short-lived. Her cognitive impairments are perceived as too great to cope with the complexities of higher-order cognitive functioning warranted by the school's standard academic curriculum. Also implicit in Mariaan's account is the view that being placed in an academically demanding context when she is not cognitively capable of meeting a wide range of basic challenges is not in Nthabiseng's best interests.

In a similar vein, her occupational therapist, Erika, feels rather strongly that, in being educated at an Afrikaans-medium school, Nthabiseng is on the receiving end of a great disservice. Erika declared:

*E: She [Nthabiseng] can carry out a simple instruction, but if it comes to more complex things, she cannot. And then I doubt that, the fact that she will be able to go on at our school academically, or then her speech...I think if she could perhaps receive stimulation in her own language, then we would have a different image of that child.* (Erika: Interview 1)

At one level, Nthabiseng is appraised as incapable of performing activities that warrant higher-order cognitive processing. A tacit assumption here is that due to her low level of cognitive functioning, Nthabiseng is effectively missing out on the full range of stimulation that she could potentially benefit from within the

therapeutic context. Moreover, Erika assesses Nthabiseng's communicative incompetence in Afrikaans as exacerbating the disabling effects of her cognitive impairments. This combination of challenges casts severe doubt on her capability for continuing with a standard academic curriculum at Anna Fourie School.

At another level, Erika suggests that because Nthabiseng is not proficient at verbally communicating the nuances that comprise her everyday thoughts, ideas and feelings in Afrikaans, a fuller image of her strengths and capabilities is glossed over in her interactions at school. In psychosocial terms, Nthabiseng seems to be silenced and isolated in her everyday social relating, while the frequency and quality of her interactions within academic and therapeutic contexts is also compromised. Clearly, unlike her Afrikaans-speaking peers, Nthabiseng does not seem to benefit as much from attending a school with other children who are similarly disabled because she is not conversant in the school's medium of instruction and functioning. It is inferred that the school's practice of inclusion, which generally functions to minimise psychologically damaging experiences of difference and otherness, has failed her in important ways. Moreover, Erika seems to perceive Nthabiseng as a helpless victim who is on the receiving end of a grave injustice on account of a broader social process. Further, proponents of a social model of disability would argue that Nthabiseng's experiences exemplify the basic principle that disability is not only about impairment (for instance, Abberley, 1987; Barnes, 1996; Hughes & Patterson, 1997; Low, 2001; Maart et al., 2007; Oliver, 1983, 1990, 1996; Soudien & Baxen, 2006).

Based on her professional opinion as an occupational therapist, then, Erika proposes that Nthabiseng would be more inclined to flourish academically and psychosocially if she were educated in her mother tongue. In her view, Nthabiseng is a more suitable candidate for being educated at either Mbali or Lethaba schools. However, it is notable that both Erika and Mariaan fail to problematise the reality that there are very real difficulties inherent in unambiguously assessing Nthabiseng on cognitive dimensions of functioning due

to her socially-derived challenges. The absence of a context in which she can express herself in her mother tongue has striking implications with respect to the assessment process and, by implication, decisions around Nthabiseng's capabilities for pursuing a standard academic curriculum. Indeed it is suggested that in view of the abovementioned dilemmas, assessments with respect to Nthabiseng's skills and capabilities as well as impairments are ultimately inconclusive.

Speaking of the difficulties inherent in determining her daughter's level of functioning, Nthabiseng's mother, Maria, made the following comments about her communicative (in)competence:

***M:** Her Sotho is perfect. You do not struggle to hear what she wants to say. I think she could have progressed more if she was speaking her own language. But now because it is another language, Afrikaans and not English, it is difficult. She is catching up with her Afrikaans, but I think as time goes by she will pick up the language. (Maria: Interview 1)*

By declaring that she is able to express herself clearly and intelligibly in her mother tongue, Maria effectively denies that Nthabiseng's lack of competence at communicating in Afrikaans is symptomatic of her diagnosis of cerebral palsy. Instead, having to function in a medium that is completely foreign to her is highlighted as the source of Nthabiseng's communicative incompetence. Moreover, Maria's assumption that her daughter would have experienced greater improvements were she speaking Sotho at school reflects a perception that Nthabiseng's incompetence in communicating in Afrikaans constitutes a significant obstacle to her achievement of gains along cognitive dimensions of functioning. At the same time, however, Maria regards functioning proficiently in Afrikaans as a goal that is firmly within the realm of Nthabiseng's capabilities. Optimistically, she seems to harbour hopes of Nthabiseng progressing smoothly over time along a developmental trajectory with respect to language learning.

Certainly, her parents' decision to enrol Nthabiseng at Anna Fourie School seems to be based on their judgement that doing so would be in the best interests of their child, educationally-speaking. However, notwithstanding their well-intentioned motivations to provide Nthabiseng with a good quality of stimulation at the best available school, an inherent complexity is that her subjective experiences at Anna Fourie School are rendered more difficult because she is constantly bombarded with verbal stimuli which is largely outside of her usual frame of reference.

In what follows, her teacher, Alida, outlines detrimental consequences for Nthabiseng's psychosocial experiences within the school context. She asserted:

*A: Yes, I think her [limited verbal] expression really influences her communication with her little friends a lot and with you [referring to adults, herself included] and so on. So her vocabulary isn't increasing that rapidly yet and it is...really has an influence on her social and emotional interaction. (Alida: Interview 2)*

Clearly, Nthabiseng has a limited repertoire of words with which to articulate and live out her feelings, thoughts and ideas in interactions with her peers and the adults at the school. Diplomatically, Alida states that Nthabiseng has not yet made significant gains in terms of her vocabulary. However, the particular delay that Alida has noticed may be accounted for in terms of Nthabiseng's cognitively-based impairments that render the developmental process of language acquisition slower than expected. Furthermore, in preventing her from expressing a full range of emotions, for instance, Nthabiseng's communicative incompetence is interpreted as a disabling barrier to meaningful psychosocial interactions and the formation of emotional bonds with her peers. Negative implications for what Ryff and Singer (1998) conceptualise as a key dimension of psychological well-being, namely positive relations with others, is inferred.

In what follows, Alida provides further insights into the struggles that Nthabiseng experiences on account of her communicative incompetence and broader cognitive impairments. In response to my enquiry as to how Nthabiseng tended to respond if she was unsuccessful at meeting a challenge, Alida disclosed that:

*A: It's really painful for her [Nthabiseng]. For her it's VERY BAD to feel she has failed, [that] she didn't achieve something. You know, there are just A LOT of things that she still needs help with, and she will really look a lot at what the little friend next to her does and do the same. So she is still a bit uncertain about her own capabilities. Sometimes she can do it and sometimes not completely master [tasks and activities]. She also tries to look to see that she is not doing something wrong. She doesn't have that much confidence in her own capabilities. (Alida: Interview 2)*

Here, Alida presents an image of Nthabiseng as an insecure, vulnerable individual who has limited cognitive resources upon which to draw within an academic context. Moreover, her frequent failure to successfully perform and master tasks in the classroom is appraised as emotionally painful and damaging to her self-esteem. A crisis of confidence with respect to her practical capabilities for performing tasks and meeting challenges that are set for the group also results. And, together with reinforcing low self-efficacy beliefs, Nthabiseng's infrequent successes in performing academic tasks serve to perpetuate a negative sense of self worth.

Alida also declares that in her experience, Nthabiseng seems to require more guidance and support than her peers. In particular, she relies very heavily on other learners' performance of a task for cues as to how to proceed with it. At one level, this could be interpreted as pointing to a delay in the development of her higher-order cognitive processing skills. Rather than drawing on her own (limited) repertoire of frameworks to make sense of the task demands,

Nthabiseng observes what her peers do, and then models the steps that she takes accordingly. At another level, her experiences of the process of learning as a *socially mediated* activity are also indicated. Hence, Vygotsky's (1978) construct of the 'zone of proximal development'<sup>26</sup> is informative here. For instance, with respect to the quality of the learning environment that is available to Nthabiseng, it is significant that due to their own idiosyncratic forms of communicative incompetence, her peers do not constitute an ideal source for facilitating the processes of learning and development. Moreover, with respect to adult guidance, it is also problematic that because her teacher and therapists are first-language speakers of Afrikaans, and not conversant in Sotho, Nthabiseng has limited opportunities to independently problem-solve under adult guidance through useful communicative exchanges with them. And, given that she is not equipped with the words to verbalise what she is unclear of, Nthabiseng lacks the confidence to approach Alida for a clarification of instructions that she might not have understood fully in the first place. Thus, it is inferred that, unlike her Afrikaans-speaking peers, Nthabiseng misses out on invaluable adult instruction and supervision that is key to the learning process. It is therefore argued that the school environment does not serve as an ideal setting for facilitating Nthabiseng's experiences of learning as well as her broader development.

Another salient point arising from the preceding extract is Alida's description of Nthabiseng as cognitively capable of monitoring and registering when she is not efficiently performing a task that was prescribed for the class. Clearly, Nthabiseng is aware of and self-conscious about experiencing more frequent failures than successes. Moreover, Alida suggests that Nthabiseng is rather hard on herself in that she makes a concerted effort to avoid carrying out the steps of a task incorrectly. Unsurprisingly, then, being as successful as her peers at educational tasks matters to Nthabiseng. In addition, feelings of being "lesser"

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<sup>26</sup> The zone of proximal development is defined as "[t]he distance between the actual developmental level as determined by independent problem solving and the level of potential development as determined through problem solving under adult guidance or in collaboration with more capable peers" (Vygotsky, 1978,p.86).

than those peers who consistently master tasks reinforce Nthabiseng's experiences of despondency and further self-doubt. In sum, it is argued that Nthabiseng's struggles, cognitively and communicatively, within the context of the classroom, have negative implications for her experiences of self-acceptance, autonomy and environmental mastery, features that Ryff and Singer (1998) regard as key dimensions of psychological well-being.

Furthermore, Nthabiseng's cognitive and communicative difficulties are also played out in the context of her performance of group-based recreational activities. Alida contended:

*A: I mean if you ask to her [Nthabiseng] to say this, or to sing a song, then...She sings many of the songs [lyrics] over and over. I mean I have not really HEARD her little voice, that she says the complete words. She will show actions, do the movements, but her [verbal] expression...I think she understands more [than she expresses], but she battles to learn words. (Alida: Interview 2)*

A few interesting features emerge here. To begin with, the extract above refers to Nthabiseng's participation in recreationally-oriented class activities such as singing songs which are accompanied by animated demonstrations that are conducted in unison. Performed in Afrikaans, and consisting largely of songs that are typical of traditional Afrikaans-speaking culture, such activities generally serve as a point of shared enjoyment for the group. However, positioned outside of Nthabiseng's frame of reference, the songs tend to be more familiar to her Afrikaans-speaking peers, many of whom would have heard them sung previously within their family contexts. And, given that such musical activities constitute a significant medium through which culture is transmitted, I wondered whether, in being socialised in Afrikaans culture while at school, Nthabiseng was not missing out on exposure to valuable traditions and practices that are key aspects of her own Sotho culture. It is also plausible that she could become alienated from the rich and idiosyncratic culturally-derived experiences that are

integral to the development of her own cultural identity and sense of self in important ways. However, functioning in the context of a language and culture that is distinct from her own Sotho language and culture is a necessary compromise in view of the lack of access to quality education in her mother tongue that Nthabiseng (along with other Black children with disabilities) must contend with.

Secondly, Alida has also noticed that on account of her poor expressive language skills, Nthabiseng pretends to sing along with her classmates by mouthing a few familiar lyrics repetitively. This indicates that she is self-conscious about, and in all likelihood embarrassed by, her poor verbal competence in Afrikaans. And, perhaps to “save face,” then (rather than being silent or non-participative and therefore more conspicuous), Nthabiseng makes a concerted effort to participate in the performance and blend into the group. Following Goffman (1959), such efforts represent attempts at “impression management” as a means to cope with the effects of her communicative incompetence. Significantly, they are also adaptive to the extent that Nthabiseng actively *compensates* for not really singing by mimicking the performances of her peers. It is remarkable that she utilises her existing capabilities (such as mimicking, for instance) to facilitate her own unique form of participation in this specific recreationally-oriented group activity.

A final salient point that Alida raises concerns Nthabiseng’s impaired cognitive processing which is played out in the realm of her expressive language functioning. While her receptive language skills are appraised as seemingly better developed, Nthabiseng’s repertoire of Afrikaans words has been slow to expand. Thus, it is inferred that such difficulties serve to limit her participation in and enjoyment of the group’s musical performances.



Interestingly, Maria indicates that Nthabiseng's distinct struggles with respect to language and communication are played out across a range of social contexts. She declared:

*M: That was my worry, the language. I was really concerned "Will she be able to cope with the Afrikaans?" Like most of the kids that are around her, the family kids, most of them they are doing everything in English-medium, so I was worried that she was going to be left behind, not understanding English. But I see she understands, even though she does not speak English. (Maria: Interview 2)*

Maria's very real concerns around Nthabiseng's poor communicative competence are interpreted as two-fold. At one level, an implicit assumption is that in view of her cognitive impairments, the barrier posed by not being conversant in the school's medium of instruction and functioning *exacerbates* Nthabiseng's experiences of *disability*, deficiency, and deviance. While her group of peers' difficulties in functioning and developmental delays is attributed to the range of impairments that they share in common, Maria questions whether Nthabiseng is capable of coping in an academic setting with an additional weighty socially-derived obstacle to overcome. Rudimentary capabilities for verbal communication and relating in socially meaningful ways with her peers are compromised by virtue of normative language practices that serve to render Sotho-speaking Nthabiseng different from the group.

At another level, Maria points out that the necessary prioritisation of communicating in the medium of Afrikaans also has negative implications for Nthabiseng's social interactions with the children in their extended family. While most of her cousins attend English-medium schools and habitually converse with each other in English, Nthabiseng's lack of verbal competence in the language

limits her participation in their social play activities. However, Maria appraises Nthabiseng's receptive language skills to be such that she "gets by" in her interactions with her cousins. Taking this point further, Maria implicitly suggests that her daughter is not really marginalised or excluded from play activities on account of her inability to speak fluent English like the rest of her cousins. Still, it is also plausible that a degree of passivity could be fostered on Nthabiseng's part. In addition, an associated lack of depth and richness in relating could potentially hinder the development of strong emotional bonds with the children in her extended family who constitute an important psychosocial resource for Nthabiseng.

Having considered the challenges that Nthabiseng faces, in what follows, a glimpse of her unique strengths is provided. With respect to Nthabiseng's independence, Alida stated:

*A: Oh, yes, she is very independent. She dresses and undresses herself. Puts away her stuff. She will lay the table for me. She likes to carry out little jobs that she is entrusted with. So she is very independent as well. (Alida: Interview 2).*

In stark contrast to the earlier image of her as vulnerable and uncertain when attempting to perform educational tasks in the classroom, here Alida presents an image of Nthabiseng as capable, assertive and independent. On the one hand, the level of functional independence that she has achieved sets her apart from her peers (see the discussion around Nthabiseng's motor capabilities below). On the other hand, her strong motivation to utilise the capabilities that she does have in ways that are useful to others is remarkable. Another implicit assumption is therefore that Nthabiseng also functions as a resource for her teacher and classmates. Clearly, Alida not only recognises and accords value to her helpful nature, but she also empowers Nthabiseng to utilise her strengths. And, while giving expression to and nurturing a sense of responsibility, dutifully taking on the

role of Alida's designated helper is also interpreted as a source of enjoyment that boosts Nthabiseng's self-efficacy beliefs and self-esteem.

