A PHENOMENOLOGICAL UNDERSTANDING OF SELF-ESTEEM IN PHYSICALLY DISABLED ADOLESCENTS IN A NON-DISABLED ENVIRONMENT

by

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(i)

ABSTRACT

By using a descriptive design, the study attempts to arrive at a phenomenological understanding of self-esteem as experienced by a group of physically disabled adolescents with cerebral palsy in a non-disabled environment. Spontaneous descriptions of their experiences are transcribed and analyzed using a phenomenological method of analysis. Within the phenomenological tradition, there is only a limited exploration of self-esteem, no comprehensive psychology of adolescence and no extensive study of disability.

The physical and social changes which occur during adolescence have been found to be associated with changes in self-concept. As body-image is an important factor in adolescent self-concept development, it is reasonable to assume that physical disability would have an effect on self-concept and self-esteem. It is also evident that with children with cerebral palsy, the permanence of the disability is truly felt during adolescence.

As we move towards a more inclusive society, it is clear that the disabled and non-disabled sectors of our communities

cannot exist in mutually exclusive ways. Therefor it becomes important to understand the encounter between disabled and non-disabled adolescents who have grown up generally separated from each other. To both the disabled and non-disabled adolescents, this encounter is an indicator of their readiness, willingness and ability to integrate effectively with the rest of society.

The experience of the body, is found to be central to the experience of self-esteem in physically disabled adolescents. While the body is experienced as socially conspicuous, non-compliant and undependable, it is also viewed as integral to the disabled adolescent's sense of self.

The study confirms the view that disability, from a phenomenological perspective, is infinitely more than a condition affecting the body. It is an important and essential component of who the disabled adolescent is, given the I-World nature of disability disruption. Disability is therefor best understood as a condition of the life-world as well as the body.

The non-disabled world views disability as something alien and invasive, and in need of restoration or correction, and responds to it accordingly. To the disabled adolescent, it is the alien nature of the relationship with the non-disabled environment, which concerns them the most. All participants expressed a need to be provided with opportunities to participate in a non-disabled environment, to compete in areas where they feel competent and confident, to be provided with choices and to exercise their ability to make decisions for themselves.

Disabled adolescents who are denied opportunities to engage with non-disabled peers, and who are denied choice and the possibility of making independent decisions, are intuitively less likely to develop a sense of self-worth and competence, and consequently less likely to participate in adult society and relationships.

From a phenomenological point of view, lowered self-esteem results from the infringement of, or impending threat to the integrity of the disabled adolescent, not simply the body and its functioning.

KEY TERMS

Phenomenological Psychology

An approach which attempts to clarify what shows itself to us and the way in which we encounter the world and others around us. It is concerned with how we experience the world and the manner in which we discover meaning in the world.

Phenomenological method

A research method which bases itself on data as presented i.e. the descriptions of the experiences as they present themselves, not the descriptions of objects and actions as they are assumed to exist outside of the experience.

Protocols

The extensive decriptions offered by participants which would be related to the experience being studied.

General re-statements

The re-formulation of significant statements of participant's experience into more general forms i.e. it is a process which transforms the concrete descriptions and language of the participants into the language of science.

Cerebral Palsy

A chronic, non-progressive condition caused by damage to the developing brain, pre-natally, during birth or in the first few years of life, and which results primarily in disorders of movement, posture and gait. A range of speech, perceptual and learning difficulties are frequently present.

Physical Disability

It can be understood as an orthopaedic or physiological event i.e. an objective impairment or loss which can be assessed by a physician, or it can be understood as an existential event, i.e. a disruption of the I-World relationship which may attend this impairment or loss.

Lived Body

A pre-reflective familiarity with one's own body and one's life-world i.e. the way in which we live it, orientate ourselves to it, experience it and move about in it before we think about it.

Non-disabled environment

A situation and encounter with non-disabled peers which is essentially distinct from, and presents a challenge to, those

experiences which the disabled individual is accustomed to in his or her limiting environment.

Self-esteem

The lived status of one's individual competence and personal worthiness at dealing with the challenges of life over time. It is a means of conceptualising the unique combination of feelings of competence and worthiness that is lived by the individuals through positive and affirmative experiences in their life-world, i.e. it is the conviction that one is competent to live and worthy of living.

Inclusion

An approach which recognises the need to harness policies and programmes which would ensure that people with disabilities participate effectively at all levels of the educational, social and economic sectors of mainstream society.

SAMEVATTING

Deur gebruik te maak van 'n beskrywende ontwerp, poog die studie om 'n fenomenologiese begrip te vorm van die belewenis van eie-waarde van 'n groep fisies gestremde adolessente met serebraal verlamming in 'n nie-gestremde omgewing. Spontane beskrywings van hul ervarings is getranskribeer en ontleed deur gebruik te maak van 'n fenomenologiese metode van analise. Binne die fenomenologiese tradisie is daar 'n beperkte eksplorasie van eie-waarde. Daar is ook geen omvattende sielkunde van adolessensie nie, en geen ekstensiewe studie van gestremdheid nie.

Die fisiese en maatskaplike veranderinge wat gedurende adolessensie ontstaan toon 'n verband met verandering in die selfbeeld. Omdat liggamsbeeld 'n belangrike faktor in adolessente selfbeeld ontwikkeling is, is dit redelik om te aanvaar dat 'n fisiese gestremdheid self-konsep en self-aanvaarding sal beinvloed. Dit is ook klaarblyklik dat kinders met serebraalverlamming die permanente aard van die gestremdheid veral gedurende adolessensie ervaar.

Soos ons in die rigting van 'n meer inklusiewe samelewing beweeg, is dit alhoemeer duidelik dat die gestremde en nie-gestremde sektore van ons samelewing nie mekaar kan of mag uitsluit nie. Derhalwe is dit belangrik om die verhouding tussen hierdie twee groepe te verstaan. Vir beide groepe is hierdie tussenverhouding 'n aanduidiging van hulle gereedheid, gewilligheid en vermoe om effektief te integreer met die res van die samelewing.

Die ervaring van die liggaam is sentraal tot die ervaring van eie-waarde in fisies gestremde adolessente. Terwyl die liggaam sosiaal beleef word as onbetroubaar, opsigtelik en nie-samewerkend, word dit nietemin beskou as 'n integrale deel van die fisies gestremde adolessente se self-belewing

Die gestremdheid word nie net beskou as 'n beperking van fisiese aktiwiteite nie, maar eerder as 'n ontwrigting van die Ek-Wereld verhouding. Terwyl die fisies gestremde adolessent baie frustrasies en teleurstellings in die gesig staar, besef hulle dat deur hulle ontmoeting en verhouding met die nie-gestremde gemeenskap, word hulle bevoegdhede toegelaat om te floreer en 'n sin van self-waardering word gekoester.

Die studie bevestig die standpunt dat gestremdheid, van 'n fenomenologiese perspektief gesien, oneindig meer is as net 'n toestand wat die liggaam affekteer. Dit is inderdaad 'n belangrike en essensiele komponent van wie die gestremde adolessent is, vanwee die Ek-Wereld aard van die ontwrigting. Gestremdheid word dus die beste verstaan as 'n kondisie wat die leefwereld sowel as die liggaam.

Die wereld van nie-gestremdes sien gestremdheid as iets vreemds en indringend, wat herstel of gekorrigeer moet word, en reageer sodanig daarop. Vir die gestremde adolessent, is dit die vreemde aard van hierdie verhouding met die nie-gestremde omgewing, wat hulle die meeste laat bekommer.

Al die deelnemers in die studie spreek 'n behoefte uit vir deelname aan geleenthede in 'n nie-gstremde omgewing. Sodoende kan hulle wedywer op gebiede waar hulle bevoegd voel, en met vertroue besluite kan neem vir hulself.

Gestremde adolessente wie ontneem word van geleenthede om met nie-gestremde portuurgroepe in interaksie te tree, en wie nie toegelaat word om onafhanklik besluite te neem nie, se kanse is minder om 'n sin van eie-waarde en bekwaamheid te

ontwikkel, en is gevolglik minder gereed om betrokke te raak in volwasse samelewing en verhouding.

Uit 'n fenomenologiese perspektief, is lae eie-waarde die gevolg van die skending of bedreiging van die integriteit van die fisies gestremde adolessent, en nie net eenvoudig die gevolg van die liggaam en sy funksies nie.

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CONTENTS

CHAPTER 1

INTRODUCTION

Commenting on the status of children with disabilities in South Africa, the Integrated National Disability Strategy (1997), had the following to say;

" South African society still regards children with disabilities as incapable, ill and a burden on society .....When born into families of poor socio-economic backgrounds, such children frequently grow up believing that their disabilities are an economic and social curse and burden on their families. As a result they often perceive themselves to be worthless......Children with disabilities fear and experience exclusion from a very young age. Separation from family, friends and peers is common. Non-disabled children, in their turn, learn that the exclusion of children with disabilities is the norm and therefore socially acceptable. These early experiences reinforce acceptance of segregation in later life." (White Paper, Office of the Deputy President, 1997,p.5).

Given the impact of disability on the self-perception of disabled children and the effect it has on their interaction with, and acceptance by, non-disabled children, one would have expected psychologists to have studied this area of interest extensively. This is not, however, the case.

Issues surrounding physical disability have been extensively studied by a few psychologists and neglected by most others (Asch, 1984). The reason could be the complexities which surround disability, ranging from the medical and technical on the one hand, to the educational, social and psychological on the other. Within the field of psychology of disability, the most researched topic concerns the effects of disability on personal adjustment (Vash, 1981; Vash, 1994). According to (Roessler & Bolton, 1978), the three questions usually examined are :

    a) Is self-esteem diminished as a result of disability ?

    b) Does disability lead to severe emotional maladjustment ?

    c) What are the effects of disability on the broad area of normal personality functioning ?

The results of numerous studies (Vash, 1981; Philp & Duckworth, 1982; Halliday, 1989; Lalkhen & Norwich, 1990) have supported three often repeated and independently derived conclusions :

   a) Specific disabilities are not associated with identifiable personality types.

   b) There is no simple relationship between severity of disability and degree of psychological impairment.

   c) There exists a wide range of individual reactions to disability.

The meaning of disability varies from person to person. Not all persons react to disabilities in exactly the same way. One's reactions and variety of adjustments is influenced by many factors deriving from both inner and outer reality. The experience of even minor forms of disability may be experienced as intensely, strongly and painfully as an objectively greater disability and, of course, the converse may be true.

   " There is plentiful evidence that children with physical disabilities experience a higher than average level of

social and emotional difficulties, and that children
whose disability is associated with neurological
impairment are particularly at risk of socio-emotional
disorders" (Cogher, et al. 1992, p.48).

The reality of one's disability is never experienced more
acutely than during adolescence. Christie Brown (1954),
himself a very severely disabled spastic quadriplegic
with dysarthric speech, very effectively described the
feelings of an adolescent with cerebral palsy :

> "...always, whatever I did, wherever I turned, I felt
> lonely and restless. It was like living in chains... all
> the friendly ties that I had formed in my childhood were
> now broken by the rift that adolescence had wrought
> between myself and the boys I had played with as a
> child. It seemed that instead of coming to a better
> understanding of my handicap as I got older, I only
> became more troubled and bitter"

It is extremely difficult to isolate the factors which
might contribute to poor social adjustment and low self-
confidence and self-esteem in young people with cerebral

palsy (Halliday, 1989). Some of the difficulties arise partially because of the diverse characteristics of the young people who make up this group. The members of this group will present with a variety of mobility competencies, some will have sensory impairments and some will have speech and language difficulties. Whatever the factors might be, a study by Tringo (1970) indicated that cerebral palsy was amongst the least socially acceptable disability amongst non-disabled people. In most situations, those with cerebral palsy were less acceptable than those with a visible disability (e.g. amputees, the blind, spinal cord injuries, etc.) or communication disorders (e.g. the hearing impaired, stutterers, etc.)

Philp and Duckworth (1982) claims that there is a tendency amongst researchers to view disability as an emotionally, as well as physically crippling event. To assume that disability will automatically result in emotional difficulties in young people is wrong. However, to hide from the fact that disability can be emotionally damaging is also wrong. Participating in routine activities of daily living and compensating for the varied and inevitable ramifications of

disability can be physically exhausting. It can also be emotionally draining as experience teaches the young person that the disability is a permanent fact of their lives.

A disability pervades all aspects of an individual's functioning. Coupled with "the sturm und drang" of adolescence, a disability exacerbates the problems associated with that period of development. The need for psychotherapy is therefore never greater.

The disabled adolescent has largely been ignored by the research fraternity, except those disabled individuals who are considered to be socially deviant (Abrahamson, et. al., 1979). Within the field of special education, most professionals have tended to concentrate on the academic and intellectual aspects of childhood and adolescence and have neglected the study of how the disabled adolescent experiences his disability, of his sense of identity, self-competence and self-worth and of his social and emotional adaptation to a non-disabled environment (Lalkhen & Norwich, 1990). According to Roberts (1990) a prerequisite for successful adaptation is a positive self-concept. A strong sense of identity, competence and self-

worth are vital traits found in resilient children and adults. School setting, in which most adolescents find themselves, is the interface between living in the family and living in society. During this period of ambivalent experiences, the adolescents also experience the nascent disintegration of the ideal-parent image. It is indeed a testing time for any person and a particularly anxious one for those individuals who are psychologically unsupported or poorly supported.

The study of disability is the study of real people, going about their everyday life and additionally coping with the effects of a disability, and the position people are placed in because of their disability.

According to Van den Berg (1973), the human being is inseparable from the world in which he dwells. Person and world are mutually implicated. Since all behaviour is intentional and relational in nature, man lives in relations to objects, his body and the people around him. Our environment, the nature of our relationships, and our perceptions of others and ourselves are objective crystallizations of our subjective needs and their unavoidable consequences.

While we are indeed, outwardly and partially, social beings, each one of us stands alone. We are alone at birth and alone at death. Alone, too, in our pain and in our innermost and often incommunicable thoughts and emotions. It would be these "incommunicable" thoughts and emotions which disabled adolescents should try to articulate and psychologists should try to comprehend.

CHAPTER 2

A PHENOMENOLOGICAL UNDERSTANDING OF BODY, SELF AND THE WORLD

2.1 The approach to body in western philosophical and scientific tradition

It is in some ironic sense quite just that the natural scientist should have such an elevated and glorified status in our society, since it has been largely through their efforts that the philosophy and worldview underpinning our society and the individual's place in it has become the dominant view to this day. As a concrete expression of this philosophy, modern science has claimed an almost complete monopoly on truth, viewing the scientific method as the only valid path towards knowledge.

Amongst these scientist/philosophers, it was Descartes who formulated most decisively the philosophical principles of the new science, its dreams of reducing knowledge to a mechanistic and purely quantitative attitude towards man and nature. This new science has unleashed tremendous, though misdirected

energies, which has resulted in a fragmented view of man and his world. Descartes' philosophy of dualism has left us with the lasting distortion of a dualism between mind and body and between man and his world (Kruger, 1988). This mechanistic, reductionist and deterministic assumptions of the Cartesian worldview has steadily but significantly permeated every aspect of our lives - from philosophy to psychology.

According to Morris (1982), within the western scientific tradition, there appears to be basically five ways in which the relation between the body and the self or person can be construed :

a) The relationship between the body and the person can be construed as one of opposition, even hostility.

b) While the body is part of the person, it is a lesser part, a part which needs to be transcended, or to be in the service of the mind.

c) The relationship between the body and the self is viewed as one of co-operation, with the body clearly playing an inferior role.

d) The body is construed as something indifferent, either relatively or totally.

e) The body is considered as a central element of

personhood, for reasons which are mainly theoretical.

Even in this case, however, very little importance is attached

to actual experience of bodies, whether one's own or those of

others.

On the whole it is clear that western philosophical tradition

has treated the body primarily as an object of investigation

and knowledge, and has almost completely ignored any

consideration of the body as lived. A consequence of this

division between mind and body, are the divisions between

behaviour and experience and the objective and subjective

aspects of the human being (Moss, 1988).

Notions of body-image, body-concept, body-schema and body-

concept, are some of the many terms which have been introduced

over the years in an attempt to re-unite the apparently dual

realms of body and mind into a living unity (Moss, 1988).

Thus, "body-image" and "body-schema" describe phenomena

showing properties of both body and mind. Body-image generally

refers to an individual's explicit picture of the body. Body-

schema on the other hand refers to the implicit knowledge

persons have of the position of their bodies, and a
disposition to action. These two concepts are closely related
(Moss, 1988).

The objective neutral stance of the natural scientific
approach has resulted in the following assumptions about body;

    a) It is assumed that a person perceives his or her own
       body in the same way a disinterested on looker notices
       anything in the surrounding world, e.g. tree, car etc.

    b) A person should form his body-image from objective,
       neutral and disinterested information.

    c) A person looking into a mirror is obtaining that
       neutral, objective information about his or her body
       (Moss, 1988).

It would therefore seem that Western philosophical tradition
treated the body as primarily an object of knowledge, and has
virtually ignored phenomenological consideration of the body
as lived.

2.2 Phenomenology of body, self and the world

Unlike the natural scientific approach, phenomenology within
psychology views the human being as a unity of body and mind

and behaviour and situation, and therefore attempts to study the whole person, including behaviour, body and the personal world of experience. Thus human action and human experience are not studied separately. The phenomenological notions of embodied-being-in-the-world and of the lived body are attempts to give a more enlarged and satisfactory perspective on the body of the human being.

The notion of the lived body is viewed by many as probably one of the most important contributions which phenomenology has made to philosophy as well as psychology. This section will rely heavily on the writings of psychiatrist/philosopher Erwin Straus and psychologist/philosopher Maurice Merleau-Ponty to expound the notion of the lived body.

The type of existence of disabled young people, is an existence in which physical functioning and mobility is to a greater or lesser degree, restricted, with all the ensuing ramifications.

However, even when our bodies function normally, corporeality is of fundamental importance to our existence, though we might not always be aware of it. It was Merleau-Ponty who

established that not only do we have a body with which we do everything, we also are our bodies.

By adopting this viewpoint, he is challenging the objective scientific approach which created an unbridgeable chasm between the cognizing subject on the one hand, and the world of objects on the other. The two consequences of this approach are that :

   a) the body is seen primarily as an object in space about which objective knowledge can be collected.

   b) there is a subjective experience of the body , which is essentially founded in the body as an object.

Merleau-Ponty more or less reverses this approach. In the very first instance there is a pre-reflective and pre-objective being-in-the-world. He indicates that this pre-objective existence in the world is nothing other than physical being. One might say that one's body is the silent base from which one learns about the world. Here "silence" refers to the fact that we are usually not conscious of our bodies. Van den Berg (1973) concurs with Merleau-Ponty on this point and refers to the bypassing of the body. This "bypassed

body", in a sense, constitutes the foundation of our corporeality.

It usually takes a special situation to make us aware of our bodies. A person who is climbing stairs is simply oriented to his destination, and in this situation, is not oriented to his or her body, having bypassed his body. If, however, that same person sprains his ankle, climbing stairs is no longer a matter of course. In this situation, the body has become the central theme in that person's existence, and it features consciously in experience (Bleeker & Mulderij, 1992).

What is the relevance of all this to a person with a physical disability? Van den Berg (1973) states that the invalidity of the body is generally bypassed as in the case of the physically healthy person. In order to live, the disabled person has to forget himself just as the healthy person has to. However, the way in which the disabled person meets this task, highlights his invalidity. The disabled person's task becomes a labourious task, an insurmountable obstacle or shaming failure. Thus for disabled persons the body is bypassed, but more frequently becomes a central theme in experience and existence (Bleeker & Mulderij, 1992).

In the case of handicapped children, a situation arises where the body dominates existence, and all too often these children have their bodies and too little are their bodies. All too often, the body as the silent base from which the world becomes known, loses its silence. The body demands attention, while in fact, it is the world to be learned about that needs attention. Thus, with regard to handicapped children, the typical childhood orientation to the world is disturbed, and with it the way in which the child relates to others and gives his world meaning.

Body image is a widely used concept in psychology and psychotherapy. The exact definition has challenged psychologists and philosophers, whose efforts have resulted in a variety of diverse and often esoteric descriptions. According to Merleau-Ponty (1962) body-image is not a product of objective, neutral and accurate knowledge concerning the body.

Merleau-Ponty (1962), regarded the person's body as it is lived and experienced as a lived body. The concept of the body-image is considered in the light of the lived body. Prior

to reflecting on or knowing his or her body, the person lives the body. As the person lives the body, he or she develops capacity for acting through the body in an action-oriented focus on some object or person. In so doing the person forms a familiarity with his or her body. The body, in fact, constitutes one's earliest capability for relating to the world of objects. Thus, according to Merleau-Ponty (1962), the body-image is constructed around the immediate pre-reflective familiarity with one's own body and one's life-world, as well as with the infinite network of actions of which one's body is capable. The body is something a person lives, an objective picture only arrives much later, if at all.

Just as in the case of the lived body, human space or lived space is essentially pre-reflective. In other words, we live it, orientate ourselves to it, experience it and move about in it before we even think about it. One's body spatiality entails the specific human situations, and the attitudes and actions one takes up toward these situations.

