GROWING UP IN A WHEELCHAIR:
A QUALITATIVE STUDY OF
ADOLESCENTS AND YOUNG ADULTS WITH
CONGENITAL PHYSICAL DISABILITIES
by
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Date **October 5, 1989**
Abstract

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The purpose of this study was to explore and describe the experience of growing up with a congenital physical disability and the effect this has on self-concept development from the perspective of adolescents and young adults who have such a disability which confines them to a wheelchair. A phenomenological approach was used to guide data collection through a series of 13 semi-structured interviews with 6 wheelchair dependent individuals between the ages of 12 and 23 years. Data analysis occurred concurrently with data collection. It was found that there were three common components to the experience: family life, peer relationships and leisure-time activities but participants had two different perspectives on this experience. Those holding the "able" perspective were optimistic, generally satisfied with their peer and family relationships and perceived themselves to be physically, socially and cognitively competent. Those with the "disabled perspective were pessimistic, unsatisfied with their peer and family relationships and did not perceive themselves to be physically, socially and cognitively competent. In terms of nursing practice, the findings indicate the necessity of supporting families in order to maintain disabled children and adolescents at home whenever possible and the importance of building positive self-concepts and high self-esteem in disabled children and
adolescents. Implications for nursing research include further exploration and description of the experience of growing up with a congenital physical disability with larger numbers of disabled informants and expansion of the body of knowledge about the impact of the disabled child or adolescent on family functioning and family relationships.
# Table of Contents

Abstract .......................................................... ii
Table of Contents ................................................. iv
Acknowledgements ................................................ vi

## CHAPTER ONE: INTRODUCTION

Background to the Problem ........................................ 1
Statement of the Problem and Purpose ............................ 3
Definition of Terms ................................................ 4
Introduction to this Study’s Methodology ......................... 5
Assumptions and Limitations ....................................... 6
Summary ............................................................. 7

## CHAPTER TWO: REVIEW OF THE LITERATURE

Introduction ......................................................... 8
The Adolescent with a Congenital Physical Disability ............ 9
Self-Concept ........................................................ 13
  Definition of Self-Concept ....................................... 13
  Components of Self-Concept .................................... 14
  Relationship between Self-Concept and Self-Esteem .......... 15
  Development of Self-Concept .................................... 16
  Factors which Influence Self-Concept ........................ 19

Impact of a Congenital Physical Disability on the
  Adolescent’s Self-Concept and Self-Esteem .................... 21

Impact of a Congenital Physical Disability on Family
  Relationships ....................................................... 26

Impact of a Congenital Physical Disability on Peer
  Relationships ....................................................... 30

Summary ............................................................. 35
# Table of Contents (cont'd)

## CHAPTER THREE: METHODOLOGY

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction</td>
<td>37</td>
</tr>
<tr>
<td>Qualitative Research</td>
<td>37</td>
</tr>
<tr>
<td>Research Role</td>
<td>37</td>
</tr>
<tr>
<td>Research Process</td>
<td>38</td>
</tr>
<tr>
<td>Implementation of the Methodology for this Study</td>
<td>40</td>
</tr>
<tr>
<td>Selection of Participants</td>
<td>40</td>
</tr>
<tr>
<td>Criteria for Selection</td>
<td>41</td>
</tr>
<tr>
<td>Selection Procedure</td>
<td>41</td>
</tr>
<tr>
<td>Characteristics of Participants</td>
<td>44</td>
</tr>
<tr>
<td>Ethical Considerations</td>
<td>44</td>
</tr>
<tr>
<td>Data Collection</td>
<td>45</td>
</tr>
<tr>
<td>Data Analysis</td>
<td>47</td>
</tr>
<tr>
<td>Summary</td>
<td>48</td>
</tr>
</tbody>
</table>

## CHAPTER FOUR: THE PARTICIPANTS' ACCOUNTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction</td>
<td>50</td>
</tr>
<tr>
<td>General Perceptions</td>
<td>54</td>
</tr>
<tr>
<td>Describing the Experience</td>
<td>54</td>
</tr>
<tr>
<td>Perceptions of Family Life</td>
<td>54</td>
</tr>
<tr>
<td>Perceptions of Peer Relationships</td>
<td>60</td>
</tr>
<tr>
<td>Perceptions of Leisure-Time Activities</td>
<td>70</td>
</tr>
<tr>
<td>Perceptions of Self</td>
<td>76</td>
</tr>
<tr>
<td>a) Perceptions of Body and Physical Competence</td>
<td>77</td>
</tr>
<tr>
<td>b) Perceptions of Social Competence</td>
<td>85</td>
</tr>
<tr>
<td>c) Perceptions of Cognitive Competence</td>
<td>88</td>
</tr>
<tr>
<td>d) Perceptions of Self-Worth and Self-Respect</td>
<td>91</td>
</tr>
<tr>
<td>Summary</td>
<td>95</td>
</tr>
</tbody>
</table>
Table of Contents (cont’d)

<table>
<thead>
<tr>
<th>Chapter</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>CHAPTER FIVE: DISCUSSION OF FINDINGS</td>
<td>Introduction</td>
<td>97</td>
</tr>
<tr>
<td></td>
<td>General Perceptions</td>
<td>97</td>
</tr>
<tr>
<td></td>
<td>Describing the Experience</td>
<td>98</td>
</tr>
<tr>
<td></td>
<td>Family Life</td>
<td>98</td>
</tr>
<tr>
<td></td>
<td>Peer Relationships</td>
<td>103</td>
</tr>
<tr>
<td></td>
<td>Leisure-Time Activities</td>
<td>106</td>
</tr>
<tr>
<td></td>
<td>Perceptions of Self</td>
<td>109</td>
</tr>
<tr>
<td></td>
<td>a) Perceptions of Body and Physical Competence</td>
<td>109</td>
</tr>
<tr>
<td></td>
<td>b) Perceptions of Social Competence</td>
<td>113</td>
</tr>
<tr>
<td></td>
<td>c) Perceptions of Cognitive Competence</td>
<td>114</td>
</tr>
<tr>
<td></td>
<td>d) Perceptions of Self-Worth and Self-Respect</td>
<td>115</td>
</tr>
<tr>
<td></td>
<td>Summary</td>
<td>116</td>
</tr>
<tr>
<td>CHAPTER SIX: SUMMARY, CONCLUSIONS AND IMPLICATIONS FOR NURSING</td>
<td>Summary</td>
<td>119</td>
</tr>
<tr>
<td></td>
<td>Conclusions</td>
<td>121</td>
</tr>
<tr>
<td></td>
<td>Implications for Nursing Practice</td>
<td>123</td>
</tr>
<tr>
<td></td>
<td>Implications for Nursing Research</td>
<td>125</td>
</tr>
<tr>
<td>REFERENCES</td>
<td></td>
<td>128</td>
</tr>
<tr>
<td>APPENDICES</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Appendix A. Information Letter/Consent Form</td>
<td>140</td>
</tr>
<tr>
<td></td>
<td>Appendix B. Sample Interview Questions</td>
<td>142</td>
</tr>
</tbody>
</table>
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CHAPTER 1:
INTRODUCTION

Background to the Problem

With the advent of amniocentesis and genetic counselling, it was assumed by many that the numbers of individuals with physical and mental disabilities in our society would diminish (Norris, 1975). However, advances in medical, surgical and nursing skills have resulted in the survival of greater numbers of babies with severe physical impairments, as well as the survival of an increasing number of children with multiple handicaps (Hobbs & Perrin, 1985; Norris, 1975; Walker, Thomas & Russell, 1971). The dramatic reduction in the mortality and morbidity of this population has resulted in a corresponding increase in the number of adolescents and adults with congenital physical disabilities (Herskowitz & Marks, 1977; Passo, 1978).

In a society such as ours which places a high value on physical health and the "body beautiful", the adolescent with a physical disability is less that fully acceptable. As Barker, Wright, Meyerson and Gonick (1953) write, "... the meaning of a disabled physique to the disabled person himself, and to others who interact with him, will depend in general upon the values of the cultural group to which they belong" (p. 67). The perception that being physically disabled is a "tragedy" is pervasive throughout our society (Weinberg & Williams, 1978; Wright, 1983). The stereotype of a person with a disability is often that of an individual who is less happy, less cheerful and less popular than the able-bodied (Weinberg, 1976). However, research findings by Cameron, Kostin, Gnadinger and Kostin (1973) do not support this assumption. In their study of the "life satisfaction" of able-bodied and
disabled people, they found that both groups were hardly distinguishable in overall adjustment or life satisfaction. Although the disabled judged their lives more difficult, they did not differ significantly from the able-bodied in the ways in which they found life satisfactory.

The available literature does seem to indicate, however, that adolescents with physical disabilities may experience more problems of adjustment than nondisabled adolescents (Calhoun & Hawisher, 1979; Freeman, 1970). Theorists widely agree that early childhood experiences are important influences in the development of self-concept and self-esteem (Burns, 1979; Cotton, 1983; Felker, 1974; Yura & Walsh, 1983) and that a good self-concept and high self-esteem are positively correlated with emotional adjustment, mental health, effective social relationships, feelings of well-being and the ability to function in the world at large (Coopersmith, 1967; Damon & Hart, 1982; Hunter, Linn & Harris, 1982; Rosenberg, 1979). Several authors have suggested that disabled individuals are exposed to a series of childhood experiences which increase the probability of developing poor self-concepts, low self-esteem, passivity and dependence (Freeman, 1970; Lindemann, 1981; Skellern, 1979). Therefore, it is not surprising that much of the disability research has focused on the relationships between disablement, self-concept and self-esteem (Roessler & Bolton, 1978; Wright, 1983). Results of these studies have been inconclusive, however, as some studies have found that physically disabled adolescents have greater feelings of inferiority and lower self-concept scores than adolescents without physical disabilities (Fleming, 1972; Smits, 1965) while several other studies have not found this to be true (Barker et al., 1953; Coleman, 1973; Juenker, 1971; Macbriar, 1983; Molla, 1981;
Williams, 1972). Possible reasons for these discrepancies include the fact that the physically disabled are not a homogeneous group and each individual is exposed to a unique set of life experiences which influences his/her self-concept and self-esteem; as well, there may be methodological inadequacies inherent in the tools used to measure self-concept and self-esteem in children and adolescents (Damon & Hart, 1982); quantitative studies may not adequately measure the adolescent’s subjective beliefs or feelings about him/herself; or the literature may be wrong in its assumption that a physical disability is linked in a direct or simple way to negative psychological consequences (Wright, 1983, p. 243).

It is evident from this discussion that we know little about the impact of growing up with a congenital physical disability and the effect this experience has on the adolescent’s self-concept development. As adolescents with physical disabilities are the most obvious source of this data, this study will focus on their perceptions of the effects of growing up with a congenital physical disability which confines them to a wheelchair.

Statement of the Problem and Purpose

The general problem to which this study is addressed is the lack of knowledge about the adolescent’s experience of growing up with a congenital physical disability that confines him or her to a wheelchair and the effect this has on self-concept development. The purpose of this study, therefore, will be to explore and describe the experience of growing up with a congenital physical disability as perceived and articulated by adolescents who have such a disability which confines them to a wheelchair. The overall question which will direct this study is:
1. What is it like for an adolescent to grow up with a congenital physical disability that confines him or her to a wheelchair?

The following subquestions will also be addressed:

a) How does the disabled adolescent perceive his/her disability?

b) How does the disabled adolescent perceive his/her relationships with his/her family and peers?

c) What factors does the disabled adolescent think/feel influence the development of self-concept and self-esteem?

d) What is the disabled adolescent’s perception of his/her competence in the cognitive, physical and social domains?

e) What is the disabled adolescent’s perception of his/her general feelings of self-esteem?

**Definition of Terms**

**Congenital physical disability:** a permanent nonprogressive orthopedic or neurological impairment incurred prenatally or at birth which interferes with normal ambulation so that the adolescent requires the use of a wheelchair for mobility.

**Adolescent:** a male or female between the ages of 12 and 19 years.

**Self-concept:** an adolescent’s perceived level of competence in the cognitive, social and physical domains.

**Cognitive competence:** an adolescent’s perception of how well he/she is doing at school or how "smart" he/she is.

**Social competence:** an adolescent’s perception of his/her ability to make friends and how well he/she is liked by others.
Physical competence: an adolescent's perception of the capabilities and limitations of his/her body and how "athletic" he/she is.

Self-esteem: an adolescent's evaluation of his/her physical, social and cognitive competence resulting in positive or negative feelings of self-worth and self-respect.

**Introduction to this Study's Methodology**

The methodology for this study is qualitative and is based on phenomenological theory. The theoretical foundation for this approach stems from the work of several nineteenth century European social theorists and emphasizes the value of understanding human behavior and human experience from the individual's own perspective (Knaack, 1984). Qualitative research is based upon the assumption that this "... 'inner understanding' enables a comprehension of human behavior in greater depth than is possible from the study of surface behavior ..." (Rist, 1979, p. 20).

Since it is not known to what extent current theories regarding self-concept also apply to disabled adolescents, a research method which is not anchored to available theories is most appropriate to this study. In qualitative research the emphasis is on discovering new concepts and theories rather than testing pre-existing ones (Bernheimer, 1986; Field & Morse, 1985; Wilson, 1977). Hypotheses and theories emerge from the data set while the data collection is in progress, and after data analysis has commenced (Field & Morse, 1985). The phenomenological approach to qualitative research permits the researcher to consider fresh data in her inductive analysis of previously generated theories and provides a structure whereby understanding can be contributed to knowledge gained from other research methods.
Many investigators believe that qualitative methodology is an appropriate tool for studying the health care of children and adolescents (Bernheimer, 1986; Bibace & Walsh, 1980; Brewster, 1982; Campbell, 1975; Perrin & Gerrity, 1979). In fact, these researchers argue that qualitative methods are essential in gaining an understanding of the child’s or adolescent’s perspective on his/her life experiences. Traditionally, however, researchers have not sought the child’s or adolescent’s perspective in health and illness-related concepts. Lewis, Lewis, Lorimer and Palmer (1974) note that it is adults, but more specifically mothers, who have typically been the sources of information regarding their children’s health and health care. As the aim of the phenomenological approach is to describe human experience as it is lived, the people who live the experience are obviously the best source of this data (Oiler, 1982). Therefore, to gain an understanding of the adolescent’s experience of growing up with a congenital physical disability and the impact this has on self-concept development, this study will seek disabled adolescent’s perspectives on their lived experience.

**Assumptions and Limitations**

The researcher approached this study with the assumption that adolescent’s have the capacity to articulate their experience in such a way that it can be understood by others. She further assumed that information shared by adolescents reflects an accurate reporting of their perception of reality. In addition, she assumed that the attitudes, values and beliefs of the society, culture and family in which the adolescent grows up are important determinants of the adolescent’s self-concept. Her final assumption was that an understanding of what the experience of growing up in a wheelchair is
like for the adolescent with a congenital physical disability can be ascertained through phenomenological research methods.