Taking such sentiments further, Alida declared:

*A: Emotionally to me she is still, because she communicates so little spontaneously in Afrikaans, to me she is more a little spectator who has really cute qualities that have come to the fore in her development. Like, for example, [with] Stacey, she went to get out her book for her, after she was here for the second day, without my asking her to do so - She's [Stacey's] a new little friend. She [Nthabiseng] likes to help out or to feel she is important. (Alida: Interview 2)*

A number of features emerge as significant here. To begin with, Alida clearly links Nthabiseng's passivity in the context of social interactions to her lack of spontaneous verbal communication in Afrikaans. Unlike Isobel and Natalie for instance, Nthabiseng's everyday experiences are characterised by struggles based predominantly on an inability to communicate in Afrikaans and relatively low levels of cognitive functioning. It is therefore an outstanding feature that her particular form of passivity masks attributes of assertiveness, empathy and altruism that set Nthabiseng apart from her peers. A significant psychosocial strength is her empathic attitude which she translates into *acting altruistically*. Indeed, through her altruistic actions, Nthabiseng gives voice to a range of positive attributes that are definitive of who she is. An example of such an attribute is her capability for identifying emotionally with an individual who is new to the school and her group of peers. While the rest of her classmates seemed politely indifferent to, and at best curious about, the newcomer, Nthabiseng appeared to draw on a finely-honed intuitive sense of Stacey as in need of a bit of kindness, and subsequently responded with a helpful gesture.

As the discussion has emphasised earlier on, Isobel was also described as verbalising a distinct interest in and empathic attitude towards her classmates. Accordingly, an interpretation around Isobel's well-developed altruistic tendencies followed from such observations. In contrast, on account of Nthabiseng's extremely limited capability for communicating in Afrikaans, similar attributes of empathy and altruism are not immediately striking or obvious to the observer. Yet, I would argue that in practical terms, Nthabiseng's altruism is more tangible and real than Isobel's altruistic attitude because she translates her genuine and spontaneous caring for others into *meaningful actions*. By assisting others in concrete, instrumental ways, Nthabiseng *transcends* the limitations imposed by her impaired cognitive functioning and lack of competence in communicating in Afrikaans. Thus, here, too, an impression of Nthabiseng as utilising the capabilities that she does have in meaningful ways is brought to the fore. Moreover, through her altruistic behaviours, Nthabiseng contradicts the popular cultural stereotype of individuals with disabilities as helpless victims. Rather, her altruistic tendencies provide a glimpse into the complex, nuanced ways in which she perceives and experiences herself as much more than "just disabled". Contextualised within a social arena, Nthabiseng's actions serve as testimony to the realisation of human potential, and her own experiences of relating with others and being helpful to them as meaningful.

A final point of interest emerging from the preceding extract is Alida's mention of the gains of "feeling important" when her helpfulness is recognised as a possible emotional payoff for Nthabiseng. Clearly, such positive appraisals around being a valued member of her group of peers would be rewarding and have an important validating effect. In addition, such attributes of empathy and altruism are regarded as useful psychosocial resources in that they entail the expression of agentic behaviours that assist Nthabiseng in fostering emotional bonds with her peers, thereby also feeding in to her experiences of psychological well-being.

### **De/constructing motor skills and in/capabilities**

Kerr and colleagues (2007) have suggested that “the motor impairments experienced by children with cerebral palsy (CP) and their consequences vary significantly across the spectrum of the condition” (p.22). Thus, in comparison to the participants discussed thus far, 5-year-old Nthabiseng’s less severe impairments in fine motor and gross motor dimensions of functioning appear to have more subtle consequences for her everyday functionality. For instance, while she shares a diagnosis of diplegic cerebral palsy<sup>27</sup> with Natalie who makes use of a wheelchair for the purposes of ambulation, Nthabiseng’s gross motor functioning is characterised by ataxia or a certain ‘floppiness’ with respect to muscle tone, and slight difficulties with respect to fine motor skills.

In this regard, her occupational therapist, Erika, stated:

*E: She has almost...To us she had a type of ataxic walk. She walks like this [demonstrates], with a broad base. (Erika: Interview 1)*

Elaborating on this description, her teacher, Alida, contended:

*A: For her [Nthabiseng]...she is...Gross motor functioning, it looks, if you look at her from behind, it looks as if she almost has “knock knees”. So she is, in terms of gross motor functioning, she is actually floppy on her feet. She is terribly afraid to sit alone on a bench for example. Her balance is not good. She holds on to you tightly. (Alida: Interview 2)*

What is noticeable to the observer is the awkwardness with which Nthabiseng walks. And, in practical terms, her broad, poorly supported, asymmetrical walk restricts her range of movement and limits the confidence and agility with which she is able to engage with her physical environment. Further, a particular fear of

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<sup>27</sup> Diplegic cerebral palsy entails the motor impairment of primarily the legs, usually with some relatively limited involvement of the arms (Best, n.d.; Finnie, 2002; Rosenbaum, 2003).

sitting on a bench independently seems to be associated with her poorly developed postural control and balance. Thus, Alida indicates that when seated, Nthabiseng clings tightly on to another person in order to steady herself so that she does not lean to one side or fall over. This suggests that Nthabiseng feels vulnerable and insecure in terms of her bodily movements and her interactions with her world.

However, over time, Nthabiseng seems to have grown more confident in her interactions with her physical environment. For instance, almost a year after she first joined the class, Alida described Nthabiseng as having made significant gains with respect to her motor functioning. She declared that:

**A:** *She is actually a motorically strong one. She will climb and scramble and push the wheel and [she] likes the active things.* (Alida: Interview 2)

It is striking that in contrast to the earlier image of Nthabiseng as unsteady, lacking in confidence with respect to her bodily movements and consistently at risk of falling, here Alida describes her as *motorically capable* and *assertive*. Instead of shying away from activities that are demanding with regard to motor skills and coordination, Nthabiseng has become proficient at engaging with them in active, autonomous ways. This indicates that her proprioceptive skills have improved, and that she has acquired a certain confidence in her embodied physicality. In addition, such experiences serve as a source of enjoyment for Nthabiseng, and suggest that nowadays she experiences her motor impairments as *less disabling*.

In a similar vein, within a year of first speaking to her, Nthabiseng's mother prioritised the following improvements in her daughter's motor functioning as particular strengths. Maria asserted that:

**M:** *Her posture is getting better... She is...normal walking and not afraid that she is going to fall or something like that...*

**P:** *You say her posture is better?*

**M:** *Yes, really improving, even when she is running. She does not fall to one side any more. (Maria: Interview 2)*

Here Maria describes the way in which Nthabiseng walks as “normal”, suggesting that her walk is no longer as asymmetrical and awkward as it was. Also, Nthabiseng’s postural control seems to have improved to the extent that she is no longer unsteady and her limbs are less ‘floppy’. And, perhaps as a result of feeling more stable, she has overcome her fear of falling. Also, because her asymmetrical movements are no longer as pronounced, Nthabiseng is capable of running with ease. In sum, Maria’s account serves to reinforce an image of Nthabiseng as *motorically capable*.

Interestingly, when asked if there is anything in particular that Nthabiseng struggles with nowadays as a result of her diagnosis of cerebral palsy, Maria proudly stated:

**M:** *Most of the things she is coping, she can do most of the things. She is no more struggling to do things herself. She does not struggle with fine motor things...She knows what to do. Buttons also, and the zip. Even if it is a bit of a struggle, any [button] hole, she puts it through. (Maria: Interview 2)*

In her account, Maria adopts a strengths-oriented perspective, acknowledging and according precedence to Nthabiseng’s strengths and capabilities. She suggests that in general, Nthabiseng manages well with daily tasks and activities. Indeed, an implicit assumption here is that Nthabiseng’s strengths effectively serve to minimise the struggles that she experiences on account of her motor impairments. Thus, Maria states explicitly that Nthabiseng’s general functional independence has increased significantly. Personal care tasks that necessitate the use of fine motor skills (such as dressing and undressing) no longer pose a struggle for her. For instance, fastening buttons through any size of buttonhole,

large or small, which requires considerable fine motor deftness is a task that Nthabiseng is motivated to perform independently and perseveres at. Moreover, it is inferred that on account of such fine motor capabilities, she has ample opportunities for experiences of success and a sense of mastery. By implication, Nthabiseng requires limited inputs from her caregivers in terms of assistance with daily functioning tasks. It is also inferred that as opposed to fostering dependence, Maria's efforts to empower Nthabiseng towards being agentic, autonomous and self-reliant have contributed significantly to her improved capabilities for functional independence.

Elaborating on Nthabiseng's capabilities with respect to functional independence, Maria declared that:

***M:** She can dress herself. She has mastered putting her arms in. Looks for the label so that she knows what is front and back, and she puts on the pants while sitting down.*

***P:** She has mastered getting dressed and undressed quite nicely?*

***M:** Erm...What I forgot to say previously that when she puts on the pants she struggles, she has to sit down. But nowadays I see she holds it and tries to get it on, and gets it right. (Maria: Interview 2)*

Here again, Maria highlights Nthabiseng's capability for dressing independently. In particular, making use of clothing labels as cues for the direction in which to put on items of clothing indicates that Nthabiseng applies a certain level of cognitive and perceptual skill to the task of getting dressed. Furthermore, while putting on a pair of pants continues to be a struggle for her, Maria observes that Nthabiseng overcomes the limitations imposed by her floppy limbs by sitting down to do so. Thus, instead of being dependent on adult assistance to get dressed, Nthabiseng utilises her problem-solving skills in adaptive ways. Psychologically-speaking, this points to resources such as a tendency to persevere, as well as a growing sense of autonomy and pride in achieving



personal care tasks independently. Positive implications for Nthabiseng's self-esteem are also inferred.

In dramatic contrast to the initial image of Nthabiseng as awkward and unsteady on account of her motor impairments, in what follows, Alida presents an impression of her as enthusiastically living out her sense of self through the medium of her embodied physicality. Alida comments:

*A: I think Nthabiseng, if she walks like she does then you can see she feels good about herself. She has this little walk going on. This stride and the zest for life. I think she has a good self-image. I think her parents also build her [confidence] up. (Alida: Interview 2)*

Having transcended the limitations afforded by her ataxic walk and poor balance, Nthabiseng's zest for life distinguishes her from her group of peers. In particular, Alida suggests that perhaps in view of the significant gains that she has made on motor dimensions of functioning, Nthabiseng exudes a great deal of confidence, assertiveness and a positive self-image. Clearly, the spring in her step indicates that she has become more accepting of herself. And, as I had observed at therapeutic horse riding sessions, too, bright-eyed, and smiley faced, Nthabiseng conveys a sense of being comfortable with and in her body as she moves with ease from one point to another, engaging with her environment in concrete ways. Moreover, complementing Nthabiseng's own efforts, Alida singles out the validating role that her parents play as an important psychosocial resource for building her self-esteem.

Interestingly, Alida has also come to perceive Nthabiseng as "not that disabled" on account of the significant gains that she has made with respect to fine motor and gross motor functioning. In response to my enquiry about the challenges that Nthabiseng experiences in her daily life, Alida declared:

*A: I don't think that her disability is a challenge for her. She walks and runs and [her] gross motor [functioning] is strong...So I think her little hands are not more affected. So I think it is more neurologically, that her challenges are, you know... where the brain damage took place. (Alida: Interview 2)*

Notably, in comparison to the rest of the participants discussed thus far who share profound physical impairments, Nthabiseng's impairments and status as a disabled individual is not as striking or obvious to the observer. Here, Alida appears to subscribe to a view of disability as necessarily implying or equivalent to an impaired physicality. She suggests that unlike those of her peers who cannot walk, climb or run for instance, Nthabiseng is highly competent in terms of fine motor and gross motor skills. Instead, the cognitive basis of Nthabiseng's impairments is appraised as posing a significant barrier to her daily functioning. Stated differently, Alida's comments reflect an understanding of Nthabiseng's symptoms as primarily cognitively-derived rather than motoric. However, as her occupational therapist and speech therapist had concurred earlier, such features pose significant challenges to functioning across therapeutic and classroom contexts. Indeed, Nthabiseng's level of cognitive function was appraised as so low that her capability for pursuing a standard academic education was placed under question.

Based on the preceding extracts, it is concluded that notwithstanding her severe cognitive impairments and particular socially-derived form of communicative incompetence, Nthabiseng's improved capabilities for functional mobility and functional independence constitute strengths that dominate her everyday experiences. Being capable of performing daily functioning tasks such as dressing independently, for instance, entails an expression of agency that contributes to her experiences of success. In addition, positive implications for what Ryff and Singer (1998) regard as a key dimension of psychological well-being, namely, a sense of mastery, are also inferred.

Having considered the effects of Nthabiseng's skills and capabilities on motor dimensions of functioning, in what follows, the discussion turns to a consideration of her experiences of participation in therapeutic horse riding.

### **Appraisal of participation in therapeutic horse riding**

From the terrified look in her tear-filled eyes and the way in which she clung to Alida's skirt at the introductory therapeutic riding session, it was obvious that, unlike the rest of her peers, Nthabiseng was petrified of approaching a horse. The treatment team therefore assured her and her teacher, Alida, that she was under no obligation to do so. And, for the rest of the first and second therapeutic riding sessions Nthabiseng's involvement was characterised by observing her peers as they took to the novel therapeutic riding experience with varying degrees of caution and enthusiasm. Much to the surprise of all concerned, at the third session, Nthabiseng spontaneously walked up to the mounting ramp and proceeded to attempt to take the place of the rider that was in the process of mounting a horse. Upon noticing this uncharacteristic, rather assertive gesture, the treatment team promptly fitted her with a riding helmet and assisted Nthabiseng to mount the horse that was next in line. As she was most familiar to her, Alida stood in as one of the side-walkers and constantly reassured Nthabiseng while praising her efforts. As the discussion that follows indicates, the gains that Nthabiseng has made within the therapeutic riding context are most remarkable in view of her prior very real fear of animals.

In this regard, her mother commented:

***M:** You know she is getting used to animals also. We do not have animals [pets at home], so that [participating in therapeutic horse riding] is a way of getting exposure and understanding how animals are. She has got a positive way of responding to the animals. (Maria: Interview 1)*

Through her participation in therapeutic riding, Nthabiseng has been successfully introduced to a new source of relating. Indeed, Maria links Nthabiseng's dramatic gains in terms of becoming comfortable with and responding positively to animals in general directly to her exposure to and interactions with horses within the therapeutic riding setting.