CHAPTER 3

TOWARDS A PHENOMENOLOGICAL APPROACH TO ADOLESCENCE

It is important to keep in mind that adolescence, in contrast to adulthood, is primarily a time of becoming rather than being. This matter of becoming implies doubts and fears that the young person has regarding his worth or ability to do anything in the world; the being of adulthood means security and a feeling of belonging, if only to an image the adolescent has created, which, however flawed, is relatively fixed (Jackson & Rodriques, 1993).

Explanations as to what takes place during adolescence have always been approached from the perspective of some theoretical orientation of cognitive and social development and psychopathology. Underlying each theory are some basic assumptions about human and psychological development and functioning. As a consequence, theories of drives, ego, separation-individuation, psychosocial interaction or the development of the self make different contributions to the

definition, the process and the expected outcome of
adolescence (Slomowitz, 1991).

Fischer and Alapack (1989) makes it clear that there is
currently no comprehensive collection of research data
available which could lead one to a phenomenological theory of
adolescent psychology. However, while a comprehensive theory
is not available, phenomenological psychology does extend an
invitation to explore the complexities, uncertainties and
richness of the adolescent experience, by providing
phenomenological foundations and qualitative research methods
in pursuing this task.

A study by Knowles (1986) goes some way towards shedding some
light on the phenomenological view on the dimensions of human
development which would be relevant in our understanding of
adolescence. In his study, Knowles (1986), acknowledges
Freud's analysis of the significance of body and of childhood
for development. He further attests to Erikson's development
of the Freudian perspective to include both social context and
stages of continuing human development. Some of the salient
features of Knowles' view could be summarised as follows

(Fischer & Alapack, 1989) :

  (a) While Freud's stress is on biological forces, and
      Erikson's stress is on the ego, both are very useful
      in developing our understanding of the adolescent,
      they both neglect what could be called "selfhood".
      The last-mentioned term focuses our attention on the
      open-endedness of our personal futures, i.e. that
      adolescents are not simply shaped by the events in
      their lives, but that they also take up these events
      in terms of their visions, goals and values as well
      as their own personal history.

  (b) Adolescents are always positioned in relation with
      themselves, others and the world. To this approach,
      which highlights the relations amongst body, ego and
      the social context, Knowles adds the dimension of the
      "self". He focuses attention on the co-constituent
      nature of the adolescents relationship with his/her
      world, and characterizes the "self" as the sphere of
      the possible.

  (c) Adolescents are always ahead of themselves, on their
      way to the possible, even as they are contained by

the facticity of their past i.e. the condition they find themselves in by virtue of history and unchosen constraints e.g. physical disability, and the ostensibly predefined character of their present condition.

(d) Knowles distinguishes the developmental crisis of adolescence in accordance with the temporal moment (given past, cognized present, existential future). The tasks of the adolescent stage could be viewed as opportunities for continued development of prior achievements.

(e) In his exposition of the fallen modes, which first appear during the adolescent stage, Knowles makes a very special contribution to our understanding of the adolescent. The fallen modes are fanaticism and faintheartedness. " In fanaticism, one closes off the ambiguous future through a forced certainty, which seeks to define one's identity once and for all....in faintheartedness, the ambiguity, uncertainty, and risk of life are avoided through remaining half-hearted, as in adolescent cynicism, and being above

it all or dismayed by it all" (Fischer & Alapack, 1989, p.103).

(f) Knowles has emphasised the existential-phenomenological theme that even though adolescents may be confronted by a disabled and changing body, they must take up these givens in their own way. Adolescents are never totally determined by givens, but co-constitute their impact for their lives. This helps us to present particular developmental tasks to adolescents while recognising that most of these tasks are still being unfinished in adult life.

(g) The adolescent comes to know himself/herself through regular fluctuations in the quest for certainty and in spontaneous openness to contrasts and discrepancies, obligations, enquiry, and reconfirmation.

Fischer and Alapack (1989) are of the opinion that Knowles' analysis is a powerful reminder that much of the adolescent's struggles are not merely adolescent.

CHAPTER 4

DISABILITY IN ADOLESCENTS

4.1 A Phenomenological understanding of Physical Disability

In order to better understand the notion of disability from a phenomenological perspective, we need to carefully examine the categories of the lived-body and the life-world as Erwin Straus, psychiatrist and philosopher and others like Merleau-Ponty, psychologist and philosopher, have done. In the case of the latter, this examination was done in Section 2.2

To Straus we owe a debt for his development of the importance of the fully wide awake and conscious individual for whom the upright posture is constitutive of his humanness and for whom the world has a distinctive and ever-changing physiognomy. (Kruger, 1988). Merleau-Ponty's major contribution remains the discovery and exposition of the significance of the habitual body, and the world which forms itself around the individual - largely passively and through the intentionality of habit (Williams, 1984).

Bernal (1984) suggests some of the reasons for the relative neglect of the phenomenon of physical disability, immobility or poor mobility in psychological research and in the investigations of health care professionals.

(a) The relative lack of interest in immobility can be traced to philosophical origins, represented by the speculations of philosophers such as Descartes. Descartes was of the opinion that the body is a machine which does not move of its own accord, but only as a response to "impressions" which it passively receives.

(b) In Descartes's philosophy, human movement has no task to perform which would qualify as contributing to knowledge. The body thus appears as a "good natured machine" which supports the mind physically but does not contribute to reason (Straus, 1969).

(c) In the natural scientific framework, space was viewed as impersonal, homogeneous, and governed by mathematical law. Consequently, human movement and action in the world came to be viewed and understood as impersonal and mechanical, taking place in the

space and the homogeneous time. Thus only the
physical rather than the psychological aspects of
movement are worthy of study (Straus, 1969).

While the present task is to develop the phenomenological
sense of disability, this would necessitate a review of
conventional terminology surrounding disability. It is
generally accepted amongst rehabilitation professionals that
"disability" refers to some objective "impairment" which is
normally assessed as such by a physician. On the other hand, a
"handicap" is assumed by convention to be the result of the
interaction between the "disability" and psychological /
social / environmental barriers (Williams, 1984).

While handicap, as described above, describes the impediments
imposed by an objective and social world upon those
individuals with disabilities, this is not the "life-world" of
which the disabled person is a member. Rather, it is the world
of objects and people with whom the disabled person interacts.
This level of interaction fails to grasp the meaning of
disability at the level of the "life-world" in which we "begin
our existence and to which we are intentionally related from

the perceptual and habitual levels to the fully wide awake and conscious levels of experience" (Williams, 1984, p.97).

Williams (1984) is of the view that the clue to the true understanding of the dynamic and plastic nature of disability lies somewhere between the power of the world in which an individual is embedded and the freedom of that individual to stand up in opposition to that world. Any view which purports that an individual completely creates himself or herself, is to leave that individual worldless from the start. On the other hand, any view which purports that the world is all powerful, reduces the individual to an organism needing physical and functional restoration.

Disability is also often equated with illness. Illness, however, connotes a pathogenic process with signs, symptoms, and test values which have meaning to a physician, and which further raises the expectation of recovery. It further connotes something alien and invasive which requires corrective action. Williams (1984) is of the opinion that it is the alien nature of the disabled individual's relationship with the world, which is the alienation which is of greater concern.

It is also important to recognise the experience of suffering. Suffering may result from internal psychic conflicts involving sense of self, self-esteem, altered ability to fulfil expectations, negative perceptions of self or others regarding disability. From a phenomenological point of view, suffering could result from violation or impending threat to the integrity of the individual, not simply the body and its functions (Langer, 1994).

To be disabled means we are speaking of something one is rather than something one has. It is not uncommon for disabled persons to consider themselves more than disability. Disability, which suggests that paraplegia is more than a condition affecting the legs, is an important and essential part of who one is because of the I-World nature of its disruptions. It is not a pathogenic process or organism which is alien in this perspective, rather it is the person in relation to the world. Disability is therefore best understood as a condition of the world as well as the body.

Some of the features of the phenomenology of physical disability as expounded by Williams (1984) could be summarized

as follows :

a) Physical disability should be understood as an existential as well as an orthopaedic or physiological event.

b) Human movement is constitutive of self-world relations. The ability to move plays a crucial role in passing time, pursuing activities, finding interesting sensory information and maintaining one's concept of self.

c) The upright posture and mobility are in some sense constitutive of what it means to be a person, an agent who is self governing, who chooses goals and meets them, and who is the centre of action and value.

d) The body and its position in time and space provide a here which allows action in the world out there.

e) It is not the loss of a major life activity through some condition which characterizes disability, rather, disability is the disruption of the I-World relation which may attend this loss.

f) With disability, the world becomes a strange place, and its geographical and temporal boundaries become

extremely shrunken and impoverished experientially.

g) The I-World relation may be a more fruitful focus in the disabled person than the objective view of function/loss and function/replacement. It is the intentional relation that opens the world to the disabled person, and in its absence closes it.

4.2 Psychological impact of Disability during Adolescence

The transition to adulthood can be an extremely difficult one for most young people but most, sooner or later, adapt to a variety of adult roles. For those on the margins of society, which includes young people with disabilities, the problems often have longer lasting effects and their transitions to adult roles may be prolonged or curtailed. A study by Clarke and Hirst (1989), showed that disability can affect the timing and sequence of transition of disabled young people to adulthood. This in turn may limit or prevent the fulfilment of a role that is considered normal in society, and thereby affect their overall self-image.

Most writers on adolescence see the central developmental task at this stage in life as being the gradual attainment of

personal independence. Erikson (1966), whose work in this area has been particularly influential, describes this as "identity formation", and views the adolescent as engaged in a gradual separation and detachment from his parents. He believes that the young person may, because of the uncertainty of his new role, experience an "identity crisis" which can lead to apparently maladaptive behaviour patterns.

Blos (1962) whose views are fairly similar to Erikson's, sees adolescence as a process of "individuation" in which a young person takes increasing responsibility for what he does, rather than placing this on the shoulders of others, in particular on the family.

While these issues apply equally to all adolescents, in the case of the disabled adolescent, the question is greatly complicated by the physical dependence of these people on others, especially their parents. Issues of independence and responsibility are, however, just some of the issues disabled adolescents have to struggle with. According to Anderson and Clarke (1982), disabled adolescents experiences social isolation, feelings of helplessness and despair, fears about

relationships with the opposite sex and concerns about vocational placement.

In their social interaction with others, young people's difficulties are usually manifested in three areas, namely over-dependency, over-independency or social isolation (Halliday, 1989). Over-dependency may lead to fearfulness and anxiety when confronted by the unknown and passivity in the face of the known. This will further limit successful experience from which to gain confidence to make forays into a world which may appear overwhelming and frightening. Over-independency may result in the young person taking unacceptable risks and behaving in a socially inappropriate manner, and thus incurring criticism. This could further compound the often inherent feelings of unacceptability and dislike. Isolation may lead to resentment of the disability which may lead to further isolation as the resentment colours the degree of self-acceptance and impedes relationships.

Freeman (1970), was of the opinion that while there is general agreement that the incidence of psychiatric disorders is greater among the disabled population, and greater still

during adolescence, there is no substantial evidence that a particular type of disturbance is typical or universal of the disabled adolescent. One may therefore expect the full range of disorders which may be prevalent in the non-disabled adolescent population. Minde (1978) found that approximately 18% of the young people with cerebral palsy studied were assessed to have definite psychiatric problems, and this was closely related with parental discord and also with having no non-handicapped friends. It is also interesting to note that Thomas (1986) found less than 5% of young adults with disabilities receiving psychiatric care. This could indicate a gradual resolution of the difficulties as the person grows older.

Abrahamson, et al. (1979) refers to a number of dialectics which characterizes this phase of development for the disabled adolescent, dialectics which comprises of struggles between two opposing needs. These include, amongst others, acceptance-rejection, independence-dependence, and expectation-performance. While these areas are not the exclusive province of the disabled, the nature of these dialectics and their ultimate resolution differs from non-disabled adolescents.

Abrahamson, et al. (1979) suggests that the importance of social acceptance is not entirely confined to how significant others perceive an individual. Sound self-evaluation and success in the arena of social life is often measured by the number of friends one has within the group. Subsequently, the more one is socially accepted within a group, the more opportunities exist to develop and to utilise one's social skills. Over time these experiences contribute towards the development of a positive self-concept.

Thus one could conclude that the cycle of either acceptance or rejection is self-perpetuating. Disabled adolescents generally experience rejection far more frequently than acceptance. They therefore find it difficult to make friends, do not easily find social acceptance and may have inadequate self-concepts. By the time the disabled child reaches adolescence, efforts on his part to become more autonomous are often viewed by others as rebellious behaviour. The adolescent, after having observed his non-disabled peers achieving increasing responsibility, independence and decision-making abilities, tries to emulate them. These efforts are often blocked by overdependent parent-child relationships as well as severe physical involvement.

The final dialect, according to Abrahamson, et al. (1979), finds most disabled adolescents in a no-win situation. Parents, teachers and peers may expect more from a disabled adolescent than what he is actually capable of performing. Significant others may also expect too little, thereby not challenging the adolescent, and causing him to under-perform.

Disability may further challenge some fundamental assumptions that are often implicit about living. Future goals and projections may be shattered. The present may be replaced by many anxieties about an imagined future. The body itself may be viewed as an opponent to intention, where disability renders physical effort and will incapable of embarking on or completing an intended action. The invitation to experience life is filled with considerations of accessibility, social acceptability, feelings of low self-acceptance, etc.

Furthemore, the suffering experienced by the adolescent is not simply a result of impaired body function. It results too from the impending threat to the integrity of the individual. It results from internal psychic conflicts involving sense of self, self-esteem, ability to fulfil expectations, negative perceptions of self or others regarding disability.

CHAPTER 5

SELF—ESTEEM

Many psychologists are of the opinion that there is no value-judgement more important to a person – no factor more decisive in his psychological development and motivation – than the estimate the person passes on himself (Kashani, 1986, Gurney, 1988, Mruk, 1995).

The nature of this self-evaluation has profound effects on the individual's thinking processes, emotions, desires, values and goals. It is often considered the single most significant key to a person's behaviour. To gain an understanding of a person psychologically one must understand the nature and degree of his or her self-esteem and the standards by which he/she judges himself/herself.

A person's need of self-esteem can therefore be considered a basic need, a need which is inherent in his nature. However, nobody is born with the knowledge of what will satisfy that need or of the standard by which self-esteem is to be measured.

This knowledge must be discovered through life experiences. Furthermore, this discovery takes on a particular significance during adolescence and especially with adolescents with physical disabilities.

5.1 Definitions of Self-esteem

Self-esteem would appear to be an extremely important phenomenon. It would appear to involve issues of identity and value, but would also reflect how individuals feel and act in a variety of circumstances. It is therefor not surprising to note that self-esteem has generated a great deal of research, and that this research represents a wide range of theoretical orientations.

Despite the popularity of the concept of self-esteem, the definition and measurement of self-esteem remains largely elusive and ambiguous. This has allowed individual definition and measurement in each research design, with researchers using the concept of self-esteem as an independent variable, a dependent variable, an intervening and controlling variable, etc. (Brennan, 1985).

Wells and Marwell (1976) concluded that there were four basic ways of defining self-esteem;

(a) Definitions which are based on the idea that the self can be treated as an object of attention, i.e. one can have an emotional, cognitive and behavioural response to oneself in the same way as one responds to other objects.

(b) Definitions which are based on the relation between different sets of attitudes, e.g. the difference between one's attitude towards one's real and ideal selves.

(c) Definitions which focus on the psychological responses one holds towards oneself, e.g. feelings of acceptance and rejection.

(d) Definitions which hold self-esteem as being part of the self or self-system.

Cheshire and Thomae (1987) in turn attempt to identify self-esteem in accordance with what they describe as the almost universally accepted components of self-esteem;

(a) The cognitive element, i.e. characterizing some parts of self-esteem in descriptive terms.

(b) The affective element, i.e. a degree of positiveness or negativeness attached to those facets identified.

(c) The evaluative element, i.e. an attribution of some level of worthiness relating to some ideally held standard.

Jackson (1984), contends that what is required is a more naturalistic approach, which can explore self-esteem in a living context. The themes that constitute self-esteem should be examined. The opportunities, the problems, the triumphs and the defeats which an individual encounters in the development of the self should be examined. At the same the investigation should not lose sight of how these themes are woven together into a person's own story.

According to Mruk (1995), a good theory of self-esteem must comply with at least three major criteria;

(a) It must be founded on a major scientific perspective to have credibility.

(b) The definition of self-esteem must include either aspects of competence, worthiness or both.

(c) It must address certain key characteristics and dimensions of self-esteem e.g. the different types of

self-esteem, the developmental nature of self-esteem, the motivational aspects of self-esteem, etc.

In perusing the many definitions Mruk (1995) contends that while each tells us something about this vital phenomena, it fails to define self-esteem definitively, or describes it as it is lived in both every day life as well as structurally. The task, he feels, falls to phenomenology to do this. In his review of the major theories on this phenomena, he concludes;

(a) We must consider competence and worthiness, as well as the relationship between them, as that which creates self-esteem.

(b) We must take into account the lived quality of self-esteem i.e. the processes of judgement and self-awareness and emotional reaction, as it is embodied in the situations of real life for any given individual.

(c) We must capture the dynamics of self-esteem, i.e. its relative stability whilst holding the possibility of change.

The development of a phenomenology of self-esteem thus shows it to be the lived status of one's individual competence and personal worthiness at dealing with the challenges of life over time. Self-esteem is construed to have two interrelated aspects: it entails a sense of personal efficacy and a sense of personal worth. It is the integrated sum of self-confidence and self-respect. It is the conviction that one is competent to live and worthy of living.

5.2   Disability and self-esteem

To fully comprehend the impact of physical disability on the self, it is important to note that body images and self images are not merely mental reflections of the physical self; they are associated with others' appraisal of and reactions to one's appearances and actions. According to van der Velde (1985);

> "...body images are fundamental dynamisms in the development of self-concept; they contribute to the characteristics of personality; they are our mental blueprints for the organization of our social behaviour." (p 527).

According to Magill and Hurlbut (1986) very little has been written on the self-esteem of adolescents with cerebral palsy, or any other form of physical disability. In order to examine the full implications of physical disability on self-esteem, it might be important to examine the different dimensions which constitute the self, namely, physical self, personal self, the self within the family and social self.

5.2.1 The Physical self

Since the handicap is constantly present in a cerebral palsied child's life, his realm of life is in that respect always different from that of a non-disabled child. Teplin, et al. (1981) suggested that cerebral palsied children begin to regard themselves as "different" as early as four years old, but the negative effect on self-esteem does not begin until much later. In the case of younger children with cerebral palsy, there is generally a higher expression of self-competence, which Ostring and Nieminen (1982), has interpreted as an attempt on the part of these children to deny their dependence.

Ostring and Nieminen (1982), has further argued that the acceptance of the dependence brought about by the handicap and its integration into the self concept are essential for positive self-concept and self-esteem of the cerebral palsied child. Should this process succeed, a positive attitude towards the handicap is achieved and the handicap is not considered a factor which causes failure. Denial of dependence leads to experiencing the handicap as lowering the human value and self-esteem.

According to Teplin, et al. (1981) the initial positive self - image which is present in the young cerebral palsied children, gradually disappears as the child grows older and he begins to experience the physical restrictions which his body places on him. Adolescence is the period when a young person has to accept the finality of his disability and to abandon the unrealistic fantasies which might have sustained him when he was younger (Freeman, 1970). During this stage the body is experienced as inferior, and influences the adolescent's willingness to participate in social activities (Minde, 1978).

During adolescence the sense of physical body becomes a central concern and influences a person's self-esteem or evaluation of self-worth. Magill and Hurlbut (1986) are of the opinion that while there is very little literature on the self-esteem of adolescents with cerebral palsy, some of the findings on the self-esteem of non-disabled adolescents can be applied to the disabled.

Puberty is a period marked by considerable change in the biological, psychological and sociocultural realms of life. During this period the adolescents struggle to determine their relationship with society, and the roles and lifestyles they will assume. The handicapped adolescent may experience more conflicting answers to the question "Who am I?". The social information his parents or teachers provide may differ radically from that which his non-disabled peers provide, and thus a lack of self-confidence may develop.

5.2.2 The Personal Self

The inability of most cerebral palsied children to perform at an age-appropriate level on the physical, social and cognitive level, has a negative effect on his development of self

competence and self worth (Richardson, 1972). These feelings of inferiority and a lack of self confidence could lead to the child withdrawing from active participation in social activities (Anderson & Clarke, 1982).

In two different studies by Richardson, et al. (1964) and Magill and Hurlbut (1986), it was found that in the former study, that girls would generally provide more negative self descriptions than would boys, and in the latter study, the self concepts of girls were significantly poorer than those of boys.

5.2.3 The Self within the Family

The first inter-personal relationship which a child develops is with his mother and other family members. This relationship to a large degree determines the basis for the child's attitude, feelings and behaviour towards others. It is through the interactions between the cerebral palsied child and his family members that the child also begins to gain some insight and understanding of how others view him. Studies have shown that the child with a disability who is given responsibility and decision making powers within the family, has a greater

chance of developing self-confidence and a positive self-concept (Anderson & Clarke, 1982). The development of independence is severely impaired, and in adolescents regression may occur, if a child is not part of the decision-making process within the family (Freeman, 1970).