The depth and richness of the data for this study are limited by the time constraints of the researcher. Such constraints account for the limited number of physically disabled adolescents interviewed and the limited number of interview sessions conducted with each participant. The researcher further recognizes that parents who consented to the participation of their adolescent in the study may readily accept their child’s disability so that the adolescent’s experience may reflect positive parental attitudes towards their disability which may not be characteristic of the experience of other disabled adolescents whose parents are not accepting of their adolescent’s disability.

**Summary**

In this chapter, the problem and purpose of the study have been introduced and the methodology briefly described. In Chapter 2 the literature from which this study is drawn is reviewed. Chapter 3 describes the process by which the methodology was implemented in this study while Chapter 4 describes and explains the accounts given by physically disabled adolescents. A discussion of these accounts is provided in Chapter 5 in relation to the literature reviewed in Chapter 2. Lastly, Chapter 6 summarizes the study and states the implications of the findings.
CHAPTER 2:
REVIEW OF THE LITERATURE

Introduction

This chapter will present a review of the literature which relates to the adolescent's experience of growing up with a congenital physical disability which confines him/her to a wheelchair. Despite extensive literature on the subjects of disablement and adolescence, little has been written on the life experience of adolescents with physical disabilities or the factors that promote or hinder optimal development of disabled adolescents (Dorner, 1973, 1975; Freeman, 1970; Lorber & Schloss, 1973; Martin, 1975; Resnick, 1984; Shurtleff, Hayden, Chapman, Bray & Hill, 1975; Thomas, 1982). In addition, much of the available literature does not differentiate between the experience of individuals who were born with congenital physical disabilities and individuals who acquired disabilities at some point later on during their lives. This writer feels, therefore, that the current literature provides a markedly inadequate portrait of the adolescent’s experience of growing up with a congenital physical disability which confines him/her to a wheelchair.

The literature to be reviewed is that which pertains specifically to the adolescent's experience of growing up with a congenital physical disability which confines him/her to a wheelchair. Research that has addressed some aspect of this experience will be reviewed and a discussion of the limitations of these studies will be presented. Discussion will be limited to the psychosocial aspects of the adolescent's experience (as opposed to medical, financial, ethical etc.) and will utilize as its organizing framework four major headings: (1) The adolescent with a congenital physical disability, (2) Impact
of a congenital physical disability on self concept, (3) Impact of a congenital physical disability on family relationships, (4) Impact of a congenital physical disability on peer relationships.

This literature review then provides a basis upon which to guide the research process toward answering the research questions. In Chapter 5, the findings of this study will be examined and discussed in relation to this same body of literature. In addition, further related literature will be drawn into that chapter as necessary to explore and discuss the descriptions generated by the adolescents and presented in Chapter 4.

The Adolescent with a Congenital Physical Disability

In North America, adolescence is generally considered to refer to the period between 12 to 19 years of age which is characterized by biological, social and emotional changes (Fischer & Lazerson, 1984; Strax & Wolfson, 1984). A review of the literature suggests that adolescents have four major developmental tasks: (1) consolidation of their identity as unique human beings, (2) achievement of independence from their parents, (3) establishment of new love objects outside the family, and (4) finding a vocation (Erikson, 1963; Fisher & Lazerson, 1984; Rutter, 1979; Strax & Wolfson, 1984).

The period of adolescence deserves special attention for the individual with a congenital physical disability for a number of reasons. Firstly, the literature suggests that adolescence is a "crisis point" for disabled young people (Freeman, 1970; Green, 1976; Skellern, 1979; Strax & Wolfson, 1984; Thomas, 1982; Travis, 1976). According to some authors, it is during adolescence that the disabled individual first arrives at a cognitive grasp of his/her disability and its implications for the future (Freeman, 1970; Green,
Disabled young children and their families are often sustained by hope for improvement or "cure" but during adolescence, the permanence of the disability becomes a reality (Freeman, 1970; Thomas, 1982). The full impact of the individual's disability collides with the emotional lability of adolescence and makes previous adaptation less successful (Freeman, 1970; Travis, 1976). Several authors have commented on the "anguish" of the disabled adolescent which may be displayed as sarcasm, flippant remarks, bravado, denial, moodiness, depression or antisocial acts (Minde, Hackett, Killou & Silver, 1972; Skellern, 1979; Strax & Wolfson, 1984; Thomas, 1982; Travis, 1976). Feelings of sadness, anger, anxiety, confusion and despair are also common as the disabled adolescent feels the limitations and restrictions of his/her disability more acutely in comparison with able-bodied peers who are engaged in many activities (Dorner, 1975; Lindemann & Boyd, 1981; Strax & Wolfson, 1984; Travis, 1976).

Secondly, adolescence warrants discussion because it is during this period that individuals engage in the important developmental task of identity formation (Fischer & Lazerson, 1984; Rutter, 1979). The formation of a personal identity is a difficult process for everyone but even more arduous for the adolescent with a physical disability (Strax & Wolfson, 1984). The adolescent's struggle to achieve an individual identity involves trying on the various identities of rockstars, teachers, sports heroes and movie stars, and discarding them when they are no longer functional (Erikson, 1968; Strax & Wolfson, 1984). As other authors note, however, there is a relative scarcity of appropriate role models for disabled adolescents which can result in an
'identity crisis' more profound than that in able-bodied adolescents (Martin, 1975). Creation of a personal identity also involves interaction with, and the support of, a peer group (Fischer & Lazerson, 1984). "Peers are a major sociological reference group for adolescents and represent a social mirror as well as a context within which to experiment and play with new social skills" (Resnick, 1984, p. 306). As Fischer & Lazerson (1984) note, "friends are probably more important in adolescence than at any other time of life" (p. 635). The need to belong is one of the basic human needs and explains the conformity of dress, behavior and speech among adolescents (Fischer & Lazerson, 1984). The typical adolescent dress code serves to delineate adolescents from both adults and children and produces a group solidarity which is helpful in the adolescent's search for identity, self-affirmation and independence (Wright, 1983). However, adolescents can be remarkably clannish and cruel in their exclusion of all those who are "different", whether it be in skin color, cultural background or petty aspects of dress (Erikson, 1963, p. 262). It is hardly surprising, therefore, that a variety of studies reveal that disabled adolescents commonly experience social isolation, teasing and peer group rejection (Altman, 1981; Dorner, 1975; Minde et al., 1972; Minde, 1978; Strax & Wolfson, 1984; Wright, 1983). Without the support of a peer group and with limited opportunities for peer group interaction, disabled adolescents may, therefore, find it more difficult to achieve a stable sense of their personal identity.

The third reason that adolescence warrants particular attention is that this developmental stage is often "prolonged" for individuals with disabilities (Freeman, 1970; Strax & Wolfson, 1984; Wright, 1983). As Wright (1983)
notes, "In our society, the status of full adulthood is generally withheld until
the advent of two outstanding circumstances: economic independence and
marriage, or at least the establishment of a separate household" (p. 252). For
disabled individuals who frequently find it difficult to obtain gainful
employment and who may be physically dependent on others for aspects of
their care, independent living and economic independence are often
impossible or at least delayed well beyond the adolescent years (Wright,
1983). The position of the individual as an adult (no matter what his/her
age) is apt to be tenuous, therefore, and instead the disabled individual, like
the adolescent, remains in a marginal state between adulthood and childhood
(Wright, 1983, p. 252). This "prolonged adolescence" may cause the disabled
individual to experience continued conflicts with parental authority, to feel
devalued as an incomplete adult and to show inconsistent, exaggerated and
emotional behavior (Wright, 1983).

Lastly, adolescence merits special consideration because at this time, the
self-concept or self-image undergoes important alterations in response to the
physical changes of puberty (Fischer & Lazerson, 1984; Wright, 1983). It is at
this time that adolescents begin to realize that their physique is the "final
edition" of themselves and their body, such as it is, is the best they can hope
for (Wright, 1983). Adolescents re-evaluate their bodies in terms of gender
appropriateness and societal norms of what are considered acceptable
masculine or feminine traits place tremendous pressure on adolescents to see
how they "measure up" (Fischer & Lazerson, 1984; Strax & Wolfson, 1984;
Wright, 1983). For physically disabled adolescents who deviate significantly
from these idealized norms, this may be an extremely difficult period (Wright,
1983). The following discussion will review the literature amassed to date on self-concept and the impact of a congenital physical disability on the self-concept of the adolescent.

**Self-Concept**

**Definition of Self-Concept**

Self-concept is a broad term encompassing an individual's own thoughts and feelings about his or her characteristics, abilities, relationships with others and the environment (Hunter et al., 1982). Most authorities view self-concept as multi-dimensional, developmental, evaluative, and organized (Broughton, 1978; Damon & Hart, 1982). However, in an attempt to provide clarity, many theorists have provided their own definitions of this concept. Coopersmith (1967) defines self-concept as "... an abstraction that an individual develops about the attributes, capacities, objects and activities which he possesses and pursues" (p. 20). Epstein (1973) proposes that self-concept is a "self-theory" that each person constructs about him or herself out of his/her experiences and which has three specific functions: "(1) to optimize the pleasure/pain balance of the individual over the course of a lifetime; (2) to facilitate the maintenance of self-esteem; and, (3) to organize the data of experience in a manner that can be coped with effectively" (p. 407). Harter (1978), however, operationally defines self-concept as "perceived competence" in the cognitive, physical and social competence domains and it is her contention that individuals do not feel equally competent in each of these domains. It is Harter's belief that children 8 years of age and older have a constructed view of their general self-worth. According to Harter (1982), the self-evaluative process is organized in a hierarchy whereby self-worth is viewed as the
superordinate construct and the competence domains are the lower order evaluative dimensions (p. 88). As it is important in this study to understand self-concept in some depth, the following discussion will review the components of self-concept, the relationship between self-concept and self-esteem, the development of self-concept during childhood and the factors which influence self-concept.

**Components of Self-Concept**

The literature reveals that theorists also have varying opinions about the components of self-concept. Epstein (1973) claims that self-concept consists of three dimensions: the body self, the inner self and the moral self. He describes the body self as the mental image and feelings that the individual has about the characteristics and appearance of his body. In contrast, the inner self is the individual's perception of his psychological attributes and the moral self is concerned with the individual's evaluation of his own behavior in terms of whether the behavior is good or bad. The moral self develops as a result of the internalization of the values and beliefs of one's parents and society. Harter (1978) argues, however, that the self-concept consists of three competence skill domains which include: cognitive competence, physical competence and social competence. She defines cognitive competence as the individual's perception of his or her level of intellectual ability; physical competence as the individual's perception of his or her athletic ability, and social competence as the individual's feelings about his or her interpersonal relationships and ability to relate to his or her peers. In addition, Harter (1978) views general self-esteem as the individual's overall feelings of self-worth which result from his or her perceived level of competence in each
of the skill domains.

**Relationship Between Self-Concept and Self-Esteem**

There appears to be much confusion in the literature regarding the use of the terms self-concept and self-esteem. It seems to be common practice to equate these terms and use them interchangeably, and yet, many writers define these terms quite differently.

As discussed previously, self-concept is a broad term used to describe an individual's own thoughts and feelings about his or her characteristics, abilities, relationships with others and the environment (Hunter et al., 1982). Self-concept is an abstraction and this abstraction is the person's idea of himself or herself to himself or herself which is represented by the symbol "me" (Coopersmith, 1967, p. 20).

In contrast, self-esteem is viewed as the evaluative component of the self-concept which is learned as a result of the multitude of experiences to which the individual is exposed from birth to death (Burns, 1979; Felker, 1974). It refers to the individual's own assessment of the degree to which he or she is competent, successful, significant and worthy (Parker, 1980). As Rosenberg (1979) writes, self-esteem is the "... positive or negative evaluation of the self ... which implies self-acceptance, self-respect and feelings of self-worth" (p. 31). Theorists widely agree that self-esteem is not fixed but fluctuates according to the nature of the experiences encountered in daily life (Burns, 1979; Felker, 1974).

The literature suggests that self-esteem consists of three components: subjective feelings of belonging, competence and self-worth (Burns, 1979; Felker, 1974). These feelings seem to develop through a process of
self-evaluation whereby the individual examines his or her physical characteristics, abilities, attributes, achievements and social relationships according to personal standards or ideals which he or she has internalized from his or her parents and society at large (Mack & Ablon, 1983).

Writers suggest that a significant factor in the individual's feelings of belonging involve feeling accepted and valued in his or her relationships with others (Burns, 1979; Felker, 1974). This causes the individual to feel respected by others and subsequently, to feel that he or she is significant and worthy. Feelings of competence are thought to develop if the individual perceives that he or she is in control of his or her own behavior and that he or she can successfully perform the behavior required to achieve his or her personal goals and aspirations (Spitzer, 1982). Many theorists suggest that an internal locus of control is the key factor in an individual's feelings of self-respect and self-worth (Brisset, 1972; Floria, 1983). As Coleman (1960) notes, feelings of self-worth are more closely related to one's ideas about oneself than one's actual achievements.

**Development of Self-Concept**

There are many different theories regarding the development of self-concept which have been widely criticized and are described by many as weak, vague and incomplete (Damon & Hart, 1982; Harter, 1982; Wylie, 1961). Many theorists agree, however, that the development of self-concept is a developmental process which progresses from a physical to a psychological perspective (Broughton, 1978; Damon & Hart, 1982; Montemayer & Eisen, 1977). That is, young preschool children describe themselves in strictly concrete terms and distinguish themselves from others primarily on the basis
of their physical characteristics. For example, the child may describe himself as the "child with blonde hair and blue eyes" (Broughton, 1978). By schoolage, children are less egocentric and use more abstract descriptions to distinguish themselves from their peers (Montemayor & Eisen, 1977). The child becomes aware that he or she is different from others not only because of different physical characteristics but because of different psychological attributes. However, schoolage children continue to describe themselves in terms of "things done" rather than "things felt" (Siemon, 1978). That is, children at this age focus on the self's "action competencies" and describe themselves in terms of their active capabilities in relation to others. For the schoolaged child, the issue is no longer what he or she can do, but how well he or she can do it in relation to others (Secord & Peevers, 1974). This is illustrated in the following example of a 9 year old boy's description of himself: "My name is Bruce C. I have brown eyes. I have brown hair. I have brown eyebrows. I'm nine years old. I LOVE Sports. ... I have great eyesight. I have lots of friends ... I play Hockey! I am almost the smartest boy in the class ..." (Montemayor & Eisen, 1977, p. 317).