In addition, Maria also links improvements in Nthabiseng's motor functioning to her participation in therapeutic horse riding. She stated:

***M:** One thing I can say about her posture and when she is running, I know from the beginning she used to fall to one side, but it has improved. She has started pedalling her bicycle, she could not do it, and now she is going on. She knows now she has to go forward. (Maria: Interview 1)*

Previously, on account of her disproportionate weight bearing and poor motor coordination, Nthabiseng tended to fall to one side when running. These difficulties in motor functioning also rendered the task of pedalling and riding a bicycle, a particular challenge. However, in the extract above, Maria identifies improvements in postural control and gross motor skills as directly related to Nthabiseng's participation in therapeutic horse riding. Notably, such features have been often cited in existing research (for instance, Bertoti, 1988, 1991; Casady & Nichols-Larsen, 2004; Cherng et al., 2004; Ludewig, 2006; Sterba et al., 2002; MacPhail et al., 1998; Winchester et al., 2002). Significantly, with respect to postural control, MacPhail and colleagues (1998) have concluded that children with diplegia in particular could benefit from therapeutic horse riding based on the rationale that this form of intervention seems to facilitate normal equilibrium reactions in response to the pelvic movement of the horse, leading to improvements in the posture. Moreover, Nthabiseng's greater stability when running serves as an indication of such gains. In addition, Maria affirms that the sensory motor stimulation that her daughter receives on horseback has carried over to improved capabilities with respect to riding her bicycle. Nthabiseng has

developed the capacity to look ahead and propel herself forward on her bicycle with a more certain pedalling action. This indicates not only that the muscle tone in her limbs has strengthened but also that her proprioceptive skills and motor coordination has improved. While Maria's account firmly links Nthabiseng's improvements in posture, motor skills, and bicycle riding to her participation in therapeutic horse riding, it is imperative to bear in mind the difficulties inherent in making such conclusions with certainty. As researchers, we need to consider the cited motor effects as the outcome of a complex interaction between Nthabiseng's participation in therapeutic riding and occupational and physical therapy as well general developmental processes, rather than therapeutic horse riding per se.

Moreover, Alida described Nthabiseng's experiences within the therapeutic riding setting in the following terms:

*A: She is very excited to ride first. It's fun for her. She doesn't even have to build up her self-confidence first. And then she enjoys the activities that are offered there. The reading of books and the looking at pictures. Colouring in. The horse figurines that are on the carpet...She also enjoys playing with them. So the whole time she is boisterous and cheerful. (Alida: Interview 2)*

In recognition of the strides that she made in courageously overcoming her fear of animals, Nthabiseng was allocated the privileged position of being the first rider to mount a horse at therapeutic riding sessions. This status served to nurture and reinforce her growing enthusiasm for horse riding. Alida also notes that Nthabiseng is responsive to and participates fully in the range of educationally oriented psychomotor activities that are available for her (and the rest of her peers) to engage in before and after the mounted activities in the therapeutic riding arena. Clearly, Nthabiseng enjoys engaging in such novel opportunities that are aimed at stimulating her cognitive faculties.

Echoing sentiments expressed earlier on in this discussion, Alida emphasises the recreational appeal that therapeutic riding has for Nthabiseng. An image is presented of her as self-assured and at home within the inherently social therapeutic riding environment. This image is in stark contrast to the initial view of Nthabiseng as terrified and uncertain, and highlights the significant gains that have been made on psychosocial aspects of her functioning.

Further, Alida contended:

*A: To me it is unbelievable how she communicates with the students. Because, I mean, she was the most introverted little one if they ask her to engage in a conversation with them. So it has meant a great deal in terms of her self-confidence and relationships, contact with animals. And it was a great boost for her when she could ride on horseback. I think that it lifted her to a level that actually had an impact on her development as a whole. (Alida: Interview 1)*

In the extract above, Alida reinforces a view of therapeutic horse riding as valuable for Nthabiseng in psychosocial terms. The therapeutic riding environment has provided her with an opportunity to overcome her very real fear of animals by experiencing horses in positive terms. And, overcoming this particular challenge has in turn served to boost her self-confidence. Moreover, the opportunity for relating with other people that therapeutic riding provides to Nthabiseng is also emphasised. Her growing self-confidence is played out in terms of her social competence, evident in the ease with which she engages with leaders and side-walkers within the “Horses for Healing” context. Clearly, Nthabiseng’s social relations in general have been impacted on in positive ways by her participation in therapeutic horse riding.

In addition, Alida explicitly appraises Nthabiseng’s experiences of success and mastery at therapeutic riding as generalising to other areas of functioning and her broader development. In other words, it is not only within the therapeutic riding setting that Nthabiseng appears more self-confident and social, but these gains

are played out in other settings such as the classroom as well. Based on Alida's comments, it is argued that Nthabiseng's participation in the therapeutic horse riding intervention has provided her with opportunities to flourish.

Commenting on how Nthabiseng conducted herself after therapeutic riding sessions, Alida declared:

*A: From everyone, she is one of the little friends who still has the most energy left over then. Who absolutely fights to push a wheelchair - which she may not do. Who is helpful and looks to see what she can carry or so.*

*P: Yes, she is helpful...*

*A: And she will also be the first one at the classroom and get there quickly. So she is not so tired. Especially not as tired as the teacher [Laughs].* (Alida: Interview 2)

Alida has noticed that in comparison to her peers who are often tired after engaging with physically demanding activities that stimulate their psychomotor functioning, Nthabiseng seems energised by her participation in therapeutic horse riding sessions. Remarkably, she utilises this burst of energy towards practically assisting those of her peers who are motorically less capable than she is. Thus, in addition to her home and school contexts, the therapeutic riding setting constitutes yet another site that fosters Nthabiseng's experiences of independence and affords her opportunities to behave agentically and altruistically. Here, too, Nthabiseng is distinguished from her peers in that she serves as a resource for others.

In sum, consistent with the experiences of the participants outlined in the preceding discussion, an appraisal of Nthabiseng's everyday experiences relates improvements in both motor and psychosocial aspects of functioning to her participation in a therapeutic riding intervention. In comparison to the rest of the

participants, Nthabiseng's gains in psychosocial terms are most remarkable in view of her initial very real fear of animals.



#### **4.7. Joanne**

##### **Biographical note**

Like Natalie and Nthabiseng, 6-year-old Joanne has also been diagnosed with diplegic cerebral palsy. However, in comparison to her peers, she is significantly more capable motorically in that she can run, climb and perform cartwheels with ease. And, while Joanne was initially a noticeably quiet child in comparison to her peers, she slowly gained in confidence and became more sociable during the course of her participation in this study.

Her bilingual family lives in a comfortable home in a middle-class suburb of the city. Both her parents are employed, with her mother, Bertha, working on a part-time basis. The couple has a younger son by two years, Callum, with whom Joanne tends to get on well.

##### **Re/negotiating communicative in/competence**

To begin with, considerations with respect to Joanne's cognitive functioning are fundamental to an analysis of her communicative capabilities. In this regard, her teacher, Alida, declared:

*A: She is one of the children about whom I am most concerned cognitively. And she is the one who has made the best progress in my class. It is just fantastic. It is AMAZING what self-confidence can mean for a child. What confidence in yourself... And also she is definitely, in terms of the learning tasks, picked up on what needs to be done, and not looking at a little friend's work to see if she certain or uncertain. She does her work on her own, so it is going well with her, but it bothers me that she sometimes still answers COMPLETELY INAPPROPRIATELY! (Alida: Interview 2)*

Reinforcing and elaborating on such sentiments, Alida stated:

*A: Her work has a good quality. The only thing that still concerns me is that if you have feedback on certain cognitive things then she will sometimes still give you an answer that ALMOST FLOORS YOU. So if you say to her: "What makes this sound: Baa?" then she will say "A cow". Or sometimes she gives such answers, or a basic colour, you will say to her "What colour is this?", then she will say "Purple," then it is a yellow cross. I don't know if she answers impulsively and doesn't think at all, but if you say to her "Look nicely," then the right answer comes. For me it is perhaps a language drawback that has a great impact on her. But to me with her general knowledge questions she is...For instance, about transport, her basic knowledge to me is still incomplete for a little girl of this age. If I perhaps asked her in English, she could perhaps have shown better insight. But sometimes I am a bit concerned about that. (Alida: Interview 2)*

In the extracts above, Joanne's cognitive functioning and development has been appraised in ambiguous terms. While Alida clearly has very serious concerns about Joanne's cognitive capabilities, this is foregrounded by a recognition of the strides that she has made in terms of functioning independently within the classroom context. What is striking is that Alida attributes the gains that she has noticed with respect to the performance of educational tasks to improvements in Joanne's self-confidence. And, while she does not say so explicitly, Alida's claim that Joanne has made the most progress relative to her group of peers with respect to functioning independently inadvertently reminds us of Nthabiseng's tendency to rely on what her classmates do as cues for how to proceed with designated educational tasks. In comparison, Joanne requires relatively little additional assistance from her teacher and/or her classmates. Further, being appraised as having made the most progress within the group of peers is rendered particularly meaningful when contextualised against Joanne's initial lack of assertiveness and introversion that was noticeable in the process of her adjusting to the school environment.

However, in the second extract above, Alida also mentions instances that have given rise to her very real concerns around Joanne's cognitive capabilities. Interestingly, she contemplates whether Joanne's struggles in the classroom are more a function of her difficulties with respect to expressive language functioning that are derived from bilingual language practices at her home, rather than a direct symptom of her diagnosis of cerebral palsy. Thus, second language learning is brought to the fore as a feature that complicates and exacerbates the difficulties that Joanne experiences in her functioning within the classroom setting. In contrast to Nthabiseng's communicative incompetence which was largely ascribed to sociocultural practices,<sup>28</sup> here Joanne's struggles with certain educational tasks have been linked to the tendency for her parents to communicate with her in English and Afrikaans on an inconsistent basis. Alida assumes that by communicating with Joanne in Afrikaans exclusively, her parents would align the language-learning environment at her home with that within her school context; this in turn could facilitate smoother engagements with learning material, and perhaps have positive implications for Joanne's broader cognitive processing and development. However, I could not help wondering whether Alida's perception of Joanne's bilingualism as a hindrance to her functioning in the classroom context could be motivated by Alida's own lack of familiarity with communicating in English.

A final point that Alida emphasised in the preceding extract is that the severe nature of Joanne's cognitive difficulties is reflected in her underdeveloped general knowledge. Yet, given that communicating in a second language warrants higher order cognitive processing skills, a certain ambiguity lies in Alida allowing for the possibility that being questioned in English might have yielded richer and fuller responses from Joanne. Overall, though, Alida's appraises Joanne's cognitive skills and capabilities as "incomplete" or underdeveloped in comparison to that of typically developing 6-year-olds. And, notwithstanding her

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<sup>28</sup> Nthabiseng was not a competent speaker of Afrikaans, the language of instruction and functioning at the school.

efforts to communicate in a second language - which I would be inclined to interpret as a remarkable strength, Joanne's impaired cognitive functioning remains a critical concern for Alida.

It was also striking that when I asked her mother to comment on Joanne's comprehension skills, the issue of communicating in English was raised once again. Bertha asserted:

**B:** *[Her comprehension is] Too good. That is the other thing that she does nowadays. She speaks a lot of English with me. "Mom, will you help me please?" It has never been like that. She used to speak Afrikaans the whole time.*

**P:** *So that is something new?*

**B:** *Hhmm. Then I answer her in English, then we have a little chat in English for five minutes, then it's over again. (Bertha & Rian<sup>29</sup>: Interview 2)*

While appraising her daughter's comprehension skills in positive terms, Bertha proudly declares conversing in English to be a recent development in terms of Joanne's repertoire of capabilities. Moreover, she reports that Joanne initiates such communicative exchanges which she in turn recognises as a meaningful mode of interaction with her daughter. Taking this further, being able to communicate in English when the normative language of communication is Afrikaans is interpreted as a particular competence which sets Joanne apart from her Afrikaans-speaking peers, with positive implications for her self-esteem and sense of self. Indeed, Bertha's validating comments are in stark contrast to her teacher Alida's less than positive appraisal of Joanne's (newfound) second language 'competence'. Here again, the differences between professional and parental experiences and appraisals of the individual children's skills and capabilities is highlighted.

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<sup>29</sup> The interviews were conducted with Joanne's mother, Bertha, but her husband, Rian, sat in on them and made a few useful comments.

In addition, Joanne's father, Rian, commented as follows:

*R: Do you remember the manipulation story? If she wants something that she speaks so softly and everything...But that is a lot less. She will now come to me directly and say she wants this or that. It is just when she is with unfamiliar people then she will come whisper, but in general she expresses herself very well, sometimes TOO well. And if she is naughty, then she will whisper too, if she knows she is in trouble. (Bertha & Rian: Interview 2)*

The reference to Joanne's tendency to speak to her parents coyly whenever there was something that she wanted lends itself to a view of her as perceptive and socially skilled. At the same time, Rian indicates that more recently, Joanne has grown increasingly self-confident and assertive enough to make direct requests when there is something that she wants. In sum, Joanne is appraised as highly competent at utilising her expressive language skills to make known her wants and needs. Importantly, in so doing, she appears to be testing the boundaries of what her parents will permit her to have or do. Such efforts could in turn feed in to her experiences of autonomy and independence.

Joanne's speech therapist, Liesl, also stated:

*L: She understands me. Her comprehension is quite good...But her communication is as if she does a lot more of her own accord...She definitely uses longer sentences, but I think it is because she has more self-confidence to speak. She is quiet though...One thinks that she is sometimes afraid to speak, but if you have won her trust, then she chats nicely. (Liesl: Interview 1)*

Liesl, too, appraises Joanne's expressive and receptive language skills in broadly positive terms. Interestingly, consistent with Alida's sentiments, Liesl also experiences Joanne as having greater self-confidence to engage with her in active ways within the speech therapy context. Further, Joanne's expressive

language capabilities are also linked to the degree to which she is familiar and at ease with the people with whom she communicates. In other words, her perceived introversion is partly accounted for in terms of Joanne not deeming others trustworthy and therefore remaining reserved in her social interactions with them. However, it needs to be taken into account that such responses are not unique to Joanne. Rather, children in general often respond in similar ways.

Moreover, in the extract below, Liesl highlights the complexities inherent in assessing Joanne's communicative competence in the following terms:

*L: So she [Joanne] understands what is going on around her and she can put things together...But the big thing just her language structure, generally good, but she sometimes leaves words out. Doesn't use complex sentences as yet. In other words, if you give her a picture to describe, with that her speech is not very well developed, but for the rest she uses good word order and everything...Her vocabulary is good. (Liesl: Interview 1)*

Here Liesl acknowledges that as a function of her capability for comprehending and integrating information in her day-to-day life, Joanne is attentive to and engages with the social world around her. In addition, she is described as having a good vocabulary. However, in contrast to her skilled receptive language capabilities, Liesl suggests that there is a delay in the development of Joanne's expressive language skills.

Unlike Rachel and Sarah, who are unable to communicate in conventional verbal terms and therefore struggle considerably in terms of social relations with others, the delay that was identified in terms of Joanne's expressive language functioning does not seem to impact in disabling ways on her relationships with either her peers at school or children outside of the school context. On the home front, Joanne has many opportunities to socialise with not only her younger

brother, Callum, but also the children of her parents' friends on a regular basis. Her mother, Bertha, asserted:

***B:** She does have little friends. [She is] Still friends with Kiara. She is really like a sister to her. They fight as well, but they are really crazy about each other and yes, if she [Kiara] comes to visit, the children are in the room...I don't even hear from them. (Bertha & Rian: Interview 2)*

Importantly, unlike Rachel and Sarah, Joanne has access to and benefits from the stimulation of playmates outside of the context of her group of disabled peers at school. Clearly, Joanne is not marginalised or excluded by other, typically developing children. Rather, such friendships serve as a key psychosocial resource for her. Thus, in terms of Ryff and Singer's (1998) model, a key dimension of psychological well-being, namely, positive relations with others, is implicated here. Further, Bertha's account also indicates that Joanne is capable of immersing herself in social play activities in generally harmonious ways. In addition, leaving Joanne to play independently and out of sight of adult supervision suggests that she has also attained a degree of autonomy as well.