5.2.4 The Social Self

The self-image a person develops is largely a result of how others relate and react to him (Dovey & Graffam, 1987). Furthermore, Du Plessis (1991) contends that interpersonal experiences lead to a continual re-creation and re-development of the self-image.

Disability severely restricts the child's ability to socialise and the child is isolated from the reactions of society. Where such contact does take place, the reactions of others are often very negative. The stigmatised views which society holds of disability has a direct impact on the self concept. Of the forms of physical disability, studies have shown that cerebral palsy elicits the most negative responses from society (Magill & Hurlbut, 1986). According to Du Plessis (1991) it is this stigmatising factor which results in cerebral palsied

children, especially in late adolescence, refusing to associate with others with disabilities. The irony is, of course, that these adolescents have equal difficulty in forming associations with non-disabled peers, and hence socialising is even further restricted.

Urbani (1982) is of the opinion that disabled children experience the world very differently from non-disabled children. He further contends that they only experience the reality of their differences when they interact with the non-disabled. This sense of being different can result in serious emotional problems for disabled children. In this regard, Halliday (1989) refers to feelings of powerlessness, anxiety and feelings of low self-worth which can result in withdrawal and fear. According to Richardson (1972), one of the major problems experienced by cerebral palsied young people was the stereotyped and often negative reactions of people who found it difficult to treat the cerebral palsied, and the disabled in general, as human beings. Besides being demoralising, such stereotypes were often so powerful and pervasive that it would have been difficult not to fall into society's conception of how they should behave.

Factors which affect adjustment are as numerous and as unique as the individuals learning to adjust. Each person brings a multitude of factors of physical competence, of social experience and of family background to their life experiences which render ludicrous the expectation to have a standardised formula which can predict or measure levels of adjustment or self-esteem.

CHAPTER 6

PSYCHOTHERAPY WITH DISABLED ADOLESCENTS

Grzesiak and Hicok (1994), suggests that the paucity of literature on psychotherapy, physical disability and rehabilitation, is due to three main reasons :

(a) Firstly, the psychotherapists who work with the physically disabled are usually identified primarily in the field of clinical psychology and psychiatry and only secondarily do they identify themselves with physical rehabilitation.

(b) Secondly, rehabilitation psychology has generally placed greater emphasis on the somatopsychological processes and ecologic-environmental approaches to the psychological difficulties of the disabled.

(c) Thirdly, the majority of the literature on intervention in physical rehabilitation has focused on behavioural approaches, which is primarily action orientated, and not insight orientated.

It is generally felt that the failure of the adolescent with a disability to. accomplish the tasks of normal adolescence results in a range of psychosocial symptoms which is characteristic of this population. This includes :

(a) emotional dependency, mainly on parents.

(b) difficulties in experiencing and expressing intimacy.

(c) depression, with features of withdrawal, helplessness, hopelessness, and marked self-depreciation.

(d) a diffused sense of identity containing a defective body-image.

(e) episodic aggressive behaviour.

(f) the persistence of the stage of concrete thinking (Brier & Demb, 1980).

Grzesiak and Hicok (1994) is of the opinion that the principles and practice of psychotherapy with physically disabled persons are no different from those who are non-disabled. There are, however, several important psychodynamic themes which are uniquely prevalent in the psychotherapy with physically disabled people. The first theme is the effect of early physical damage on the developing ego. Some authors have

focused on the destructive aggression that might be expressed as a result of ego defects secondary to physical disability (Castelnuovo-Tedesco, 1981). Others believe that the psychological consequences of disability could be a more positive vitality that would allow unexpected achievement. Yorke (1980), for example, holds the view that physical disability can act as a spur for compensatory achievement or as a convenient focus onto which all difficulties and frustrations can be bitterly projected. Jureidini (1988) further points out that many physically disabled people lack the physical skills necessary to give expression to normal aggression, while physical restrictions combine with the disabled individual's treatment by the environment to make successful individuation a more difficult achievement than it is the case for the non-disabled.

The second theme revolves around the importance of parental acceptance of the disability. The birth of a disabled child is a narcissistic blow to the parents who grieve the loss of their fantasised "normal" baby. Conflict arises between drives to protect the helpless child and revulsion and shame at the abnormality. Thus the mutual mirroring between mother and

child is disrupted (Kohut, 1972). It is thus possible that feelings of inferiority arise in disabled people because of the withdrawal of maternal love rather than because of the disability itself (Poznanski, 1984).

The third theme refers to the relationship of mind and body and how that relationship determines the special role of fantasy in the inner world of disabled people. Winnicott (1954) did not consider the mind as a separate entity, but as those aspects of mental processing with which the infant accommodates the mother's inevitable failure to adapt perfectly to the infant's needs. Thus he saw the function of mind as allowing adaptation to an imperfect and traumatic environment. In the case of the disabled child, should mothering be too erratic, there would be an overdevelopment of this mental processing so that the mind could begin to take over from the mother in organizing the caring functions. As a result the psyche, which should bear an intimate relationship to the whole body, could become falsely localized in the mind and the individual loses the ability to live in his body.

Disabled individuals are vulnerable to this course of events because of the practical and emotional difficulties of mothering a disabled child. Thus there is a tendency to identify the mind as an ally against the body, and for fantasy to become localised in the mind rather than the body (Ogden, 1973).

Ogden (1973) remarked that psychotherapy of a patient with cerebral palsy highlights particular issues focusing on self-representation, body representation, and the handling of aggression. Ogden (1973) further concluded that there was very little hope of addressing issues of aggression while the body was experienced as the executor of aggression and the self was experienced as a separate, powerless observer of the body. Thus integration of self and body representations had to take place, before any progress in any other area could take place.

On reviewing the psychotherapeutic methods which have been found to be effective when working with disabled adolescents, two assumptions emerge. Firstly it is assumed that the developmental stage of the disabled adolescent is fundamentally different to that of the non-disabled adolescent

in that the traditional tasks of "normal" adolescence are often not accomplished by this population (Lewis, 1993). Secondly, it is assumed that when one treats disabled adolescents, the therapist must take into account a range of cognitive deficits of such individuals (Brier & Demb, 1980).

On the reasons for the appropriateness of group psychotherapy as a form of psychotherapy for disabled adolescents, Rudnitzki (1988), expressed himself as follows;

"...the whole may have a complementary meaning for the part, in particular for the incomplete individual who, in addition, is excluded, rejected and devalued...the whole group can function as an image of the whole body; likewise the potential of others in the group can represent parts of the body and physical completeness. This concept of group experiences inspired us to use group analysis with disabled young people as a kind of psycho-social prosthesis. The many dimensions of group experience make up for the deficient individual experience." (p.173).

Many disabled adolescents tend to be overly self-critical, tend to attach pejorative labels to themselves, anticipate failure, feel different and/or strange and are generally ill-confident. They often refer to themselves or think that others refer to them as "mentally retarded". They are overly concerned with the possibility of failure and tend to interpret the behaviour of others as consensually validating this concern. They often interpret others as being rejecting and/or disapproving even when they are not. The psychological crisis engendered by the existential feeling that they have no identity or definite sense of themself is, perhaps, the most profound existential crisis a human being can experience. The most exaggerated form of this feeling means that they do not have faith in their existence as a person. This is particularly so when, in their attempt to crystallize their identity, they feel seriously alienated, lonely or confused.

The psychotherapist can therefore play a unique role in the healing process itself. Cassell (1992) notes that a therapeutic goal includes maintaining or restoring the integrity of the person. Goldberg (1978) points out that in general, psychotherapy with adolescents demands a conservative

approach in that one sees a self in the midst of restructuring

or reorganizing, and only careful consideration of the

particulars of intervention will allow this self-development

to proceed.

CHAPTER 7

RATIONALE FOR STUDY AND PROBLEM STATEMENT

A disabled child has to face many unique and complex developmental tasks in addition to the usual ones in adjusting to himself, to his disabling condition and to his immediate environment. It has been pointed out that, despite the commonly held, but erroneous view of a single neat effect of disability, a physical disability, and especially cerebral palsy, may, in fact, impair not only motor functioning, but also one or several other functional capacities, namely sensory, behavioural, cognitive or social. The effects of a physical disability influence all aspects of the child's growth and development, and thus all areas of his life (Dunn, et al. 1988).

Battle (1974) has pointed out that both the mandatory parental relationship in the first year of life and the voluntary social relationships from age three through to the school years, are influenced significantly by the presence of a

physical disability. In reviewing the socialisation process of the very young disabled child, Battle (1974) examined general modes of interacting with the environment, dependency and independence, emergence of a clear body-image, self-concept, self-esteem, relationships with siblings and the peer group, and opportunities for play and for participation in interpersonal relationships and concluded that each of these aspects of early childhood socialization is markedly altered in the disabled young child. In considering the magnitude of the social disruptions and barriers for the young disabled child, Battle (1974) cautions that these barriers are likely to increase as the child grows older.

Adolescence is an appropriate age to examine the relations between mental health and self-understanding because it is an age during which adjustment disorders arising from self-concept and self-esteem problems are relatively common. Damon & Hart (1991) contends that studies have shown that during adolescence, self-criticism is highest and that throughout adulthood people are most likely to identify adolescence as the worst period in their life (Damon & Hart, 1991).

Rosenberg (1985) in fact, has written that adolescence is the

age at which there are most likely to be disturbances and conflicts in self-concept and self-esteem.

In their report on the health needs of the adolescent, the World Health Organization (WHO, 1977) has pointed out that an able-bodied adolescent can worry unduly about being physically or mentally different from others. In the case of the physically disabled adolescent, additional sources of anxiety at the time of sexual maturation are likely to occur, such as the search for an identity compensating for the disability, and the prospect of probable or possible failure in the emotional, social and occupational spheres.

The physical and social changes which occur during adolescence have been found to be associated with changes in self-concept. (Simmonds, et.al, 1987; Ellis & Davis, 1982). As body-image is an important factor in adolescent self-concept development it seems reasonable to assume that impairment of motor functioning could have adverse effects on self-concept and self-esteem (Harvey & Greenway, 1984). Anna Freud (1952) and Greenacre (1958) were pioneers in exploring the effects of physical disability on the developing ego, identity and body

image. Previous studies of children with cerebral palsy have shown adverse effects, including low self-esteem (Richardson, et al. 1964; Minde, 1978).

Although there is considerable literature about the self, it is a complex field which has generated diverse and often contradictory theoretical frameworks. Current theories generally assume that self-concept involves a description an individual uses to identify his or her characteristics. Self-esteem is seen to involve an additional evaluative component and is usually defined in terms of personal judgements of worth (Brennan, 1985), or alternatively in terms of attitude towards the self as object (Rosenberg, 1985).

The natural science orientation of treating self-esteem as if it is an actual phenomenon is limiting. Phenomenologists view self-esteem as a construct, it is a means of conceptualising the unique combination of feelings of competence and worthiness that is lived by individuals through positive and affirmative experiences in their life-world. Therefore, self-esteem cannot be the object of study, but what should be studied is "the actual experiences that enhance or lessen one's competence and worthiness at living" (Mruk, 1983).

Of relevance to this particular study is the fact that within
the phenomenological existential tradition, there is only a
limited exploration of self-esteem (Mruk, 1983), no
comprehensive psychology of adolescence (Fischer & Alapack,
1987), and as far as this researcher is aware, no significant
study of disability has been undertaken within this
perspective.

Furthermore, very little has been written about psychotherapy
with the physically disabled. The majority of the literature
on psychological intervention in physical disability has
focused on behavioural approaches (Grzesiak & Hick, 1994).

The exceptions to the behavioural approach are few, e.g. the
use of psycho-analytic psychotherapy with cerebral palsied
patients (Ogden, 1974) and the use of group analysis with a
group of physically disabled adolescents (Rudnitzki, 1988).

From a phenomenological viewpoint, before one can assist the
physically disabled adolescent with his or her life's journey
it is essential to consider one's view of being human.
Although man is more than his body, he inhabits the world
with his body, and he makes contact with the world of objects

and people through his body. It is the experiences which people have of their bodies, which provides us with access to all that can be directly known, because all knowledge is ultimately grounded in human experience.

The body comprises one's earliest capacity for relating to, and interacting with and experience of the world of objects and people. Phenomenological psychology emphasises the total structure of our activity and experience. It also discloses the structural inter-dependence of ;

    (a) the individual's lived body and its surroundings.

    (b) the individuals actions and experiences.

    (c) those actions and experiences, and the organization of the individual's personal life-world (Moss, 1989).

Therefore, when we encounter another person in psychotherapy, we make contact with another person whose actions and experiences all occur within a personal life-world. These actions and experiences have meaning for that person only within their personal life-world. Thus we have to understand the personal organization of that person's life-world, if we wish to understand who that person is for himself or herself

and for others. To explore the life-world of an individual, is to confront continually the role of the lived body in organizing that life-world (Moss, 1989).

A disabled body will of necessity exert an influence on how a person relates to himself and to his world. The disabled person is firstly a human being, but he is also, as a result of his disability, a special human being. The special nature of his being human must be understood before he can be helped to deal with the world which often offers little understanding, and frequently even less acceptance.

The purpose of this study is to investigate from a phenomenological perspective, the self-esteem of a group of physically disabled adolescents who have been diagnosed as cerebral palsy. The study will attempt to understand the changing relationship between body, self and the world as experienced by these individuals during this specific stage of their development.

Why a changing relationship ? Essentially because adolescents experience regular fluctuations in their quest for certainty. They are constantly confronted with the dilemma of choice

between independence and dependence, acceptance and rejection and expectation and performance. For the physically disabled adolescent, these dilemmas are exacerbated because this period also heralds a change in the meaning of their relationship with themselves, their bodies, their families, their social peer group and broader society. The non-disabled adolescent community also start to develop interests which often exclude the disabled adolescent. These changing perceptions and relationships could influence their sense of self-worth and competence.

What is it about the encounter or relationship between non-disabled adolescents and disabled adolescents which can elicit the experience of self-esteem or a change in the experience of self-esteem ? Many studies have shown that differences, whether physical, academic or social are experienced most acutely during adolescence (Schegel & Barry, 1991).

Physically disabled adolescents realise that they are part of a mainstream society, and that they need to establish some form of relationship beyond the restricted environment which they might have become accustomed to and comfortable with, eg.

special schools. On a personal, social and emotional level, their encounter with their non-disabled peers is an indicator of their readiness and ability to integrate effectively.

Mainstream society also realises that it cannot continue to ignore and marginalise the disabled. As we gradually move towards a more inclusive society at all levels, it becomes increasingly more important to understand this encounter between disabled and non-disabled adolescents.

CHAPTER 8

RESEARCH DESIGN

The research design was descriptive, using a phenomenological method of protocol analysis of transcribed, unstructured and open-ended interviews with 8 cerebral palsied adolescents. The researcher attempted to obtain spontaneous descriptions from the participants of their subjective experience of feeling good or bad about themselves in their contact with their non-disabled peers. Polkinghorne (1988) reminds us that the phenomenological interview focuses on the the life-world experience of the interviewee and is thus theme-oriented rather than person-oriented. Rather than seeking general views, the interview focused on specific situations and actions which could be considered as instances of the theme under investigation.

A phenomenological explication bases itself on the data as presented. The data of phenomenological research are the descriptions of the experiences as they present themselves, not the descriptions of objects and actions as they are

assumed to exist outside of the experience. This faithfulness
to the phenomenon resulted in the listing of a wide range of
expressions and descriptions whether or not believed
worthwhile by the researcher.

8.1 Description of the sample

The sample was purposive, based on the potential participants
ability to identify and to clearly describe an encounter with
a non-disabled peer group which led to them experiencing
either positive or negative feelings about themselves and
their handicap.

Eight adolescents aged between 15 to 19 years from Std 8 - 10
(Gr.10 - 12) participated in the study. Five of the
participants were girls and three were boys. From those pupils
approached, it would appear as if the girls were more ready to
discuss and explore such a personal experience.

All the participants had a disability known as cerebral palsy.
Cerebral palsy is a chronic non-progressive condition caused
by damage to a developing brain. This damage normally occurs
during pregnancy, at birth or in the first few years of life.

Cerebral palsy is not quite a single condition, but is an umbrella term to describe a variety of conditions which result in movement disorders (Stopford, 1987).

There are three major types of cerebral palsy, namely Spasticity, Ataxia and Athetosis, and the participants were representative of these three groups. These classifications are according to the area of the brain damage, the muscle tone and associated movement characteristics. In addition to these factors, there are other secondary difficulties which characterise these three categories, e.g. learning ability, speech difficulties and hearing difficulties (Stopford, 1987).

Four of the participants were classified Spastic. In Spasticity the motor cortex is damaged. Movement is often stiff and jerky with a loss of control in the affected limbs. Muscle tone is increased and limbs involved tend to be stiff but weak (Stopford, 1987).

Two of the participants were classified Athetoid. Athetosis is a result of damage to the basal ganglia. This area of the brain ensures smooth and organised movements. Injury to this

area is therefore characterised by increased and involuntary, jerky and irregular movements with an apparent lack of control over the whole body. Anxiety can often intensify these jerky movements. People with athetosis may lack facial control, leading to grimacing and dribbling and this was the case with two participants. These facial movements often evoke adverse responses from people who may wrongly make presumptions based upon them. These presumptions are mostly unfounded, since young people with athetosis tend to have unimpaired learning and intelligence (Stopford, 1987).

The third classification is known as Ataxia, and two participants were in this group. Here damage is to the cerebellum, which governs balance and co-ordination. Ataxia is consequently characterised by unsteady movements and difficulty in balance and co-ordination (Stopford, 1987).

Since cerebral palsy is a heterogeneous disorder whose physical parameters are clear and in which associated handicaps are commonly present and diverse in nature, the lack of data with regard to emotional problems, socialization and self-esteem should not be surprising (Freeman, 1970).

What is important to note however, is that the social interaction of children with cerebral palsy may for example at the very onset be hindered by their physical difficulties. Abnormal facial expressions and grimaces, slurred speech and waving arms and clenched fists, can easily disrupt the so-called "infant elicited social behaviour" of adults. People quickly conclude that the child is being difficult when it comes to making contact with others. This often leads to problems of attachment, which in turn is predictive of poor patterns of peer relations (Erwin, 1993).

CHAPTER 9

DATA COLLECTION

After having obtained approval from the Governing Board of the institution, the researcher proceeded to obtain the written consent from the individual participants and their parents to participate and to be recorded. The researcher then made an appointment to conduct the interviews at a time and place convenient to each participant.

Each participant was asked to recall a particular situation in which they were in contact with a non-disabled peer group and to describe what was good or bad about this encounter. They were requested to describe their experience as they remembered it, including their thoughts, feelings and perceptions as they remembered experiencing them. They were further requested to continue to describe this experience until they felt it was fully described. Clarifying questions were asked at appropriate times during the course of the interview. However, suggestive and leading questions were strictly avoided.

The questions were left as open-ended and non-directive as possible. More specifically, the questions were not phrased around aspects of worthiness and competence. The researcher believes that in the participants' descriptions of their encounter with non-disabled peers, those very aspects of self-esteem would be reflected.

These recorded interviews were then transcribed and typed out. The researcher read the transcript and where certain areas were not too clear, the participants were then consulted in order to obtain greater clarity about certain areas.

CHAPTER 10

DATA ANALYSIS

The following analytical process adapted from Colaizzi (1983), and utilised in a study by Haase (1987) was used;

1.Listening to and transcribing the taped interviews in order to acquire a sense of each protocol's meaning.

The researcher acquired a feeling for and a familiarity with the descriptions (protocols) provided by the participants by listening to the audiotapes a few times and then transcribing them. All participants could readily recall a specific and significant encounter with a non-disabled peer group which had evoked a sense of high self-esteem or low self-esteem. Because of the speech difficulties of some participants, this was a time consuming exercise. All the participants were requested to relate the specific encounter with a group of non-disabled peers in a fair amount of detail, describing how they felt and what they thought at that time, as well as how the situation

was resolved. Encounters with non-disabled peers appeared to have been very rare and therefor made quite an impression on most of the participants. Most of the participants appeared to have had few opportunities to share such experiences with others and seemed very keen to relate these to the researcher.

2.The extraction of significant sentences and phrases which directly pertains to feelings of self-esteem.

Within the eight protocols a total of ninety-five significant statements and phrases were identified which pertained to aspects of self-esteem.

3.Formulating the significant statements into a more general re-statement.

The re-formulation of significant statements into more general forms known as re-statements. The purpose of this is to transform the concrete descriptions and language of the participants into the language of science.

4.Significant statements and their re-statements are studied to derive and record a sense of their meaning, the formulated meaning.

Significant statements and re-statements are then studied to derive and record a sense of their meanings. Each of these formulated meanings is developed keeping its context in mind. Concepts, labels and processes were thus identified and clarified.

5.The formulated themes are derived from the formulated meanings and organized into theme clusters and theme categories.

Themes which were organized from the formulated meanings were then organized into theme categories and clusters to allow for the emergence of themes common to all participant protocols. According to Colaizzi (1983), it is important to note that where certain discrepancies appeared in themes, these would not necessarily be eliminated since logical discrepancies could nevertheless be existentially real and valued. Nor were data ignored which on the surface did not seem to fit. The researcher should here rely upon his tolerance for ambiguity

and should be cautious about prematurely generating any theories in order to eliminate the discordance.