In comparison to younger children, adolescents describe themselves quite differently. The adolescent's self-descriptions are much more complex and abstract and focus on personal beliefs and personality traits which uniquely characterize himself or herself. The following example is from a 17 year old girl: "I am a human being. I am a girl. I am an individual. I don't know who I am. ... I am a moody person. I am an indecisive person. ... I am a radical. I am a conservative ..." (Montemayor & Eisen, 1977, p. 318). However, this is not to imply that physical appearance is not an important
part of the adolescent’s self-concept. In fact, physical appearance tends to assume a heightened importance during adolescence, for it is at this time that the values of society bring tremendous pressure on the young person to examine the self in terms of the criteria of his or her gender role (Wright, 1983). Marriage and children are highly valued in North American society and conformity of appearance, dress and behavior are seen by adolescents as the criteria for success in romantic relationships (Wright, 1983).

Many theorists argue that the developmental transformation in self-conceptions throughout childhood parallels the cognitive development of the child (Broughton, 1978; Damon & Hart, 1982; Montemayor & Eisen, 1977). Piaget (1952), a leading cognitive-developmental theorist, identifies four periods of cognitive development between childhood and adulthood: the sensorimotor period (birth to 2 years), preoperational period (2 to 6 years), concrete operational period (6 years to early adolescence) and formal operational period (adolescence through adulthood). The individual’s cognitive abilities undergo important qualitative changes during each period and Piaget views these changes as progressing from the simple sensory and motor actions of infancy towards the more concrete thinking of the preschool and schoolage years, and in adolescence, to the ability to think logically and abstractly. These cognitive changes are similar to the changes in self-concept which occur throughout childhood, as with increasing age, the child’s self-concept also becomes more abstract and less concrete (Broughton, 1978; Damon & Hart, 1982; Montemayor & Eisen, 1977).

Although much has been written about self-concept development in able-bodied children, it is not known whether the disabled child’s self-concept
also develops in a similar fashion. A review of the literature reveals the assumption that self-concept development is the same for both groups, but few, if any, studies have been done with disabled children at various developmental stages to determine their self-descriptions. It is this author’s belief that while current self-concept theories offer some common sense validity, one cannot assume that they are universally relevant. Thus, a study which explores the self-descriptions of disabled adolescents seems warranted if we are to gain insight into the development of self-concept in the disabled child as well.

Factors Which Influence Self-Concept

Theorists generally recognize that feedback from significant others and the positive and negative experiences of childhood are important influences in the development of self-concept and self-esteem (Burns, 1979; Cotton, 1983; Felker, 1974; Yura & Walsh, 1983). It is widely accepted that, in the early years, parents are the primary contributors to a child’s sense of worth and self-esteem (Burns, 1979; Felker, 1974; Samuels, 1977). The emotional reactions and attitudes of parents are conveyed to their children in the nature of their verbal and nonverbal interactions with them. Parents who communicate warmth, acceptance, praise and support to their children are likely to have children with good self-concepts and high self-esteem (Coopersmith, 1967; Rosenberg, 1979). Conversely, parents who humiliate, criticize and ridicule their children are likely to produce children with poor self-concepts and low self-esteem (Coopersmith, 1967; Rosenberg, 1979). As the child grows older, however, teachers and peers become more influential in the development of the child’s self-concept (Burns, 1979; Felker, 1974, Samuels, 1977). The
acceptance, praise and support of this expanded group of significant others becomes highly valued during adolescence. Studies in this area have, however, focused solely on able-bodied children and it is not known whether feedback from parents, peers and teachers is an important influence in the development of self-concept and self-esteem in disabled children and adolescents as well. As disabled children and adolescents may have less contact with peers and teachers than able-bodied children, it is plausible that parents of disabled children and adolescents play a more significant role in the development of their children's self-concept than do parents of able-bodied children (Darling, 1979). A study which seeks disabled adolescents' views on parental and peer relationships seems appropriate, therefore, to gain a clearer understanding of factors that are significant in the development of self-concept in the disabled adolescent.

The literature also suggests that self-concept is influenced by one's perception of where one sees oneself standing in comparison to others in the immediate environment (Cotton, 1983; Felker, 1974; Festinger, 1954; James, 1961). It is widely accepted that a comparison group is important as a basis for making estimates of one's self-worth, thereby influencing the individual's level of self-esteem. Research indicates that one's peer group is commonly used as the basis for comparison and is crucial in arriving at a clearer and more realistic picture of one's assets and liabilities (Burns, 1979; Secord & Peevers, 1974). As members of the same society as the able-bodied, it is assumed that the disabled internalize the same North American values and standards for desirable physical attributes (DeLoach & Greer, 1981; Wright, 1983). Therefore, the disabled adolescent whose physical appearance is not
congruent with the sociocultural standards or norms would appear more likely to have a poor self-concept and suffer detrimental effects to his or her self-esteem (Harvey & Greenway, 1984; Mack & Ablon, 1983; Norris, 1970). Although this is a "commonsense view", it is not supported by the vast amount of research amassed to date (Wright, 1983). One possible reason for these findings may be that disabled adolescents view other disabled adolescents, not able-bodied adolescents, as their peers and as such, utilize other disabled adolescents as their basis for comparison and for making estimates of their self-worth.

The following discussion is a summary of research studies found in the literature which relate specifically to the impact of a congenital physical disability on the child's or adolescent's self-concept and self-esteem.

**Impact of a Congenital Physical Disability on the Adolescent's Self-Concept and Self-Esteem**

The literature suggests that physical appearance is particularly important during adolescence (Birenbaum, 1979; Resnick, 1984; Skellern, 1979; Wright, 1983). The adolescent is forced to focus on his/her body because of the rapid physical changes that are taking place as a result of puberty (Skellern, 1979). The adolescent's egocentric thinking leads him/her to think that others are as preoccupied with his/her appearance and behavior as he/she is. This heightened self-consciousness causes the adolescent to be concerned about the slightest deviations from normal (Skellern, 1979). Many writers suggest that the adolescent who is obviously physically different is, therefore, at risk for a poor self-concept and low self-esteem (Green & Levitt, 1962; Harvey & Greenway, 1984; Mack & Ablon, 1983; Norris, 1970; Pond, 1977; Roessler &
Bolton, 1978; Skellern, 1979). However, research in this area has revealed contradictory findings.

Harvey and Greenway (1984) administered the Piers-Harris Children's Self-Concept Scale to 33 physically handicapped children and their siblings nearest in age. When their responses were compared with the responses of 36 non-handicapped children and their siblings, it was found that the total mean scores of the disabled children were lower than those of the able-bodied controls. The researchers concluded from their data that the presence of a congenital physical handicap is associated with an adverse effect upon the measured self-concept of the physically handicapped child and the sibling nearest in age. In general, when compared to able-bodied children of the same age and social class, the physically handicapped children had a lower sense of self-worth, greater anxiety and a less integrated view of self.

In their comparative study of 20 adolescents with spina bifida and 20 physically normal adolescents (matched for age and sex), Hayden, Davenport, and Campbell (1979) utilized the Offer Self-Image questionnaire, the Tennessee Self-Concept Scale and the Wahler Self-Description Inventory. Their data indicated that the disabled adolescents had lower self-esteem and showed poorer adjustment than the control group of able-bodied adolescents.

Similarly, in their study of adolescents with cerebral palsy, Anderson and Klarke (1982) also found that the disabled adolescents had lower self-confidence and self-esteem than the control group. In addition, the authors noted that the disabled group frequently worried about their handicaps and lack of skills, and frequently showed signs of unhappiness, depression and misery. Anderson and Klarke concluded that one-half of the
disabled adolescents in their study had satisfactory adjustment, while about one third showed marked problems. Although those adolescents with the most severe disabilities were at highest risk for maladjustment, psychological and developmental problems were not limited to those with severe limitations.

However, in her study of 19 children between the ages of 8 and 17 years with spina bifida, Macbriar (1983) found no significant difference in self-concept scores between the disabled children and their 30 siblings, as measured by the Piers-Harris Children's Self-Concept Scale. As it has been suggested by others (Harvey & Greenway, 1984) that a congenital physical handicap is associated with an adverse effect upon the self-concept of the sibling nearest in age to the disabled child, these findings may not be significant. However, Macbriar's data did indicate that children with the greater degree of disability had lower self-concept scores than children who had a lesser degree of disability, that is, who looked and acted similar to normal children.

Similarly, Molla (1981) also utilized the Piers-Harris Children's Self-Concept Scale in her study of 50 children with physical disabilities (aged 7-12 years) and found no significant difference in self-concept scores between children who do and do not have physical disabilities. As her definition of physical disability included any orthopedic condition of four or more weeks duration that required two or more hospitalizations, it is possible that the physical disability was not of long enough duration to be integrated into the child's self-concept. She did find a significant difference, however, between the two groups in their perceptions of their behavior, levels of happiness and
satisfaction, and school and intellectual status. That is, the physically disabled children considered themselves to be less happy, less positive about their intellectual and school status, and less positive about their behavior because they felt that they were unable to meet the behavioral expectations of their families and peers.

In contrast to the above findings, Coleman (1973) found that disabled children matched with able-bodied children on age, sex, race, IQ, socioeconomic status and family constellation scored significantly higher than their matched counterparts on a standardized personality test measuring self-worth. In addition, the author found that disabled children tended to show greater self-reliance and better self-concepts than the able-bodied children.

Similarly, in a comparative study, Williams (1972) found that the self-concept and self-acceptance of blind adolescents was significantly more positive than that of a matched group of sighted adolescents.

Possible reasons that may account for these inconsistent findings are: first, the studies (Harvey & Greenway, 1984; Macbriar, 1983; Molla, 1981) which utilized the Piers-Harris Children's Self-Concept Scale may have methodological problems inherent in the tool. This tool has been widely criticized by Damon and Hart (1982) and Harter (1982) who argue that the question format of the tool tends to elicit socially desirable answers and does not take the developmental transformation in self-concept during childhood and adolescence into account. Second, the conflicting results of studies which compared disabled children or adolescents to able-bodied children or adolescents (Anderson & Klarke, 1982; Coleman, 1973; Hayden, Davenport &
Campbell, 1979; Williams, 1972) may be a function of the difficulty of establishing adequate control groups. Although the groups were matched on several variables (age, sex, social class, race), the studies did not control for the parent-child relationship, peer relationships or the degree of parental acceptance of their child's disability. As the self-concept literature indicates that these factors are highly significant in the development of the individual's self-concept, they may have played a major role in influencing the findings of these studies. Third, the studies which compare physically disabled individuals to a matched sample of able-bodied individuals (a common research design) assume that any differences between the two groups are due to a "psychological deficit" while, in fact, they may represent an understandable difference in coping that results from exposure to different life circumstances (Hobbs & Perrin, 1985). It is conceivable that test responses that would ordinarily be considered "deviant", may, in fact, be normative responses for physically disabled children or adolescents who face very different life circumstances.

These studies illustrate the limitations in research based knowledge regarding the impact of a physical disability on the self-concept or self-esteem of the child or adolescent. It is clear from this discussion that self-concept scores, feelings of inferiority and negative psychological consequences are not related in any systematic way to physical disability. As Wright (1983) notes, "... the objective fact of disability is an extraordinarily poor criterion for judging which individual is unduly beset by self-depreciation and which individual is not" (p. 155). She argues that people with disabilities as a group are not distinguishable from the non-disabled with respect to inferiority
feelings and that the presumed association between inferiority feelings and a typical physique is unwarranted by the facts. A study which seeks the perspectives of disabled adolescents on their experience of growing up with a congenital physical disability may be helpful, therefore, in gaining a greater understanding of the relationship between self-concept, self-esteem and physical disability and factors which play a significant role in the development of self-concept in the disabled adolescent.

**Impact of a Congenital Physical Disability on Family Relationships**

A review of the literature reflects the prevalent view that the presence of a disabled child within a family can be an emotionally draining, demanding and stressful experience for each family member (Herskowitz & Marks, 1977; McCormick, Charney & Stemmler, 1986; McMichael, 1971; Mori, 1983; Routh, 1988; Simeonsson & McHale, 1981). Problems in individual coping and adaptation, marital adjustment and sibling relations have been documented (Dorner, 1973; Friedrich, 1977; Gath, 1972; Kolin, Scherzer, New & Garfield, 1971; Krulik, 1980; Tew, Laurence, Payne, & Rawnsley, 1977; Venters, 1981). However, studies on family adjustment and marital harmony following the birth of a disabled child reveal contradictory findings (Martin, 1975). Wallander, Varni, Babani, Banis and Wilcox (1986) found that the families of spina bifida children in their study were significantly more cohesive, expressive, organized and controlling and less conflicted than were the control families. In contrast, Dorner (1973), in a preliminary report of her study of 37 families with an adolescent with spina bifida, describes these families as suffering major disorganization of their routine, limited social lives, and
maternal depression. Similarly, Kolin, Scherzer, New and Garfield (1971) who studied the emotional and social adaptation of 13 families who had school age children with meningomyelocele also found that the majority of parents had a difficult time adapting to a life that included a disabled child. They noted that marital breakdown occurred in 46 percent of these families in contrast to 25 percent in matched control families. The authors concluded that the degree of physical impairment was not the most important factor in the level of family adjustment and that parents with a stable marital relationship of at least five years' duration were better able to cope with the crisis of the birth of a disabled child. These findings concur with those of Tew et al. (1977) who studied 56 British families with a spina bifida child and found that their divorce rate was nine times higher than that of the local population. The authors noted that marriages which followed a prenuptial conception were especially vulnerable and concluded that the strain was greatest when the relationship had not been cemented before the arrival of the disabled child. These findings are in sharp contrast to other studies, however, which give marital breakdown figures of 2 to 3 percent (Walker et al., 1971), 7 percent (Freeston, 1971) or state that marital breakdown in these families is no more prevalent than in the general population (Dorner, 1973; Martin, 1975).

Investigators have also suggested that siblings of children with physical disabilities are at risk for emotional problems (Minde, 1978; Pozanski, 1969; Simeonsson, 1981; Trevino, 1979; Tew & Laurence, 1973; Walker, Thomas, & Russell, 1971). Tew and Laurence (1973), in their study of 44 siblings of children with spina bifida (aged 2 to 15 years) and 63 siblings of matched
control healthy children, concluded that siblings of the disabled children were four times more likely to show evidence of maladjustment than siblings of the control children. Their conclusion was based on the scores obtained by the children of both groups on the Bristol Social Adjustment Guide. Similarly, in his study of 34 children with cerebral palsy, Minde (1978) reported that 14 of the 19 families who had other children claimed that the non-handicapped siblings had suffered psychologically by being deprived of attention and care. In addition, 10 families described a great deal of discord between the children. However, other well designed studies indicate that the mental health of siblings of disabled children is not necessarily impaired but may be vulnerable (Hobbs & Perrin, 1985). In their comprehensive study of families of children with cystic fibrosis, cerebral palsy, myelodysplasia and multiple handicaps, Breslau, Weitzman and Messenger (1981) found that siblings of disabled children did not manifest higher rates of psychological impairment or greater overall symptomatology when compared to control subjects. Siblings did, however, score significantly higher on two scales measuring interpersonal aggression with peers.