On a more candid note, however, Erika, her occupational therapist, summed up Joanne's social functioning in the following terms:

***E:** I don't think she is ever going to really be a social butterfly if I can say that. She's not going to have an outgoing personality...She wants to cooperate, but she is not going to be the leader in the group. She will cooperate and do her best, but she is not going to make plans and so on... (Erika: Interview 1)*

In Erika's view, Joanne is not particularly inclined towards or does not assert herself in social situations. However, her appraisal of Joanne's social functioning needs to be contextualised against her concerns as an occupational therapist. Perhaps in recognising the inappropriateness of her comment around Joanne not

having the potential to “really be a social butterfly,” Erica qualified her statement with the disclaimer “if I can say that”. Clearly, from her commentary above, Erika has the other children in mind as a yardstick against which she evaluates Joanne. For instance, her appraisal of Joanne as not having the drive or potential to be the leader in her group of peers implies a comparison to other children such as Isobel who tends (as discussed earlier) to be more easily social, as well as more assertive and directive in her interactions with her peers. Thus, in terms of the dynamic of comparison that is at play here, Joanne is perceived as not having leadership qualities or potential. However, it counts as psychologically significant that, as I had noticed, she is still recognised as very much a part of her group of peers.

While she had been largely described as a rather introverted and shy child, my comment (during the second year of her participation in this study) that Joanne seemed to be less introverted, was responded to by her teacher (Alida) in the following terms:

*A: That is true, and it is...so that she has begun to behave assertively. That she will say if she doesn't like what a little friend is doing. Or that she just sometimes will shove the little friend away on her own. Sometimes she has reason to...She doesn't let herself be intimidated. She is such that she really can handle herself within her group of little friends, and won't allow that they hurt her. She plays extremely nicely. Especially now that Natalie comes to school more regularly, they place nicely together. (Alida: Interview 2)*

Alida describes Joanne's newfound assertiveness as played out in the context of her social relations with her peers. Thus, while she might not be the leader in the group, she is self-assured and assertive enough to stand her ground within the context of group dynamics and occasional conflicts. And, while she is described as getting on well with her peers in general, Natalie is singled out as a playmate



whose company Joanne particularly enjoys. In sum, the extract above reinforces a view of Joanne as socially integrated into her group of peers.

Moreover, when commenting on Joanne's strengths, Alida made specific reference to her capabilities for sociality. She asserted:

*A: Good self-image. Motivated to work – keen to work. Will come and ask...If the day is not interesting enough, she will come and ask for stimulation. Her perseverance. Her independence...To stand on her own two feet. Good social capabilities with her little friends. (Alida: Interview 2)*

Here Joanne is appraised as having a positive sense of self. Rather than being apathetic or disinterested within the classroom context, her positive self-image manifests in Joanne being enthusiastic and intrinsically motivated in her engagements with educational tasks. Interestingly, the rather assertive habit of requesting additional stimulation when she experiences the activities of the day as insufficiently stimulating is raised as a significant strength that distinguishes Joanne from her group of peers.<sup>30</sup> In addition, in the extract above, Joanne's independence and perseverance are again highlighted, while her social relations with her peers are also emphasised as important psychosocial resources. In sum, Joanne's independence, social skills, and intrinsic motivation count as psychologically significant and feed in to her positive sense of self and experiences of psychological well-being.

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<sup>30</sup> During therapeutic riding sessions too, I observed that in contrast to the rest of the participants, Joanne was most keen to try new psychomotor activities while mounted on horseback. It was striking that apart from a tendency to respond enthusiastically to novel activities, she also sought out challenges of her own accord, and subsequently persevered at them.

Consistent with Alida's account, Bertha responded as follows when I asked her to comment on her daughter's strengths:

***B:** Perseverance, I would say, yes. I think her biggest thing is her self-esteem though. If she didn't have that, she wouldn't have achieved with the rest. That's my opinion.* (Bertha & Rian: Interview 2)

Like Alida, Bertha highlights Joanne's perseverance and self-esteem as particular psychosocial resources. Interestingly, Bertha also sees the development of greater self-esteem as having generalised to different dimensions of her daughter's functioning, and thereby having fed in to Joanne's experiences of success and mastery. In turn, her repertoire of psychosocial resources has been extended.

As the discussion that follows indicates, the effects of her improved self-esteem were also evident across motor dimensions of Joanne's functioning.

### **De/constructing motor skills and in/capabilities**

Given her diagnosis of spastic diplegia, Joanne has experienced a number of struggles along motor dimensions of functioning. At the same time, she has been able to overcome such challenges to a significant degree. For instance, she is capable of eating independently, and can dress herself. Thus, in comparison to the rest of the participants, Joanne requires limited assistance with self-care activities.

During the second year of Joanne's participation in this study, Alida noticed the following shifts with respect to her motor skills and capabilities:

***A:** Initially she used to fall a lot when she just began [at the school], but she is a lot more steady on her feet and she is capable of avoiding obstacles or passing over them. To lift up her little foot if there is a wire or a rope. She runs. And*

*because we don't have a fast class, she keeps to the speed. And even like to walk to the computers, it is a long path and she can definitely keep up with the rest of the class, whereas previously she would have been behind. She has definitely developed out of, a lot of her own potential. She can climb and clamber, swing. (Alida: Interview 2)*

Here Alida presents an image of Joanne as a *motorically capable* child who can move around her physical environment independently and with ease despite her spastic limbs. She is capable of not only walking but also running as well. Moreover, Joanne can use the motorically demanding jungle gym equipment at the school as well as the therapeutic riding setting with confidence. Thus, reference is made to the noticeable strides that she has made with respect to her balance, visuo-spatial and motor coordination, and gross motor functioning.

However, while Joanne is quite agile in other respects, like Isobel, she also struggles with climbing stairs. In this regard, Alida declared:

**A:** *She is much more fixed on her feet, but she still climbs – she needs a railing to climb down. (Alida: Interview 2)*

On a similar note, Joanne's mother stated:

**B:** *We haven't had the opportunity to test her on many stairs. She is comfortable with the stairs here at home. She really wants to do it on her own. Climbing up is much easier than climbing down. She won't approach it herself. She will do it herself, but she must be able to see you. She will never do it by herself. If you are not there, nearby, she will not do it. (Bertha & Rian: Interview 2)*

As I had observed on my visits to her home, Joanne was able to climb up and down the 4 steps that are located (without a railing) at the entrance to the house, somewhat cautiously but independently. Rather than waiting for a hand to hold

on to, she was quite comfortable for there to be an adult nearby as a safety net in the event of her stumbling. While Joanne has had ample opportunities to practice the balance as well as visuo-spatial and motor coordination that climbing stairs entailed within the context of her home - an environment that she negotiates with her impaired body on a daily basis - Alida's account above indicates that in other contexts, she tends to be more comfortable with the use of a railing for assistance with climbing down stairs.

In addition, Bertha made the following comments with respect to her daughter's motor capabilities:

**B:** *I must say her fixation with the right hand is gone. So now and then if she tries to run fast, then the hand is back, but most of the time if she walks, the fixation of her fist is gone. So it tells me her balance is getting better. She still falls if she gets very tired, but it is more, she bumps herself.* (Bertha & Rian: Interview 1).

Here Bertha reports that Joanne's impaired right hand tends to be raised in front of her trunk only when she runs, rather than on a permanent basis,<sup>31</sup> a development that is interpreted as an indication of her improved balance. Further, Joanne's tendency to fall down when tired (referred to earlier by Alida as well) is also mentioned here.<sup>32</sup> However, the qualification that she bumps into objects rather than falls outright is offered. This contributes to an impression of Joanne's struggles on motor dimensions of functioning as less severe than they had been in the past.

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<sup>31</sup> This development serves as a point of contrast with Isobel, whose spastic left hand remains raised in front of her trunk when she walks and runs. On the one hand, once again, the expression of impairments is highlighted as distinct to individual children. On the other hand, the different ways in which each child manages her impairments is also indicated.

<sup>32</sup> Interestingly, commenting with regard to the experiences of children with motor impairments, Bleeker and Mulderij (1992) regard falling down as a clear example of the 'unreliability of the body'.

The following assertions reinforce the preceding sentiments:

**R:** *What she also does outside though is cartwheels, then she makes like a handstand...Everything that is funny that she can do with her little body, throw herself this side [gestures], and then she rolls and spins around.*

**B:** *Now that it is summer, she wants to run races with the little friends that come to play and when we must always “Ready, steady, go!” and then they run together.* (Bertha & Rian: Interview 2)

Commenting on physical vitality, Bleeker and Mulderij (1992) have insightfully pointed out that childhood existence is generally characterised by a great abundance of movement and while the body of the child with motor impairments fairly regularly refuses to do what the child wants it to do, the need for vitality is not frustrated in every respect. Certainly, the extract above indicates that Joanne seems to enjoy experimenting with and almost testing the limits of what her body can do within the context of recreational activities. And, in the process of engaging in sensory motor experiences, she has become more comfortable in and with her body. Thus, Joanne seems to enthusiastically explore how it feels to have a *body that works* by engaging with her environment in active, physical ways, including performing cartwheels and handstands. In so doing, Joanne successfully mimics what she has observed in the other, typically developing children who come to play with her. In addition, she is both confident enough in her body’s capabilities and seems sufficiently skilled proprioceptively to seek out and enjoy running races on the expansive front lawn of her home. This also reinforces an image of Joanne as being neither marginalised nor excluded from play activities by the (able-bodied) children who visit her at her home. Further, an implicit assumption here is that she enjoys having her parents as an audience when engaging in such profound bodily activities. In sum, the preceding extract indicates that Joanne is motorically capable. As a result, her interactions with her physical environment appear to be richer and more dynamic. Moreover, such experiences are tied to positive self-perceptions, an enhanced self-efficacy and a

greater sense of mastery. A final point here is that Joanne's motor capabilities tend to assist her in fostering positive social relations with her playmates, a feature that Ryff and Singer (1998) regard as key to experiences of psychological well-being. In this regard, Joanne's psychosocial experiences are in stark contrast to those of Rachel, whose severely impaired physicality served to hinder her attempts to make contact with and relate to other children.

### **Appraisal of participation in therapeutic riding**

In keeping with the experiences of the rest of the participants, the therapeutic riding context has also served as an environment in which Joanne has made a number of strides psychosocially. Remarkably, in recognition of her efforts and improvements, she was awarded the prize for the best progress achieved at the school's annual prize-giving event during the second year of her participation in therapeutic horse riding sessions.

When asked to comment on whether the improvements that she had noticed in Joanne could be related to her participation in therapeutic horse riding, Erika, her occupational therapist, had the following to say:

*E: You know I don't know what they do at the riding, so I cannot honestly tell you yes, it is the horse riding...But I think the success that she achieves there DEFINITELY carries over to that which she does in class and at therapy. I think a person can draw a relationship there. She achieves success, so now she believes she can do other things that are difficult. She can also do them. She doesn't have to stand back and say she cannot do it, because she is getting something right. So I think, just, that there is a link. (Erika: Interview 1)*

Erika cautiously points once again to the complexities and difficulties inherent in directly attributing improvements in functioning to an individual's participation in interventions such as therapeutic riding. At the same time, however, she offers a positive evaluation of Joanne's participation in therapeutic riding. Here Erika

seems to recognise that the activities within therapeutic riding, and riding a horse in particular, is a psychomotorically demanding task for individuals in general, and children with physical impairments in particular. Hence, the experiences of success and mastery that Joanne has attained at therapeutic riding sessions are appraised as building her self-esteem. Moreover, this sense of self-worth and self-efficacy is regarded as generalising to her experiences in the educational setting and other therapeutic arenas. Stated differently, rather than approaching novel or challenging tasks with apprehension, the success that Joanne experiences when engaging with often difficult tasks and activities within the therapeutic riding context is interpreted as affording her a sense of self-efficacy; this means that she is assertive and willing to approach tasks and activities in other settings with confidence and enthusiasm. At one level, Hammer and colleagues' (2005) elaboration on the argument for the acquisition and mastery of new skills in which they declare that apart from therapeutic gain, a positive motivational factor for the rider is added, is salient here. At another level, positive implications for experiences of autonomy and mastery, key aspects of Ryff and Singer's (1998) model of psychological well-being, are inferred here.

When asked to describe Joanne's behaviour when travelling to therapeutic riding sessions, Alida stated:

*A: She is very jokey together with the kids and chats. And if she sits in front with me and I speak about say, for instance, road safety or about the garbage truck or the garbage bags, I must say Isobel will give also more feedback than Joanne. I can speak to her and point out things to her. There is still not something like, "Look at that!" or "Are they taking the garbage away?" For me there is not yet good insight and more than what you say to her or more than what you ask her about, or not that she shares herself. That aspect is still lacking. (Alida: Interview 2)*

Here an image is presented of Joanne as a child who enjoys affiliating with her peers in a spontaneous and light-hearted manner. However, in contrast, her conversations with Alida are appraised as almost barren and rather unsophisticated; they are limited to simple question and answer type interactions without further elaborations or enquiries on Joanne's part. Such engagements serve as a stark contrast to Isobel who has been described as more responsive and talkative. Moreover, while Natalie is not mentioned explicitly, we are also reminded of the rather sophisticated conversational exchanges with her (during the bus trips to and from therapeutic riding), which Alida had reported as enjoyable and stimulating. In contrast, here Alida indicates that Joanne has limited insight into what she is exposed to. Such sentiments feed in to her earlier sentiments reflecting serious concerns around Joanne's capabilities on cognitive dimensions of functioning.

The tendency to engage with her peers in social ways when travelling to "Horses for Healing" that (Alida had mentioned above) also carried through to therapeutic riding sessions. In response to my observation that Joanne would wave to and try to initiate interactions with her peers whenever they rode past in the therapeutic riding arena, Alida commented:

*A: Yes, she is actually really at ease and she lives herself out in that which happens and [she's] involved with the kids and students and chats with them, whereas she was really introverted and quiet and really almost stressed. They give her a boost, the students and also make her feel special. So they have a great impact on that. (Alida: Interview 2)*

Echoing Mutrie and Faulkner's (2004) sentiments that the provision of physical activity in a supportive group environment represents one of the mechanisms by which opportunities for valuable positive social interactions may be provided, precedence is accorded to the social value of Joanne's participation in therapeutic horse riding. This feature is rendered more meaningful when



considered against her initial quite introverted, almost anxious manner. Moreover, both Alida and I had observed first-hand that Joanne tended to respond positively to and thrive on the attention and praise from the students who acted as leaders and side-walkers. They served not only as a source of conversation, but also validated and facilitated Joanne's experiences of success and mastery. Moreover, such experiences of self-efficacy and positive appraisals from others served to impact positively on her self-confidence and sense of self. Thus, positive implications for key dimensions of psychological well-being theorised by Ryff and Singer (1998), namely, positive relations with others and experiences of mastery, are highlighted yet again.