6.Integration of themes into an exhaustive description of the experience of self-esteem.

An exhaustive description of the self-esteem in physically disabled adolescents in a non-disabled environment was derived. This is a narrative integration of all the themes, theme clusters and categories of themes. The exhaustive description was developed to gain insights into the structure of the lived experience of self-esteem in physically disabled adolescents in a non-disabled environment.

7.Formulation of the statement of the essential structure of self-esteem.

From the exhaustive description, the essential structure was derived. The essential structure of self-esteem is viewed as an integration of the common components of self-esteem identified in the exhaustive descriptions.

8. Validation of the essential structure of self-esteem by the participants.

All the participants were available for a short discussion on the essential structure of self-esteem as derived from their descriptions in this study. The full description of the essential structure was read to the participants, with the occasional clarification when concepts and terminology were considered complicated. Participants asked questions when anything was unclear. To ensure that there were no areas of uncertainty, the researcher also paused frequently to enquire whether specific elements of the essential structure were experienced by the participants. There was agreement that the essential structure reflected their experience.

To demonstrate the above-mentioned analytical process, two of the case studies (protocols) will be analysed and discussed. The analysis of the other six case studies will be found in the Appendix.

Case study 1

Most of my friends are disabled. I feel very uncomfortable with non-disabled people. There is this girl who stays opposite us who is my age, and who only comes to visit me about once a month. Anyway, I don't really mind because she is a tomboy, she likes playing rugby and soccer and moves around with the boys. This might be why she does not come to visit me a lot.

Sometimes I feel I don't really belong with other people. I'm not..that...I'm not the type of person to be with them...the type of person they are...they may feel I shouldn't be with them. That's how I feel. That I'm something different. Like people, if they see an alien, they'll think that they are totally different to you, to humanity...but that's how I feel, like I'm something different...I'm not a person, yeah, like that. (sigh). Feeling like something different, you don't feel like a person at that time.

Sometimes it's also like that at home. When my cousins go to the shop, they'll never allow me to go, or there are so many things they never allow me to do just because I'm disabled.

They just say no and it stays no. You have no choice. But if
it is like my brother who is younger than me, then they say :
"Yes you can do it anytime". But with me...uhm...it is always
no, no, no. Even when I argue with them, they get all angry,
that's why I just leave them the way they are. Because if I
must like just tell them that I feel hurt and that they are
like that with me just because I'm disabled...they feel that
they can just tell me what to do, and I must just do it just
because I'm disabled. Then it gets...I don't know...I don't
know what they think...but they probably think that I am bad
or something.

I can get quite angry. Just say sometimes like...gosh...ok,
like sometimes my mother...uhm...now I'm slow, I'm very slow,
and I can't help it, it is part of my disability. Now I don't
know how to explain it to her. Now she always says: "Can't you
move faster, can't you do that faster, must you always be so
slow"...and everything...and then I told her that her that it
is part of my disability, and she says that you are hiding
behind your disability all the time hey, Is that now going to
be your excuse everytime I tell you to do something. I tell
her: "Not for everything, there are certain things

that...uhm...it is part of my disability, and I can't just change overnight...and being very slow, I can't change it at all".

They can't take it...like they never got used to it, even though I've been like this since the age of two when I fell ill. Even though they have known me for so long, and they've been living with me since I became disabled, they still can't accept it...they can't take it...like sometimes it looks like my mother is going to explode or something when I am so slow, I try to be fast, but it is so difficult. Like once something was on the stove...I was busy with my homework, and something was burning. My mother called me to take it off, but I couldn't get there fast enough. She almost exploded. Disability just gets in the way of everything...that's how she most probably feel...ok...being slow not with everything, just sometimes.

Case study 1.(a)

2.The extraction of significant sentences and phrases which directly pertain to feelings of self-esteem.

1.1 " Most of my friends are disabled. I feel very uncomfortable with non-disabled people."

1.2 " Sometimes I feel I don't really belong with other people."

1.3 " I'm not...that...I'm not the type of person to be with them...the type of person they are."

1.4 " They may feel I shouldn't be with them. That's how I feel. That I'm something different. Like people, if they see an alien, they'll think that they are totally different to you, to humanity...."

1.5 " That's how I feel like I'm something different...I'm not a person, yeah, like that.(sigh)Feeling like something different. You don't feel like a person at that time.

1.6 " When my cousins go to the shop, they'll never allow me to go, or there are so many things they never allow me to do just because I'm disabled."

1.7 " They just say no and it stays no. You have no choice."

1.8 " Even when I argue with them, they get all angry, that's why I just leave them the way they are."

1.9 " Because if I must like just tell them that I feel hurt and they are like that to me just because I am disabled...they feel that they can just tell me what to do, and I must just do it just because I'm disabled. Then it gets...I don't know...I don't know what they think...but they probably think that I am bad or something."

1.10 " Just say sometimes like...gosh...ok, like sometimes my mother...uhm...now I'm slow, I'm very slow, and I can't help it, it is part of my disability. Now I don't know how to explain it to her."

1.11 " I told her that it is part of my disability, and she says that you are hiding behind your disability all the time hey! Is that now going to be your excuse every time I tell you to do something?"

1.12 " They can't take it...like they never got used to it, even though I've been like this since the age of two when I fell ill."

1.13 " Even though they have known me for a long time, and
they've been living with me since I became disabled,
they still can't accept it...they can't take it...like
sometimes it looks like my mother is going to explode
or something when I am so slow."

1.14 " Disability just gets in the way of everything...that's
how she must probably feel."

Case study 1.(b)

3. Formulating of the significant statements into a more general re-statement.

1.1 Being with non-disabled people makes me uncomfortable.

1.2 I don't feel I belong with other people.

1.3 I am not like other people, and therefore they do not want

   to be with me.

1.4 Other people might not want to be with me, and that just

   makes me feel that I am very different from them.

1.5 The feelings of being different makes me feel less of a

   person.

1.6 Others prevent me from doing things because of my

   disability.

1.7 When others decide something affecting me, I feel I have

   no choice.

1.8 When I try to stand up for myself others get angry, so I

   leave it alone.

1.9 Others feel they have the right to treat me in a certain

   way just because I am disabled, and when I express my

   unhappiness about it they make me feel bad.

1.10 I find it difficult to explain the implications of my
disability to my mother.

1.11 My mother feels that I hide behind my disability and use
it as an excuse.

1.12 No matter how long they have known about my disability
my family still can't accept it.

1.13 Even though they have lived with my disability for a long
time they still become angry at my slowness

1.14 My mother feels that my disability gets in the way of me
functioning normally.

Case study 1.(c)

4.Significant statements and their re-statements are studied to derive and record a sense of their meaning, the formulated meaning.

1.1 Non-disabled people can evoke feelings of anxiety, insecurity and ill-confidence in her.

1.2 She sometimes has feelings of being unworthy and incapable of being with other people.

1.3 She often feels that she does not possess all the qualities and abilities which other people have, and therefore she sometimes has feelings that others do not wish to interact with her.

1.4 When others find it difficult to interact with her it reinforces the feelings of being different.

1.5 The feelings of being different from other people make her question her worth and competence as a person.

1.6 Her disability restricts her from doing things, and prevents others from seeing what she is capable of doing.

1.7 Others have almost complete control over her life and give her no choice in matters concerning her.

1.8 Non-disabled persons do not respond well to her

confronting them, and therefore they just withdraw

and leave her alone.

1.9 Disability places her at a disadvantage when

it comes to relating to non-disabled people, where she

finds it difficult to express her true feelings, for

fear that others may form an incorrect opinion of her.

1.10 Communication with her mother regarding the implications

of disability in daily life is very difficult.

1.11 Her mother believes that she uses her disability as a

means to exercise control over her.

1.12 The family finds it very difficult to accept and adjust

to her disability.

1.13 Not only has the family not adjusted well to the

her disability, but they also respond to it with anger

and rejection.

1.14 She views her disability as an obstacle to effective

normal functioning in all areas.

Case study 1.(d)

Description of themes emerging from the participant's narration.

Being with non-disabled persons is an unfamiliar situation for the participant. The presence of non-disabled persons evoke discomfort, anxiety, insecurity and ill-confidence, as it highlights differences. Physical disability limits the ability to visit others, but it also limits visits from others. The participant is also aware of the differences in others, e.g. the tomboy friend, and believes that this difference can explain certain behaviour, e.g. lack of contact with the participant.

There is a sense of lack of belonging, of a difficulty others have to be associated with her. This difficulty others have to be associated with her reinforces the feelings of being different. There is a feeling of being different, almost to the point of feeling, like a non-human, a non-person. This raises feelings of unworthiness.

The disability not only restricts her from doing things, but it also prevents others from seeing what she is capable of doing. She loses a sense of control over her life, leaving her with little choice over issues which affect her directly.

There is also a sense of discrimination, where people less competent than herself are viewed as more capable. Her competence is constantly questioned and in turn she begins to constantly question her own competence.

Being disabled can also be very disempowering, giving rise to feelings of impotence, of having no voice to argue her case. Others also do not respond well to assertiveness from her, giving rise to a sense of resignation and feelings of being "bad" in the eyes of others.

Others become impatient about the practical consequences of the disability, e.g. the slowness, and this can result in feelings of anger. Poor communication leads to incorrect perceptions about the implications of the disability, poor adjustment to the reality of the disability and poor acceptance by others. Because of the rejection and

unreasonable demands of others, she is beginning to develop a feeling of responsibility for the implications of the disability.

Disability is viewed as the major stumbling block, cutting her off from meaningful interaction and relationship with others and limiting her possibilities and confirming her umwelt and mitwelt.

Case study 2

First I want to say that I have not had many experiences with non-disabled children my age. Now I'm sure you are familiar with the MusicActive programme. I joined them this year and I met a few people there, and I'd like to speak of that. Now all the people I met there...I did not have a chance to have nice long conversations with them...Whoever I met, I only met for a short time, although I did meet some of the people regularly everytime I met...mostly I met little groups of people everytime. Anyway, I think I liked it that way because I wanted to meet as many people as I can.

First of all, I would like to say that I met this girl...her name was Shireen. She is in Matric now and she also came to the MusicActive. So, like for the first three weeks, she was always with me, always around...like helping me with the wheelchair and so forth. Then I met another girl, that was also in the third week, and then I introduced her to Shireen, and so then Shireen did not speak to me anymore...not such a lot. Then she was with this other girl, Lynette, all the time. So...I didn't like feel bad, because I know like...that normal

people like to flock together...uhm...like birds of a feather.
So, I know that, it always happens and it's not the first time
for me, that something like that had happened.

But I just want someone to...like always be the same with
me...to react in a certain way towards me. Like Shireen was
very friendly, never sounded critical or anything. So I would
just like someone to stay with the same feeling, not change
after a while. Whereas normally you would get a normal person
reacting to disabled person as...based on first sight..saying:
"Oh look at her she can't do this, she can't do that...".
Shireen thought I was okay, I was nice to be friends with...
I don't like it when people change like that towards you. It
makes me feel bad. Because, I mean...(interruption). Now where
was I? Feelings...well...I just feel bad if that
happens...like Lynnette and Shireen becoming friends...even
though I know why that is happening, because...uhm...they
like...uhm...to be friends with one another, or they would
like to move off. I can understand, and I don't feel that bad
anymore. I've become used to it. Before, when I was younger, I
thought now why is this happening, although that time I also

could not understand it, but it sort of felt worse than now.
So..I don't really mind what happened.

There was this one boy at Music Active...his name was...
uhm... Isaac. We spoke a lot to me during the six weeks. He
actually ... he never went straight to another friend or
anything...although he was also mingling with others, he
always spoke to me in a certain way...with the same feeling.
He said I was a decent person...and...I mean he always sort of
thought the same of me. When I told him I did music at school,
so he asked me what kind of songs I liked.

We had a nice conversation. And that one I liked. Shireen
never reacted badly towards me. After she met Lynette, Lynette
and she would always talk to me, they would never leave me
out, but they were always more buddy-buddy. They were closer.
Like whatever Lynette wanted, they would do it. They would'nt
like ask me or anything, if I would like to go upstairs or if
I wanted to go outside at break. I really didn't think it was
fair of them...uhm ...I mean I'm also human, I would also
like to be asked you know. But I have been through it all...it
happened many times before.

So I usually don't meet people my age who are not disabled, it
was only at Music Active. I normally meet people older than
me. At home, also because I can't go out to play outside, and
people don't want to come inside. So, I speak to my brother
who is two years younger than me...and my two year old
sister...we have lots of fun with her.

I have come to terms with my disability long ago. I mean I was
at an ordinary school before I came here. I already then
understood my problems. I don't expect much...too much of
myself. Although at the other school I was a bit more normal.
I mean I have peripheral neuropathy, that is a weakness in my
nervous system. Even though my bones are still strong, because
of the nerves they don't carry the message from the brain to
the muscle, therefore I can't walk. I wished I could do more.
But I know, okay maybe one day I could do things again, but I
am not expecting anything. When I was younger I had a
recurring thought that children were talking about my
disability. I think normal people are scared of the difference
between us and them. That we can't do so much as them,
frightens them somewhat I think.

Case study 2.(a)

1. Extraction of significant sentences and phrases which directly pertain to feelings of self-esteem.

2.1 " Then I met another girl,...and then I introduced her to
Shireen, and so then Shireen did not speak to me
anymore...not such a lot. Then she was with this other
girl Lynette all the time. So...I didn't feel bad,
because I know like...that normal people like to flock
together...uhm...like birds of feather.

2.2 " But I just want someone to...like always to be the same
with me...to react in a certain way towards me."

2.3 " Like Shireen was very friendly, never sounded critical
or anything."

2.4 " So, I would just like someone to stay with the same
feeling, not change after a while."

2.5 " I don't like it when people change like that towards
you. It makes me feel bad."

2.6 " Although he was mingling with others, he always spoke to
me in a certain way...with the same feeling. He said I

was decent person...and...I mean he always sort of thought the same of me."

2.7 " They wouldn't like ask me or anything, if I would like to upstairs or if I wanted to go outside at break."

2.8 " I really didn't think it was fair of them...uhm...I mean I'm also human, I would also like to be asked you know."

2.9 " I have come to terms with my disability long ago. I mean I was at an ordinary school before I came here. I already then understood my problems. I don't expect much...too much of myself."

2.10 " I wish I could do more. But I know, okay maybe oneday I could do things again, but I am not expecting anything."

2.11 " When I was younger I had a recurring thought that children were talking about me...about my disability."

2.12 " I think that normal people are scared of the difference between us and them."

2.13 " That we can't do so much as them, frightens them somewhat I think."

Case study 2.(b)

2. Formulating of the significant statements into more general re-statements.

2.1 When my non-disabled friends click together, I understand that non-disabled people prefer each other's company.

2.2 I want people to react the same towards me all the time.

2.3 I like people who are friendly and non-critical

2.4 I want people to convey the same feelings all the time.

2.5 When people change towards me I feel bad.

2.6 I don't mind it when non-disabled people mix with others as long as they still have the same feelings and thoughts about me.

2.7 They never asked me when decisions had to be taken

2.8 I would like to be asked things, I thing it is fair and my right as a human being.

2.9 I understand my disability and have come to terms with it, therefor I do not expect too much of myself.

2.10 Despite my disability I wish I could do more, and while I still hope, I do not expect anything.

2.11 I used to have a constant feeling that non-disabled
     children were discussing me and my disability.

2.12 I think that the concerns non-disabled people have are
     often based on their fear of the differences they see
     between us and them.

2.13 Non-disabled people are afraid when they see how disabled
     we are.

Case study 2.(c)

3. Significant statements and re-statements are then studied to derive and record a sense of their meanings.

2.1 She accepts that non-disabled people relate to each other in ways which can easily exclude her.

2.2 She needs to feel assured that the non-disabled person can form a constant and consistent pattern of interaction with her.

2.3 She wants non-disabled people to relate to her in a friendly and non-judgemental way.

2.4 She feels that the basis for the relationship should be genuineness, trustworthiness and reliability.

2.5 When she detects a change in non-disabled people's attitude towards her, she feels very vulnerable and negatively disposed towards herself.

2.6 She does not demand an exclusive relationship with non-disabled people, as long as she is assured that others' attitude towards her remains positive and unchanged even

when they are with their non-disabled friends.

2.7 Non-disabled persons should consult her about anything which would indicate a recognition of her needs being considered.

2.8 Being asked for her opinion is a recognition by others of her worth and competence as a person.

2.9 She recognises the limitations imposed by her disability and accepts the need to curtail expectations about her own abilities.

2.10 She remains hopeful still for improvement in her condition, but realistically she is not expecting anything.

2.11 She used to have a strong feeling that others would discuss her because of her disability.

2.12 She feels that the differences in abilities and appearance between disabled and non-disabled people can evoke a sense of fear in non-disabled people.

2.13 She feels that the inability of disabled people to perform the range of functions which non-disabled people can perform routinely can evoke fear in non-disabled people.

Case study 2.(d)

4. Description of themes emerging from the participant's narration.

Although the participant has had only infrequent and irregular contact with non-disabled people, she expressed a desire to meet as many people as possible. She expressed concern that when non-disabled people interact, they relate to each other in ways which exclude her. This used to hurt her, but she has since developed an understanding of why this is happening. She does not demand an exclusive relationship with non-disabled people, but does not want them to change their feelings and attitude towards her because of her disability.

She is also concerned about the erratic nature of people's response towards her and expressed a wish that people should relate to her in a consistent manner. She was also concerned about the tendency of non-disabled people to form an opinion based entirely on appearance and their perception about what a disabled person can do based on physical appearance.

It is important for her to be consulted before any decisions are taken which would affect her. She views this as a recognition of her needs being considered by others and this is ultimately a recognition of her worth as a person.

She comments on the restriction placed on her to go and visit and interact with people her own age and also mentions the restriction her disability places on others visiting her. Her relationships are therefore mainly restricted to close family members older or younger than her.

While she often still fantasizes about an improvement in her condition, she has developed a realistic understanding about the nature of her disability. She recognises the limitations imposed by her physical disability and accepts the need to curtail her expectations about what she is able to do.

She recognises the difficulty non-disabled people have in dealing with the differences in appearance and ability. She describes this feeling as fear on the part of non-disabled. They are fearful, because seeing how disabled someone else is makes them feel vulnerable and powerless.

5.The formulated themes are then organized into theme clusters and theme categories.

Themes which were organized from the formulated meanings are then organized into categories and clusters to allow for the emergence of themes common to all participant protocols. According to Colaizzi (1983), it is important to note that where certain discrepancies appeared in themes these would not necessarily be eliminated since logical discrepancies could still nevertheless be existentially real and valued. Nor were data ignored which did not seem to fit.

The following 5 theme categories, consisting of 20 theme clusters were delineated:

1. Characteristics of the social encounter

1.1 Theme clusters

1.1.1 The sense of the unfamiliar

Others speak of matters you have no knowledge of, they relate to each other differently, they have experiences which you cannot relate to, the pace of activities are unfamiliar, views

non-disabled setting as "normal", and hence different, feels

removed from the everyday experience of non-disabled peers,

1.1.2 Irregular nature of the social contact

Need to meet more non-disabled people, only make contact when

invited to functions, only meet non-disabled under exceptional

circumstances, relate mostly with disabled peers,

1.1.3 Physical difficulty in establishing contact

Disability limits visits to others, and to get visits from

others to you, contact limited to family, younger children and

adult supervisors, views disability as the primary cause for

exclusion from social activity,

2. Experience of the social encounter

2.1 Theme clusters

2.1.1 Awareness of physical differences

Presence of non-disabled raises awareness of physical

differences, others' impatience at slowness, others'

reluctance to accommodate physical limitations, exclusion from

physical activities, feels isolated and conscious of limitations.

2.1.2 Awareness of different social standing

Difficulty others have to communicate and associate with disabled, feelings of being a non-person, a non-human, an alien, mentally and/or emotionally disturbed, non-disabled speak about the disabled in the third person,

2.1.3 Emotional response to social encounter

Feels responsible for obstacles to social interaction, presence of non-disabled evokes feelings of discomfort, anxiety, insecurity, ill-confidence and lack of trust in others and in self, feelings of not belonging, feelings of disempowerment, no decision-making ability, competence is queried by others and by self, sense of resignation, feels bad in the eyes of others, feels inadequate and incompetent, unpleasant experience, sense of anger, evokes feelings of isolation and resentment,

2.1.4 Experience of exclusion

Irregular contact with non-disabled, non-disabled relate in ways which exclude disabled, disability limits possibilities of meaningful interaction and relationships with non-disabled, non-disabled have common experiences which exclude disabled, non-disabled perceive disabled as different, incompetent, dependent on others, difficult to communicate with, emotionally unstable, difficult to manage and to accommodate in activities, disabled have feelings of loneliness, non-disabled people ignore presence of disabled person, disabled feels invisible, physical limitations are not taken into account when planning activities, easy to forget about disabled person's presence.

3. Experience of the body in the social encounter

3.1 Theme clusters

3.1.1 Body as central theme in existence

Awareness of physical limitations in a non-disabled setting, need for assistance to move around, difficulty in walking up

stairs, the activities of the non-disabled peers highlights limitations of the body.

3.1.2 Body as non-compliant

Unable to participate in games, complete a short hike, freely visit others, freedom of movement observed in others emphasises restrictive nature of physical condition.