Possible reasons for the discrepancies in the above findings may include: first, the study by Tew and Laurence (1973) which documented that sibling maladjustment and psychological impairment may be a function of a crisis reaction rather than a long-term maladjustment. Second, the study (Breslau, Weitzman & Messenger, 1981) which showed no negative psychological impact on the siblings did not control for the influence of the sex, age spacing or birth order of the siblings and the disabled child. Recent studies have found that aggression is more common with closely spaced siblings, as
well as same sex siblings (Minnett, Vandell & Santrock, 1983). Third, studies
(Tew & Laurence, 1973; Breslau, Weitzman & Messnger, 1981) which attempt
to separate normal behavior from that which is maladjusted or disturbed, are
faced with a dilemma. As Cullinan et al. (1983) are careful to point out, the
difference between normal and maladjusted or disturbed behavior is one of
degree, not kind. That is, crying, spitting, fighting and throwing temper
tantrums are behaviors seen in all children. Only the situations in which
disturbed children perform these acts and/or the rate at which they occur set
them apart from normal children (Cullinan et al., 1983). Fourth, the findings
of studies (Kolin et al., 1971; Walker et al., 1971) which examined the impact
of a disabled child on family life may reflect many factors other than the
presence of a disabled child within the family. For example, financial
problems, number of children within the family, lack of support systems, and
poor interpersonal communication may all have played a role in the
emotional and social adaptation of families with disabled children.

Relatively few studies have explored perceptions of family relationships
and family life from the perspective of disabled children or disabled
adolescents (Thomas, 1982). Many writers have suggested that the family is
the most critical source of emotional support for the disabled young person as
the disabled are likely to be isolated from interaction with able-bodied
persons outside of their family members (Caplan & Killilea, 1976; Darling,
1979; Litman, 1974; Litman & Venters, 1979). Although it is widely accepted
that the family is an important influence in the development of self-concept
and self-esteem in the able-bodied, it is not known to what extent family
relationships influence the development of self-concept and self-esteem in
disabled children and disabled adolescents. Therefore, a study which explores
the life experience of disabled adolescents may be helpful in gaining a greater
understanding of the role of the family in the disabled adolescent's
self-perceptions.

**Impact of a Congenital Physical Disability on Peer Relationships**

The literature generally reflects the notion that the praise, acceptance and
support of the peer group is highly influential in the development of
self-concept (Fischer & Lazerson, 1984; Rosenberg, 1979; Rutter, 1979; Yawkey,
1980). Many writers have suggested that one of the most serious problems
disabled children face, especially as they grow into adolescence, is a lack of
friends (Anderson, 1979; Dorner, 1973 & 1975; Hayden, Davenport &
Campbell, 1979; McAndrew, 1979; Minde, Hackett, Killou & Silver, 1972; Strax
& Wolfson, 1984). Numerous studies have shown that children with obvious
physical disabilities are less preferred as friends than are their able-bodied
peers (Centers & Centers, 1963; Force, 1956; Friedman, 1974; Kleck & Dejong,
1983; Richardson, 1970; Richardson, Hastorf, Goodman & Dornbusch, 1961;
Richardson, Ronald & Kleck, 1974). In his study of the effects of modeling
on choosing acceptable playmates among non-disabled children, disabled
children in wheelchairs and facially disfigured children from grades 7 to 11,
Friedman (1974) found that they all modeled identically. That is, they all
chose as friends the non-disabled first, wheelchair bound next and facially
disfigured last of the 3 groups.

Kleck and Dejong (1983) also examined the role of physical disability
and physical attractiveness in social outcomes in children's small groups.
Their subjects were 61 girls and 60 boys ranging in age from 8 to 14 years who were attending a 3 week summer camp. In this group, 28 had obvious physical disabilities. The children were divided into 24 cabins and the physically handicapped children were distributed throughout the 24 groups. The subjects were each interviewed to obtain data regarding who they liked best and to judge each child in their group as either attractive or unattractive. The results of the study indicated that the children with obvious physical handicaps were less well liked than were their able-bodied small group peers. As well, the physically disabled were perceived as less attractive than their able-bodied peers, particularly for the girls.

In another study, Richardson (1970) presented 10 to 11 year old children with 6 drawings of children who were depicted with various kinds of physical disabilities in order to determine their friendship preferences. The six drawings were of a normal child, a child with crutches and a brace on one leg, an obese child, a child with a deformity around the mouth, a child with one hand missing and a child in a wheelchair with legs covered with a blanket. He found that the children consistently expressed a preference for the physically normal child. Even a mild physical handicap in the subject did not alter the rankings; the normal child was consistently chosen first and the obese child last. Richardson replicated his study many times using over 600 children in various parts of the United States and found that the rankings were consistent. In addition, Richardson, Ronald and Kleck (1974) presented the same pictures as above to 114 non-disabled children at summer camp for 2 to 3 weeks with 163 disabled children. They presented the pictures at the beginning and at the end of the camp experience and found no change in the
average ranking of the children's preferences.

In a study of 63 families with an adolescent with spina bifida, Dorner (1975) found that the non-handicapped friends of pre-adolescent spina bifida youngsters were lost during adolescence. About 50 percent of the adolescents with spina bifida in his sample were judged to be socially isolated. That is, these adolescents had not been visited at home, nor had they themselves visited or gone out with any friend of their own age, handicapped or non-handicapped, for at least one month prior to the study. Dorner concluded that the more mobile the adolescent was, the less social isolation he or she experienced.

Minde et al. (1972) also found in their study that 22 of the 31 (70%) disabled children over the age of 8 years had no constant non-disabled friends during the summer and only 4 had contact with normal peers during the winter months. Although each child was said to be fully accepted by his or her peer group when they began attending the special school, within 2 years their previously tolerant non-disabled friends at home had grown up and now wanted little or nothing to do with them. Similarly, in a follow-up study of 34 adolescents with cerebral palsy, Minde (1978) found that 64 percent of the adolescents had few meaningful relationships with non-handicapped people and instead lived exclusively through their equally handicapped friends. Of the 36 percent of disabled adolescents who did have regular contact with non-handicapped friends, most commonly the friendships were with individuals 1 or 2 years older and generally consisted of conversations and some common outings.
In an intensive study of 20 adolescents with spina bifida, Hayden, Davenport and Campbell (1979) also found that overall the disabled adolescents had far fewer friends than the control group. Although adolescents in both groups stated that they make friends easily, the disabled adolescents participated in fewer team sports, group and extracurricular activities. The disabled teenage girls also expressed a great deal of concern about social isolation and loneliness. Adolescent boys in the study, however, were more concerned about sexuality and mastery of the environment.

In contrast, Wright's (1983) analysis of seven autobiographies of persons with disabilities (Baker, 1946; Brown, 1955; Carlson, 1941; Criddle, 1953; Goldman, 1947; Ohnstad, 1942; Viscardi, 1952) revealed that in only one of the seven personal accounts did the adolescent lack group companionship. Each of the others reported a great deal of interaction at work and at play with other young people. Wright (1983) noted, however, that these accounts revealed a "... deep and sometimes overwhelming loneliness ... not because of lack of friends but because they could not share in the attachments of boy-girl relationships" (p. 253). These findings concur with those of Nigro (1976) who found that adolescents and adults with myelomeningocele frequently lack the kind of meaningful personal relationships which might go on to become sexual. Similarly, Dorner (1977) reported that only 7 of the 63 adolescents (11%) with spina bifida in his study were going out on dates while 80 percent were definitely interested in doing so. The major reason they gave for not dating at this time was a lack of peer contacts.

The discrepancies between the findings of the above studies (Kleck & Dejong, 1983; Richardson, 1970; Richardson et al., 1974) and the few existing
personal accounts of disabled individuals regarding their peer relationships may be due to several factors. Firstly, it is possible the findings of the studies by Kleck and Dejong (1983) and Richardson et al. (1974) reflect able-bodied children's initial reactions and attitudes towards disabled children and that a 2 to 3 week camp experience was not long enough to overcome internalized negative societal attitudes towards the disabled. Secondly, the studies which have shown that children with obvious physical disabilities are less preferred as friends than are their able-bodied peers (Kleck & Dejong, 1983; Richardson, 1970; Richardson et al, 1974) assume that it is the disabled child's disability itself which accounts for the lack of relationships with able-bodied peers. It is equally possible, however, that disabled children may be less preferred as friends by able-bodied children because of the limited time and opportunities for social interaction between the two groups. That is, disabled children often attend special schools or special classes within the regular school system, may require intermittent hospitalizations and time consuming physical treatments, and are unable to participate in many extracurricular activities due to their physical limitations and architectural barriers in the community. Thirdly, the above studies (Kleck & Dejong, 1983; Richardson, 1970; Richardson et al., 1974) all explore the friendship preferences of able-bodied children. It is hardly surprising that, when given a choice, able-bodied children prefer other able-bodied children as friends. However, little is known about the friendship patterns of disabled adolescents as relatively few studies have explored the life experience of physically disabled teenagers (Dorner, 1973 & 1975; Freeman, 1970; Lorber & Schloss, 1973). Therefore, it is not known who disabled adolescents view as members
of their peer group. A study which explores disabled teenager’s perceptions of their peer relationships seems warranted if we wish to gain an understanding of this perspective and perhaps gain further insight into the role peers play in the development of self-concept and self-esteem of disabled adolescents.

**Summary**

This chapter has presented a review of the literature which pertains to the adolescent’s experience of growing up with a congenital physical disability which confines him/her to a wheelchair. This literature review has revealed limitations in the available research regarding the development of self-concept and self-esteem in disabled children and adolescents and the impact of a congenital physical disability on the adolescent’s self-concept, self-esteem, family life and peer relationships. It is clear from this discussion that there is much that we do not know about the adolescent’s experience of growing up with a congenital physical disability which confines him/her to a wheelchair. This writer believes that if nurses fail to understand the experience of disabled adolescents, they will have no sound basis upon which to predict problems, provide support, or assist in the prevention of future difficulties. While the available theories offer some common sense validity, one cannot assume that they are universally relevant.

This study has been designed to explore and describe the perspectives of adolescents with congenital physical disabilities that confine them to wheelchairs. The phenomenological paradigm of qualitative research, as briefly discussed in Chapter 1, has been selected as the most suitable methodology for this exploration. The manner in which this method was
applied to the research questions in this study will be described in the following chapter.
CHAPTER 3:

METHODOLOGY

Introduction

The methodology for this study is qualitative and is based on phenomenological theory. The following chapter briefly describes this methodology and the manner in which it was interpreted and implemented for this study.

Qualitative Research

Qualitative approaches in science are distinct modes of inquiry oriented toward understanding the unique nature of human thoughts, beliefs, behaviors and intentions (Benoliel, 1984; Bernheimer, 1986). The phenomenological paradigm of qualitative research seeks to describe human experience as it is lived (Oiler, 1982) and assumes that "there is value to an analysis of both the inner experience and outer behavior of a subject as viewed by both the researcher and the participants" (Rist, 1979, p. 19).

Research Role

Qualitative research requires a research role which is significantly different from that required by quantitative methodologies. The primary role of the phenomenologist is to reveal the meaning of an event, that is, to understand the experiences of the participants (Knaack, 1984). In contrast to quantitative methods which require an independence of the researcher, the phenomenological approach recognizes, identifies and even exploits the researcher's involvement in the situation in which she is studying (Oiler, 1982). In phenomenology, the researcher engages in cooperative dialogue with the "subject-informant" and the essential ingredient in this approach lies
in developing a trusting relationship between the researcher and participants (Knaack, 1984). A basic assumption is that both the researcher and the informant are changed as a result of the research process.

**Research Process**

In the qualitative approach, data collection methods and analysis techniques are also significantly different from those employed in quantitative research. As the purpose of qualitative research is to understand the phenomena under investigation, it is apparent that subjects who are able to provide information about such phenomena may not be evenly distributed throughout the population (Field & Morse, 1985). Therefore, samples in qualitative research are often not "representative" in the quantitative sense (Sandelowski, 1986, p. 32) and instead, the researcher is guided by the principle of opportunistic sampling to acquire subjects, called informants, from the population according to the quality of their relationship with the researcher and their ability to articulate and to provide explanations for the researcher (Field & Morse, 1985). Informants are viewed as competent to provide the knowledge and understanding that is sought by the researcher largely because of their participation in the experience under investigation for sufficient time to become "enculturated". The task of the qualitative researcher is to establish the position of all informants in relation to the group they represent and the meaning of their "slices of life" (Sandelowski, 1986). The researcher must, therefore, constantly verify information obtained from "key informants" with "secondary informants" to ensure the validity of her research findings (Field & Morse, 1985; Sandelowski, 1986).
The major method of data collection in qualitative research is interviewing (Field & Morse, 1985). The fundamental aim of qualitative interviewing is to provide a framework within which respondents can express their own understandings in their own terms (Lofland, 1971). There are essentially two types of interviews which are compatible with this methodology: the focused interview and the unstructured interview (Bernheimer, 1986). In the focused interview, certain types of information are sought from all subjects but the wording and sequencing of questions is flexible. That is, questions are phrased in language familiar to the subject and questions are sequenced according to the subject’s willingness to discuss a particular topic. In contrast, the unstructured interview is based on the spontaneous generation of questions that occurs in the natural flow of conversation. The interviewer aims to elicit from the subject what he or she feels to be important questions relevant to the topic, thereby discovering what kind of things are happening. Interviews are usually tape recorded and transcribed so that the researcher can review the different participants’ accounts of their experience. In addition, the researcher keeps fieldnotes to record pertinent observations, thoughts or experiences which occur in the course of collecting data.

Unlike quantitative research, there is no clearcut line between data collection, processing and analysis in qualitative work. These processes occur simultaneously and there tends to be a continual blurring and intertwining of all three operations from the beginning of the investigation until near its end (Diers, 1979). Transcribed interviews and fieldnotes provide the data base to which the researcher applies the analytic process. It is through data analysis
that the researcher elucidates the essence of the phenomenon under investigation and arrives at an understanding of the meaning of the experience for the informant. To accomplish this, the researcher reviews each transcript in order to identify and code the major thrust and meanings of the various paragraphs and passages throughout the interview (Field & Morse, 1985). As the researcher collects more data through repeated in-depth interviews, relationships among the data emerge. The researcher then formulates tentative propositions about these relationships and hypotheses are generated (Wilson, 1977). The usual notions of reliability and validity are inapplicable to qualitative methodology. Rather, the criteria by which the research may be judged are the richness of the data and the credibility of the concepts and theories developed from them (Diers, 1979). A qualitative study is credible when it provides such accurate descriptions or explanations of a human experience that people having the experience would immediately recognize it as their own (Sandelowski, 1986, p. 30).