Like Nthabiseng and Sarah, Joanne has also participated in equestrian shows. Commenting on whether doing so has had an impact on Joanne's life, her mother and teacher offered the following opinions:

**A:** *For me the show was VERY POSITIVE. What she does at the show, to be able to ride on the horse, she can do that well, and she enjoys it, and she has enough self-confidence to do it well. She has received recognition for something that she has achieved and I think that that did her a world of good, to feel special and to feel she stands out.* (Alida: Interview 2)

and,

**B:** *On Saturday after the show she was completely like a jack in the box. She was very excited and full of energy and a chatterbox. Not necessarily about the horse or the show, but as a result of that. So it means a lot to her. And yes, that she got the prize and everyone makes a fuss and so on. For me it was a BIG thing.* (Bertha & Rian: Interview 2)

The extracts above point to a number of interesting features. Firstly, Joanne's participation in the public sporting arena of an equestrian show is appraised as

inherently meaningful for her. In particular, reference is made to her self-efficacy beliefs and competence at performing the designated tasks as noteworthy. Interestingly, the 'feel-good effects' of participating in the show were described as not momentary but rather lasting well after the show was over. Her excitement was evident in that she was uncharacteristically talkative and much more exuberant than usual. Moreover, the positive appraisals from the judges, spectators and her family were also acknowledged to have had positive psychosocial effects. Applying Fredrickson's (2001) thinking to the context at hand, it is inferred that Joanne's experiences of positive emotion within the therapeutic riding setting served to 'broaden-and-build' her opportunities for other positive psychosocial experiences. Finally, for Bertha, too, it was meaningful that concerted efforts were made to praise her daughter's efforts and validate her as a unique individual with specific strengths and capabilities. In other words, her participation in equestrian shows reinforced an image of Joanne as *more than disabled*.

Moreover, at therapeutic riding lessons I had observed that in comparison to the rest of the participants, Joanne had become much more adept at stretching exercises on horseback, a sensory motor experience that has the relaxation of spastic muscles as a goal, while also targeting balance and proprioceptive skills as well. I mentioned this development to Alida in the following terms:

*P: I see she can also stretch very well in comparison to last year, she can just about touch the horse's ears, which she couldn't do before. So she is a lot more flexible with her body...*

*A: For me THAT IS AMAZING. I think the combination of greater courage and self-confidence and what the horse riding does for her PHYSICALLY, has made her strong. (Alida: Interview 2)*

Alida agreed with and took further my appraisal around Joanne's improved motor flexibility as evident in her ability to stretch forward and touch the horse's ears

while on horseback, a task that is demanding in terms of balance as well as visuo-spatial and motor coordination as well. In particular, Joanne's improved self-confidence was cited together with her willingness to try more demanding tasks as a successful combination of motor *and* psychosocial strengths and capabilities. Positive implications for her experiences of success and a sense of mastery are also highlighted here. Finally, broader implications in terms of the resilience that Joanne displays in the face of the motor and psychosocial demands and difficulties that she experiences on account of her diagnosis of cerebral palsy are also inferred.

However, when I mentioned that at therapeutic riding, I experienced Joanne as inconsistent at identifying whether she is on top of the horse or on the ground, and in front of the line of children on horseback or behind them, Erika responded:

***E:** I think that that has a lot to do with position in space. She hasn't yet heard those understandings and really made them hers. The more one is going to do it, and if one starts to do it in therapy and in the class as well, then it is perhaps going to be better for her. Because with the horse riding she experiences it PHYSICALLY. She is on top of the horse, she is alongside Isobel, she is behind or in front, which...a situation that you don't always have in [occupational] therapy, so you must do it with her from where she sits. You sit at the table, or behind the table and I sit in front of the table, and your feet are under the table or on top of the chair. But if she has first internalised it, then I think it's going to stay there. (Erika: Interview 1)*

In the extract above, Erika links the stimulation of Joanne's proprioceptive skills to her participation in therapeutic horse riding. In particular, she identifies the unique inputs that this form of intervention provides to Joanne in terms of opportunities for participating in activities that facilitate her becoming spatially aware of and oriented to the position of her body in space. As Benda and colleagues (2003) have argued, heightened vestibular and proprioceptive

stimulation, continually changing visual fields, and constant shifting of the rider's center of gravity provide important movement learning experiences that children without disability acquire during play on a daily basis. Notwithstanding her consistent acknowledgement of the difficulties inherent in making attributions around direct therapeutic effects then, Erika suggests that therapeutic riding offers certain uniquely physical or practical, tangible situations and activities that Joanne would not necessarily encounter in occupational therapy for instance. This serves to reinforce the sentiment that therapeutic riding has a distinct role to play within the context of a multidisciplinary treatment team. And, on an optimistic note, Erika suggests that cognitively and perceptually, Joanne does have the potential to assimilate the sensory motor experiences that target the stimulation of spatial awareness and proprioceptive skills into her existing repertoire of capabilities.

In sum, Joanne is arguably the most capable participant in relation to the hierarchy of motor skills and capabilities that has been identified as operating within her group of peers. Accordingly, she appears to be the most independent with regard to self-care activities. Interestingly, Natalie shares Joanne's diagnosis of spastic diplegia, but her use of a wheelchair for the purposes of ambulation, and her efforts to move and run in her own idiosyncratic manner serve as stark points of contrast. Once again, the diverse presentation of symptoms and different degrees of impaired motor functioning within the cerebral palsy syndromes (Kerr et al., 2007) as well as the idiosyncratic and adaptive ways in which the children manage their impairments has been highlighted here. Further, notwithstanding her good comprehension skills and her notable efforts to communicate in a second language, Joanne's broader cognitive functioning has been regarded as in need of much attention. Finally, her participation in therapeutic riding has been appraised as an opportunity to express her emerging sense of sociality, while also serving as an arena for experiences of success and mastery which are generalised across different domains of functioning and different contexts.

## CHAPTER FIVE: DISCUSSION OF FINDINGS AND REFLECTIONS ON THE RESEARCH PROCESS

### 5.1. Introduction

The discussion that follows summarises this study's critical findings and contextualises them against existing bodies of work. Further, in an attempt to be reflexive about my role in the research process, the discussion engages in efforts to be self-conscious about the methodology and outlines some of the theoretical and practical issues and caveats that have been grappled with.

This study's location within the South African context renders it fertile ground for considerations highlighted by a social model of disability. Historically, socio-political features have contributed (and continue to contribute) in unique ways to the resources, opportunities and disabling barriers that structure and define the everyday social experiences of individuals with disabilities (Maart et al., 2007; Soudien & Baxen, 2006). It is therefore unsurprising what within such a context, the everyday lives of the participants in this study have been characterised by experiences of difference and othering in relation to non-disabled individuals.

A more striking finding, however, was that the group of participants was subject to a dynamic of difference and othering *in relation to each other*. This dynamic seemed to be dependent on the nature of their impairments in expressive and receptive language functions, as well as motor functioning, features that are cited as key to a diagnosis of cerebral palsy (Rosenbaum, 2003; Rosenbaum et al., 2007). Interestingly, the participants' communicative and motor capabilities have impacted on the degree and quality of their engagements with their environments. In addition, distinct implications for their experiences of sociality were reported. Also, social relations with their disabled and non-disabled peers, as well as with their siblings and parents were highlighted as potentially important protective factors and psychosocial resources that impact on the children's everyday experiences and psychological well-being. In this regard, the

participants' experiences were consistent with reports in the developmental psychology literature around the psychosocial functioning of typically developing children (Berk, 2003; Louw & Louw, 2007). Moreover, because their teachers and therapists tended to struggle (seemingly more so than their parents) to communicate with and engage the participants in practical ways, the degree and quality of stimulation attained from educational and rehabilitative inputs was also compromised by impairments on communicative and motor dimensions of functioning.

Moreover, the participants' experiences of their impaired physicalities were also exacerbated by socioculturally derived barriers in the form of damaged social attitudes and cultural stereotypes around deficit and deviance. A remarkable finding was therefore that the participants tended to utilise their bodies, the site of their impairments (and the source of their experiences of difference, othering and social exclusion), to engage with their environments and social others in their own idiosyncratic and agentic ways. And, by virtue of the tendency to negotiate and often transcend their impaired physicalities, the participants were perceived as motorically capable and indeed functionally autonomous. This in turn also served to challenge the invalidating socioculturally derived stereotypes and attitudes that they were often subject to as individuals with profound forms of physical disability.

Further, it needs to be taken into account that the social context has had a crucial role to play in the participants' everyday experiences as well. The adults who constitute an important part of their social worlds (i.e., their caregivers, teachers and therapists) recognised, were responsive to, and indeed accorded precedence to the children's propensity for negotiating and transcending their impaired physicalities.

And, despite living in a developing country that is relatively resource-poor and often struggles to meet the health care, educational and rehabilitation needs of

children with disabilities (Maart et al, 2007; Saloojee, Phohole, Saloojee & IJsselmuiden, 2006; Soudien & Baxen, 2006), the participants in this study were well cared for in their immediate social environments. Interestingly, in their accounts, the mothers in particular tended to accord an 'ordinary human value' to the participants, affirming that their children have a shared ontological worth in common with other individuals in society. In so doing, they have reinforced the sentiments expressed by McDougall, Swartz and Van Der Merwe (2006) and Murray (2006) around viewing disability as ordinary and everyday, and perceiving and experiencing children with disabilities as *more than disabled*. In other words, the mothers regarded disability as a single (important) facet and not the sum total of their children's identities. Such a validating stance is important given that society places a lesser value on the personhood of individuals with disabilities, an approach that is reflected in negative social attitudes as well as practically in terms of resource allocation and infrastructure.

Having considered the general findings yielded in relation to the children's everyday lives, the discussion that follows highlights their experiences of participation in a therapeutic horse riding intervention.

## **5.2. Therapeutic Horse Riding**

Largely consistent with findings in the limited body of extant, mostly European and North American studies, the participants' experiences of therapeutic horse riding was reported to be characterised by positive psychosocial effects. These included increases in experiences of success and mastery, increases in self-efficacy beliefs and autonomy, improved self-esteem, as well as enhanced social participation and social skills (Bizub et al, 2003; Carlson, 1983; Crawley et al, 1994; DelGiudice & Berg, 2003; Farias-Tomaszewski et al, 2001; Grobler, 2004; Helfer, 2006; Kaiser et al, 2006; Lehrman & Ross, 2001; Ludewig, 2006; MacKinnon & Ferreira, 2002; MacKinnon, Noh, Lariviere, MacPhail, Allan & Laliberte, 1995; Miller & Alston, 2004; Rufus, 1997; Stuart, 1998; Tredoux, 2000; Von Moltke, 2002; Wood, 1990). Importantly, such positive psychosocial

experiences were reported as generalising to contexts beyond the therapeutic riding setting.

In contrast, to existing bodies of work which have yielded findings such as improvements in balance, coordination and muscular control, as well as strength, posture and joint mobility, in addition to enhanced gross motor functioning (e.g., Bertoti, 1988, 1991; Biery & Kaufmann, 1989; Cherng et al., 2004; MacKay-Lyons et al., 1988; MacPhail et al., 1998; Sterba et al., 2002; Van Dyk et al., 1994; Winchester et al., 2002), here physical effects were observed to be rather short-lived. For instance, both Isobel and Joanne's spastic muscles tended to relax noticeably within strides of entering the therapeutic riding arena, but then promptly returned to their spastic state not long after the children dismounted their horses. However, in terms of the pathways through which therapeutic riding works, positive psychosocial experiences were implicated in subtle shifts that had been reported with respect to motor dimensions of functioning. Importantly, a positive sense of self also had encouraging effects across other domains of functioning and different settings. For example, with respect to Natalie, such positive psychosocial experiences were reported to have contributed to her being able to 'stand' on her knees for longer periods of time and with greater ease. This then impacted positively on her ability to participate in a domestic activity that she valued highly, that of clearing the dining table with her mother. For Nthabiseng, too, sensory motor stimulation on horseback was associated with improved motor coordination and spatial awareness that resulted in greater skill and confidence in riding a bicycle, a recreational activity that she had aspired to for some time.

To summarise, in the course of engaging with psychomotorically demanding therapeutic riding activities during their participation in this study, the participants came to experience their bodies as competent and functional. This experience of their bodies as *bodies that work* in turn had positive implications for how they felt about their bodies and themselves. Moreover, an enhanced sense of personal



worth tended to minimise their experiences of their bodies as impaired and disabled. In this way, their participation in therapeutic horse riding facilitated the children's experiences of themselves *as more than disabled*.

### **5.3. 'What Counts as Therapeutic?'**

In reflecting on the aforementioned findings, it is useful to acknowledge that the question of "What counts as therapeutic?" was an issue that I grappled with on a consistent basis (from formulation to writing up stages) while conducting this study. Indeed, establishing therapeutic efficacy in unambiguous ways is a challenge that has pervaded not only this study in particular and rehabilitation practice, but also work in psychotherapy research.

A number of reasons underlie the particular challenge to the research design posed by limiting the focus of study to investigating the effects of participation in a single therapeutic intervention. At one level, it needs to be recognised that for children with quite profound forms of impairment, simultaneous and ongoing involvement in a range of interventions is a fairly standard approach to treatment within a multidisciplinary team. In the present study, too, the choice of research design was dependent on the reality that the participants with cerebral palsy were already involved in a range of therapeutic interventions apart from therapeutic horse riding. Importantly, within the field of disability and rehabilitation, research decisions around not suspending participation in other potentially valuable forms of therapy tend to be ethically driven. Here, too, the position that it would not be in the best interests of the child to place research agendas above that of the possible gains that could be attained by participating in a range of therapeutic interventions on a continuous basis was adopted. At another level, it is important to acknowledge that features of natural maturational processes render establishing cause-effect relationships that attribute specific gains with complete certainty to participation in certain interventions an elusive task. Thus, Dockrell and colleagues (2002) have insightfully declared, firstly, that "children's behaviour or performance does not necessarily change (develop) in a

straightforward and additive manner” (p.49), and secondly, that this is unsurprising in view of the range of influences that operate in the course of development.

My own grappling with the issue of what counts as therapeutic was also reinforced by the literature which revealed that existing (largely quantitatively oriented) work in the therapeutic riding field was often lacking methodologically, rendering the available knowledge base somewhat inadequate (MacKinnon, Noh, Laliberte, Lariviere & Allan, 1995; MacKinnon, Noh, Lariviere, MacPhail, Allan & Laliberte, 1995; Pauw, 1998, 2000). As disconcerting was that theorising around the mechanisms and processes by which therapeutic horse riding effected the changes that had been reported was largely absent. To this end, I saw it fit to draw on theoretical frameworks within psychology to delineate possible mechanisms and processes by which therapeutic horse riding as an adjunctive intervention could potentially effect shifts in the everyday functioning of the children with disabilities who participate in such interventions.

#### **5.4. Mechanisms and Processes Involved in Therapeutic Shifts**

In terms of the dynamics and processes that this study had outlined (refer to Chapter Two), the attributes of therapeutic horse riding stated below (in no particular order) stood out as definitive of the participants’ experiences.

Firstly, in contrast to other, overtly clinical forms of intervention, therapeutic riding’s recreational nature held particular value. In this regard, Graham (2000) has declared that therapeutic riding provides a novel and creative form of intervention for individuals who might have been accustomed to and become disillusioned by treatment within traditional settings. Indeed, Benda, McGibbon and Grant (2003) have viewed therapeutic horse riding as a site for nurturing and developing capabilities that may be untapped through conventional treatment. Also informative is All and colleagues’ (1999) contention that horse riding, out in the fresh air and away from facilities associated with chronic illness and disability,

imparts a sense of general well-being. Further, while the participants were involved in a range of interventions, therapeutic riding was appraised as an enjoyable experience that held particular appeal on account of its location within a natural setting that afforded opportunities for social interactions with human and animal others.