3.1.3 Body as undependable

Need to present himself as competent and independent, falls in front of others, feeling humiliated, vulnerable, frail and inadequate, need for assistance from others.

4. Coping with the social encounter

4.1 Theme clusters

4.1.1 Dealing with prejudices and expectations

Views inappropriate behaviour of non-disabled as lack of insight, deals with inappropriate behaviour in a humorous way, conceals hurt at prejudiced behaviour, non-disabled does not expect disabled to achieve or perform competently.

4.1.2 Concealing disability

Limits conversation for fear of revealing inadequacies, limits number of non-disabled persons to communicate with, avoids situations which focuses attention on physical disability, refuses to attend functions where non-disabled are present, does not reveal the special school attending, hides scars on legs by wearing long pants, concealing disability avoids uncomfortable situation for non-disabled friends, views relationship between disabled and non-disabled as unequal, hence the need to conceal disability to be treated as equal, disability prevents others from seeing and appreciating the real person.

4.1.3 Utilising potential

Others are unaware of disabled person's potential, uses every opportunity to display skill, when feeling confident and competent to perform, disabled person does not hesitate to perform, when feeling confident about performance, then others' responses are less important, competes to assess own sense of self-worth and competence, competes to measure non-disabled people's openness to accepting disability and

abilities, opportunities to demonstrate competencies, enhances sense of self-worth.

5. Developing relationships with others

5.1 Theme clusters

5.1.1 Initiating contact

Fearful of initiating contact, poor experience of contact with opposite sex, concerned about poor impression disabled might present to non-disabled, concerned about communication skills, concerned about evoking a negative response from non-disabled

5.1.2 Understanding difficulty of non-disabled people

Forms opinions based on physical appearances, assumes that disabled is unable to comprehend conversation, communicate effectively, make own decisions, assumes others are more capable to speak on disabled person's behalf, non-disabled bypass disabled when needs are addressed, inappropriate offers of assistance by non-disabled, fear by non-disabled people of behaving inappropriately, making inappropriate comments or asking inappropriate questions, avoid contact with disabled,

non-disabled people have ambivalent feelings about achievements of disabled, can treat disabled in a condescending and over-protective way, tries to conceal awareness of disability.

5.1.3 Understanding nature of friendship

Understands that non-disabled peers have much in common, does not demand exclusive friendship with non-disabled, wants consistency, no erratic change in attitude or feelings, friends change when in the presence of non-disabled peers.

5.1.4 Acknowledging disabled person's needs

Important to be acknowledged as having worth as person and to be competent, wants consultation on matters affecting the disabled, wants to be able to make decisions, disabled need to speak for themselves.

5.1.5 Gaining acceptance

Need to prove sense of worth to non-disabled, requires opportunities to gain acceptance, need to work harder than others to gain acceptance, not afraid to confront and correct

misperceptions, not be filled with self-pity or to refrain from tackling a difficult situation, need to convince non-disabled that achievement and success is not incompatible with disability, find acceptance only within familiar settings eg. special schools.

5.1.6 Embracing disability

Awareness by others of disability, compels disabled to embrace disability, will take time to recognise it as an essential part of self, accept the dependent and vulnerable nature of disability, manage difficulties in a positive and constructive way, conscious of the abilities, competencies and strengths of disabled, embrace disability as a permanent and unchangeable part of self, embracing disability eliminates restrictive nature of the disability.

5.1.7 Communication

Uncertain about communication with non-disabled, tends to avoid communication with non-disabled for fear of eliciting negative responses and further rejection, poor communication can lead to incorrect perceptions, feels that non-disabled

talk behind their backs, need to engage non-disabled in a positive manner, regular and open communication can lead to acceptance as equal, positive input from significant others allow disabled to look beyond limitations and become empowered.

5.1.8 Family relations

Difficulty of family to accept disability, lack of understanding of the implications of disability, difficult to accommodate implications of disability in daily activities, poor communications and relationships within family, sense of alienation within the family, desire to improve family relations, but not always successful.

6. Integration of themes into an exhaustive description of the experience of self-esteem.

An exhaustive description of self-esteem in physically disabled adolescents in a non-disabled environment was derived. This is a narrative integration of all the themes, theme clusters, and categories of themes. The exhaustive description was developed to gain insights into the structure of the lived experience of self-esteem in physically disabled adolescents in a non-disabled environment.

The experience of the body is central to the experience of self-esteem in physically disabled adolescents in a non-disabled environment. By virtue of the exclusive nature of the two environments, disabled and non-disabled, there is an unfamiliarity and strangeness that pervades the encounter between physically disabled adolescents and their peers. Neither have the experience and skill to interact and communicate effectively.

The encounter presents the disabled adolescents with an extra-ordinary situation where their body is experienced as corps-objet, i.e. it is thematized. The body is experienced as

socially conspicuous, non-compliant and undependable. Physical difference and limitations confront them at every turn.
The world for the disabled adolescent is a strange place where geographical and temporal boundaries are extremely shrunken and impoverished experientially .

Disability, however, is viewed not so much as a limitation in physical activity, but as a disruption of the I-World relation which accompanies disability. While to the non-disabled person, the disability is viewed as alien, to the disabled adolescent it is the relationship to the world which is the alienation which is of greater concern.

The experience of being perceived by others as ill, socially incompetent, mentally handicapped or emotionally immature, angers and hurts the disabled adolescent. The difficulty of non-disabled peers to communicate effectively with the disabled is viewed as a logical result of this misperception.

Disabled adolescents also experience exclusion from the life-world of the non-disabled. They perceive others as sharing common experiences and relating to each other in ways

which exclude them. Very little attempt is made to accommodate their needs. They often feel ignored and invisible in the presence of their non-disabled peers. There is a sense of loneliness, both within social settings as well as within their families. They recognise the limitations of friendships with non-disabled peers, and demand only recognition, affirmation, acknowledgement of needs and a sense of acceptance and respect.

Disabled adolescents are frequently also impeded in their attempts to initiate contact, by their own anxiety and concerns about estranging their non-disabled peers because of their perceived communication difficulties or socially inappropriate behaviour. They often feel themselves unworthy of and incompetent in forming and sustaining a relationship with their non-disabled peers. To compensate, they attempt to conceal their disability, minimise their contact with others, limit conversation and avoid encounters with non-disabled peers.

Disabled adolescents also develop a deep understanding of the challenge that disability presents to the non-disabled

peers. The prejudice, fear, inappropriate behaviour, erroneous expectations, ambivalent feelings and condescending manners of the non-disabled peers, arouse anger and pain in them. At the same time, however, it also awakens a sense of fulfilling a task. They realise that their task is to conquer insurmountable barriers, overcome humiliating failure and labour endlessly to gain acceptance and to convince others and themselves that disability is not incompatible with performance and competence.

They begin to recognise that while disability might be alien to others, it is not alien to who they are as persons. The initial disdain and denial in response to others' fears and prejudices is slowly replaced by a reclaiming and a reconnection with the scattered pieces of their identity. By embracing their disability, they again feel whole and intact. They recognise their potential, and feel confident to demonstrate their competencies to others. It is through involvement that potential is allowed to flourish and self-esteem is fostered. They do face frustrations and disappointments in their inability to accomplish certain tasks in the same manner as their non-disabled peers. How they deal

with these frustrations depends to a large measure on the reactions and responsiveness of their world.

7. Formulation of the statement of the essential structure.

From the exhaustive description, the essential structure was derived. The essential structure of self-esteem is viewed as an integration of the common components of self-esteem identified in the exhaustive description.

The phenomenological understanding of self-esteem of physically disabled adolescents in a non-disabled environment could be described as follows;

The lived experience of self-esteem in physically disabled adolescents in a non-disabled environment, is an interpersonally assigned characteristic that occurs with the interaction of the individual with non-disabled peers.
The initial phase of the lived experience entails a conflict with the strangeness and unfamiliarity of the non-disabled world, the perception of exclusion from this world, a sense of loneliness, feelings of being invisible, a non-person.

An understanding develops of the conflict and difficulty in non-disabled people to relate appropriately to disabled people. There is a recognition that the fears, prejudices and condescending or hostile feelings exhibited by non-disabled people towards disability, often reflect their own unconscious anxieties and feelings of vulnerability about wholeness, perfection, loss and weakness, anxieties which are readily aroused by contact with the disabled.

As the nature of the situation is revealed, it is viewed as demanding and perplexing, but not futile. A variety of negative and positive responses are experienced. There is an initial feeling of detachment and disavowal of the disability. Concealment and avoidance of contact are some of the initial responses. Minimising communication for fear of incurring rejection or experiencing humiliation are also common.

This is followed by a recognition of their intactness, of recognising the disability as an integral part of who they are, a part they cannot live without. The problem is not the disability itself, but the disruption in their relationship with the non-disabled environment brought about by the

disability that is the problem. By embracing their disability they can now engage and challenge their environment. They seek opportunities to demonstrate their competence, demand a recognition of their needs, insist on being consulted, becoming involved in decision making and acceptance by others as equals. There is a feeling of growth taking place. The adolescents are encouraged to continue to maintain and improve their relationships with others.

They endeavour to develop skills to navigate the non-disabled world, to put others at ease when they fear their own words in conversation with the disabled, to firmly decline assistance while simultaneously showing genuine appreciation of the helping motive, to secure a helping hand when needed, or even to reach out and force their presence on others who have not acknowledged them. A feeling of acceptance occurs when the disabled adolescent acknowledges that their disability is not incompatible with feelings of self-worth and demonstrations of competence.

8. Validation of the essential structure by study participants.

Since all the participants were easy to reach, and available, they were contacted and asked to confirm that the essential structure of self-esteem was the same as they had experienced it. They were interviewed and asked whether the descriptive results accurately reflected their experience. Care was taken to explain complex concepts and terminology, and all participants were encouraged to ask clarifying questions. They all agreed that the description of the essential structure of self-esteem accurately reflected their experience.

CHAPTER 11

DISCUSSION ON FINDINGS

While the non-disabled community has over the years developed a considerable intellectual tolerance and empathy of disabled conditions, beneath the surface, most people still unfortunately have feelings of pity, abhorrence and even involuntary revulsion. On the surface these feelings are often masked by outward signs of kindness, over-concern or embarrassment. Generally, however, the majority of the non-disabled community simply avoid any contact with disabled people, and therefore do not even have to deal with their true feelings with regard to disability.

Studies on children's understanding of their physical disabilities has found that by the age of 8 years children have developed an understanding of the functional limitations and implications of their disability (Dunn, et al. 1988). This knowledge did not, however, significantly affect their ability to socialise with others, or increase their understanding of why certain children might not want to play

with them. As disabled children grow up, they begin to develop an understanding as to why non-disabled people might be avoiding them. The realisation that they are being avoided because of their disability, is usually a most painful discovery. As a result the child either wants to correct the disability or fantasizes about it "disappearing" completely, but realizes that it is out of his control and cannot be changed. The permanence of the disability is truly realized during adolescence. In the end, the young person could begin to feel impotent, defective and inferior; self-image is altered and self-esteem plunges.

Frequently, low self-esteem is reinforced over the years, as negative attitudes toward the disabled have been shown to increase with age in children (Kashani, 1986). It is also interesting to note that as the disabled child becomes older, he becomes more aware of society's ideal image, and like his normal peers is also reluctant to be associated with other disabled children (Du Plessis, 1991). This awareness of societal norms unfortunately also leads to a degree of self-rejection (Seidel, et al. 1975).

Cerebral palsied adolescents are unique among the disabled population, since they have never lived in a non-disabled body. Rather, the disability is an inherent part of their sense of body and self. Like other salient parts, the disability contributes to a sense of identity, and is in need of acceptance, appreciation and affirmation from the environment.

This study, as well as other research on the attitudes of non-disabled people towards disability, reveals a preponderance of negative perceptions. These include that disabled people are sick, helpless, childlike, incompetent, asexual and inherently socially and intellectually inferior. In short they are often perceived as non-persons.

In part, these perceptions reflect a lack of contact with and realistic information about the lives of disabled people. Non-disabled often use their own incomparable experiences with illness and temporary disability to arrive at assumptions about the helplessness and dependency of disabled people. Unfortunately, non-disabled people fail to appreciate the process of adaptation and creative problem-solving which can occur over time as a result of living with a disability.

It must also be recognised that the root of non-disabled people's fearful and sometimes hostile feelings towards disability, reflects their own unconscious anxieties regarding wholeness, perfection, loss and weakness, anxieties which are readily stimulated by contact with disabled people.

The disabled adolescent is particularly sensitive to the responses and reactions of their non-disabled peers. There is an almost immediate sense of exclusion and alienation from meaningful interaction with the non-disabled environment. From a phenomenological perspective this can be understood in the context of their perception of their body, which constitutes a central theme in the lives of physically disabled young people.

The explanation offered by Moss (1989), may be useful in this regard :

> " Unlike all other objects, my body is something I live and only secondarily know. I act through it, perceive the world through it, and without explicitly reflecting on the body....It is one's own body that phenomenological psychology calls the lived body."
>
> (p. 68).

The lived body is normally bypassed. Something out of the ordinary has to happen for the body to become subject to reflection and analysis.

For disabled adolescents it is often the very encounter with the non-disabled environment, with all its negative perceptions, inappropriate responses and unwarranted fears which constitutes such an extra-ordinary situation. People confront the world through their whole body. They are their body, i.e. it is bypassed (corps-sujet), more than they have a body, i.e. it is thematized (corps-objet). This study reveals that 'having a body' very often dominates when it comes to disabled adolescents.

The body is construed by the disabled adolescent as non-compliant, unreliable and socially conspicuous. Such a body is thematized in a negative way. According to Mulderij (1996);

> " We humans seem to be programmed in such a way as to pay attention to everything which is the slightest bit different; and so we look at disabled children. A persistent phenomenon. Many children feel uneasy about being caught in another's gaze. All of a sudden, and

unasked for, a mirror is held up to the body, which was hitherto not conscious of itself." (p.315).

Thus being looked at is a central experience in the lives of disabled adolescents in a non-disabled environment. The gaze from others is a constant reminder of them being physically different.

Along with this sense of being physically different, the disabled adolescent finds himself or herself excluded not simply by the environment as such, but by definition because of the limitations of his or her body. They are left on their own, and loneliness can dominate the existence of adolescents with disabilities. Many are very adult-oriented or over-reliant on family members. According to Erwin (1993):

> " Loneliness is associated with negative patterns of self-perception and low self-esteem, a self-blaming attributional style, lower expectations for social outcomes, social skills deficits such as inappropriate self-disclosure, excessive self-attention, an inability to establish comfortable intimacy, and a tendency to make negative judgements of self and others." (p.216).

This sense of being different is accompanied by feelings of being a non-person. The manner in which others interact and relate to the disabled adolescent reinforces such feelings.

The mutual difficulty experienced by both disabled and non-disabled young people to initiate effective communication and develop meaningful relations was very apparent. On the part of the non-disabled there were fears of behaving inappropriately, lack of insight into the nature of the disability and preconceived notions about various social, intellectual and emotional implications based entirely on physical appearance. On the part of the disabled adolescent, there appeared to have been unsubstantiated concern about their inability to communicate effectively, fear about receiving rejection because of poor social skills, concern about their ability to perform in a socially appropriate manner because of their physical difficulties and a fear of being abandoned by newly found friends.

Disabled adolescents expressed a great need to be provided with opportunities to participate in a non-disabled environment, to compete in areas where they feel competent and

confident, to be provided with choices and to exercise their ability to make decisions for themselves. Young disabled people who are denied choice and the possibility of making independent decisions are intuitively less likely to develop a sense of responsibility, self-worth and competence, and consequently less likely to participate in adult society and relationships (Clarke & Hirst, 1989).

The study confirms the view that disability, from a phenomenological point of view, is more than a condition affecting the body, it is an important and essential component of who the disabled adolescent is because of the I-World nature of its disruptions. Disability is therefore best understood as a condition of the world as well as the body.

It is important also to recognise that the ordeal of anguish and distress often experienced and reported by the disabled adolescents, may result from amongst others, internal psychic conflicts involving sense of self, self-esteem, inability to fulfil expectations or negative perceptions of self or others regarding disability. From a phenomenological perspective, anguish, distress and feelings of lowered self regard, results

from infringement of, or impending threat to the integrity of

the individual, not simply the body and its functions

(Williams, 1984).

CHAPTER 12

CONCLUSIONS AND RECOMMENDATIONS

12.1 Introduction

There is nothing simple and straightforward about peer relationships for children with cerebral palsy. According to Field, (1984);

> " Poorly developed social skills, peer rejection and few friendships are major defining characteristics of handicapped children. Furthermore, they are persistent characteristics, not subject to spontaneous recovery or easy treatment". (p.75)

Not only are friendships important for social, cognitive and emotional development of children, but links have also been established with functioning later in life during adolescence and adulthood (Cooper & McEvoy, 1996).

Children with cerebral palsy have been found to be hindered early in life in their social interaction. Distorted countenance, slurred speech and abnormal gait and posture, can easily disrupt the so-called 'infant elicited social

behaviour' of adults. The child easily acquires the reputation
of being difficult to make contact with. "Handicap often leads
to problems of attachment, and poor attachment is predictive
of poor patterns of peer relations." (Erwin, 1993, p. 200).

When young people approach adolescence, they become fully
aware of the long-term implications of that disability, and
this initial realisation can be exceedingly stressful. This
may coincide with the stresses of adjusting to the demands of
school, changes in the relationships with parents and siblings
or the exposure to new situations and encounters with non-
disabled peers or others who appear to be more competent.

To presume that this initial realisation will be enough to
ensure that the disability is assimilated without effort into
a mature but active acceptance is to be oblivious to nature of
awareness. Awareness is a process not an event. Young
peoples initial realisation of the implications of their
disability will be built on, and coloured by, life experiences
and by attitudes and events both external and internal to
themselves.

The factors which affect self-esteem are as numerous and as unique as individuals' learning to organise their experiences and fulfil their needs. Each person brings a multitude of factors of physical competence, of social interactions and personal needs and family background to their life experiences, which render ludicrous the application of an objective and empirical formula to predict and understand levels of self-esteem in disabled adolescents.

To understand the dynamic and plastic nature of disability, is to understand the realm between the power of the world in which an individual is embedded and the freedom of that individual to stand up in defiance and opposition to that world. To conclude that an individual creates himself and herself entirely, is to leave that individual worldless. On the other hand, to conclude that the world is all powerful, is to reduce the disabled individual to an organism which requires physical and functional restoration (Williams, 1984).

The non-disabled world often views disability as something alien and invasive which requires restoration and correction. To the disabled adolescent, however, it is the alien nature of

the relationship with the non-disabled environment, which is the alienation which is of greater concern. The study has shown that social acceptance is not only about how others perceive the non-disabled adolescents. There is a greater reward accompanying social acceptance. The more disabled adolescents are socially accepted within a group, the more opportunities exist for them to develop and to utilise their social skills . Over time these experiences contribute towards the development and enhancement of self-esteem (Abrahams, et al. 1979).

12.2 Promoting self-esteem in disabled children

The question of how best to prepare young disabled people for their interaction with and inclusion in the mainstream society is a question which confronts parents, doctors, educators and psychologists alike. Each one of these role players has a very specific and demanding task.

There is firstly a responsibility on the medical profession to treat the whole child and not simply the disability. Since physical treatment is likely to be the most manifest aspect of the treatment program in the early years, parents see

professional interest and attention to physical development taking priority over other facets of development, namely, intellectual and social development. Since the medical approach and treatment is most often directed towards the child's areas of greatest disability, parents in turn find themselves concentrating most heavily on the child's deficits, and failing to appreciate or positively respond to areas of competence and uncomplicated development. Should the focus be almost entirely on the physical disability, it would come as no surprise that parents exhibit some loss of affection and positive acceptance when there is no significant improvement in their child's physical condition.

The disabled child's understanding of physical differences is influenced by his or her perception of how parents and the environment perceive the difference. It would seem that one of the most important determinants of the body image of any child is not so much the actual characteristics of the body, but rather parental and cultural attitudes towards these characteristics.

For all children, disabled or not, the acceptance and approval
in response to all aspects of the child's body and self is
essential for the development of healthy self-esteem. This
includes the parent's ability to show pride and pleasure in
the disabled part of the body, as one valid aspect of the
child, and to communicate appreciation and respect for the
child's unique and often different-looking ways of doing
things. The result can be an environment at home which allows
children to develop their potential and feelings of competence
as well as positive feelings about body and self.

It must also be conceded, however, that parents do not
wittingly add to their children's difficulties. They all too
often experience great difficulty dealing not only with their
own feelings of pain, guilt, confusion and prejudice, but also
the cruelty, intolerance, ignorance and hostility of the
environment. Even those parents who adequately resolve their
own conflicts, and fully appreciate their child, cannot always
protect the child from society's negative perceptions.

Parents need help in finding ways to explain prejudice to
their disabled children, to distinguish facts about their

disability from societal distortions about these facts. When parents do not make direct and factual statements about disability, space is created for fantasy and confusion.

Parental silence can be experienced as a confirmation of social stereotypes, whereas parental communication can serve as a counterbalance. While parents cannot single-handedly change conventional views about disabled people, they can help counter these misperceptions through direct statements which communicate positive and realistic expectations about their disabled children.