**Implementation of the Methodology for this Study**

**Selection of Participants**

Opportunistic sampling directed the researcher to select informants from the population who were willing to talk and who had special knowledge of the phenomena under investigation (Field & Morse, 1985; Sandelowski, 1986). As spina bifida is the second most common chronic congenital physical disability affecting the pediatric population after cerebral palsy (Berbrayer, 1987), adolescents with this type of disability were the population from which the sample for this study was originally recruited. By adolescence, 70 to 100 percent of individuals with this neural tube defect are wheelchair dependent,
although some teenagers may continue to have limited household ambulation with the use of braces and crutches (Berbrayer, 1987).

**Criteria for Selection**

The initial criteria used in selecting individuals for participation in this study included the following:

1) an individual between the ages of 12 - 19 years with a congenital physical disability that is not terminal in nature and which requires the use of a wheelchair for mobility;

2) a minimum of 5 years in a wheelchair;

3) the ability to communicate in English;

4) geographical proximity to the Greater Vancouver area.

However, due to difficulty in recruiting individuals for this study, after several months the age criterion was revised as follows:

5) an individual between the ages of 12 - 23 years.

**Selection Procedure**

Individuals for this study were recruited from a variety of sources in the Greater Vancouver area. Initially, however, a list of potential participants was provided by the nurse clinician in the outpatient spina bifida clinic at a local pediatric hospital. This list was reviewed in consultation with the researcher to establish the compatibility of clients with the research criteria and then the Information Letter/Consent Form was mailed to 23 adolescents and their parents (see Appendix A). Upon receiving the form, if the adolescent was interested in participating, his/her parents signed the form and returned it to the spina bifida clinic in the envelope provided. When the form was received, the researcher made telephone contact with the parents to discuss
the study further and answer any questions that they or the adolescent had. Following this, if parents still agreed to their adolescent's participation, an appointment was made for the initial home interview. Parent/s and adolescents who agreed to participate signed the consent form at the beginning of the initial interview.

Copies of the Information Letter/Consent Form were also given to the nurse clinician in the spina bifida clinic so that contact might be made with appropriate individuals and their parents during scheduled clinic appointments. Upon reading the information letter, if the adolescent and parent/s expressed interest in the study, they signed the form indicating their willingness to be contacted by the researcher by telephone. During subsequent telephone contact with parents, the researcher discussed the study in further detail and answered questions. Parents who agreed to their adolescent's participation then made an appointment for the initial home interview.

However, both of these approaches resulted in only 3 adolescent participants for the study. One letter was received from a parent who declined to have her son participate because he was currently "seeing a doctor about his feelings with being in a wheelchair, as well as his feelings about his parents' recent divorce." No replies were received to the other 19 letters.

After 6 months of unsuccessful attempts to recruit participants through the spina bifida clinic, the researcher approached another pediatric facility in the Greater Vancouver area. The research study and criteria for participant selection were reviewed with a physician in the agency and then he was provided with 30 copies of the Information Letter/Consent Form for
distribution to suitable adolescents. Over the next 2 months, the Information Letter/Consent Forms were given to a total of 18 adolescents and although several adolescents expressed interest in the study, none agreed to participate. Most declined explaining that they were "far too busy" and "couldn't possibly fit it in."

Fifty leaflets advertising the study were also distributed at the Vancouver "Wheel-a-thon," Fall 1988. Although there was no way of ascertaining whether the leaflets were given to adolescents with congenital or acquired physical disabilities, this recruitment method did not result in any further participants for the study. In addition, a total of 5 advertisements were placed in the newsletters of the Spina Bifida Association of B.C. and the Cerebral Palsy Association between May and November 1988, requesting participants for this study. This method was also unsuccessful in acquiring any further research participants.

With hopes of recruiting additional informants, the age range for participation in the study was extended to 23 years of age in January 1989. Posters advertising the study were displayed at 2 local community colleges known to have students with physical disabilities and the researcher met with a college counsellor responsible for students with special needs to solicit her help in recruiting participants. Within a few days, 4 individuals expressed their willingness to participate in the study by leaving their name and telephone number on the researcher's answering machine. During the researcher's subsequent telephone contact with these individuals, the research study was explained and questions were answered. Although all 4 individuals agreed to participate, one individual did not meet the criteria for
selection and therefore she was informed that she would be unable to participate. At the request of the other 3 individuals, the interviews were conducted at the community college rather than in their homes. As well, a consent form was signed by only one of these participants as the others were unable to write due to their physical disability. Instead, during the initial interview, these 2 individuals gave verbal consent to participate in the study. No further participants were acquired for the study from either college during the remaining six week period that the posters were displayed.

**Characteristics of Participants**

A total of 6 individuals participated in the study — 3 males and 3 females. All of the participants were Caucasian, English speaking and resided in or near Vancouver. All participants required a wheelchair for mobility and had been wheelchair dependent since early childhood.

Of the 6 participants, 3 had spina bifida (myelomeningo-cele form) and 3 had cerebral palsy (rigid/spastic type). The participants with spina bifida ranged in age from 12 to 15 years and lived at home with both parents and one sibling. The participants with cerebral palsy were 22 to 23 years of age and 2 of these participants lived in group homes while 1 participant lived at home with his parents and 2 older siblings. One young adult participant with cerebral palsy was employed while the other two were part-time students.

**Ethical Considerations**

Prior approval for this study was obtained from the University of British Columbia’s Screening Committee for Research Involving Human Subjects. In addition, approval for the study was also obtained from B.C. Children’s
Hospital Research Review Committee. The rights of participants were protected in the following ways:

1. No interviews occurred without the written consent of parents of adolescent participants and without verbal or written consent of the participants themselves.

2. A description of the study and an explanation of the researcher's expectations of participants was given to all participants and to the parents of all adolescent participants.

3. All participants were advised that participation in the study was voluntary and non-participation in the study would in no way affect the treatment or care they received.

4. Prior to interviews, participants were reminded that their right not to participate, by leaving the interview or remaining silent, would be unconditionally respected.

5. All participants were informed that taped material would be kept confidential, that tapes would be erased upon completion of the study and that written transcripts or reports of the study would not use any names or other identifying features.

6. Participants were informed that participation involved no apparent risks. Potential benefits to participants were limited to those inherent in contributing to nursing knowledge and to sharing their experiences with another human being.

Data Collection

The data were collected in a series of intensive semi-structured interview sessions in the homes of 3 participants and in a private office at a local...
community college for the other 3 participants. A set of sample questions was used for the purpose of providing a loose structure for the initial round of interviews (see Appendix B).

The data were constructed through a series of 13 interviews with a total of 6 participants. Each participant was interviewed twice, although one individual was seen three times. This occurred because the participant became so emotional during the first few moments of the initial interview that she asked to stop the interview and voluntarily rescheduled it for the following week. The interviews took place over a period of 11 months and ranged from 30 minutes to 2 hours in length. Due to a malfunction of the tape recorder during one 2 hour interview, only 15 hours of dialogue was recorded on audio tape. Detailed fieldnotes were made immediately following this unrecorded interview.

Although individuals spoke freely in the presence of the tape recorder, one participant requested that the researcher stop and erase parts of the tape at frequent intervals throughout both of the researcher's interviews with her. In this situation, portions of the tape that dealt with her family history and her current living situation were erased in her presence. At the end of the second interview, this individual also requested that the audio tape of the first interview be replayed in part, just to ensure that no personal family details had inadvertently been left on the tape.

The verbatim transcriptions of the audio tapes of each interview session made up the bulk of the data base for this study. However, field notes made after some interviews and telephone calls to participants also contributed to the data for this study.
Data Analysis

The participants' accounts were analyzed using the analytic process developed by Giorgi (1975). Giorgi specifies five essential steps to the data analysis process:

1. The researcher reads the entire description straight through to get a sense of the whole ...

2. The researcher reads the same description more slowly and delineates each time that a transition in meaning is perceived with respect to the intention of discovering the meaning of ... [the phenomenon under investigation]. After this procedure one obtains a series of meaning units or constituents.

3. The researcher then eliminates redundancies, but otherwise keeps all units. He then clarifies or elaborates the meaning of the constituents by relating them to each other and to the sense of the whole ...

4. The researcher reflects on given constituents, still expressed essentially in the concrete language of the subject, and transforms the meaning of each unit from the everyday naive language of the subject into the language of ... science ...

5. The researcher then synthesizes and integrates the insights achieved into a consistent description of the structure of ... [the phenomenon] (pp. 74-75).

Therefore, following the transcription of each interview tape, the researcher read through the transcript and identified "meaning units" within the account. As analysis proceeded, these meaning units were compared and contrasted within and across transcripts and, from this analysis, conceptual categories or
themes were identified. These themes were then compared with those from the accounts of other participants to identify common themes and variations. In subsequent interviews, these themes were validated and clarified by the participants. Thus, the themes were continually refined as the researcher gained an even deeper understanding of the lived experience as described by the participants.

Although data collection and data analysis are discussed here separately, these processes occurred simultaneously throughout this study. The emerging themes identified from the data analysis became content for subsequent interviews. Once all interviews were complete, the researcher continued her data analysis until the themes were synthesized into an organizing framework that described the participants' experience of growing up with a congenital physical disability and explained the effect this had on their self-concept development.

Summary

The methodology for this study was qualitative and based on phenomenological theory. Informants were selected by virtue of their participation in the experience under investigation for sufficient time to become "encultured". A total of 6 individuals with congenital physical disabilities, ranging in age from 12 to 23 years, participated in 13 interviews over an 11 month period.

The data were comprised of transcribed audio tapes and field notes from these interviews. Data analysis took place concurrently with data collection as the researcher reviewed and analyzed each transcript for recurrent themes. Conceptual categories were developed as interrelationships between the data
were identified and these categories shaped the final framework used to describe and explain the common experience of the participants in the study. The participants' accounts of their experience of growing up with a congenital physical disability and the effect this has on self-concept development will be presented in Chapter 4.
CHAPTER 4:
THE PARTICIPANTS' ACCOUNTS

Introduction

This chapter will present the accounts given by the six participants of their experience of growing up with a congenital physical disability that confines them to a wheelchair. Although each participant’s account of his/her experience is unique in its details, common themes representing the shared aspects of their experience were readily discernible within the various accounts. The following discussion uses these themes as an organizing framework for presenting the participants’ accounts. It is the contention of the writer that exploration of each of these themes and how they relate will facilitate an understanding of the participants’ experience of growing up with a congenital physical disability. Throughout this discussion, verbatim excerpts from the participants’ accounts will be used to illustrate the findings of the study. This not only provides a rich and vivid illustration of the researcher’s interpretation of the experience but also enables the reader to "audit" the description of the experience with the original data from which it was derived (Sandelowski, 1986).

During the interview process, participants constructed accounts of their experience of growing up with a congenital physical disability. Their accounts revealed three major components to this experience and these were: family life, peer relationships and leisure-time activities. The overwhelming feature of their accounts was, however, that there were two radically different perspectives on what it is like to grow up with a congenital physical disability. In this researcher’s interpretation of the data, these two different
perspectives appear related to the participants' perceptions of themselves as either "able" or "disabled". The first part of this chapter will present these two groups' different perspectives on their life experience and the last section of this chapter will discuss participants' general perceptions of themselves. Differences between the "able" and "disabled" groups' self-perceptions will be addressed in some detail to clearly illustrate the dramatic differences between these two groups.

**General Perceptions**

The accounts of the participants revealed that there were two different perspectives on what it is like to grow up with a congenital physical disability. These two different perspectives appear related to participants' perceptions of themselves as either "able" or "disabled". Four participants in this study had an image of themselves as "able" and viewed living with a congenital physical disability in a positive way. These participants saw themselves as having much to offer in spite of their physical disability. They had an awareness that although they had a physical disability that impaired their mobility, there was potential for growth and life ahead. These participants focused on things that they could do rather than things they could not and saw life as a challenge not a threat.

P: Well, I've kind of adapted everything so it doesn't stop me from doing anything, being in a wheelchair (uh huh). Because as soon as some -- like I said before, as soon as somebody says to me "Oh, it looks like you won't be able to do this", I go, "Hah, do you want to see me do it?" (laughing). And then I always find a way ... So it doesn't make any difference to me because I always look at people, well -- and I just think, well, they're doing that. Well, I can do it too. All I got to do is work that little bit harder.

---

P = participant
R = researcher
P: ... So actually, I think being a little different now is -- actually right now, I think I have a definite advantage over most people.

R: In what way?

P: Well, some can't swim. I can swim like a fish. Some can't even do two lengths. I can do about 64 in an hour ...

P: And because I've been to all these doctors and stuff like that, who really, you know, don't know very much. They think they do but they don't really know that much. Like I know myself better than anybody (uh huh). So even though they say, "Oh well, you're going to be like this forever and you're never going to do this, you're never going to do that". Well, I just tell them, "To heck with that. I'm going to do it. I'm going to prove you're wrong!"

P: ... I would spend lots of times in the hospital in oxygen tents and I got through a lot of surgery to extend muscles and decrease the spasticity, so all the way through I've been, you know, faced with these challenges.

P: Yeah and say, "Look, I'm going to make the best of this bloody situation and there's going to be a lot of people on the way who are going to make it hard but I'm going to rise above it and really push.

One older participant in the "able" group expressed the belief that he was, in fact, a "better person" as a result of his disability.

P: ... everybody thinks of a disability in a negative way for some strange reason. But, I mean, I take it as an asset to me because it has built up my character 100 percent to what it would've been if I would've been walking around ... And I would've been, you know, just one of those jerks stalking around ... in my jeans and teeshirt, if it hadn't been for me when I had to pull everything together and get my courage and my challenge, and it really made me a 100 percent person.

In contrast, two of the older participants with cerebral palsy had a view of themselves as "disabled". That is, their disability and the things they could not do were first and foremost in their minds. To them, life was difficult, a never ending struggle against obstacles that were often overwhelming. These
participants saw the future as bleak and felt vulnerable or "at the mercy" of forces outside themselves.

P: ... I've struggled. I've struggled to this point and I'm convinced I'll struggle right til death's door. I struggled to get into this world and I'll struggle out the door.

P: I'm missing a lot of things right now but I don't know what to do. My hands are sort of tied ...

P: ... so it's hard because I really hate, you know -- I dream about the days that maybe I'll be able to walk how I used to ... It's a fantasy but it keeps me going cause some days it's just like too much. No matter what I do, it seems upsetting. Some weeks, some months ...

P: ... It's hard. Let me tell you it makes me cry everyday to see a normal person walking around. Not being able to do it on my own (yeah) and it's very touchy for me to be in a wheelchair looking at a person who can walk.

P: ... I like bedtime. I go to bed and go to sleep. It's the only comfortable safe place I can go ... Forget the world!! Cause it's too big, it's too painful, it's too --

R: Too hard?