A related point is that precedence was accorded to therapeutic riding as providing an opportunity for riders to live out their socialities and foster positive relations with others. For instance, the therapeutic riding setting afforded Joanne, who was initially the most introverted child amongst her group of peers, an opportunity to slowly become less anxious and more confident in her interactions within the group of children. In addition, for Nthabiseng, the opportunities for exposure to and relating with horses provided an arena within which to overcome her fears of animals. And, for participants such as Isobel and Natalie, the therapeutic riding context served as yet another site within which to live out their natural inclinations to be social. Perhaps more striking was that for Rachel, who was home-schooled and rather isolated from contact with other children, being outdoors and away from the socially isolated classroom at her home was accorded precedence. Indeed, utilising her own idiosyncratic (if often misinterpreted) forms of communication to engage with her social environment and relate with her peers in particular was reported as psychologically significant. In sum, the participants' psychosocial resources were elaborated and extended in terms of social bonds with their peers. Also, the leaders and side-walkers served a facilitating role in relation to affirming and validating the participants' efforts and identities.

Thirdly, participation in this form of intervention constituted a profound bodily experience that fed in to the riders' experiences of positive emotions. In particular, feeling good about their bodies and themselves was noted. As stated earlier, this often had further positive consequences in terms of the participants

being more functionally autonomous on other dimensions of functioning and across different settings.

Fourthly, it was indicated (primarily by Erika, an occupational therapist) that, in concert with the other forms of therapy that they participated in, therapeutic riding served to maintain riders' current levels of functioning and prevent further deterioration, particularly in relation to motor capabilities. This was particularly interesting to me in view of the standard tendency within treatment and rehabilitation contexts to aspire to therapeutic goals that are dominated by value-laden judgements with regard to tangible and easily observed 'progress'. However, here their proxies came to value the small shifts as meaningful for the participants.

Finally, therapeutic riding's tendency to offer the experience of participation in a sporting activity was highlighted. Previous research in the field (e.g., MacKinnon & Ferreira, 2002; Wood, 1990) has tended to conceptualise this dimension of therapeutic horse riding in terms of providing an opportunity for the rider to be competitive, and participate in an activity that is recognised as a sport (MacKinnon & Ferreira, 2002; Wood, 1990). What was striking here was that an added dimension, that of a consciousness-raising role, was accorded to such experiences by Sarah's mother, Maya. Participation in the sporting dimension of therapeutic riding, namely equestrian shows, was interpreted as a challenge to and a rejection of the pathologising stereotypes that individuals with quite profound forms of disability are subject to by society at large. Indeed, participation in equestrian shows was appraised as providing tangible evidence of children with disabilities as capable, and of their impaired bodies as *bodies that work*. In this way, therapeutic riding served as a context that could facilitate an understanding of disability as but one important facet of the children's identities.

Interestingly, my own grappling with the issue of how to establish therapeutic efficacy in the course of research with children with quite profound disabilities was also reflected in the (unprompted) accounts of certain respondents. The accounts of the occupational therapists, Erika and Sumari, revealed that they, too, had sought to make sense of what therapeutic riding entailed and could offer to the children. While they were experienced practitioners in the field of occupational therapy, both Erika and Sumari were unfamiliar with what therapeutic riding entails. They seemed to agree in principle that riding a horse could hold therapeutic value, but contemplated the specifics around the ways in which it works to be therapeutic. To an extent, Sumari resolved this question by emphasising therapeutic riding's input into the rider's emotional well-being. In addition, Erika focused on the role that therapeutic riding plays with respect to the maintenance of current levels of functioning within the context of the multidisciplinary treatment team. Interestingly, Isobel's mother, Mariette, also contemplated what counts as therapeutic, and resolved this question for herself by offering the rationale that therapeutic horse riding is one amongst a limited repertoire of sporting activities available for her daughter to participate in. Moreover, therapeutic riding's role in providing Isobel with the sensory-motor stimulation that is critical to the treatment of her quite profound motor impairments was also highlighted. Thus, Mariette's sentiments echoed that of the literature (e.g., Finnie, 2002; Rosenbaum, 2003) which tends to accord primacy to the motor dimensions of functioning as the focus of therapeutic attention where children with cerebral palsy are concerned.

In view of the foregoing considerations around what counts as therapeutic, it was clear to me that the interviewees had not harboured any naïve illusions about the effects of therapeutic horse riding, and felt comfortable enough with the interviewing relationship to express their ambivalence with regard to the efficacy of this form of intervention. This indicates to an extent that the rapport that was built during our initial interactions was such that the interviewees were at ease in

expressing their perceptions, thoughts and feelings (which might not necessarily have been overtly validating of therapeutic riding) to me freely.

### **5.5. Research with Children with Disabilities**

Continuing to reflect on methodological considerations, a review of the literature has also served as a reminder of the unique challenges that apply specifically to research with children with quite profound disabilities (Begley, 2002; Detheridge, 2002). For instance, Begley's (2002) observation that children with disabilities have a slow rate of development that is marked by very subtle and small shifts was informative here. I was also well aware that in selecting the experiences of children with cerebral palsy as a focus of study, such symptom features as low levels of cognitive functioning and a range of difficulties in expressive and receptive language functioning were going to be a particular challenge.

The research questions and the nature of the impairments that children with cerebral palsy characteristically experience were taken into account in selecting an appropriate method of inquiry. In particular, this study utilised a range of proxy reports in combination with my own participant observations of children's everyday lived experiences toward building what could be regarded as case-like histories of each child. Through the medium of proxy accounts from key role players in the children's lives (namely their mothers, teachers and therapists), an attempt was made to 'capture' and make sense of the situations, emotions, thoughts, actions, inconsistencies and ambiguities that characterise the participants' life worlds.

### **5.6. My Involvement with "Horses for Healing": Implications for Conducting this Study**

Insightfully, Shipman (1997) has declared that the motives for researching the human condition have always included the hope of improving it. While such sentiments are applicable here, my observations during the months of volunteering as a leader and side-walker at "Horses for Healing" that I had

engaged in as a precursor to commencing with this study were useful on a number of levels. In relation to hopes of seeing changes in functioning, my involvement helped me to acknowledge and discard any preconceived expectations of grand-scale improvements in functioning that I might have initially nurtured. In addition, throughout this study, I had to be watchful of seeing improvements where there might have been none. In other words, I had to avoid self-fulfilling effects or outcomes in relation to the influence of therapeutic horse riding. Moreover, I also made a concerted effort to avoid raising expectations or influencing proxies' perceptions of what does and might occur through participation in therapeutic horse riding. Indeed, given that the participants constituted a group of individuals whose experiences are often invalidated in the broader society, I was all the more careful about standard ethical issues that apply to research with human participants, including those of informed consent, avoidance of deception, and confidentiality (Woodhead & Faulkner, 2008). Moreover, the ethical principle of beneficence, which Grieg and Taylor (1999) have described in terms of an obligation to weigh and balance benefits against harms, was strictly adhered to.

An important consideration attached to involvement in therapeutic riding is the recognition that as animals, the well-schooled horses could and sometimes do behave in unpredictable ways. And, especially where individuals had quite profound physical impairments, and were new to being on horseback, it was necessary to be particularly alert to safety procedures. As a result of being mindful of safety risks and precautions, I was not casual in my approach to the practicalities of this study, and the safety of the children in particular. This stance seemed to have been recognised by gatekeepers<sup>33</sup> such as Alida who, while initially a bit cautious about whether I would look beyond the research agenda towards safeguarding the participants' interests more broadly, seemed to have been convinced otherwise by her observations of my initial interactions with them

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<sup>33</sup> Gatekeepers have been defined as essentially individuals who manage the research site or control access to individuals who are intended research participants; they have the safeguarding of participants' interests in mind (Grieg & Taylor, 1999).

within the therapeutic riding setting. I suspect that if Alida had not been satisfied that my intentions were sound and that I would be respectful of the participants as individuals, she would not have served the key role that she did as the gatekeeper to my access to the children, parents, and therapists with the degree of commitment that she showed. Echoing the sentiments of Greig and Taylor (1999), I found that good communication with gatekeepers such as Alida and Hester, the manager of the therapeutic riding facility, was prerequisite to conducting this study in authentic and ethical ways.

Another key aspect of conducting myself as a researcher in ethical ways was about being genuine or real with, empathic towards, and respectful of the participants. As researchers we need to be cognisant of the fact that how we conceptualise children with disabilities is key to the research process. Like Davis and colleagues, in my study, I, too, endeavoured to take seriously their role as “social actors negotiating their own social worlds” (Davis, Watson & Cunningham-Burley, 2008, p.227). Reflecting such a view - one that was shared importantly, within the therapeutic riding setting by Hester - the children were empowered to make choices with regard to their participation in therapeutic riding lessons upon their arrival at each session.<sup>34</sup> In so doing, they were involved inadvertently in choices about whether to participate in this research project on a continuous basis. And, within each therapeutic riding session, the participants were free to choose whether they wanted a snack to eat and something to drink before riding if they so wished. In terms of psychomotorically-oriented play activities as well, the children were able to choose from a range of available items. Being presented with and having to respond to the choices mentioned above on a continuous basis formed part of concerted efforts to facilitate the participants’ experiences of themselves as autonomous and capable individuals within the therapeutic riding context. Such experiences of autonomy and

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<sup>34</sup> On the rare occasions when they were not keen to ride, I found that non-speaking participants, Rachel and Sarah, were also able to indicate to that effect in an unambiguous manner. This formed part of my lesson in reading their communications.



competence were reported as having generalised to contexts outside of therapeutic riding sessions.

Despite such efforts, the issue of representation was one that I grappled with during the course of this study. In particular, it was necessary to consistently interrogate whether as an able-bodied adult, among other memberships, I could tap in to, understand, and represent the experiences of children with profound disabilities in authentic ways. Insightfully, in asking the question “Do you have to be one to know one?” Brian Fay (2001) has made a useful distinction between knowing and being. Fay (2001) has argued that knowing an experience does not mean just having it, but rather refers to being able to express or articulate what it is. In addition, he has posited that “knowledge consists not in the experience itself but in grasping the sense of the experience” (Fay, 2001, p.27). And, precisely because knowing entails grasping meaning rather than merely experiencing, being one is, according to Fay (2001), neither necessary nor sufficient for knowing one. Thus, knowledge as interpretive understanding takes precedence over a conceptualisation of knowledge as psychological identification. Further, Fay (2001) has argued that even though I need not necessarily be one in order to know one, as a researcher I would need to gain insight into the lived experiences of the participants in this study. To this end, I relied heavily on data from interviews with a range of proxies, including mothers, teachers and therapists, to ‘capture’ and make sense of the everyday circumstances, emotions, thoughts, actions, ambivalences and inconsistencies that constitute the children’s life worlds.

### **5.7. Personal Memberships and the Research Process**

In reflecting on the relationships that had developed between myself and the group of interviewees who served as proxies, a number of idiosyncratic features could account for the interpersonal dynamics at play. Clearly how teachers, parents and therapists experienced, interpreted and reported on the participants’ behaviours was contingent on their professional and personal memberships and

backgrounds, including their prior experiences, preconceptions, prejudices and values. These factors impacted unavoidably on the quality of data that was co-constructed in the interviewing process.

I was also compelled to contemplate my own sense of identity and difference in relation to disability in order to address the dilemmas engendered by my position as a member of a privileged group of 'able-bodied' individuals. Thus, I realised early on in my thinking around this study that, like many individuals in society, I tended to take my position as an able-bodied individual for granted. Indeed, up until the psychology of disability became a research interest, individuals with disabilities were not a part of my frame of reference. However, my own myopia needs to be contextualised within the broader South African context, for in our society there is a definite silence that operates in relation to disability. McDougall and colleagues (2006) suggest that part of the reason for this silence, or secrecy even, may be that disability is sometimes seen as a shame or a disgrace, representative of something to hide away, and a source of stigma. These reactions are based on the idea that disability is freakish or monstrous, a perception that continues to haunt the ways in which disability is seen, as well as affect the experiences of individuals with disabilities and their families (McDougall et al, 2006). Thus, my own myopia in taking for granted my able-bodied status reflects the often marginalised, hidden, almost invisible social status that is accorded to individuals with disabilities in our society (Holt, 2004; Hughes & Paterson, 1997; Paterson & Hughes, 1999; Woolfson, 2004).

### **5.8. My Body and Disability Status**

Given that this study was concerned with investigating the subjective experiences of a group of children with cerebral palsy, it followed that issues around the body, embodiment and physical impairment constituted significant features for analytic consideration. Yet, in drawing attention to my own body in this discussion, I have attempted here to move away from what Ellingson (2006) has described as the tendency within academic discourse for "[health care]

researchers' bodies to remain unmarked - and hence naturalised as normative" (p. 300). Insightfully, Ellingson has observed that "If I am outside the boundaries of normalcy, I become a reference for the normal, an example of what is wrong that serves to affirm what is correct" (2006, p.299). With regard to power differentials within the researcher-research participant relationship then, it needs to be taken into account that it is with reference to the participants' disability status that my own identity as 'normal' and 'able-bodied' is privileged. Such dynamics are inherently problematic in that they lend themselves to inadvertently reflecting the status quo. Certainly, I was aware that, as Marks (1999b) suggests, perhaps because of the ways in which individuals with disabilities are marginalised and excluded from society, some people react (unsurprisingly) by feeling threatened psychologically by individuals with disabilities. As a result, it was crucial for me in my role as the researcher conducting this study to be sensitised to the movement between 'non-disabled' and 'disabled' or what has aptly been described as the contingency of the status of 'disabled' and the status of 'non-disabled' (Breckenridge & Volger, 2001; Marks, 1999b; Siebers, 2006). In other words, the insight that disability is not a fixed identity and that as human beings we are all open to taking on a 'disabled status' served to inform my interactions with the participants and their proxies in significant ways.

Such a stance was made more real for me during an instance of hospitalisation on account of a cardiac complication, where, for a brief period in time, my body ceased to be 'a body that works'. The frustrating need for assistance with previously taken for granted capabilities such as utilising cutlery to cut up my food on a dinner plate independently, combing my hair, and reaching for a light switch highlighted my feelings of dependence and placed me in a position of vulnerability. Indeed, the interaction of my temporarily impaired physicality and the ironically disabling physical environment of the hospital ward were brought to the fore. At the same time, however, I was well aware that my experiences were qualitatively different from those of the participants with quite profound physical impairments on account of their temporary nature. Obviously, a temporary

experience of my body as a body that did not work would not have deep and long lasting implications for my sense of self as I did not share in the experience of impairments as permanent nor was I subject to the disabling sociocultural barriers around difference and deficit that individuals with disabilities are systematically confronted with. However, applying Frank's (2004) thinking to the context at hand, it was my experience that acknowledging the body served to reaffirm my common humanity with the participants by keeping me on the same (messy, imperfectly controlled) level where these individuals with cerebral palsy must live. Indeed, following Frank (2004), a certain compassion and generosity toward this study's research participants was warranted as integral to my analysis and theorising of their everyday experiences. Overall, my own experiences afforded me a newfound empathy and respect for the resilience, courage and vulnerabilities of individuals with disabilities more broadly, and the young participants in this study in particular.