Children also need to develop an awareness that social interaction is frequently more burdensome for disabled people because of social stigma and prejudice. They will often experience unjust rejection based solely on their physical appearance. Parents can continually provide opportunities for disabled young people to talk about their pain and confusion. Parents can assist adolescents to distinguish real prejudice from typical frustrations everyone feels when negotiating social and sexual relationships. Parents need to let their children know that socializing can be an arduous and often a

precarious exercise, but it is not impossible, and when
navigated properly can be very exciting and rewarding.
Finally, parents should not succumb to the prejudices of
society and restrict their children's interaction with the
non-disabled environment, nor should they allow feelings of
guilt to make them become over-protective. The basic rule
about improving peer relations and gaining social acceptance,
is to start as early as possible. Language and communication
skills and social relationships with the non-disabled
environment, should be fostered as early as possible. If one
waits until adolescence, one would find non-disabled peers
showing greater impatience with the limitations and less
acceptance of the disabled individual.

After the parents, the disabled adolescent's educators are the
most influential adult figures in their lives. The function of
the education programme for children with disabilities is to
develop and foster optimum independence and functioning. It
should, however, not only focus on ensuring that the
adolescent has the necessary cognitive tools, vocational
and daily living skills for independent survival, but should
give equal attention to developing social and personal skills.

Educators can play a vital role in developing the adolescent's understanding and ability to adapt, the skill to initiate and form new relationships, to negotiate and resolve conflict, to develop an enquiring and inquisitive disposition, to assume personal responsibility in all activities and to involve them in as many decision-making processes as possible. Educators should realise that they are required to educate children for living and not simply to earn a living. Needless to say, it would be extremely beneficial if this programme started as early as possible, and ideally within a mainstream school setting (Anderson & Clarke, 1982).

12.3 The need for psychotherapy

Finally, there is the possibility, and frequently the need, for individual psychotherapy or group therapy to assist the adolescent to develop a more positive self-concept. Many of the disabled adolescents expressed themselves in their descriptions as being overly self-critical, anticipating failure, feeling different and strange in a non-disabled environment, and consider others as being rejecting, discriminating or disapproving even when they are not. The

existential feeling that you have no definite identity, that you are a non-person, is perhaps the most profound existential crisis a person can experience. The most exaggerated expression of this feeling could mean that the individual has no faith in his existence as a person. These feelings are particularly evident during adolescence , when the individual is attempting to crystallize his identity, and feels seriously alienated, lonely or confused. Psychotherapy can play a unique role in this healing process.

Psychotherapy should focus amongst others on restoring the integrity of the person (Cassel, 1992). In the case of congenital disabilities like cerebral palsy, the loss experienced by the adolescent is not a loss of body part or function, but rather the loss of their original sense of intactness and completeness as human beings with disability as an integral part of who they are. Psychotherapy with disabled people is often about restoring self-esteem rather than developing it. Future research could focus on the phenomenological explication of the experience of psychotherapy, both within an individual or group context, with physically disabled adolescents.

12.4 Summary

The phenomenological method of investigation has made it possible to explore aspects of self-esteem in physically disabled adolescents, which would not easily be accessible through an empirical study. By allowing the participants to describe their interactions with others in a non-disabled environment as fully as possible, they have conveyed not only their experiences, but also the meanings contained in these experiences. These meanings transcend the subjective experience and make available to others worthwhile knowledge about disability and self-esteem.

The phenomenological method provides us with a deeper and clearer understanding of what the experience of disability is like for disabled adolescents in a non-disabled environment. The research results amplify our understanding of these experiences and could lead to two important consequences. Firstly, we can begin to appreciate and be more aware of and sensitive to those involved in these experiences, a particularly significant consequence for those in the helping and education professions. Secondly, social action and

public policy can be amended and directed in a way that is more responsive to the needs of the disabled community.

More importantly, however, this study has shown that not all physically disabled adolescents have severe difficulties with self-esteem. Many young people have confronted and adequately resolved the intactness/defectiveness dilemma they face daily in a non-disabled environment. They ensure that they are accepted and respected as complete people, and have survived society's negative perceptions of them. They have on the whole developed and perfected a valuable skill. They can navigate the non-disabled world without renouncing their disabilities as a vital aspect of their self. They recognise, and at times are deeply hurt and angered by the prejudice they observe and experience around them, but they refuse to accept it as an accurate portrayal of who they are. When necessary, they may seek to conceal the limitations which their disability imposes on them, at times they may even seek to conceal their disability, but they never seek to conceal themselves.

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APPENDIX

Case study 3

'n Vriend van my het my genooi na 'n kamp...dit was 'n jeuggroep se kamp. Ek hou baie van kamp en sy het dit geweet, en toe sê ek: "Okay ek gaan met julle". Toe ek nou daar kom, toe voel ek so uit want almal kyk so na my. Maar anyway, hulle kyk toe na my, maar ek kyk nie vir hulle snaaks terug nie, ek smile na hulle.

Dit was die Vrydag...Vrydag-aand het ek nie much met hulle geworry nie, hulle het net so onder mekaar gepraat. Die Vrydag-aand, toe ons eet, hulle maak toe koffie, maar in plaas dat hulle vir my direk vra: "Hoeveel suiker drink jy, of drink jy tee of koffie?", vra hulle vir my tjommie, en hulle maak asof ek glad nie daar is nie. En ek...ek kyk maar en sê toe maar niks nie. Nou bring hulle die koffie, en ek sê toe dankie aan die jongetjie wat die koffie bedien. Mark was sy naam...Mark sê dit was 'n plesier...en hy sê toe vir my: "Moet ek die koffie vir jou vas hou?". (Lag). Nou wil ek nie lag nie en sê vir hom: "dis nie nodig nie, ek sal dit vas hou". Nou loop hy weg, nou sê ek vir my tjommie: "Hoekom treat hulle dan

vir my soos 'n invalid". Sy sê toe vir my dat sy nie sal weet
nie.

Maar anyway, ek het toe nie vir hulle verder uitgevra nie.
Hulle bring toe vir my kos...nou skree die vrou wat die kos
opskep uit die kombuis: "Eet sy pampoen". My tjommie sê toe:
"Ja sy eet pampoen, met 'n bietjie botter oor". "Hoeveel rys
wil sy hê, wil sy een of twee lepels hê". Hier raak my tjommie
mos toe kwaad, want elke keer as hulle iets vir my wil gee,
dan vra hulle vir haar. Hier sê my tjommie: "Kan julle nie
self vir haar vra nie?". Hulle sê toe: "Nee net maar kan sy
nie haar mind op maak nie, en 'n mens weet nooit hoe om met
haar te praat...kan sy verstaan as 'n mens met haar praat ?".
Nou raak ek rêrig kwaad...ek raak skoons warm hier om my ore.
Ek staan toe op en sê vir hulle: "Wat dink julle, dink julle
ek is 'n zombie, ek verstaan, ek kan my eie besluite neem, ek
kan alles doen, ek is fisies gestremd, ek is nie mentally
disabled nie". Ek kon sien hulle almal skrik toe, en hulle sê
toe hulle is sorry.

Okay, die Saterdag-oggend...uhm...ons was mos, maar die
showers is buite. Hulle stuur toe 'n meisie om my te kom help
aantrek. Ek sê toe vir haar nee dankie, maar ek kan myself

aantrek. Na ons aangetrek is, gaan ons toe op 'n hike. Maar die ding is hulle het geweet ek kom, en ek het vir my tjommie gese sy moet vir hulle laat weet dat daar is dinge wat ek kan doen, maar ek doen dit stadig en moeilik. Ons gaan toe op die hike, maar die route is baie moeilik, daar is baie obstacles op die route. Ek sukkel mos want my bene is nie so sterk nie. Ons loop toe en ons kom toe by die boomstam, en aan die ander kant van die boomstam is daar 'n dammetjie. Ek kan toe nie maklik oor klim nie, en het maar op die boomstam gesit en my bene oorgelig. Ek het nie die dammetjie water gesien nie, en ek val toe in. Almal lag toe, en ek lag maar toe saam, maar voel seer gemaak, maar ek dink toe ek gaan nie vir hulle wys nie.

Ons gaan toe aan met die route. Ek sukkel baie. En toe kom ons by 'n styl rots, waar jy eintlik moet op gly voordat jy by gelyke grond kom. Ek sukkel toe baie, en my tjommie try om te help. Haar boyfriend sê toe: "Los haar af man, los daai kind, sy maak net dat ons laat is, los haar hier man, en ons tel haar op as ons terug kom". My tjommie sê toe nee. Ek kon toe sien dat hulle raak toe kwaad vir mekaar. Almal sê toe : "Sy loop te stadig, sy hou vir ons almal agter, ons wil nog baie

doen, maar sy is net soos 'n ou vrou". Ek sê toe vir hulle :

"gaan julle maar aan, ek sal hier vir julle wag totdat julle

terug kom". My tjommie vra vir my of ek alright gaan wees, en

ek sê vir haar sy moenie worry nie.

Vrydag was ons twee nog okay, maar die Saterdag, van die

Saterdag af begin dit lyk asof sy skaam is vir my. Ons

doen...soos ons sal in 'n groep wees nê, maar sy sal nie met

my kom praat nie, sy is net met die anders en so. Maar anyway,

sy gaan toe verder op die walk, en ek sit toe daar, maar nou

huil ek, ek huil en dink toe hoekom ek nie normaal kan wees

nie, dan kon ook saam met hulle gegaan het.

Ek sit toe lang daar. Ek wil toe eers teruggaan maar ek was

bang ek gly en maak myself seer. Ek sit toe maar, en dit raak

toe donker. Stadigaan begin ek toe terug loop. Na 'n tydjie en

toe kom die groep aan, en hulle sê toe almal : "Ons is sorry,

ons het skoons van jou vergeet, ons het so 'n lekker tyd

gehad." Ek voel toe hartseer toe ek dit hoor, en wonder toe of

hulle geworry het as iets met my sou gebeur het.

Anyway, die next dag, Sondag, het Shaun, die leader van die

groep, hy kan toe 'n bietjie kitaar speel. Anyway, die Sondag

vra hy vir 'n volunteer om kitaar te speel, want hy gaan uit

die Bybel lees. Ek volunteer toe om die kitaar te speel. Almal

kyk my toe aan. Hulle kan nie glo dat ek kitaar speel nie. Ek

is links en speel die kitaar toe die way ek geleer het,

onderstebo. Almal lag toe, maar ek het my nie geworry nie,

want hulle sien toe dat daar is goed wat ek kan doen wat hulle

nie kan doen nie.

Na die kamp sê Shaun, die leader van die groep dat hy sorry is

vir enigiets wat die die anders gedoen het, maar hulle weet

nie hoe om...hulle is...hulle weet nie hoe om gestremde mense

te handle nie, want hulle is bang dat hulle iets gaan sê of

doen en dan is dit verkeerd, en dan kry die persoon seer. Toe

sê ek dat as julle bang is, en julle weet nie hoe als werk

nie, vra, want julle sal nooit iets leer as julle nie vra nie.

Vir my het dit gevoel dat ek moet my eers bewys aan die groep,

want na dit, het ek klomp tjommies gehad. Daarna voel ek dat

anders vir my nie sommer net so aanvaar nie, net soos ek is

nie, ek moet moet myself eers bewys voordat hulle my aanvaar.

Ek dryf myself baie hard om aanvaar te word.

Case study 3.(a)

1. Extraction of significant sentences and phrases which directly pertains to feelings of self-esteem.

3.1 " Toe ek nou daar kom toe voel ek so uit want almal kyk so na my. Maar anyway, hulle kyk toe na my maar ek kyk toe nie vir hulle snaaks terug nie, ek smile na hulle."

3.2 " In plaas dat hulle vir my direk vra: Hoeveel suiker drink jy, of drink jy tee of koffie?, vra hulle vir my tjommie, en hulle maak asof ek glad nie daar is nie."

3.3 " Hy sê toe vir my: 'Moet ek die koffie vir jou vas hou?'. Nou wil ek nie lag nie, en sê toe vir hom: 'Dis nie nodig nie, ek sal dit vas hou'. Nou loop hy weg, nou sê ek vir my tjommie: 'Hoekom treat hulle dan vir my soos 'n invalid?'"

3.4 " Hulle sê toe: 'Nee net maar kan sy nie haar mind opmaak nie, en 'n mens weet nooit hoe om met haar te praat nie...kan sy verstaan as 'mens met haar praat?'"

3.5 " Nou raak ek rerig kwaad...ek raak skoons warm hier om my ore. Ek staan toe op en sê vir hulle: 'Wat dink julle,

dink julle ek is 'n zombie, ek verstaan, ek kan my eie

besluite neem, ek kan alles doen, ek is fisies gestremd,

ek is nie mentally disabled nie.' Ek kon sien hulle

almal skrik toe, en hulle sê toe hulle is sorry."

3.6 " Ek volunteer toe om die kitaar te speel. Almal kyk my

toe aan. Hulle kon nie glo dat ek kitaar kan speel nie."

3.7 " Ek is links en speel die kitaar toe die way ek geleer

het, onderstebo. Almal lag toe, maar ek is nie geworry

nie, want hulle sien toe dat daar is goed wat ek kan

doen wat hulle nie kan doen nie."

3.8 "...hulle weet nie hoe om gestremde mense te handle nie,

want hulle is bang dat hulle iets gaan sê of doen en dan

is dit verkeerd, en dan kry die persoon seer."

3.9 " Vir my het dit gevoel dat ek moet my eers bewys aan die

groep, want na dit het ek klomp tjommies gehad."

3.10 " Daarna voel ek dat anders vir my nie sommer net so

aanvaar nie, net soos ek is nie, ek moet myself eers

bewys voordat hulle my aanvaar."

3.11 " Ek dryf myself baie hard om aanvaar te word."

Case study 3.(b)

2. Formulating the significant statements into more general re-statements.

3.1 The stares of other people can make me feel that I do not belong.

3.2 Instead of addressing me directly they ask my friend about what I need, as if I do not exist.

3.3 When they offer help with tasks I can manage, it makes me feel like an invalid.

3.4 Non-disabled people feel that I am not able to make up my own mind or understand what they say to me.

3.5 I became very angry, and asked them whether they thought I was a zombie who cannot understand things or make decisions.

3.6 When I volunteered to play the guitar, everybody looked surprised that I could do it.

3.7 When people laughed at the way I was playing the guitar it did not bother me because I knew I was showing them that I could do something which they could not do.

3.8 Non-disabled people do not know how to relate to disabled people, fearing that they would say or do things which could hurt them.

3.9 I felt like I had to work harder to prove I was good enough before I was accepted by the group.

3.10 I began to feel that being who I am was not good enough, I had to do something to prove I was good enough before I would be accepted by non-disabled individuals.

3.11 I work very hard at gaining acceptance from non-disabled individuals.

Case study 3.(c)

3. Significant statements and their re-statements are
then studied to derive and record a sense of their
meaning.

3.1 The non-verbal messages which non-disabled people convey
to her make her feel that she does not belong.

3.2 Non-disabled people tend to bypass her when they address
her needs, resulting in feelings of non-existence.

3.3 Through their inappropriate offers of assistance, non-
disabled people can make her feel incompetent.

3.4 Non-disabled people have misconceptions about her
competence to comprehend and to exercise her decision-
making abilities.

3.5 The inability of non-disabled people to relate
appropriately to her can arouse feelings of
extreme anger.

3.6 Any manifestation of competent behaviour by her
are often met by expressions of disbelief.

3.7 When she is fully aware and confident of behaviour which is skilful and competent, then the responses and reactions from non-disabled people are less important.

3.8 Non-disabled people become very anxious about communicating verbally with her for fear of saying the wrong things.

3.9 Finding acceptance with a non-disabled group does not come easily, it requires hard work from her.

3.10 She feels incomplete and not worthy of acceptance by the non-disabled, and has to first proof that she is worthy before acceptance is possible.

3.11 It is a hard struggle everytime she requires acceptance by a group of non-disabled people.

<u>Case study 3.(d)</u>

<u>4. Description of themes emerging from the participant's narration.</u>

When she is in the presence of non-disabled people their stares make her feel uncomfortable and it makes her feel that she does not belong. She responds to this situation by engaging others in a positive manner.

Non-disabled people tend to ignore her presence and bypass her when they want to address her needs. This makes her feel that she is invisible. They also assume that others are more competent to make decisions on her behalf.

Non-disabled people often make her feel inadequate and incompetent, like an invalid, through their inappropriate offers of assistance. She normally deals with this inappropriate behaviour and lack of insight on the part of non-disabled people, by viewing it in a humorous light.

When non-disabled people form misperceptions about her physical ability based on her appearance, she can normally

deal with the situation by laughing about it. However, non-disabled people often also assume that simply because she is physically disabled, she is also unable to comprehend conversation, communicate effectively or make decisions for herself. This infuriates her and she is not afraid to confront and correct their misperceptions.

Even when she informs people about her physical limitations, this is not taken into account when planning activities. In a non-disabled environment, the needs of the disabled are secondary to the needs of the non-disabled.

When she falters in front of others and they laugh, it hurts, but she has learnt to hide her feelings and laugh with others. She also detects a change in the attitude of her friend when she is with other non-disabled people. She also feels that non-disabled people relate to each other in ways which can marginalise her very easily. The ease with which they forget about her is very painful.

When she feels competent about a certain activity she does not hesitate to participate. Any display of competent behaviour by her, is often met by disbelief from non-disabled people.

When she is fully aware and confident of behaviour which she considers as skilful and competent, then the responses and reactions of others which might be less favourable, are considered as less important.

She is aware of the difficulty non-disabled people have in relating to and communicating with disabled persons. Their fear of behaving inappropriately can only be overcome through greater contact, openness and willingness to learn about the disabled.

She feels that gaining acceptance from a non-disabled group does not come easily and requires hard work. Acceptance comes only after she has proven herself worthy of it.

Case Study 4

Dit was by 'n jeuggroep...uhm...die vriend van my het vir my die Vrydag-aand gevra dat ek met hulle moet gaan. Ek sê toe nee ek wil nie, because ek het geweet dat daar kinders gaan wees wat so te sê normaal is...nie-getremdes. Toe sê ek nee. Toe sê sy dit sal nie saak maak nie, because...uhm... Anyway, ek het gevoel ek wil gaan kyk hoe dit daar is. Toe ons daar kom, toe was almal daar.

Ek het nie geweet dat daar so baie kinders sal wees nie. Daar was 'n klomp kinders, van 'n ander skool, en van 'n ander jeuggroep. Ek het besluit om net daar te sit en met die ander te praat. Later het hulle begin om games te speel. Toe het hulle die specific game gespeel, maar ek kon nie saam met hulle speel nie. Jy moes drie keer om die kamer hardloop. Toe sê ek vir myself ek gaan nie saam speel nie, ek kon mos nie hardloop nie.

Die ander kinders vra toe hoekom ek nie wil saam speel nie. My tjommie sê toe "sy is mal man, sy wil nie saam speel nie omdat sy nou gestremd is". Toe sê ek dit is nie daai nie, dit is net

baie uncomfortable vir my om saam te hardloop. Toe die
volgende game begin, toe moes ek weer uitsit, want ek kon nie
op een been hop nie. Toe sê ek laat ja ek wil huis toe gaan.

Die anders sê toe dat die aand nog jong is. Toe sit ek net
daar by myself en wonder toe hoekom ek gestremd moet wees,
hoekom gebeur dit nou saam met my. Toe kom die een jeug leier
oor na my en vra toe hoekom ek so alleen sit. Toe wil ek amper
begin huil. Ek sê toe vir hom dat ek wil huis toe gaan, en ek
wil in die eerste plek nie hierheen gekom het nie. Hy vra vir
my of dit omdat ek gestremd is. Toe sê ek vir hom ja, dis min
of meer so. Omdat ek nie sekere dinge kan doen wat anders kan
doen nie, dan voel ek so out of place en kwaad vir myself.
Vir my het dit gevoel asof ek uitgesluit word uit alles.
Because, toe ek die eerste keer na die groep gekom het, toe
vra hulle vir my tjommie, "gaan sy nog skool?". Vir my het dit
gevoel asof hulle, asof sommige van hulle miskien gedink het
"nou bring julle nogal 'n gestremde persoon na ons toe". Toe
dink ek by myself hoekom het hulle so 'n indruk gehad. En as
ek iets doen dan is dit asof hulle dink, "hoe is dit moontlik
dat 'n gestremde persoon so iets kan doen?". Ek het baie seer
gevoel.

Soos ons gesels, en hy sê toe vir my dat dit is niks om oor kwaad te wees nie, elkeen is unique, realize ek dat ek nie so kwaad moet wees nie, want anders kan doen wat ek nie kan doen nie, maar daar is sekere dinge wat ek kan doen wat hulle nie kan doen nie.

Toe die games weer begin, toe wil ek eers weghardloop. Hulle sê toe almal vir my dat ek nie so sleg moet voel nie, God het elkeen van ons different geskappe, en dit baat nie dat jy so sleg voel nie. Toe ek nou klaar daar gesit het, en sorry gevoel het vir myself, staan ek op, en sê toe vir myself, "if you can't beat them, then you join them". Toe ons klaar is vir die aand, toe nooi hulle my terug vir die volgende aand.