P: Yeah. It's awful ...

Thus, participants had an internal image of themselves as either "able" or "disabled". Four participants in this study viewed themselves as "able" and focused on their abilities rather than their disability. They perceived life as a challenge with obstacles that they could readily overcome. However, two of the older participants with cerebral palsy who lived in group homes viewed themselves as "disabled" and could barely see themselves beyond their disability. To them, their personal limitations were in the forefront and life was viewed as a never ending struggle against overwhelming obstacles.

The following section will now present the dramatically different
perspectives of the "able" and "disabled" groups on their experience of growing up with a congenital physical disability. The purpose of this section is to illustrate these two different perspectives in the language of the participants themselves.

**Describing the Experience**

**Perceptions of Family Life**

In their accounts, participants revealed two different perspectives on their experience of their family life. The four participants who perceived themselves as "able" described their family life as harmonious and perceived their family relationships to be loving and supportive.

P: Well, luckily for me, I've always had my parents 100 percent behind me -- so they've been a real supporting factor...

P: If it wasn't for my family, I wouldn't be here, where I am now (uh huh). I give lots of credit to my mom, my dad and a lot of friends...

R: ... sort of like hassles with your parents or (yeah) stuff like that?

P: Yeah, which are very few and far between.

R: Is that right? ... So you get along fairly well with your folks then?

P: Yeah.

R: What was it like when you were a teenager? Did you get along with them well then?

P: I always did.

R: Why do you think that is?

P: Well, because my dad and I have a lot of the same hobbies, right (uh huh). So we kind of do it together all the time.

The accounts of these four participants also revealed other similarities in their perceptions of their family life. Firstly, they all perceived their families...
to be managing or coping well with their disability.

P: Well, because they (parents) you know, went through a lot of stages where they were feeling guilty and stuff like that.

R: About you being disabled?

P: About me being disabled and about what I've been having to go through and, you know, the rest of my life is ahead of me, but with my positive attitude and their positive attitude, together we kind of blocked that all out.

R: How did you know they were feeling guilty? Did they tell you about that?

P: No, it's just — you know, you can feel it. It's not something that we had to state. It was like there for both of us but we knew that we couldn't let that get in the way. We knew we had to rise above it.

R: How do you think your parent's have coped with your disability?

P: I think, I think they're doing just fine. I know that they get really, really stressed out when I go in for my operations and stuff, and it really seems to bother them because they get really upset. And I mean, that's what parents are for, right? (laughing)

R: So they worry about you?

P: Yeah.

The participants in the "able" group also perceived communication patterns in their family to be open. That is, it was their perception that in their family, problems and concerns were openly discussed and members of the family felt comfortable discussing the participant's disability.

P: But we've always had a good line of communication so that we could always talk about everything that came up ... You know, we've always been 100 percent honest. We could talk about anything that comes up (uh huh) so if anything's bugging us we just have it out in the open and don't let it build up.

P: ... I got told everything that was going on with me cause my mom is so open (uh huh) that she doesn't hide anything from me.
R: ... So who would you talk to if you had problems? ... What about at home? Would you talk to --

P: My parents, my brother. I can talk to both of them. ... I used to think that -- well, no one -- but now I've got my counsellor at school, the vice principal, my mom and dad, my brother ...

Another similarity in the accounts of the participants who perceived themselves as "able" was that they all felt that their families were encouraging and fostered their independence.

R: And your parents weren't overprotective with you?

P: No. They just kind of shoved me out and said, "Do it. I know you can."

R: It sounds like your mom really encouraged you, like teaching you how to dress and be as independent as possible.

P: She's still doing it.

P: And so my dad was looking after me and he just said, "Here are your clothes. Get dressed." And I said, "What? You want me to do this all by myself?" He said, "Yeah, you get dressed yourself. Don't come out until you're all dressed." And, you know, of course for the first time I was shocked (uh huh) and I wasn't sure what to do, but, I mean, the first time it took me four hours to get dressed (uh huh) and then ever since then they just tried to throw me to the wolves because they know I can adapt and do whatever needs to be done ...

Lastly, the accounts of the "able" participants revealed that their families frequently spent time together doing things as a family. That is, they went on family vacations or outings and their parents were commonly involved in or attended their games, races and other activities.

P: ... Actually, my dad and I used to go to hockey games together. Actually, we still do ...

R: ... So it's kind of a special time with your dad then? Just you and your dad go?

P: Yup. We go to Wendy's (restaurant) or something ... go to the game. Have nachos, chocolate bars, malts and get fat! And watch
the game.

P: ... Whatever they (parents) did, I always did with them. So I never got left and there was always a way adapted so that I could do it.

R: Were your mom and dad there (at the race) watching you?
P: Yup. My dad was there with the video camera taking it all.

P: End of June, I'm going to Hawaii. Went to Jamaica, Oregon, California -- twice.

R: With your family?
P: Yup.

However, the two participants who perceived themselves as "disabled" gave very different accounts of their family life. The accounts of both these participants revealed that they were institutionalized at the ages of six and nine years respectively, when their families were no longer able to cope with their care at home. One participant perceived that it was parental alcoholism that ultimately resulted in his placement in an institution. He described his life at home prior to this as stressful, chaotic and frequently abusive.

P: Well, my mom and my dad, I love them dearly ... but my mom couldn't handle my disability. She went wild. She got drunk. The money that was to go for the food went for the drinking ... One time I was dragged across the living room floor cause she went on a rage and told me to shut up and stop crying.

P: Every time I turned around there was something awful at home. Get one thing solved and my mom would do another dirty trick. She banged her head on the bus once and came in and shook me and told me to shut up. You know, I cried all the way to school and I cried for five hours straight. And they threatened to take me to (name) hospital but eventually I stopped. I think I almost, in my books, had a nervous breakdown at 10 years old.
This participant's account revealed that an unsatisfactory family life has continued until the present day.

P: You know, everytime I go home for weekends it's awful.

R: So it didn't end just cause you went into (names institution)? 'Cause you were still going home for weekends.

P: Yeah ... And (now) she'll have me home once a month. And we sit there and watch TV and read (laughs).

R: So it's not very satisfying for you?

P: No. So when she says I don't want you home, I go, "okay - alright mom."

In contrast, the other participant who perceived herself as "disabled" described the early years with her family as loving and supportive. However, when this participant's mother died, and her father was no longer able to provide care at home, this participant was placed in an institution.

P: ... So she took me in her arms and took me home and started working with me until I began to move (uh huh) and she took care of me until the day she died ... And she taught me how to talk, how to use my hands (uh huh), how to do certain things ... And I never got given up on (uh huh) from my parents. ... My mom spent 24 hours out of bed and in bed looking after me.

R: Uh huh. So her whole life was devoted solely --

P: Towards me.

P: ... I used to live in my parent's house to begin with ... and then my mom died ... and then I had to be shoved into the hospital after that because my dad couldn't handle it any longer (uh huh) and I figured that wasn't fair because I knew the rest of my family would be out ...

R: It must have been awful for you when you were little, to be moved from your family to a hospital. I mean, it must have broken your heart.

P: It did ... I ended up crying everyday ...

There were also other similarities in the perceptions of family life of the
two participants who perceived themselves as "disabled". Firstly, in their accounts, both participants revealed that communication in their family was impaired. Family members did not discuss their disability with them nor did they discuss their problems and concerns.

R: Did they (parents) ever talk to you about your disability?

P: No. No.

R: Would that have been a helpful thing to do, if they sat down with you and said -- you know --

P: Yeah, a lot of things would have been helpful but they just couldn't.

R: What kinds of things, looking back, would have been helpful for them to --

P: Honest communication. Um, they hid a lot of things underneath the rug.

P: ... and she (mother) decided she wasn't going to tell me ... She wrote on a kleenex (to aunt) "Should we tell her?" And I could see that they were writing "Should we tell her?" And my aunt went "Yeah, you should" ... And you see, my mom didn't tell me anything ...

A third similarity between the "disabled" participants' accounts of their family life was the minimal involvement of family members in their present day to day life.

R: Do you have a relationship with your sister?

P: If you can call, um, phoning her once every six months a relationship. Yeah.

R: So you're not close in any way?

P: No.

R: Do you still see your parents?

P: Yes, I do.
R: How often do you see them then? Do you spend time with them or talk to them or --

P: I talk to them almost every two weeks ...

R: So have you got any other brothers and sisters then?

P: Yes. I just don't see them.

Therefore, participants revealed two very different perspectives on their experience of family life. The four participants who perceived themselves as "able" described their family life as harmonious, loving and supportive. These participants perceived that members of their family were able to communicate well with each other and enjoyed participating in family outings and activities. As well, the "able" participants perceived their families to be encouraging and felt that their families fostered their independence. In contrast, the accounts of the two "disabled" participants revealed a dramatically different perception of their family life. Both members of this group described their families as unable to cope with their disability which resulted in their institutionalization during their elementary school years. One participant attributed his family's inability to cope with his disability to his mother's alcoholism while the other participant described her mother's death as the cause of her institutionalization. In addition, both participants described communication in their families as poor and have minimal contact with their families in their present everyday life.

Perceptions of Peer Relationships

Participants in this study also had two different perspectives on their relationships with peers. Overall, the accounts of the four participants who perceived themselves as "able" revealed that they were generally satisfied with their peer relationships. Although none of the participants described
themselves as having a "best" friend, all appeared to be part of a larger group or circle of friends, either at school or in the community.

R: Who would you say is your best friend at school? Have you got a best friend?

P: No, not really.

R: No one person that you chum around with particularly?

P: No.

P: ... unless they're my really good friends ...

R: So you've got some really good friends --

P: Yeah.

R: -- that are you're own age?

P: Uh huh.

R: And are your really good friends, are they in wheelchairs or, you know, able-bodied?

P: Mixed ...

R: ... what kinds of things do you do with your friends?

P: We go out to movies and stuff like that. Go out for dinner every once in a while. Go out and have a beer. Whatever. Go out to the ball games. You name it, we do it.

R: So do you get along fairly well with the kids in your class?

P: Uh huh. A fair amount. There's one or two that I hate (laughing). Only in Math though ...

R: Do you have any special friends?

P: Yeah. You could say that.

R: Girls or boys?

P: Girls!!! ... One of my friends just lives down there. ... And there's two that live up the street ... And then there's the boys ... Actually I go up and talk to them every once in awhile. Sometimes I hang around with them and stuff. And in grade 7 I did sometimes too
but I haven't really seen much of them cause we really don't have much time to get together except at lunch and even then you don't have much time either so ...

These participants also revealed their interest in relationships with members of the opposite sex and all expressed their desire to one day get married and have children.

R: ... So you'd like to get married and have kids?
P: Yeah, someday.

R: ... Have you got a girlfriend or are you just cruising?
P: Just cruising right now. Actually, I have a few "friends". Oh, girls. They always call me. Drives me crazy!! Drives me bananas!! They're younger than I am, you see.

R: Uh huh, yeah. So they've got a crush on you?
P: Something like that, yeah.

P: But I'm willing to take one step at a time. It's (marriage) going to happen when it's going to happen. You can't really think about it. It's just one of those things that -- well, it will happen when the time is right.

R: Yeah. Would you like to have kids at some point?
P: Uh huh. Cause I really love kids.

However, in spite of their overall satisfaction with their peer relationships, these participants did experience some difficulties at school. All participants attended regular classes in the public school system (or in the case of the older participant in this group, had attended a regular class before high school graduation) and usually, were the only one in the school in a wheelchair. As a result, they were highly conspicuous among the other students and reported being the frequent target of teasing and ridicule.

P: ... I think next year will be better for me cause I'll be more comfortable if I'm around kids that are the same as me cause there'll be a couple of other kids coming up to the school in
wheelchairs.

R: Yeah, it must be hard being the only one in the school.

P: It is!!

R: Then it makes you sort of the --

P: Outsider.

R: Did you hang out with the other kids at lunch hour and that?

P: Umm - a little bit but most of all, I'd, you know, just go and do my homework or go talk to some of the students that were in the higher grades.

R: Did you seem to get along better with the older kids than ...?

P: Yeah, yeah. Than the younger kids ... And then I'd spend a lot of time too talking to the staff that were there. ... So anyway, that was really good because then I got to know all the teachers. So the teachers were more my friends than the students.... So I would spend time talking to the teachers and they would ask me how things were going and they would always help me....

R: Did you go to the same elementary school the whole time or did you switch schools?

P: No, I stayed in the same school from kindergarten to grade 7.

R: So you were with pretty well the same group of kids that whole period of time?

P: Yup. I was with the same brats. The same big shots.

R: You had some kids in your class that gave you a hard time?

P: Most of them.

R: Most of them? It doesn't sound like elementary school was a great place to be?

P: Not at all. High school is a bit better because they're more mature. They know how to handle things better. Most of them anyway.

P: ... Also I was the only kid in a wheelchair in the school. So I was different too.
R: What was that like being the only kid in a wheelchair?

P: I didn't find it that great ... I was glad to get out of there.

R: How come?

P: Well, there were all these little kids, little bratty kids. They thought they were all cool, right (uh huh) and so they're acting tough ...

R: Did they give you a hard time cause you were in a wheelchair?

P: Oh yah! I didn't go through one day without getting rude comments, a couple of stupid questions.

R: It must be hard.

P: It was! Especially when I didn't know what to do back then....

However, these participants did not appear particularly distressed by their peers' teasing and ridicule. Instead, in their accounts they revealed various strategies they used to cope with teasing and being "bugged".

P: So all of a sudden I was just kind of thrown out there, and I was the only guy in the school, right, in the whole school --

R: That was in a wheelchair?

P: -- that was in a wheelchair or disabled, and they hadn't seen anybody before, right? And like it was hard for me to accept the students, too, because they were always bugging me all the time which is normal.

R: What were they doing that was kind of --

P: Oh, teasing me and stuff like that, and that used to really bug me until I, you know, realized, well, it's them, it's not me. So that was difficult. ... So up to high school I hated school. I had to be dragged to school in the morning.

P: Although you tend to outgrow stuff like that. You learn to ignore stuff (teasing and ridicule) like that. Like a guy being in a wheelchair is like a "nerd" in school.

R: Is like a "nerd"?

P: Yah ... Like wears dark rimmed glasses and a bandaid on their nose.
R: You think they see you as a nerd if you’re in a wheelchair?

P: Well, they sort of think people are like that. It is pretty horrible. Now I hardly ever get bugged cause I’m with the older kids. They’ve seen more handicapped kids and stuff like that. So you don’t get as many rude comments and stuff like that.

R: What about elementary school, did you hang out with the kids when you went to regular school or, you know, what were your friends like?

P: Again, it was more the teachers than the students.

R: And why was that, do you think?

P: Ummm -- I’m not exactly sure but I know that once I realized that it was, you know, they didn’t exactly like the idea of having a disabled person in the school.