### **5.9. A Facilitating Factor in the Research Process: An Overlap of World-Views**

The discussion that follows argues that a number of factors such as social class, gender and language contributed to an overlap of world-views with the proxies, a feature that facilitated the research process in significant ways.

It needs to be taken into account that during the initial meetings with the participants' parents, teachers, and occupational therapists for the purposes of data gathering, I received neither verbal nor non-verbal indications that the interviewees were ill at ease with me, and was given warm welcomes into the participants' lives, families and homes. So, while at one level, being Indian clearly distinguished me from the participants and their proxies, it is my view that at another level, sharing a middle-class background with the majority of the interviewees went some way toward glossing over differences in racial backgrounds. This shared membership also seemed to assist in building

relationships with the interviewees and facilitated access to quite frank accounts of the participants' subjective experiences.

As a researcher, having gender in common with interviewees<sup>35</sup> was also an important source of identification. This shared membership seems to matter more so in the case of the mothers whose accounts sometimes entailed sharing and reflecting on quite difficult, sensitive experiences. A prominent argument within work on feminist methodology concerning the issue of gender as a point of social cohesion in research with women is informative here (Burman, 1994; Kitzinger, 2004; Maynard & Purvis, 1994). Indeed, I believe that had I been a male researcher, they might not have spoken about the participants' life worlds and everyday experiences with such spontaneity, ease and unbridled honesty.

Perhaps coming from a university, an institution of higher learning, could also have added a certain credibility to my role as an interviewer/researcher. Apart from the status that was accorded to the middle-class occupation of a lecturer, it was my experience that the proxies perceived me, and the research task that I had undertaken, seriously. Further, while informed consent had been granted, and the interviewees and the children were free to suspend their participation in this study at any point in time, I could not help wondering whether they would have taken me less seriously if I had been a student only and was not employed as a lecturer as well. Thus, in contrast to students, whose interests and involvements tend to be perceived as somewhat temporary or impermanent in nature, I seemed to be accorded a higher status and respected as the lecturer who was responsible for formulating and managing the research project as well. Perhaps my academic background was interpreted to mean that I was doing important work in terms of contributing the education of others at a tertiary level, thereby affording me a certain respect and credibility within the research context.

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<sup>35</sup> Interestingly, along with the participants, all the interviewees were female, with the exception of Joanne's father, Rian, who chose to participate in the interviews as well.

It also counted as significant that I was not a researcher approaching this study without prior practical knowledge and experience with horses and horse riding. And, while volunteering as a leader and a side-walker on a part-time basis in the months leading up to this study, I familiarised myself with the “Horses for Healing” setting in terms of the physical layout (such as where to get to the riding helmets from if they were not on hand when riders arrived for lessons) and routine. This afforded me an opportunity to blend in to the therapeutic riding environment. And, during this time I was granted privileged access to such spaces as the tack room – a domain that had previously been reserved for the therapeutic riding instructors and other personnel at “Horses for Healing”. Moreover, I perceived this access to therapeutic riding spaces as an indication that I was trusted with the riders as well as with the horses and quite expensive equipment that was necessary for therapeutic riding lessons. Perhaps this easy assimilation had to do with Hester (the manager at the therapeutic riding facility) recognising my own involvement with horses and horse riding as both a recreational activity and a sport, a pastime that had predated and indeed inspired my role as the researcher conducting this study. Certainly, my own horse riding background served not only practical utility but as a point of shared interest, it facilitated the development of an easy rapport between myself and the members of the therapeutic riding team.

In this study, it was also important in my role as researcher to ensure that the young participants were comfortable in their interactions with me, and communicating with those who were Afrikaans-speaking in their mother tongue seemed key to facilitating smoother social interactions. With this weekly exercise in conversing exclusively in Afrikaans at therapeutic horse riding, I (and individuals within my immediate life contexts) found that my spoken and written Afrikaans improved considerably. Moreover, this newfound language competence was generalised to contexts beyond the present study. Unfortunately, I could not afford the same courtesy to Nthabiseng’s Sotho-speaking mother, as I was not at all conversant in the language. However, Maria

was bilingual, and very obliging about, and comfortable with, interviews being conducted in English. Further, I found that the process of interviewing in Afrikaans was very time-consuming in terms of preparation, and took a fair amount of getting accustomed to on my part. However, the interviewees were most forgiving of my errors in grammar, and seemed to appreciate my attempts at communicating with them in their mother tongue. In my experience such efforts played a role in gaining the parents' approval, cooperation and confidence in me as a researcher working with their children. The same sentiments applied with respect to the rest of the Afrikaans-speaking interviewees in this study.

And, while I had been somewhat concerned about how to communicate with non-speaking participants such as Rachel and Sarah in particular, my role as researcher/participant observer offered me the opportunity to notice and familiarise myself with the distinct, idiosyncratic yet agentic ways in which they utilised their physicalities to communicate their thoughts, feelings and intentions. In the course of my interactions with the participants over the two-year period, I grew reasonably conversant in reading and interpreting their communications, and could therefore relate with greater ease to insights in this regard offered by their proxies within the interviewing context.

In an earlier attempt to conduct this study in ways that were more inclusive of the participants, I had piloted the option of capturing their experiences through audio-visual recordings with a hand-held video camera. I had rather mixed feelings when I found that for the most part, the children were aware that they were being video-recorded and therefore tended to 'perform' for the camera, altering their behaviour in what appeared to be significant ways, a classic example of the 'Hawthorne effect' (Myers, 2005). This experience contributed to my decision to utilise qualitative interviews with a range of proxies as a primary source of data. As stated earlier, this decision was also dominated by an appreciation that as children with cerebral palsy, the participants had quite profound forms of impairment including low levels of cognitive functioning and a range of difficulties

in expressive and receptive language functioning, thereby rendering proxy accounts from key role players to be a significant and most useful source of data.

In concluding this discussion, it is important to recognise that in this study, which has been interpretive in nature, precedence has been accorded to the value of “thick” descriptive accounts that are grounded in (rather than divorced from) the concrete situations that they are supposed to reflect. As Shipman (1997) has declared, the findings of this interpretive study provide insights but not generalisations. Moreover, we need to appreciate that their strength and weakness lies in that they remain in context (Shipman, 1997).



## **CHAPTER SIX: CONCLUSION: DIRECTIONS FOR FURTHER RESEARCH**

Particularly when one is interested in investigating the subtle shifts that could occur in the functioning of children with quite profound disabilities, the nature of their impairments, and the practicalities related to such considerations render conducting research an extremely challenging enterprise. Early on in this study, I found myself unimpressed by the globalisation of existing, largely quantitatively oriented research about therapeutic effects in relation to children with disabilities. I therefore had little choice but to think in qualitative terms about how to explore and ‘capture’ the everyday experiences of a group of children with cerebral palsy who were participants in a therapeutic horse riding intervention. In other words, an interpretive approach was deemed as more suitable than large scale, quantitative approaches. Adopting a qualitative, interpretive approach to inquiry, the present study examined the everyday experiences of a group of six children with cerebral palsy who participated in a therapeutic horse riding intervention programme over a two-year period. The discussion that follows outlines a number of key issues and directions for further research in the field of childhood disability and rehabilitation. These suggestions were prompted by the “thick descriptions” and “thick interpretations” of accounts of the participants’ day-to-day lives as well as some of the limitations of this study.

To begin with, an interesting finding in the present study was that in highlighting the participants’ inconsistent, often contradictory everyday experiences and complex humanity, idiosyncratic differences between children with cerebral palsy were illuminated. This served to reinforce the idea that they constitute a heterogeneous group of individuals while simultaneously challenging existing bodies of work that have tended to gloss over differences between them. Further, this study found that in the context of their everyday lives, the children with cerebral palsy were subject to exclusionary practices and experiences of difference in their relations with non-disabled individuals. This finding is not new, and may be contextualised within the extensive body of work with respect to a

social model of disability (e.g., Abberley, 1987, 1992; Barnes, 1996; Barton, 1996; Hughes & Paterson, 1997; Low, 2001; Maart et al., 2007; Oliver, 1983, 1990, 1996; Paterson & Hughes, 1999; Shakespeare, 1996; Smith & Sparkes, 2008; Soudien & Baxen, 2006). More striking, however, was that the participants were subject to experiences of difference and othering in relation to their disabled peers as well. Interestingly, such experiences may be accounted for in terms of a hierarchy of impairments with respect to their capabilities for communication and motor functioning that was identified as operating within the group of participants. This finding around group dynamics in relation to children with disabilities constitutes a key insight that is worthy of further research attention.

Moreover, consistent with work by McDougall and colleagues (2006) and Murray (2006), for instance, it was also significant that in this study, the mothers' accounts revealed a view of the participants as possessing 'an ordinary human value'. Such a view seemed to form an integral part of more affirming, validating perceptions and experiences of their children as *more than just disabled*. An important consideration here is that the application of less pathologising frames of reference within treatment and rehabilitation contexts would render individuals with more profound forms of impairment easier to identify with and relate to. This could in turn facilitate rapport building between health care professionals and children with disabilities as well as their families. And, in the long term, more affirming relationships with health care professionals could be a starting point for distilling and challenging broader sociocultural stereotypes of children with disabilities as other, and thereby work towards reducing their experiences of marginalisation and exclusion from society.

Further, contextualised against a social model of disability, it is argued that in a developing country such as South Africa, with its distinctive socioeconomic and political history, social class needs to be further examined as a factor which impacts on access to educational and therapeutic resources, quality care, and stimulation in often significant ways. Indeed, the role that social class plays in

facilitating the development of both enabling and disabling psychosocial and physical environments for children with disabilities warrants due research attention.

Given the diversity of individuals within the South African context, it follows that exploring how disability and impairment are conceived of and lived within and across different cultural groups constitutes a useful direction for further research. In practical terms, this would mean that studies should consist of samples that are more inclusive of individuals from the different cultural groups. And, ideally, the individuals responsible for the collection of data should be capable of communicating with participants in their mother tongues.

In addition, an option that this study was unable to investigate on account of its all-female group of participants was the possibility that children's experiences of disability could be gendered in nature. While this issue has received some attention in relation to adult populations (e.g., Meekosha, 1998; Morris, 1994; Murtagh & Hubert, 2004; Nosek & Hughes, 2003; Thomas, 2001), there seems to be a dearth of research engagement with gender as it pertains to experiences of childhood disability. Accordingly, future studies could for instance explore whether group dynamics remain distinguished in terms of individuals' communicative and motor capabilities when the sample of children with disabilities consists of participants of both genders.

While a limited sample of six participants was used here, it needs to be recognised that in qualitative methodology, too, a larger sample affords one a clearer sense of identifying tendencies and making claims. In other words, the value of aggregating "thick descriptions" and "thick interpretations" with respect to a larger number of participants needs to be appreciated. Yet, in working qualitatively, researchers who utilise a larger sample than that of the present study are just as likely to encounter the challenge of being overwhelmed by and drowning in an overly extensive body of data that I had struggled with. However,

fewer financial constraints on research resources would mean that trained research assistants could go some way towards assisting the primary researcher with the process of data collection, especially where a triangulation of methods and sources of data are utilised. While this would reduce the labour intensive nature of this type of qualitative work, it is imperative that where possible, the primary researcher should identify and thoroughly specify the fine indicators and dimensions that research assistants should look for and aim to capture.

Moving on to insights with regard to therapeutic interventions, as researchers we need to be cognisant of the fact that different individuals respond not only to different interventions, but also to the same intervention in a range of idiosyncratic ways. Moreover, we also need to recognise that there are a host of features at play in the dynamic process of child development that contribute to the complex and ambiguous nature of the task of establishing therapeutic efficacy. Bearing in mind the foregoing assumptions, the aims of this study with respect to the therapeutic effects of therapeutic horse riding were illustrative rather than definitive in nature. And, as I discovered from my own engagement with the critical issue of 'What counts as therapeutic?' during the course of this study, what we can say as researchers about therapeutic effects which link in direct ways to interventions is inherently complicated and actually rather speculative in nature. That said, the findings in this study suggested that there are two prominent pathways through which such therapeutic effects may work. One possibility is that therapeutic horse riding might well effect direct changes on physical dimensions of functioning; improvements in posture and trunk control served as typical examples in this study. Another possibility is that therapeutic riding's effects might operate in much more intangible and emergent ways. Indeed, what was highlighted in this study was that participating in the profoundly physical activity of horse riding served to impact in positive ways on the participants' experiences of their bodies as *bodies that work*, as well as their experiences of a sense of mastery and self-esteem which fed in to their experiences of a sense of self. In other words, what was offered as therapeutic

was more about a positive sense of self that derived from being on horseback and engaging with the horse and social others in active, autonomous ways. And, those positive experiences translated into being-in-the-world bodily, which in turn generalised to skills and capabilities on other domains of functioning and in other contexts. In sum, to the extent that therapeutic horse riding forms a part of efforts to optimise children's functioning and promote their psychological well-being, it may be aptly described as a catalyst for therapeutic improvement.

It is also important to recognise that a lack of success in pinpointing effects conclusively on the research front does not negate the therapeutic value of interventions in general and therapeutic horse riding in particular. In this regard, the present study finds itself in good company as studies with regard to psychotherapy, for instance, have also struggled to establish therapeutic efficacy with certainty. Yet this has not shaken the foundations of psychotherapeutic work. Indeed, psychotherapy is a field that continues to thrive in the present day. Hence, it is suggested that future research in the field of childhood disability and rehabilitation would do well to pursue and clarify the lines of investigation regarding therapeutic efficacy raised in the foregoing discussion. Moreover, because future research could also be looking at often subtle, ambiguous shifts that would not be reasonably captured through quantitative measures, researchers need to continue in developing qualitative approaches to the study of experiences of childhood disability and impairment so as to further interrogate the issues that were highlighted in this study.

Certainly, this study concurs with the existing body of knowledge which has identified the possible use of specialised techniques and methods for capturing the experiences of children with quite profound forms of cognitive and communicative impairment as a challenge that researchers will continue to grapple with for some time (Begley, 2002; Beresford, 1997; Davis et al., 2008; Detheridge, 2002; Dockrell, Lewis & Lindsay, 2002; Lindsay, 2002; Rabiee et al, 2005). Incorporating this specific group of individuals in more active yet ethical

ways remains an issue that future studies should work towards developing alternatives for. At the same time, however, practical considerations around the availability of and accessibility to participants with quite profound forms of impairment who participate in therapeutic interventions are likely to remain an ongoing challenge to research initiatives.

While the preceding insights have been geared to the level of data, specific theoretical shortcomings in research within the field of therapeutic horse riding also warrant due emphasis. In particular, existing studies have rarely moved beyond simply stating differences found in psychosocial and physical aspects of functioning without further theorisation or contextual grounding. Attempts to look at processes and dynamics that could account for identified shifts also seem to be lacking. In response to such a gap within existing bodies of work, this study engaged in theorising the mechanisms and processes involved in effecting often subtle shifts on different dimensions of individuals' functioning. These were dominated by, but not limited to a) considerations around the implications that horse riding as an embodied, self-making activity had in relation to identity; b) considerations around the therapeutic nature of relationships within the therapeutic riding context; c) an appraisal of the activity of horse riding in terms of the beneficial psychosocial effects of exercise and sport; and d) an appraisal of the effects of sensory-motor stimulation and feedback on bodily control as an important facet of participation in this form of intervention.