Die volgende week het hulle weer 'n game gespeel waar jy kaal bene moet wees. Ek wil nie my langbroek uit trek nie, want ek was skaam oor die scars op my bene, van al die operasies. Toe wil almal weet van my operasies, hoeveel het ek gehad, of dit seer was, en so on. Ek het vir hulle explain hoe "uncomfortable" dit was, en hoe baie ek gehuil het.

Toe wonder ek hoekom ek nie soos my broer gewees het nie. My pa sê altyd dat laat ja, ek sal nog sulke dinge oorkom, waar ek "out of place" voel, en mense gaan my vra om goed te doen wat ek nie kan doen nie, dan gaan ek kwaad wees vir myself, maar ek moet uithou. My ma vra toe vir my of ek kwaad is omdat daar merke op my bene is. Toe sê ek ja dit lyk lelik, dit lyk of ek gate in my bene het. Ek voel somtyds baie "out of place", as gevolg van al die gate in my bene. Dit is nie lekker nie. Dit gaan seker nog 'n lang tyd neem voordat ek kan sê;" Ek is gestremd en ek is wie ek is afgesien van my bene. Ek moet van hulle vergeet, want ek sal ander mense nooit kan oortuig dat ek nie lelike bene het nie"

Case study 4.(a)

1. Extraction of significant sentences and phrases which directly pertain to feelings of self-esteem.

4.1 " Ek sê toe nee ek wil nie, because ek het geweet dat daar kinders gaan wees wat so te sê normaal is...... nie-gestremdes."

4.2 " Toe sit ek net daar by myself en wonder toe hoekom ek gestremd moet wees, hoekom gebeur dit nou saam met my."

4.3 " Ek se toe vir hom dat ek wil huistoe gaan, ek wil in die eerste plek nie hierheen gekom het nie. Hy vra vir my of omdat ek gestremd is. Toe sê ek vir hom ja, dis min of meer so. Omdat ek nie sekere dinge kan doen wat anders kan doen nie, dan voel ek so out of place en kwaad vir myself."

4.4 " Vir my het dit gevoel asof ek uitgesluit word uit alles"

4.5 " Because toe ek die eerste keer na die groep gekom het, toe vra hulle vir my tjommie:'gaan sy nog skool?'

4.6 " En as ek iets doen, dan is dit asof hulle dink, 'hoe is dit moontlik dat 'n gestremde persoon so iets kan doen?' Ek het baie seer gevoel."

4.7 " ...toe realize ek dat ek nie so kwaad moet wees nie,

want anders kan doen wat ek nie kan doen nie, maar daar

is sekere dinge wat ek kan doen wat hulle nie kan doen

nie."

4.8 " Toe ek nou klaar daar gesit het, en sorry gevoel het vir

myself, staan ek op, en sê toe vir myself, 'if you can't

beat them, then join them."

4.9 " Toe wonder ek hoekom ek nie soos my broer gewees het

nie."

4.10 " Ek voel somtyds baie out of place, as gevolg van al die

gate in my bene."

4.11 " Dit gaan seker nog 'n lang tyd neem voordat ek kan sê :

" Ek is gestremd en ek is wie ek is, afgesien van my

bene."

4.12 " Ek moet van hulle vergeet, want ek sal ander mense

nooit kan oortuig dat ek nie lelike bene het nie."

Case study 4.(b)

2. Formulating the significant statements into more general re-statements.

4.1 I wanted to avoid any contact with non-disabled people, because I felt different from them.

4.2 When I was with non-disabled people I felt left out and wondered why this disability had to happen to me.

4.3 I wanted to get away from the situation, because my disability made me realise that there were certain things I could not do, and this made me feel out of place and angry.

4.4 My disability caused me to be excluded from everything

4.5 I felt left out from the group by the insensitive questions they were asking about me, regarding my competencies and abilities.

4.6 It hurt me when I tried to do something and it looked like they were wondering how it was possible that a disabled person could do it.

4.7 I realized that I needed to be less angry, since I was able to do things which the other person could not, just like they could do things which I could not do.

4.8 I convinced myself that there is nothing to be gained by feeling sorry for myself, and it is better to involve yourself in activities than to oppose it.

4.9 At times I still wonder why I cannot be non-disabled.

4.10 My disability makes me feel like I do not belong with others.

4.11 It will take a while for me to acknowledge who I am with or without my disability.

4.12 I will need to learn to live with my disability, because others will always be aware of it.

Case study 4.(c)

3. Significant statements and their re-statements are then studied to derive and record a sense of their meaning.

4.1 She will actively avoid any contact with non-disabled people, as it evokes a feeling of discomfort and a sense of being different.

4.2 In the company of non-disabled people she experiences a feeling of isolation and questions are asked of herself as to the reason for the disability.

4.3 She wants to flee from her encounter with non-disabled people, because it highlights the restrictions of her disability and evokes feelings of isolation and anger.

4.4 She attributes her exclusion from social activity to her disability.

4.5 The initial form of questioning by the non-disabled group to initiate communication, lacks insight and sensitivity and increases the sense of difference and isolation.

4.6 She feels hurt by the lack of understanding and acceptance displayed by the non-disabled group of her abilities.

4.7 She makes sense of the encounter by realising that each of us have abilities which the others might not be aware of or which they might not have.

4.8 She makes a conscious decision to refrain from self-pity, since there is more to be gained by confronting a difficult situation.

4.9 She would occasionally wish that she was non-disabled and did not have to deal with the difficulties presented by her disability.

4.10 She sometimes feels alienated from others, and a sense of not belonging, because of her disabilities.

4.11 It will take a while to fully embrace her disability, to fully accept it and make it part of who she is.

4.12 Others' awareness of her disability, compelled her to embrace it as an essential part of who she is.

Case study 4.(d)

4. Description of themes emerging from the participant's narration.

She limits her social contact with non-disabled people and when the opportunities for such contact present themselves, she will attempt to avoid it. She views non-disabled people as being different to her, as normal.

In the presence of non-disabled people she feels isolated and conscious of her limitations and she begins to question herself regarding her disability. She wants to avoid such a situation, because it not only places the focus on her limitations as a result of her disability, but it also evokes feelings of isolation and resentment. She views her disability as the primary cause for her exclusion from social activity.

When she is in the company of non-disabled people, their attempts at communication are often filled with inappropriate comments and questions, which can lead to increased feelings of exclusion and difference. Others' misperceptions or lack of

acceptance or misunderstanding of her abilities, can be very painful to her. She attempts to rationalise the situation by recognising that we all have abilities which others might not have, or know about.

She feels that the only way to deal with a difficult situation is not to refrain from it, or to be filled with self-pity because of the lack of understanding from others, but to face the situation, and manage it on others' terms. She often feels that it would have been preferable not to be disabled, so that she did not have to struggle with these situations.

She realises that it will take time for her to come to terms with her disability, to fully embrace it, and to recognise it as an essential part of who she is. The awareness of others of her disability, almost compels her to embrace her disability.

Case study 5

Mense wat my ken, sal my behandel soos een van hulle...asof daar niks met my verkeerd is nie. Maar mense wat ek net ontmoet, sal moontlik voel dat ek heel verskillend van hulle is. As hulle sien dat jy gestremd is, dink mense dat jy nie so lekker in die kop is nie. Ek will baie graag he dat daardie verhouding moet verander.

Ek kan nie onthou in watter standerd ek was nie...so tussen st. 6 en st. 7. Ek het voorbereiding klasse geloop. Meneer weet mos as jy aangeneem word by die kerk? Die kerk het altyd kampe gereel om vir ons bymekaar te bring. Die kamp is by Doordeveld naby Malmesbury. Dit is n soort afgesonderde kamp. Daar het ons die bybel gelees en vrae bespreek wat ons moet ken, en ander goed rondom aanneming. Daar was nie eintlik n swimming pool by die kamp en jy moes toe buite die kamp gaan om te gaan swem.

Vrydag-aande was die deurmekaarste. Jy moes kennis maak met die ander kinders. Ek was die enigste een wat gestremd was. Nadat ons uitgepak het, het ons mekaar se name begin vra, ook

van waar elkeen kom. Alles was baie lekker, ons het games gespeel en ons het mekaar baie lekker gevind. Baie van die kinders was van ander kerkdenominasies. Dit was 'n baie lekker aand. Saterdag het ons weer lesse gehad. Ons het ook games gespeel, en buite bymekaar gekom. Ek het soms gestruikel, maar dit was nie 'n probleem nie.

Die dag het ons almal saam ge-eet. Toe ek opgestaan het, het ek oor een van my nuwe vriende se voet gestruikel. Ek was ontsteld want my bord het uit my hande geval, en my oorskiet kos het uit eenkant gelê. My vriende het niks gese nie, of gedoen nie. Hulle het ook nie gelag nie. Daarom het ek baie sleg gevoel. Om te val voor mense beteken vir my baie...dit is asof ek 'n gek van myself maak...asof ek myself verneder.

Agterna het ek kamer toe gegaan, en baie gedink hoekom ek altyd so 'n gek van myself moet maak en oral val. Ek het maar probeer vir myself uitwerk en worstel toe met die gedagte... my eie gedagtes en tot die slotsom gekom dat daar sal sulke oomblikke in my lewe kom. Daarna het ek opgestaan en uit my kamer gekom en van die episode vergeet. Die middag het toe lekker verloop.

Maar dan was daar ook ander goeie insidente. Ek neem deel aan body-building as 'n stokperdjie. Met my eerste kompetisie was ek baie bang...ek het nie geweet hoe mense my sal aanvaar aangesien ek gestremd is nie. Ek het besluit om deel te neem om te sien hoe hulle sal reageer, en ook om te sien hoe ek sal reageer.

Ek het my uitgetrek en blink gesmeer. My vriende het my baie moed ingepraat, en gesê dat ek goed lyk en dat ek gaan wen. Die ander deelnemers het nie so goed gelyk nie. Die kompetisie het goed afgeloop, en toe hulle die wenner aanwys, was dit ek. Ek kon dit eenvoudig net nie glo nie...ek het regtig gedink dat ek derde plek sou behaal. Die gehoor was in ekstase, omdat ek nog gestremd ook was, en nog gewen het.

Soos ek alreeds genoem het, die meeste mense dink dat as jy gestremd is kan jy nie in normale aktiwiteite deelneem nie, of dat jy miskien ook verstandelikgestremd is. Ek dink dat ons moet help om daardie persepsie te verander.

Case study 5.(a)

1. Extraction of significant sentences and phrases which pertain to feelings of self-esteem.

5.1 " Mense wat my ken, sal my behandel soos een van hulle...asof daar niks met my verkeerd is nie. Maar mense wat ek net ontmoet, sal moontlik voel dat ek heel verskillend van hulle is".

5.2 " As hulle sien dat jy gestremd is, dink mense dat jy nie so lekker in jou kop is nie".

5.3 " Toe ek opgestaan het, het ek oor een van my nuwe vriende se voet gestruikel. Ek was ontsteld want my bord het uit my hand geval, en my oorskiet kos het eenkant gelê. My vriende het niks gesê of gedoen nie. Hulle het ook nie gelag nie. Ek het baie sleg gevoel".

5.4 " Om te val voor mense beteken vir my baie...dit is asof ek 'n gek van myself maak...asof ek myself verneder".

5.5 " Agterna het ek kamer toe gegaan, en baie gedink hoekom ek altyd so 'n gek van myself moet maak en oral val. Ek het maar probeer vir myself uitwerk en worstel toe met

die gedagte...my eie gedagtes en tot die slotsom gekom dat daar sal sulke oomblikke in my lewe kom".

5.6 " Ek neem deel aan body-building as 'n stokperdjie. Met my eerste kompetisie was ek baie bang...ek het nie geweet hoe mense my sal aanvaar aangesien ek gestremd is nie".

5.7 " Ek het besluit om deel te neem om te sien hoe hulle sal reageer, en ook om te sien hoe ek sal reageer".

5.8 " My vriende het my baie moed ingepraat, en gese dat ek goed lyk en dat ek gaan wen."

5.9 " Die gehoor was in ekstase, omdat ek nog gestremd ook was, en nog gewen het."

5.10 " Soos ek alreeds genoem het, die meeste mense dink dat as jy gestremd is kan jy nie in normale aktiwiteite deelneem nie, of dat jy miskien verstandelik gestremd is. Ek dink dat ons moet help om daardie persepsie te verander".

Case study 5.(b)

2. Formulating the significant statements into more general re-statements.

5.1 People who know me treat me like I am one of them, ignoring any difference between us, while those who do not know me might treat me like I am completely different from them.

5.2 When people see that you are disabled, they assume that you are also mentally impaired or emotionally disturbed.

5.3 When I fell in front of my new friends, I felt bad even though they did not laugh or say anything.

5.4 When I fall in front of others, it is not a small matter, I feel like I am humiliating myself.

5.5 I thought very hard about why I make such a fool of myself by falling, and concluded that these kinds of incidents will happen in my life.

5.6 When I first competed in the body-building competition I was fearful that my disability would make it difficult for people to accept me.

5.7 I decided to participate as it would provide me with an opportunity to assess my own responses to the challenge and the responses of others.

5.8 My friends' encouragement was important, and made me feel positive about the situation.

5.9 The audience was surprised to see a disabled person being successful.

5.10 Most people feel that because you are restricted in some ways by your physical disability that you are also intellectually impaired. Something must be done to correct this misperception.

Case study 5.(c)

3. Significant statements and their re-statements are then studied to derive and record a sense of their meaning.

5.1 The non-disabled individuals encountered for the first time are often more aware of the difference between the disabled and the non-disabled. With time these differences seem to become less important.

5.2 Non-disabled people often conclude that his physical appearance ie. his disability, is an indication of intellectual impairment or emotional disturbance.

5.3 Irrespective of the responses of others, he experiences a sense of humiliation should the disability result in an embarrassing situation in front of non-disabled people.

5.4 Falling in front of others is an indication of his vulnerability and it makes him appear weaker and more vulnerable in relation to others.

5.5 He resolved that these humiliating incidents will be a constant pattern in his life, and he had to manage it effectively.

5.6 Even when competing on an equal basis with others, with no consideration of disability, he is still concerned that his disability would deny him acceptance and approval by others.

5.7 Competing on an equal basis with non-disabled individuals is a measure of a sense of his self-worth and competence and a measure of others' openness to accepting disability and his abilities.

5.8 Positive input from significant others in his life, makes him look beyond the limitations of his disability.

5.9 Non-disabled people are ambivalent about his achievements and find it difficult to associate success with disability.

5.10 Non-disabled people often conclude that his physical disability implies some form of intellectual impairment. It is a situation he feels he needs to help others to change.

Case study 5.(d)

4. Description of the themes emerging from the participant's narration.

Non-disabled people encountered for the first time are probably more acutely aware of the differences between himself and themselves. He feels that the initial judgement is based primarily on his physical appearance, and therefore they conclude that he is intellectually impaired and emotionally disturbed. It is a situation he feels he needs to help others to change. He finds however that with non-disabled people who have regular contact with him and communicate frequently with him, he is considered their equal.

He is concerned about socially appropriate behaviour and would feel humiliation and shame, should his disability result in an embarrassing situation in front of his non-disabled peers, even if they should not respond to it in any way. Falling in front of others is an indication of his vulnerability and frailty in relation to others. He resolved his anguish about the incident by concluding that such

situations will be a permanent feature of his life and that he had to learn to manage it in a positive way.

In an open and competitive environment, he is concerned that others would deny him acceptance and approval because of his disability. He feels compelled to compete on an equal basis in order to assess his sense of self-worth and competence, but also to measure other people's openness to accepting his disability and his abilities.

He feels however, that non-disabled people have ambivalent feelings about his achievements, and possibly finds it difficult to associate success and achievement with disability. He finds that positive input from significant others in his life, makes him feel empowered to look beyond the limitations of his disability.

Case study 6

Dit was verlede kwartaal by die Volkswagen Music Active
program. Ek het vir die afgelope 6 weke, vanaf Maart tot Junie
deelgeneem aan die program. Ek het gereeld kontak gehad met
nie-gestemde persone. Met die eerste week van die program het
ek nie so goed gevoel nie, omdat almal van die kinders wat
daar was, was normaal en hulle kon almal vrylik rond beweeg.
Daar was baie trappies, en soos 'n mens maar is, is jy maar
skaam om te vra vir hulp.

Ons het toe verdaag na die verskillende ateljees waar hulle
nuus lees. Almal het toe sommer by die deur uitgeborrel. Ek
het maar gesit en wag, en was dit nie vir die onderwysers wat
my gehelp het nie, sou ek seker daar moes bly sit. Die ander
kinders het ook sommer die sitplekke afgeneem waar die
aanbieder ons plekke aangewys het. Vir my was dit 'n baie
lelike ding. Dit het my ook sommer laat negatief teenoor
myself voel. Ek het ook myself dan afgevra waarom ek dan self
aan die program deelgeneem het. Ek het ook gedink as ek nou
net sit en bejammering teenoor myself toon, gaan dit vir my
nêrens bring nie, motiveer jouself, en moenie sleg voel oor

wat gebeur het nie, daardie soort dinge sal altyd gebeur. Skyf jou gevoelens op die agtergrond, en wys vir die wêreld wat jy kan doen.

Dan het ek ook 'n bietjie opgewonde gevoel. Ek het dit as 'n geleentheid beskou vir my om miskien vir die buite-wêreld of normale kinders te wys waartoe nie net ek, maar alle gestremdes in staat is, wat ons regteg kan doen alhoewel ons gestremd is. Vir my basies het dit 'n tydjie geneem om aan te pas want die atmosfeer was nie so lekker gewees nie.

Die tweede week het dit beter gegaan. Ons het begin vriende maak en kommunikeer. Ek het selfs vergeet dat ek gestremd is. My gebrek sit my nie eintlik af nie en staan ook nie in my pad nie. Daar is niks wat jy daaraan kan doen nie, en ek is trots op wat ek tot dusver bereik het.

Toe die program aan 'n einde loop, was ons gevra om in rye te staan, om te hoor of ons 'n rol in die nuwe produksie losgeslaan het. Toe dit ons, dit wil sê die gestremdes, se tyd kom, het die ko-ordineerde gesê dat ons nie hoef in te kom nie. So te sê dat julle dit nie kan doen nie. My hart was baie seer, omdat ons nou al so vêr gekom het. Ons kon miskien nou

die rol losgeslaan het, maar is nie 'n kans gegun nie. Dit sou

my meer waardig gevoel het as ek 'n kans gegun was.

Case study 6.(a)

1. Extraction of significant sentences and phrases which directly pertain to feelings of self-esteem.

6.1 " Met die eerste week van die program het ek nie so goed gevoel nie, omdat almal van die kinders wat daar was, was normaal, en hulle kon almal vrylik rond beweeg".

6.2 " Daar was baie trappies, en soos mens maar is, is jy maar skaam om te vra vir hulp".

6.3 " Almal het sommer by die deur uitgeborrel. Ek het maar gesit en wag, en was dit nie vir die onderwysers wat my gehelp het nie, sou ek seker daar moes bly sit".

6.4 " Die ander kinders het ook sommer die sitplekke afgeneem waar die aanbieder ons plekke aangewys het. Vir my was dit 'n baie lelike ding. Ek het my ook sommer laat negatief teenoor myself voel."

6.5 " Ek het ook gedink as ek nou net sit en bejammering teenoor myself toon, gaan dit my nêrens bring nie, motiveer jouself, en moenie sleg voel oor wat gebeur het nie, daardie soort dinge sal altyd gebeur."

6.6 " Skyf jou gevoelens op die agtergrond, en wys vir die
wereld wat jy kan doen."

6.7 " Dan het ek ook 'n bietjie opgewonde gevoel. Ek het dit
as 'n geleentheid beskou vir my om miskien vir die buite
wêreld of normale kinders te wys waartoe nie net ek,
maar alle gestremdes in staat is, wat ons regtig kan
doen alhoewel ons gestremd is."

6.8 " Ons het begin vriende maak en kommunikeer. Ek het selfs
vergeet dat ek gestremd is."

6.9 " My gebrek sit my nie eintlik af nie en staan ook nie in
my pad nie. Daar is niks wat jy daaraan kan doen nie, en
ek is trots op wat ek tot dusver bereik het."

6.10 " Ons kon miskien nou die rol losgeslaan het, maar ons is
nie 'n kans gegun nie. Dit sou my meer waardig gevoel
het as ek 'n kans gegun was."

Case study 6.(b)

2. Formulating the significant statements into more general re-statements.

6.1 I did not feel so good when I first made contact with non-disabled children at the programm and I was very aware that unlike me they could move around freely.

6.2 Because of the physical environment, it was difficult at times for me to move around, but I was too shy to ask for help.

6.3 I could not keep up with the physical activity of the other children, and without assistance I would have been completely excluded.

6.4 I was unable to do anything when the children took my seat, and this made me feel very negative about myself.

6.5 I realised that feeling sorry for myself would not help matters, I had to force myself to do something, since I will always encounter difficulties.

6.6 I had to control my emotions and show others what I am capable of doing.

6.7 I felt elated and I saw the need to grab the opportunity to show non-disabled people what I and other disabled children can do despite our disability.

6.8 With friendship and communication, I forgot all about my disability.

6.9 I do not allow my disability to stop me from doing things. The disability is an unchangeable part of who I am, and I am proud of what I have achieved.