R: The other students didn’t?

P: The other students didn’t like it. And I thought, well, that’s fine because it’s their loss, right. So then, I’ll just move up to the teachers.

P: ... If it’s some jerky comment, I just go (makes a face). That guy’s also disabled, right? In the brain department. So I just kind of laugh it off and for me, a major part of it has been humor that has got me through.

P: ... Well, I just turn on them with some smart remark, right? So they don’t know what happened. They’re just kind of taken aback ... I must admit that’s one of my good qualities. Cause when somebody thinks they hung me out to dry and it’s just hilarious, right, I turn it around within less than 2 seconds -- bang! -- they’re hung out to dry and I’m sitting there, so.

The "able" participants also described the curiosity, pity and romantic notions of their able-bodied peers as barriers to relationships between the disabled and able-bodied.

R: Do you get a lot of dumb questions and --

P: Oh yeah! "Why are you in a public school and not a segregated school?" ... "How do you go to the bathroom?" "How do you get dressed?"
R: So people are real curious about all the ways you manage your life?

P: I'd say they're not curious. I'd say -- well, they are curious but I'd say they're rude too (uh huh). I mean, you don't go up to a guy and ask him how you go to the bathroom!!

P: ... I think being in hospital maybe you make more friends. Cause they (able-bodied peers at school) felt sorry for me. They were kind of interested in what it was like.

P: Everyone wants to go in (the wheelchair)! They say "Oh, it's so fun!" and I'm going, "Yah, right! How would you like to be in it for the rest of your life?" "Oh well, maybe I'd just like to be in it for a day or something 'bout."

P: Oh, just some of the kids in my class find it hard to believe that I've been in the wheelchair ever since I was just a kid, right, and I could never really walk. So they just say, "You know it must be horrible being in a wheelchair all your life", right. And other kids from a different point of view say, "You know, you're lucky being in a wheelchair. You don't have to walk around all the time."

In contrast, the two participants who perceived themselves as "disabled" had a different perspective on their peer relationships. Their accounts revealed that they were generally dissatisfied with their relationships with others and in fact, had no close friends or confidants. Both participants described feeling lonely and socially isolated. Although both participants had attended segregated schools for the disabled during their school years, where one might assume that it would be easier for them to make friends, both described feeling lonely and socially isolated at that time as well.

R: So did you have, when you were going to school, did you have friends at school or any relationships with any of the kids there?

P: Not really. I spent a lot of time trying to do school work or trying to sort out home stuff.

P: ... Which is really scary because if something ever happened today
and I needed a support person, I don’t know if I could find anybody.

R: So you feel really alone and on your own?

P: ... Yeah. So I guess we all have had supportive people around when they’re -- but the big question is are they still around? And they’re not really.

P: And -- it’s hard cause I want them to come over but I don’t want to be the instigator. I don’t want to be the only one saying "Well, won’t you come over?" I want them to say "Are you free tonight and want to do something?" So questioning who my friends are is another big one. It’s a hard one. I’ve gone through that alone too before when things were really bad at home. I had everybody’s phone number in my book and I knew who my friends were when my dad died. You certainly find out really fast in a situation like that ... I’ve gone through 3 phone books and now I’ve come to the fact that I’m going to write everybody in pencil and if I don’t hear from them in a year, they’re coming out of my book.

R: So you’ve had a lot of people disappoint you?

P: Disappear, disappoint. Yeah.

Although both of these participants expressed interest in having relationships with others, including members of the opposite sex, they had difficulty initiating and maintaining such relationships.

P: ... And they (able-bodied friends) were so "gung ho" at first. They want you to come over to their house and they want to take you out in the summertime and they want to do all this stuff and I get all built up, thinking "wow", we can do something, I’ve got another friend I can do more things with and then, "Bang! Bang!" ...

R: So they’re friends with you for awhile and then they just sort of turn around and walk out of your life?

P: Yeah. That’s it exactly ... And I can’t believe that everytime that that happens that it’s them. It’s happened too many times for me to believe that thing. And then when we try to talk they go, "Oh no, it wasn’t you." Oh yeah? Well then, why aren’t you phoning me if it wasn’t me? ... Well, I’ve never walked out ... And if you have that too many times in your life, you start questioning everything ... You start questioning why did that person react that way? Why when she walked in the room did she look mad already before she even looked at me ... And when that happens 30, 40, 60 times in one day, you just go "uggh"...
... And my good friend and I are not talking to each other right now which is really hard.

R: Is this a woman friend or a man friend?

P: A man friend ... He needed some time to sort his life out but in the meantime I'm sitting there waiting for his call. Well, not waiting. I quit waiting but I mean, you know, when I'm going through a tough time, I thought I could phone him and say "Come and take me out. Tell me who I am." Cause I don't know who I am.

R: Who would you say, or have you had a significant person in your life?

P: Well, there's been a few. But again they've sort of drifted out and in and out and some of them I've never seen again. Like when my mom and I were having real problems, my friend -- my friend was there and was really supportive. Their family was supportive but today I don't see them or talk to them ... In fact, I tried to track them down the other day to see if we could get together. If I could find them but --

R: So they moved and stuff?

P: Yeah.

These two participants seemed to have only minimal insight, however, into the reasons they had such difficulty with peer relationships. In their accounts, both participants revealed that they were just so wrapped up in themselves and their pain that they had nothing to give to others. They talked endlessly about themselves and their disability and it appeared that their peers soon tired of this.

P: ... Cause I'm one of these people who like to talk about disabilities, learning, um, anything -- but if all they're going to talk about is the weather -- and I've got enough of that crap hanging around in my head without making -- people say, "Oh, you don't laugh enough". Well look, have you thought that maybe I'm not the kind of person who laughs? There are people around who have a very difficult time doing that. Laughing life away, it's not for me ... Accept me for where I'm at or not at all ... I always get accused of being too self-centered. Always!
R: ... Why do you think they say that?

P: Cause it's true probably. But if they gave me some other things, their life or what they like to do or whatever, the table would turn a little bit. Maybe over time, gradually.

R: What do they mean when they say self-centered?

P: Well, I talk about me a lot ... Especially when I was a little kid ... But I had to have somewhere to put all this hurt and upset and crying -- just somebody.

P: My friend was very supportive but he asked me not to wait for his call. I've waited three weeks now and I don't know if I'm going to wait three weeks, six months or three years ... He said wait for me to call you ... He tells me that it's not me and I can honestly think I can trust him but still, I can't even phone to say hello.

Therefore, the accounts of the participants in this study revealed two different experiences of their peer relationships. The "able" participants described their involvement with a large group of both able-bodied and disabled peers at school and in the community and generally felt satisfied with their peer relationships. Although these participants experienced teasing and ridicule from some of their able-bodied peers at school, they did not appear overly distressed by this and had developed strategies for dealing with it. These strategies included: ignoring it, humor and sarcasm. In addition, all participants in this group expressed interest in members of the opposite sex and hoped to one day marry and raise a family. However, the participants in the "disabled" group gave quite a different account of their peer relationships. They both expressed considerable dissatisfaction with their relationships and in fact, currently had no close friends or confidants. Their accounts revealed that they were socially isolated and had difficulty initiating and maintaining their relationships with others. Both participants appeared to have only minimal insight, however, into the reasons for their difficulty.
Perceptions of Leisure-Time Activities

In their accounts, participants also revealed dramatic differences in their involvement in leisure-time activities. The participants who perceived themselves as "able" were involved in a great number and variety of activities or hobbies. These included passive activities such as watching television, reading, and talking on the telephone, and more active recreational pursuits such as fishing, hunting, gardening and camping. Although some of these activities were pursued with peers, more commonly, these participants engaged in these activities with other family members.

P: ... my brother, he's involved in some sports. I like them right and um ... My brother, he's involved in baseball (uh huh). I go to his baseball games -- watch his baseball games and um, he's been in soccer. I watch that too with him ...

R: So what other things have you been doing for kicks? Swimming, you said?

P: Um, babysitting ... And I'm going to be singing in a (relative's) wedding coming up.

R: So what kind of things have you been doing since you got home from summer camp?

P: Um, playing with my computer.

R: Seeing many friends or anything? Any people over?

P: Not really. No. I phoned my friend ... I phoned her a couple of times (uh huh). Uh huh. So I don't know. I think I'm keeping myself busy. Watching TV ...
P: Well, right now I've got two Apples (computers) at home and an IBM (oh) that my dad and I both have. It's really a good hobby.

R: So you spend time doing computer stuff together?

P: Uh huh. Yeah, it's fun.

R: ... So does your family do much stuff together other than travelling?

P: Yup. We play games every weekend. Or we try to. We go picnic -- we have barbecues out the back with our next door neighbours ... 

R: Like what other things do you do after school and --

P: ... Mostly, I don't know. Watch TV, um, one of my favorite things. One of my good things.

R: Watching TV?

P: Yeah ...

However, these participants were also involved in many leisure-time activities that involved members of their peer group. These activities included disability related activities such as wheelchair sports, summer camp for disabled teens, groups for disabled riders and groups for disabled teens. Although these activities served to separate participants from their able-bodied peers, they did bring them together with their disabled peers.

The accounts revealed the particularly important role of wheelchair sports in the lives of the "able" participants. All four participants were currently involved in some form of wheelchair sports at school or with other agencies.

P: ... When I was a kid of nine I used to treat it (being in a wheelchair) pretty bad. It used to be quite hard but now I'm used to it. Now with all the sports ... Yeah, cause I've heard about all these -- when I was 12 or 11 -- I heard about all these sports that I could try and "Yay !!" "Great!!" I'll try it so -- so it made a big difference.

R: So it made a big difference getting involved in wheelchair sports?
P: Yeah, it made a big difference!!

P: ... before I really did that I was just a lazy slob and decided I better do something about it ... and then a coach saw me and he said, "What's your name? I want you on my team now!" So I got that and I just slowly built my way up so now I've been to New York, Belgium, Texas to compete, so -- ... right now I'm the best in B.C. in my class (uh huh) in my events and I hold three Canadian records.

The older participant who perceived himself as "able" described why he thought wheelchair sports were so important for disabled people.

P: I think they (wheelchair sports) are really important (why?). Well, because they get us together (uh uh) and they give us an avenue to take out our frustrations and just get rid of that anxiety ...

R: What anxiety?

P: Well, you know, like everybody has it, like with work and stuff like that, and most people can go out and kick a ball if they get, you know, fed up or whatever else, but I like to go and do my sports ...

In their accounts, the "able" participants revealed that wheelchair sports also provided them with positive role models. The "able" participants strongly identified with other wheelchair athletes, such as Rick Hansen, and as a result, seemed inspired with hope for their own future.

P: Well, my track coach makes me work fairly hard. She's been born -- she's born in a wheelchair too so she's been doing track a lot longer than I have ... She has the same problem that I do. She's got spina bifida like I do and all that. She's coping. She drives a car and everything -- a nice Camaro!!

P: ... I've been in front of -- I've been on TV in front of like 20 million fans so -- I was part of Rick Hansen's homecoming ...

R: Who would you say is the most significant or inspirational person in your life?

P: (Names coach). She's my trainer. But she's training now herself for the Seoul Wheelchair Olympics so I don't see her right now ...
She was the best in Canada ...

P: And Paul Clarke (wheelchair athlete) was there ... He was one of the top world wheelchair athletes. Hansen, Andre Bignet. They had a couple of unique athletes there to help us. So they're pretty inspirational to us. They sort of show us the way. Set you in the right direction.

R: ... Who would you say is the most significant person in your life?

P: Like who is most inspirational? (Yeah). Rick Hansen is pretty inspirational.

R: Who would you say is the most significant person in your life?

P: Rick Hansen. I raised money for his tour and I gave him a lucky penny which he took all around the world with him. It was taped on the sun visor in the motor home so he could look at it everyday. He called me from Australia when he was down there. I had to stay up really late because of the time difference ...

Thus, for the "able" participants it seemed that there was a positive psychological benefit of seeing other individuals in wheelchairs succeeding and even excelling in their personal endeavors. Clearly, Rick Hansen and other wheelchair athletes had achieved "hero" status in the eyes of these participants and were viewed with admiration and respect.

The "able" participants' accounts also revealed that some of their leisure-time activities with peers were unrelated to their disability. These activities included such things as playing computer games, going to movies, swimming and just "hanging out" and brought them together with their able-bodied peers.

P: I go up there (video arcade) and play video games. I used to anyway but now I have a computer ... I have games underneath there. I play games ...

R: ... Do you ever have friends come over and play games and stuff with you?
P: Sometimes. My next door neighbour comes over once in a while with games. She brings some discs over and we play.

R: So you share games?

P: Yeah. We play around.

R: Is she about your age?

P: No she's about (5 years younger).

R: So what kind of things do you do?

P: ... Go out with some of my friends -- some of the girls around my street (uh huh). Um, there's a girl I know down here (points) that I phone sometimes to come down so -- ask her if she wants to come down.

R: What kind of things do you do when she comes over?

P: Oh, everything. Um, sometimes we sit and be bored ... sometimes we go there (store) just around the corner ... It's that candy store ... we buy stuff and come home and eat (laughter).

However, participants who perceived themselves as "disabled" described involvement in very few activities or hobbies. Largely this seemed to be caused by a lack of people to do things with, the lack of adequate wheelchair transportation and the extra effort required by others to lift and transfer participants from their wheelchairs to the car and back again.

P: It bothers me on occasion. It depends on how much I want to go. Like Tuesday night, if I don't get a bus -- well, I'm an honorary member for this meeting but I figure if I can't get there, I can't get there.

R: So transportation is really a problem for you then?

P: Oh yeah ... So I end up saying, "No, I'm not doing it." Or I end up phoning people and saying I don't want to be on the committee 'cause I can never be there.

R: So do you do any things now for recreation? Go to movies or --

P: Oh, I go to the odd movie ...
R: And you said you went swimming. Is that a recreational thing?

P: Yeah and a therapeutic thing...

P: But people don't like to take me to the movies either cause they say, "Well, I have to lift you" and they don't like lifting. They don't offer very much.

Therefore, the activities the "disabled" participants were involved in were generally those that could be done alone and at home. These activities included watching television, listening to music, reading and playing with their computer. Thus, these activities served to increase the social isolation and loneliness of these participants.