With respect to the role that an adjunctive intervention such as therapeutic horse riding can play in the lives of children with quite severe forms of impairment, the maintenance of current levels of functioning and the prevention of further deterioration across the different (physical, cognitive, and psychosocial) dimensions of functioning have been pointed to as valued therapeutic goals. The suggestion then, is that future studies need to be reframed to look beyond a preoccupation with grand-scale improvements. Instead, an examination of the role which therapeutic interventions can play in terms of seemingly negligible but

meaningful shifts in functioning as well as the maintenance of current levels of functioning needs to be prioritised. Importantly, the maintenance of functioning through participation in childhood therapeutic interventions could have broader social and economic implications. Applying Pretty's (2004) assumption to the context at hand, it is plausible that children with disabilities who participate in therapeutic interventions (therapeutic horse riding included), and experience gains that seemed to be linked to their engagements in those interventions such as being both physically more capable and having higher levels of psychological well-being are likely to make less frequent use of health care services. In the long term, this could serve to reduce the rising costs of health care. Further, maintaining such positive health and well-being outcomes during childhood is likely to impact positively on health and well-being during adolescence and adulthood as well.

Another remarkable insight in this study that is worthy of further research attention - one that did not seem to appear in previous research findings, concerns the consciousness-raising role that has been linked to therapeutic horse riding. To reiterate, participation in equestrian shows was regarded as providing tangible evidence (within a public, sporting arena) of children with disabilities as capable, and of their impaired bodies as *bodies that work*. Such efforts represented a challenge to and a rejection of the pathologising stereotypes that individuals with quite profound forms of disability are subject to by society at large. Given that such attributions may be contextualised within understandings of disability as socioculturally derived and embedded, it is suggested that proponents of a social model of disability would do well to embrace this issue in future studies.

Turning to a consideration of directions for future research in relation to psychology in particular, it is significant that the discipline is infamous for its longstanding contribution to propagating pathologising ways of conceptualising disability and ways of thinking about individuals with disabilities that prioritise

attention to difference as meaning deviance and deficit (Abberley, 1993; Olkin & Pledger, 2003). Existing research has accorded precedence to issues of adjustment and coping in relation to children with disabilities and their families (Rentinck, Ketelaar, Jongmans, & Gorter, 2006; Woolfson & Grant, 2006). Work on resilience, too, operates with stress and adversity as a frame of reference, examining how individuals overcome challenging life circumstances and focussing on the prevention of psychopathology (Masten, 2001; Rutter, 1987, 2007). Yet, characteristically, studies of childhood disability have made intermittent reference to strengths, capabilities, well-being, and flourishing in rather cursory and taken-for-granted ways. Consequently, research in the field remains largely ungrounded with respect to formalised theorising around such concepts. In attempting to address this gap, as well as contribute to what has been described as an enabling alliance between psychology and disability studies (Lawthorn & Goodley, 2006), the present study has identified the nascent sub-discipline of positive psychology, defined earlier as “the science of understanding human strengths and the practice of promoting these strengths to help people psychologically and physically” (Dunn & Dougherty, 2005, p.305), as a field that holds significant research utility. In particular, it has demonstrated that positive psychology’s conceptual tools can clarify, refine and elaborate issues and experiences addressed with respect to the psychology of disability.

Given its overarching prioritisation of strengths and capabilities, a significant part of positive psychology’s appeal lies in its potential to extend current conceptualisations of impairment, disability, health and well-being. As significant is its capacity to interrogate pre-given understandings in ways that leave them open to other ways of knowing and being. Still, within academic circles, the field has been subject to a fair share of healthy criticism. More recently, positive psychology’s largely individualistic stance and its seemingly inadequate engagement with issues that are cross-cultural in nature, as well as its North American perspective and agendas have featured as some of the topics for debate in a special edition of the respected international journal, *Theory and*



*Psychology* (October, 2008). However, such critical examination is a necessity if significant contributions are to be made to theory, research and practice. Thus, while wholly cognisant of the debates cited above, this study maintains that the underlying principles within positive psychology hold significant value in relation to the study of disability. By turning on its head the pathologising lens that has long dominated psychology's approach to analysing and making sense of the experiences of children with disabilities, the field affords researchers (myself included) an opportunity to examine children's propensity to *function optimally* and *flourish* in the context of their daily lives.

In this study, two of positive psychology's key conceptual tools, Ryff and Singer's (1998) model of psychological well-being and Fredrickson's (2001) broaden-and-build theory of positive emotion, were drawn on in an attempt to analyse and make sense of the everyday experiences of a group of children with cerebral palsy. As such, the data often raised, overlapped with, and sometimes challenged many of the issues and ideas that Ryff and Singer (1998) and Fredrickson (2001) had outlined. Further, it is suggested that Ryff and Singer's (1998) model in particular could be extended and strengthened by taking cognisance of the inherently social nature of being human. Thus, at one level, while their model makes reference to positive relations with others as a dimension of psychological well-being, an overt recognition of the social aspects of well-being could complement and elaborate their current conceptualisations.

At another level, based on this study's findings it is suggested that Ryff and Singer's (1998) view of autonomy (see Chapter Two) could be more useful to future work in the study of disability if the construct was re-thought to mean functional autonomy. In particular, the data indicated that in view of their profound forms of impairment, the participants' everyday experiences were distinguished in terms of the functional ability to communicate and be social, as well as to be mobile and capable of interacting motorically with their environments. As such, the participants differed in terms of their experiences of

functional autonomy, and this had broader implications with respect to relieving the burden of their care to an extent.

Perhaps Ells' (2001) view of autonomy as "emerging from the experience and existence of an embodied, relational, socially situated self" (p.611) might be valuable for the purpose of further exploring such issues. Similarly, Cardol, De Jongh and Ward's (2002) description of autonomy as a continuous and personally unique variable that exists in different degrees, depending on a person's circumstances is promising in that it entails an understanding primarily in terms of 'individual preferences' as opposed to 'general competencies'. Moreover, if we recognise the inherently psychosocial nature of being human, then Cardol and colleagues' (2002) suggestion that interdependence should be viewed as a characteristic of human life, and not an aberration associated solely with illness or disability is informative here.

Importantly, it also needs to be taken into account that within a multicultural context such as South Africa, autonomy might not necessarily feature as a critical part of the experience of living well for all individuals in society. In more collectivist-oriented cultures social responsibility and the good of the group are highly valued attributes (Visser, 2007). In line with such sentiments, it was telling that Nthabiseng, a Black, Sotho-speaking participant, differed significantly from that of her white, English-speaking and Afrikaans-speaking peers in terms of the sense of altruism and social responsibility that she expressed in her interactions with them. Certainly, a more culturally diverse sample of participants would have afforded an opportunity to further examine, as well as corroborate and/or contradict such findings. It might also be worthwhile for future studies to explore experiences of autonomy in terms of interdependence and interconnectedness with particular reference to children with disabilities who require forms of assistance with their daily care and functioning that is qualitatively different from that of their able-bodied peers.

Overall, though, echoing the sentiments of De Chavez and colleagues (2005), a key suggestion here is that those conducting future research need to be very clear about what psychological well-being means to them. Such conceptual clarifications have critical implications for operationalisation, assessment, and the data that is derived and interpreted, and can therefore impact in significant ways on the bodies of knowledge that are developed in the future.

Another conceptualisation that needs to be placed on future research agendas concerns the potential for therapeutic interventions to serve as opportunities for the promotion of optimal experience in children with disabilities. To this end, it is proposed that one of positive psychology's key conceptual tools, a state of flow, could hold research utility. According to Csikszentmihalyi, a key proponent in the field of positive psychology:

Flow denotes the holistic sensation present when we act with total involvement...It is the state in which action follows upon action according to an internal logic which seems to need no conscious intervention on our part. We experience it as a unified flowing from one moment to the next, in which we feel in control of our actions, and in which there is little distinction between self and environment; between stimulus and response; or between past, present, and future. (1975, p.43)

A review of the literature indicates that the concept has been applied extensively in research pertaining exclusively to non-disabled populations. Within that context, flow's value has been established in terms of acting as a buffer against adversity and preventing pathology (Csikszentmihalyi & Csikszentmihalyi, 1988; Csikszentmihalyi, Abuhamdeh & Nakamura, 2005; Nakamura & Csikszentmihalyi, 2005). While references to experiences of flow were not derived from the data in this study, an exploration of whether, and the conditions under which, children with disabilities experience a state of flow could be useful. Certainly, flow experiences could arise from a range of possible contexts,

therapeutic engagements included. Taking this further, research could then look at how to increase opportunities for such quality flow experiences, with a view to improving the overall functioning and psychological well-being of children with disabilities (and their families). Promoting optimal experiences in this way could form a crucial part of efforts to create a healthy environment for individuals with disabilities in which to flourish and not flounder.

In sum, it is argued here that the nascent field of positive psychology needs to be developed further so that disability and impairment come to be utilised as their own frames of reference. This implies a shift away from focussing on its original population of interest, namely typically developing individuals. As the findings in this study have indicated, individuals with quite profound forms of disability can be healthy, utilise their impaired bodies in idiosyncratic, functionally autonomous ways, and enjoy experiences of psychological well-being. These findings represented a significant shift from the pathologising orientation that has been assumed in much psychological work within the field of disability and rehabilitation to date. In so doing, the field could contribute to the study of disability and rehabilitation by evolving into a positive psychology of disability and impairment.

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## **APPENDIX A: INTERVIEW SCHEDULE**

### Issues raised within interviews

The interview schedules used in multiple in-depth interviews did not assume a standardised format, given the idiosyncratic nature of the participants' disabilities, and the range of individuals that were interviewed with regard to participants' everyday lived experiences. Some examples of the issues covered in the initial interviews with the children's parents appear below. Similar issues were raised and extended where appropriate in interviews with the team of therapists and teachers with a view to clarifying similarities and differences in proxies' accounts.

"Thanks for providing me with the basic information regarding Rachel's medical history and details around the different aspects of her everyday functioning. Before we start with today's interview, is there anything that you would like to add to or alter regarding the basic information that you've given already, or anything else of relevance that you'd like to mention?"

### Personality and behaviour generally

"Would you like to start off today's interview by describing Rachel in terms of her personality and behaviour generally? For instance, how would you describe her to someone who does not know her at all?"

### Typical day in the child's life

"I think it might be useful in understanding your child further, if you would you describe for me in detail what a typical day in Rachel's life entails, from the time she wakes up in the morning, to when she goes to bed at night."

a) Self-care entailing functions of eating, drinking, toileting, dressing, bathing & hygiene

These empirical measurements will be carried out regarding self care and the specific function of feeding (for instance) in the following manner :

“Can the child eat a meal herself?”

“ For how long has this been her experience of feeding?”

“What is the level of ease/difficulty with which Rachel eats a meal?” “For instance in the proxy’s view, does she eat easily, with difficulty, with great difficulty, or only with assistance from caregivers?”

b) Motor functioning entailing fine and gross motor function, positioning, balance, and functional mobility indoors and outdoors

c) Communication entailing functioning in terms of verbal comprehension; non-verbal behaviours such as vocalisation, facial expression, eye-gaze, body posture and gesture

Eg. “And could you tell me about how Rachel communicates with you and with others?” “I just want to ask in terms of comprehension, could you tell me whether there is anything that she finds difficulty in understanding?” “Also, how does she cope in terms of being able to express herself?” “Would you expand a bit on her capabilities for expressing herself?” “So, if she wants to share a feeling, thought or an idea with you, or if she wants or needs something, does she find it relatively easy, or a bit difficult to express this to you?” “To what extent does Rachel rely on non-verbal communication, given the difficulties with speech that you’ve already mentioned?”

d) Socialisation entailing functioning in terms of play & leisure time, interactions with peers and family members, and ability to cope in relating with others in familiar and unfamiliar social contexts

#### Challenges experienced as a result of or associated with disability

“Would you describe to me the kinds of challenges that Rachel tends to experience in her everyday life as a result of the functional limitations of her

disability?” “What I am trying to ask is with what does Rachel experience problems with gross motor functioning (like walking and climbing for instance) or fine motor functioning (like the use of her right hand, given that the right hand side of her body is spastic)?” “So what tasks are difficult for her to complete, given her physical impairments?”

“And if you set a bit of a difficult challenge for Rachel, and then encourage her to complete it, how does she respond?”

“So we’ve talked about those fine and/or gross motor aspects of her everyday functioning that she struggles with. But I would also like to know if you have noticed any shifts. In other words, are there are also basic capabilities that you’ve noticed her struggling a bit less with or get better at nowadays? Can you tell me about anything that that you have noticed her to be her way to mastering a little better? In other words, what sort of shifts, if any, and however small, have you noticed recently?”

“And what impact has struggling less with and getting better at \_\_\_\_\_ had on Rachel’s life in general, and on how she feels about herself specifically?”

#### Rachel’s capabilities and strengths

“The study we’re involved in looks at disability, but with a shift in focus away from dis-ability and what the child cannot do towards acknowledging just as much what the child can do. So we need to take into account not only Rachels’ disability but also her personal capacities, strengths and resources as well as the strengths and resources of your family. Could you perhaps start off by giving me an idea of where you would say Rachel’s strengths lie at this point in time (given her functional difficulties with \_\_\_\_\_)?”

“What can you tell me about her self-confidence nowadays?”

### Family strengths and resources/social support

“And if we turn to look at your family, how does Rachel get on with her sister nowadays?” “Has this been the dynamic between them for the past while, or have you noticed any shifts in the way they relate to each other over the years that you can tell me about?”

“What would you say are some of the strengths and resources of your family?”

“And would you describe the extent to which you are able to manage with Rachel, in terms of care-giving for a child with a disability in particular, and the demands and challenges that this role might involve?”

### Extended family and friends

“When you need assistance with taking care of your child’s particular needs, for instance with a practical task like fetching her from school or if you are concerned about her and you need emotional support whom do you turn to? For instance, your spouse, or others in your wider family? I’m basically asking here about your resources and your social support.”

“Would you tell me if you have (regular/particular) contact with extended family members (your and your husband’s parents and siblings, nieces and nephews), and who your extended family consists of?”

“Would you describe the nature of the contact, and the role that these individuals play in Rachels’s life in particular?”

“Are there any friends (or your work colleagues or church friends for instance) that you and your child also come into contact with on a regular basis? Would you describe the role that these individuals play in your lives and in the life of your child in particular?”

### Therapeutic horse riding participation

Thank you for giving your consent for Rachel's participation in the therapeutic horse riding and in this study. Is there anything that you would like to ask me about the therapeutic horse riding? And since Rachel started with therapeutic horse riding, is there anything in particular that you have noticed or that has stood out that you would like to comment on today?

### Other issues to raise

Is there anything that you feel stands out about Rachel that we haven't covered, that you would like to talk about? So if there are any particular concerns that you have that you would like to mention, we can talk about them as well now.

### Follow-up interviews

"The last time you talked at length about Rachels' \_\_\_\_\_. Could we go back to that for a moment, and is there anything that has shifted in this regard, or stayed the same, that is notable for you? So, since our last interview have you noticed anything striking that you feel you would like to raise today? In comparison to when we last spoke, what aspects of her everyday life have tended to stay the same? And could you tell me a bit about if and whether you've noticed any changes in her everyday functioning, especially motorically and in her relations with others, since we last spoke?

The same and/or similar topics were raised, with probing for further detail, based on an interest in instances of similarity and difference in experience, within and across proxies. Also probed further with regarded to issues that were raised in previous interviews, and across the accounts of the different proxies.