6.10 I felt that if we are given opportunities, we might succeed. Even if we don't, just having been given the opportunity to participate makes us feel better about ourselves.

Case study 6.(c)

3. Significant statements and their re-statements are studied to derive and record a sense of their meaning.

6.1 His first contact with this non-disabled group was unpleasant, and highlighted the difference between himself and his non-disabled peers, especially with regard to mobility.

6.2 Poor mobility created a dilemma since he often required assistance but was too reluctant to request assistance from others, which would emphasise his lack of independence and competence.

6.3 Because of the robust behaviour of his non-disabled peers, he would have been completely excluded from the activities without the assistance of the adults present, highlighting his dependence on others.

6.4 He felt powerless to confront others who were encroaching on his rights and his space, and this negatively affected his sense of self-worth.

6.5 Self-pity was not going to be a solution, he felt he had to initiate change himself, since these difficulties will always be a part of his life.

6.6 He had to refrain from allowing his true feelings from restricting him in his activities and interactions, and work towards convincing others of his capabilities and competence.

6.7 He felt compelled to utilise the occasion to show others what he and other disabled children are capable of achieving, in order to highlight the fact that achievement and disability are not incompatible

6.8 When he develops friendship and effective communication with non-disabled people, then the restrictive implications of his disability become less obvious and problematic to him and to others.

6.9 He sees the need to embrace his disability as an unchangeable part of who he is, and therefore not to allow it to prevent him from fully participating in activities and interacting with others.

6.10 He feels he needs to be provided with opportunities to experience the full extent of his capabilities, as this will serve to enhance his sense of self-worth.

<u>Case study 6.(d)</u>

4. Description of themes emerging from the participant's narration.

His first encounter with the non-disabled group, was an unpleasant experience. He was immediately confronted by the difference between himself and others. The freedom he observed in them moving about emphasised the restrictive nature of his physical condition. The physical environment itself presented him with a reminder of his poor mobility. His reluctance to request assistance from others indicates his need to present himself to others as competent and independent.

The nature of the boisterous activities of his non-disabled peer group, compels him to seek assistance from others, to ensure that he is not completely excluded. This probably emphasises his dependence on others in certain situations.

He experiences a sense of disempowerment, when others infringe on his rights and he is unable to confront them. This leaves him with a sense of low self-worth. He recognises this as a

problem situation he will encounter again in different situations and the solution does not lie in self-pity, but in asserting oneself and endeavouring to change the situation.

He has to control his emotions, and not allow them to impede him in his activities and social interactions aimed at convincing others of his true capabilities and competence. He views these social occasions as an opportunity to highlight his own abilities and in so doing the abilities of other disabled adolescents, so that disability is not equated with incompetence.

He finds that with increased contact and communication friendship can develop to a point where differences disappear. He experiences a sense of equality with others where the restrictive implications of his disability becomes less obvious and problematic to him and to others.

He embraces his disability as a permanent and unchangeable part of his self and in doing so he eliminates the restrictive nature of the disability in his own mind and possibly in practice.

He yearns for the chance to be provided with the opportunity to demonstrate the full extent of his capabilities. Should he not succeed completely, it will still serve to enhance his sense of self-worth.

Case study 7

Die eerste voorval waaroor ek wil gesels, was toe ek saam met
my vriend na sy meisie vriendin se huis gegaan het. Wat my
'n bietjie afgesit het is dat sy Engels-sprekend is. Terwyl
ons daar was het hulle toe oor skool begin gesels. Ek wou nie
saampraat nie aangesien ek by 'n gestremde skool is en ek was
bang dat hulle ongemaklik gaan voel teenoor my wat gestremd
was. Hulle sal my dan wil help soos 'n klein kind en ek wou
dit nie hê nie. Hulle het my ook begin uitvra na myself, en ek
het hul vrae meer begin vermy want ek het gevoel as hulle
uitvind van my gestremdheid gaan hulle anders teenoor my
optree. Ek het so min as moontlik probeer opstaan. Ek wou ook
graag vermy dat hulle my moes vra waarom ek dan so "limp", en
ek het nie gevoel om met vreemde mense daaroor te praat nie.

Een Saterdag het ons movies dopgehou, toe vra die meisie se ma
vir my waar ek skool gaan. Ek het eers gesê dat ek in
Bridgetown skool gaan. Hulle wou toe weet waar in Bridgetown.
Ek sê toe dat ek by Eros Skool is. Hulle wou toe weet waarom
ek by Eros Skool gaan, aangesien daar niks met my verkeerd is
nie. Ek het toe vir hulle my been gewys en gesê dat ek 'n

linker hemipleeg is. Hulle wou toe weet waarom ek nie lankal

vir hulle gesê het nie. Daarna het hulle vir my koffie gebring

en ek het gevoel dat hulle die spesifieke dag vir my meer as

ander dae doen. Ek wou nie dit hê nie. Dit het vir my gevoel

dat hulle vir my wou pamperlang noudat hulle weet van my

gestremdheid. Ek wil nie anders as gewone mense behandel word

nie. Ek wil gelyk wees. Ek het met hulle oor my gestremdheid

gesels en hulle woorde was dat dit nie by hulle saak maak nie.

Voorheen as mense gehoor het dat jy gestremd is, is dit asof

hulle hulself terugtrek of onttrek van jou af. Hulle wou nie

eintlik met jou praat nie. Dit is asof jy nie bestaan nie.

Dan is daar nog iets waaroor ek graag wil gesels. Dit is te

doen met 'n meisie. Ek het vir haar so 'n paar dae na Kersfees

ontmoet. Sy was 'n baie mooi meisie, en ons het mekaar gereeld

gesien. Ek het so iets begin voel vir haar en ek was seker dat

sy diesefde teenoor my voel. Ons het altyd oor skool gesels.

Ons het altwee skool gehaat.

Sy het tehore gekom by haar tante dat ek gestremd is, en sy

het my daarna uitgevra. Ek het eers stilgebly en was bang wat

sy sou sê. Die volgende dag het ons twee winkel toe gestap, en

toe het ek vir haar gevra om my vriendin te wees. Sy het nee

gesê. Sy het toe gesê dit is omdat dit deur my gestremdheid

is. Ek het baie sleg gevoel want ek het gevoel dat sy my nie

as 'n normale persoon sien nie, maar as iemand wat gestremd is.

Nie die gawe persoon wat ek van binne is nie, maar slegs die

gestremde persoon van buite. Ek kon nie verstaan dat sy so

anders gereageer het nie. Sy het selfs 'n gestremde broer

gehad, en alles moet vir hom gedoen word. Ek kan nie verstaan

dat 'n mens nie die verskil tussen 'n verstandelike gestremde

en 'n fisiese gestremde persoon kan verstaan nie.

Case study 7.(a)

1. Extraction of significant sentences and phrases which directly pertain to feelings of self-esteem.

7.1 " Wat my 'n bietjie afgesit het is dat sy Engels-sprekend is."

7.2 " Terwyl ek daar was het hulle toe oor skool gepraat. Ek wou nie nie saampraat nie aangesien ek by 'n gestremde skool is en ek was bang dat hulle ongemaklik gaan voel teenoor my wat gestremd was."

7.3 " Hulle sal my dan wil help soos 'n klein kind en ek wou dit nie hê nie."

7.4 " Ek het hul vrae meer begin vermy want ek het gevoel as hulle uitvind van my gestremdheid gaan hulle anders teenoor my optree."

7.5 " Dit het vir my gevoel dat hulle vir my wou pamperlang, noudat hulle weet van my gestremdheid."

7.6 " Ek wil nie anders as gewone mense behandel word nie. Ek wil gelyk wees."

7.7 " Voorheen as mense gehoor het dat jy gestremd is, is dit asof hulle hulself terugtrek of onttrek van jou af."

7.8 " Hulle wou nie eintlik met jou praat nie. Dit is asof jy

nie bestaan nie."

7.9 " Ek het baie sleg gevoel want ek het gevoel dat sy my nie

as 'n normale persoon sien nie, maar as iemand wat

gestremd is. Nie die gawe persoon wat ek van binne is

nie, maar slegs die gestremde persoon van buite."

7.10 " Ek kon nie verstaan dat sy so anders reageer het nie.

Sy het selfs 'n gestremde broer gehad en alles moet vir

hom gedoen word."

7.11 " Ek kan nie verstaan dat 'n mens nie die verskil tussen

'n verstandelike gestremde en 'n fisiese gestremde

persoon kan verstaan nie."

<u>Case study 7.(b)</u>

<u>2. Formulating the significant statements into more</u>
<u>general re-statements.</u>

7.1 I was initially not concerned about the physical
   differences, but rather about the language differences.

7.2 I was afraid to participate in the conversation in case
   they discovered that I am disabled, and this would make
   them feel awkward and differently about me.

7.3 Should they discover that I am disabled they will treat me
   differently, like I am a child.

7.4 I avoided full participation to hide my disability and
   thus avoid them changing their attitude towards me.

7.5 The knowledge of my disability made them over-protective
   and possibly feel pity towards me.

7.6 I want to be treated the same as everybody else, like a
   normal person.

7.7 When people become aware of your disability, they withdraw
   and want to disassociate from you.

7.8 The lack of communication makes you feel that you do not
   exist.

7.9 I felt bad that she was unable to look beyond my disability and did not see the pleasant person I am inside, only the disabled person I am on the outside.

7.10 I cannot understand why she would behave in such a discriminatory way towards disability when her own brother is disabled.

7.11 I cannot understand why the average person cannot distinguish and understand the difference between a physical disability and a mental disability.

Case study 7.(c)

3. Significant statements and their re-statements are studied to derive and record a sense of their meaning.

7.1 He initially felt that his physical disability was concealed enough for him to be more concerned about the other aspects of socialising which could present as barriers.

7.2 He considers concealment of his disability as necessary for his own protection but also to avoid a tense and awkward situation for his non-disabled friends.

7.3 Disclosure of his disability could result in a patronising and condescending attitude towards him.

7.4 He often restricts the conversation and participation to avoid discovery of his disability and thus avoid the possibility of a change in attitude from the non-disabled towards him.

7.5 Knowledge of his disability could result in an over-protective attitude towards him from his non-disabled friends.

7.6 He does not want to be treated differently and wants as little distinction to exist between himself and his non-disabled friends.

7.7 Knowledge of his disability could also result in others limiting their interaction and withdrawing from him socially.

7.8 The reluctance of people to communicate with him could evoke feelings of non-existence and a sense of depersonalisation.

7.9 His non-disabled friend tended to focus on his external physical appearances, and tend to ignore the positive personality qualities he has.

7.10 He cannot understand why his friend's personal experience of disability within her family, did not result in a greater understanding and acceptance of him.

7.11 He is concerned that the average non-disabled person equates physical disability with mental handicap.

Case study 7.(d)

4. Description of themes emerging from the participant's narration.

Concealing his disability is important to him. At his initial contact with non-disabled peers he felt comfortable enough about his camouflage to be more concerned about his communication and language skills.

He views the concealing of his disability as essential for keeping his own sense of self-worth and competence intact. He also wants to avoid a dilemma for his friends by not placing them in a strained and uncomfortable situation where they would possibly behave inappropriately, and in that way jeopardise the possibility of building a friendship.

He is particularly concerned that others would want to avoid social contact with him and treat him in a condescending, over-protective and belittling manner and in this way impinge on his sense of self-worth and competence. When others display a reluctance to interact and communicate with him, it evokes feelings of non-existence, as if he is a non-person.

To evade any reference to his disability, he limits his conversation and social participation and inadvertently becomes a captive of his own anxiety and apprehension regarding others perception of his disability.

He wants to be considered as normal and treated on an equal basis to others. The relationship between disabled and non-disabled is viewed as unequal, hence his concern about concealing his disability.

He is also disturbed about the perception that his friend forms an opinion of him based entirely on his physical appearance, and fails to see and appreciate what he considers as his real self.

He expects people who have contact with disabled people to develop an understanding and acceptance of disability and to suspend feelings of prejudice. He is concerned that this lack of insight has resulted in the equation of physical disability with mental handicap.

Case Study 8

Dit was eenkeer in die "Mall" gewees. Ek het 'n paar van my niggie se vriende ontmoet. Ek het nie lekker met hulle gekommunikeer nie omdat ek nie eintlik geweet het waarvan hulle praat nie, aangesien ons nie dieselfde skool bywoon nie. Hulle is nou almal in matriek en amper al uit die skool. Jy voel ongemaklik want jy weet nie dalk of hulle van jou gaan praat nie aangesien jy 'n gebrek het. Party mense maak gewoonlik asof hulle nie jou gebrek raaksien nie, maar ek weet hulle kan. Ek kry altyd die gevoel dat mense nie so lekker met ons meng nie.

My niggie se vriende het nie eintlik met my gepraat nie. Ek het nie eintlik vriende nie. Ek gaan elke dag na Melanie toe, want ek bly naby haar. My niggie se vriende weet dat my naam Nadine is en dat ons familie is. Hulle praat nie eintlik met my nie. Ek gaan gewoonlik alleen "Mall" toe.

Ek kommunikeer nie maklik met mense nie. Sommige mense laat jou voel asof jy nie reg in jou kop is, of sommige dink dat jy 'n "psycho-case" is. Daarom dat ek maar gewoonlik op my eie

rond is. Ek moet sê dat sommige mense doen eintlik niks om my

so te laat voel nie. Partykeer wil hulle iets doen, maar dan

besluit hulle daarteen. Dit hang net van die persoon af. Ek

sal nooit eerste praat nie, en is altyd bang dat ek nie

terugvoering sal kry nie. Ek is altyd bang dat... dat ek

myself sal verkeerd uitspreek en dat die ander persoon my dan

'n onbeskofte antwoord terug sal gee.

Ek het al probeer om 'n gesprek aan te knoop. Die sekere

outjie wil soms met my praat, maar dit is asof iets hom weghou

om met my te gesels. Ek het eenkeer vir die outjie gevra wat

die tyd was, en al wat hy geantwoord het, was dat dit laat

was. Ek het gevoel dat hy 'n beter antwoord kon gee. Hy kon net

die tyd gesê het. Dit was nie nodig om so 'n antwoord te gee

nie.

Soms praat ek nie baie by die huis nie. My ouers kan nie dit

verstaan nie. Soms is ek 'n bietjie onbeskof by die huis.

Hulle sê soms dat dit die rede is hoekom ek nie vriende het

nie. By die skool is dit 'n ander storie. Ek kommunikeer

maklik met die onderwysers en gesels ook baie lekker gemaklik.

By die huis probeer ek ook hard maar ek gee alles en ontvang

dan niks terug nie.

Case study 8.(a)

1. Extraction of significant sentences and phrases which directly pertain to feelings of self-esteem.

8.1 " Ek het nie lekker met hulle gekommunikeer nie, omdat ek nie eintlik geweet het waarvan hulle praat nie, aangesien ons nie dieselfde skool bywoon nie."

8.2 " Jy voel ongemaklik want jy weet nie dalk of hulle van jou gaan praat nie aangesien jy 'n gebrek het."

8.3 " Party mense maak gewoonlik asof hulle nie jou gebrek raaksien nie, maar ek weet hulle kan."

8.4 " Ek kry altyd die gevoel dat mense nie so lekker met ons meng nie."

8.5 " My niggie se vriende het nie eintlik met my gepraat nie. Ek het nie eintlik vriende nie."

8.6 " Ek kommunikeer nie maklik met mense nie. Sommige mense laat jou voel asof jy nie reg in jou kop is nie, sommige dink dat jy 'n 'psycho-case' is."

8.7 " Ek moet sê dat sommige mense doen eintlik niks om my so te laat voel nie. Partykeer wil hulle iets doen, maar

dan besluit hulle daarteen. Dit hang net van die persoon af."

8.8 " Ek sal nooit eerste praat nie, en is altyd bang dat ek nie terugvoering sal kry nie."

8.9 " Ek is altyd bang dat...dat ek myself sal verkeerd uitspreek en dat die ander persoon my dan 'n onbeskofte antwoord terug sal gee."

8.10 " Ek het al probeer om 'n gesprek aan te knoop. Die sekere outjie wil soms met my praat, maar dit is asof iets hom weghou om met my te praat."

8.11 " Soms praat ek nie baie by die huis nie. My ouers kan dit nie verstaan nie. soms is ek 'n bietjie onbeskof by die huis."

8.12 " Hulle sê soms dat dit die rede is hoekom ek nie vriende het nie."

8.13 " By die skool is dit 'n ander storie. Ek kommunikeer maklik met die onderwysers en gesels ook baie lekker gemaklik."

8.14 " By die huis probeer ek ook hard maar ek gee alles en ontvang dan niks terug nie."

<u>Case study 8.(b)</u>

<u>2. Formulating the significant statements into more
general re-statements.</u>

8.1 I had difficulty communicating with them because we did
not seem to have anything in common to talk about.

8.2 I feel uncomfortable with non-disabled people, because I
am never sure whether they are going to talk about me
because of my disability.

8.3 I sometimes feel that others would pretend not to notice
my disability, but I am sure that it is noticeable.

8.4 I get the feeling that non-disabled people find it
difficult to interact and socialise with disabled people.

8.5 I have no friends of my own, and my cousin's friends were
not interested in talking to me.

8.6 I find it difficult to communicate with non-disabled
people, because they can make me feel that I am
different from them and have emotional and behavioural
problems.

8.7 I feel like this even though people do not do anything to
make me feel this way.

8.8 I will not initiate a conversation, because I fear that other people may not want to talk to me.

8.9 I am afraid that I will express myself poorly and then I will get a negative response from others.

8.10 I have attempted to have a conversation with a boy, but it is as if something about me stops him from communicating with me.

8.11 I do not communicate easily at home and sometimes I can be rude and abrupt. My parents find it difficult to understand me.

8.12 My parents feel that my poor behaviour is the cause that I do not have friends.

8.13 In school I communicate easily and freely with the teachers.

8.14 At home I feel I give a lot and get very little in return.

<u>Case study 8.(c)</u>

<u>3. Significant statements and their re-statements are studied to derive and record a sense of their meaning.</u>

8.1 She finds that the lack of common experience impedes the ease with which she is able to communicate with non-disabled peers.

8.2 The presence of non-disabled people arouses feelings of insecurity, distrust and discomfort in her, and a suspicion that others are discussing her behind her back because of her disability.

8.3 She feels that non-disabled people often try unsuccessfully to conceal their awareness of her disability.

8.4 She feels that non-disabled people do not want to, or do not make enough effort to encourage or improve interactions with non-disabled people.

8.5 She acknowledges her loneliness at not having friends, and the lack of interest others appear to show in her.

8.6 Part of the difficulty she has with communicating with others is the perception she has that others consider her to be mentally handicapped or emotionally unstable.

8.7 She experiences this sense of rejection by others, even when the behaviour of others is to the contrary.

8.8 Her fear of what others might say or do to avoid communicating with her, prevents her from initiating conversation.

8.9 She also limits her communication with others because she fears that she may express herself poorly and elicit a negative response and rejection from non-disabled persons.

8.10 Previous attempts at communication with a member of the opposite sex had been thwarted by his awareness of her disability.

8.11 She has no relationship and understanding with her parents and hence the reluctance to communicate with them.

8.12 She believes that her parents attribute her lack of friends to her poor behaviour rather than to her disability.

8.13 In familiar and secure settings and with trusted adults,
she tends to communicate easily.

8.14 She has a need for meaningful relationship and
communication at home, but feels that she is failing in
this despite her efforts.

Case study 8.(d)

4. Description of themes emerging from the participant's narration.

She considers her primary difficulty to be in the area of communication. She feels removed from the everyday experiences which she feels her non-disabled peers have in common. This makes her feel uncertain in her communication with them. Her lack of regular contact and communication with non-disabled people has also given rise to feelings of distrust, discomfort and insecurity about their trustworthiness. She feels that her disability is discussed by others behind her back.

Their mere presence makes her feel very conscious of her disability. She feels that they often attempt unsuccessfully to conceal their recognition and curiosity about her disability, but she knows that her disability is visible for all to see.

She feels that her failure to interact and relate effectively with non-disabled peers is not a personal failure, but it is

due to the difficulty that most non-disabled people have in relating to disabled people in general. She feels that non-disabled people consider her to be mentally handicapped and emotionally unstable.

She acknowledges that this feeling of rejection she experiences from others is prevalent, even if the behaviour from others does not warrant such a reaction. Her fear of what she perceives others might say or do in response to her efforts at communication precludes her from initiating conversation with them. Previous attempts at communication with members of the opposite sex were thwarted, either by her poor communication skills or their awareness of her disability.

Besides the perceived responses from others, she also expresses concern that her own poor communication skills could elicit a disapproving response from others towards her, and hence further rejection. She indicates that her parents believe that her difficulty with forming friendships is probably due more to her poor social and communication skills than to her disability.

She acknowledges her lonesomeness at not having friends and the perceived indifference others display towards her. Besides the broader social setting, she also feels alienated within her family, where there is no relationship and understanding between her and her parents. She expresses a need for this to improve, but feels that despite all her efforts she is failing in establishing meaningful relations and communication with her parents.

The only setting within which she feels accepted and understood is the special school she attends. Within such a familiar and secure setting and surrounded by adults that she trusts, she tends to communicate easily and feels a greater sense of self-worth and competence.