In summary, "able" participants were involved in a wide variety of leisure-time activities. Broadly speaking, these activities were either home-based and involved members of their own family or community-based and involved members of their peer group. Some examples of home-based activities in which they participated include watching television, gardening and playing computer games, whereas some examples of community-based leisure activities include wheelchair sports, swimming and going to movies. The accounts of the "able" participants revealed the particularly important role of wheelchair sports in their lives. Wheelchair sports seemed important for a number of reasons. Firstly, they provided the "able" participants with positive role models, such as Rick Hansen and other wheelchair athletes, with whom they could strongly identify. Secondly, they provided numerous opportunities to get together with peers who were also in wheelchairs. Lastly, wheelchair sports provided the "able" participants with an activity in which they could participate and compete with others. In contrast, "disabled" participants were
involved in very few leisure-time activities outside the home. The activities in which they did participate were generally those that could be done alone and at home, such as reading, watching television and listening to music. Thus, the leisure-time activities of the "disabled" participants served to increase their social isolation and loneliness while the leisure-time activities of the "able" participants provided opportunities for socializing with peers and increased their interaction with mainstream society.

Thus, participants in this study had two different perspectives on their experience of growing up with a congenital physical disability that confined them to a wheelchair. Although the participants' accounts revealed three common components to the experience, their perspectives on their family life, peer relationships and leisure-time activities were radically different. These two perspectives appear related to participants' perceptions of themselves as either "able" or "disabled".

The final section of this chapter will address the factors that distinguish the participants who perceive themselves as "able" from those who perceive themselves as "disabled". The differences in participants' perceptions of themselves will be discussed under the following headings: perceptions of body and physical competence, social competence, cognitive competence and feelings of self-worth and self-respect.

**Perceptions of Self**

In their accounts, participants also revealed two different viewpoints or perspectives on their physical characteristics, capabilities and self-worth. Overall, those participants who viewed themselves as "able" regarded themselves in a positive way while those participants who viewed themselves
as "disabled" generally regarded themselves in a negative way. The following
discussion will describe these differences in self-perceptions in greater detail.

a) **Perceptions of Body and Physical Competence**

All participants in this study clearly had a mental image of their body
and its capabilities and limitations. However, participants who viewed
themselves as "able" tended to minimize their disability and focused on their
physical abilities rather than their physical limitations.

P: Basically, it's like everything else. The fact that I'm different
physically doesn't effect me too much. I can talk. I used to walk
with crutches and braces. I can swim. I can do all the things they
can and probably even more (uh huh). The fact of being in a
wheelchair means I move different than they do ...

P: And to me it (wheelchair) doesn't make any difference. It's just an
extension of my body. Like if I need it to go through a door, I'll
open the door, prop the door against my chair and then push
through, right? And it's just an extension of my body so it doesn't
mean anything to me ...

P: Like in my legs, I'm a little spastic and also in my left hand side,
my hand like is a little bit goofy sometimes. But other than that,
like I have leg braces that I walk on ...

P: ... in 1984, I had to go in for a shunt operation -- because they said
I had this cyst that was growing and it needed to be taken off ... so
that was no big deal. I didn't really think anything of it.... I have a
headache everyday. It just depends on how severe it is.

R: Oh, that must be troublesome?

P: Huh, it's no big deal. You just learn to work through it.

P: Well, I've had people ask me, "Why do you have legs if you don't
use them?" ... You know, I mean, it's part of me!! ... I can stand up
in a standing frame so if I didn't have legs I wouldn't be able to
stand up ... That's not as dumb as other questions like, "Why do
you wear shoes? Why not just socks and slippers?" I say, "Well, I
wear shoes in case my wheelchair breaks down!" (laughing).
These participants also perceived themselves to be physically competent in spite of their physical disability and described their physical accomplishments with a great deal of pride.

P: The amazing thing is that I can swim faster than my dad for a short while. I can out swim him in endurance. I can do 42 lengths in an hour. So I can swim a lot further than my dad, but then, he's a lot older than me. He's about twice my age ... I can do a length without breathing. I don't speed or anything. I just swim at a regular pace -- I don't want to boast.

P: ... When I was coming home from school today I had -- there was this woman behind me pushing a stroller ... My brother and his friend were in front. They were fooling around and I had to stop cause I was so tired. I was going pretty fast up the hill and my arms were getting pretty sore and I was resting them. So she comes and asks me, "Are those clowns capable of pushing you?" I go, "Yeah." Well, she says, "Why don't they?" "I don't need a push. I can handle it." As if she didn't know!! She saw me going up that hill. I was going up just fine!!

P: And I won five gold medals in the swim meet ... Yeah, I guess you could say I'm a real athlete ... Not really strong, I've just built up endurance and speed.

P: I passed this one guy. He was in a racing chair and I wasn't ... I passed him. He's a lot better than I am. He's been working a lot harder than I have but I passed him and finished before he did ...

R: That must have made you feel good?

P: It did!! It was the first time ever that I've beat him ...

P: I do field events -- shotput, discus and javelin. And I've represented -- right now, I'm the best in B.C. in my class -- in my events I hold three Canadian records.

Clearly, participation in wheelchair sports and other physical activities provided these participants with opportunities to interact with their peers, to compete and be successful, thus promoting the development of feelings of physical competence, self-worth and self-respect.
The accounts of the three adolescent participants in the "able" group did reveal, however, that they did have some concerns about their appearance. In spite of their physical disability, most of their concerns were similar to the concerns of able-bodied adolescents. That is, they were more concerned about their hair, height, clothes and the presence of pimples than their physical disability per se.

P: I'm youngest, unfortunately (unfortunately?) ... and smallest ... Yeah, but if I didn't have this -- my rods done -- I'd be 2 inches shorter. I'd be 4 foot 7. Now I'm 4 foot 9 ... I'm taller than a few kids in our school.... I guess all through life people the same age as me will always be taller than me. So I'll have a wife that is taller than me. My kids will be taller than me ... I think it would be neat to be about 6 feet or five 10.  

R: That's what you'd like to be?  

P: I don't think I'll grow much more. I think I'll only grow to reach 5 feet. The doctor says he thinks I can reach 5 feet ...  

R: ... and how they think it is important to look good to the other kids. Do you have any thoughts or ideas about that?  

P: I used to. Well actually, I still do sometimes. Now I just try to be myself. I don’t really care. Except for my pimples. I hate them!!! I do! They're all over. I can feel them ... All over here and here. On my face and all over my chin and everything. Just all over!!  

R: So do you worry about things like how your hair looks and all that?  

P: Yes, I do. Yah, I do kind of worry about that and going to school I wish I had all the clothes that (name) and (name) have. They're so in!! I wish I had looks like them. They've got no pimples for goodness sake ...  

P: My feet are so small. I only wear a size 12!! My brother's feet are bigger than mine and he is only eight!! My feet are really funny too. The toes are really wierd cause they are sort of bumpy.
The youngest participant in the "able" group was particularly concerned about the appearance of the scar on her back from the repair of her meningomyelocele shortly after her birth.

P: I'm -- you know another thing -- when you're looking for a bathing suit, now that's frustrating. Like I had an operation on my back and it's sort of gross, right?

R: You've got some scars on your back?

P: Very bad, yeah. A guy comes up to me and says, "you've got a road map of Canada on your back. With mountains!", he says. He was just being funny ... They all have low backs now.

R: Yeah, that's right. So you've been trying to find one that's got a higher --

P: High back.

R: Uh huh. In one piece too?

P: Yeah. Because otherwise a whole part of my back would be showing!

P: Oh yes. Um -- my, the um, like my back -- my skin on my back isn't very good so --

R: What do you mean, not very good?

P: I got a really bad scar from an operation on my back ... when I was first born.

R: So that -- the skin is a bit sensitive or something?

P: No, it's not very thick. It's thin ... what happened is that after that, awhile after that, my skin rotted (oh) so they had to um, give me a skin graft ...  

Participants in the "able" group were well aware of their physical limitations, however, and talked freely about them during the interview. One physical limitation that was frequently discussed by all "able" participants in this study was their inability to walk "normally". Although all four participants in this group could walk with leg braces and crutches, they made
a distinction between the way that they walked and walking "normally".

P: ... I don't really walk, I sorta jump ... I'm just getting back into my walking again ...

R: So could you walk when you were younger?

P: No. I used braces and a walker.

Nonetheless, their accounts revealed that walking with braces and crutches was very important to these participants for a variety of reasons.

R: Can you still walk in braces now?

P: I really don't know. My doctor said I shouldn't cause if I fell or something, I might break my rod. And I go, "Oh, that's a very comforting thought now that I want to get back to walk, you know." Cause I want to one day walk down the aisle. Instead of wheel down the aisle. There's a difference -- a very big difference!!

R: What would be better about walking down the aisle than wheeling?

P: Standing next to your husband instead of sitting down and then him having to bend down to kiss you ... In fact, I don't want to look up to the minister like I have to do to my teachers. Especially when they come really close. Then I really got to look up ... 

P: Well, the only reason I walk is for my own exercise and because I want everything to hang properly, like so I don't get all scrunched over and everything. And I really enjoy it because it gets me upright and it gets me breathing properly ... All my doctors at (names hospital) and that, say "why are you still walking?", right? (uh huh). And I said to them, "well, if I can walk, why shouldn't I walk? Give me one good reason. If it's one of the things I can do, why should I stop doing it?"

R: ... Why do you walk?

P: Cause it feels good. It feels good to get up standing.

Two "able" participants described how walking and standing also gave them a different perspective on the world and made them less "visible" to others. From their point of view, it was important to be as inconspicuously
different from their peers as possible.

P: Well, because they -- the people -- like if you're walking, the people don't really seem to notice you. You kind of fit in with the crowd, right? (uh huh) But if you're in a wheelchair, people are always kind of -- you're the odd one out that doesn't quite -- doesn't quite fit, so ... Like they say, "Oh, it's that guy in the wheelchair," and everybody knows who they're talking about.

P: Well, just cause when I'm standing, I'm like everybody else (uh huh). Standing up I'm four foot nine, when I stand, and I look down on some kids.

R: So you have a different perspective on the world?

P: Yeah, cause when I'm in a big crowd, like when I was at Expo, there was a big crowd going out. Or I used to go to the hockey games at Christmas time. After the game, there's all these people. It's like a big traffic jam and all I'm ever looking at is rear ends!!

Although the "able" participants viewed walking as important and desirable, there were several reasons why they did not walk very much.

R: Do you walk with you leg braces much?

P: I usually try and walk for about maybe an hour every week, when I can -- because I'm so busy that, you know, I've got different things going on ... Just because it's the time factor, that's all. And using them, I don't have the time ... It's quicker to be in my chair.

P: Yeah, I can walk with braces but not too far. Say from here to there but if I were to fall, I'd look ridiculous.

R: So short distances you can manage?

P: Yeah. Say if I was to walk from my seat to my chair everybody would say "wow". But if I had to walk from my seat out to the baggage claim (at the airport), I'd need time to rest. I can't handle a lot of distance.

P: I've noticed that I -- I can only maybe go 15 minutes. My arms get tired, so. I used to go all day practically. Just little breaks in between and --

R: So you're a little bit out of shape for walking?

P: Well, sort of. But I haven't walked for two years or three years, is
what it is ... You can notice a lot that you get a lot tired -- real
easy. And one day I went over to answer the phone and --
(walking?) Yeah. And I tried to pick up the phone. I said, now if
I do this am I going to fall over? I used to go pick it up, put it
down, right? Fine, easy. So I had to -- I was holding onto the
counter really good (uh huh). Some things really freak me out still.

Therefore, although walking was highly valued by these "able"
participants, the physical effort and time it involved realistically limited its
usefulness as a viable mode of transportation.

In contrast, participants in this study who viewed themselves as
"disabled" had a different perspective on their physical characteristics and
capabilities. That is, in their accounts, both of these participants focused on
the details of their disability, physical limitations and health problems and
there was a noticeable absence of data regarding their appearance, abilities
and accomplishments.

P: ... I had to go into the hospital to get my knee opened up because
my knee froze into that bent position and then my hip broke ... My
hip was sticking out like an inch, like that ... And then finally, I
had to go in for an operation before my move (uh huh) to this new
house of mine and they had to strengthen my muscles in between
my legs (uh huh) in order for me to have my knees bent out again
so I could get up on my feet again.

P: ... I’ve got a thing called scoliosis now -- where I can’t -- I can still
do something about it but I find it hard because, for one thing, I
can’t breathe that well anymore because I’ve been in a wheelchair
for so long and I can’t -- where I’m trying to exercise my lungs to
get them to open up better (uh huh) and all around it’s better for
life ... And another thing is, I’m legally blind --

P: I’m now back in braces because of those -- because of (names
hospital) and I will never be able to get the bones and the -- I’ll be
able to get the courage back but I’ll never be able to get my
muscles strong enough (uh huh) to be able to move my legs
without my braces anymore.

P: ... and then I had to fight with my wheelchair cause I was so angry
at it, because I couldn’t go on many field trips. I couldn’t do this,
couldn't do that. I couldn't transfer so I needed a special bus ...

These two participants also revealed the importance of walking to them. However, their reasons for walking seemed related to all the things they saw themselves as able to do "if only" they could walk. Their accounts revealed their sadness and regrets at not being able to walk like a "normal" person.

P: ... the doctor said I couldn't walk (uh huh). The doctor said when I was born -- I got hassled from the beginning - the doctor said I wouldn't be able to do a thing ... I used to be able to walk two blocks until they threw me in the hospital.

R: How far can you walk now?

P: To the living room and back and then my feet start to hurt.

R: Is it important to you to walk?

P: Yes. Otherwise there's no point in even -- there is some point in trying with people that couldn't do it before, but I find if you try and do it at a later stage, it's too late.

R: Why do you think it's important to walk? ...

P: Because it will stop them having bedsores. It will stop them from being embarrassed. It'll stop them from being stuck in hospital. It'll help them to go to the bathroom better (uh huh). It'll help lots of things. Like their muscles from atrophying (uh huh), their feet from getting smaller ... and all around it's better for life.

R: So there's some definite physical reasons for walking. What about the psychological reasons for walking?

P: They won't get so frustrated. They will be able to transfer on the buses. They won't need -- they will need some supervision but they won't need as much ...

P: ... Let me tell you, it makes me cry to see a normal person walking around. Not being able to do it on my own. And it's very touchy for me to be in a wheelchair looking at a person who can walk ... And I wish that nothing went wrong (at birth) but something did and I have to face that road ahead of me ...

R: You think about walking? ...

P: ... I can walk. And I believe that if I had had the proper physio
way back when, maybe things would be different. And I do believe in "healing" so. That's a different side to that question maybe than you've heard.

R: Right. So "healing" in terms of like God healing?

P: Yeah. Something I used to believe in very strongly but at the moment, like I said, my faith is sort of down ...

P: .... I dream about the days that maybe I'll be able to walk how I used to -- well, I still do -- the days I could walk, or want to walk. It's a fantasy but it keeps me going ...

Thus, "able" and "disabled" participants had different perspectives on their physical characteristics and competencies. In their accounts, participants who viewed themselves as "able" minimized their disability and focused on their physical abilities rather than their physical limitations. These participants regarded themselves as physically competent in spite of their physical disability and were proud of their physical accomplishments in wheelchair sports and in walking with braces. In contrast, the "disabled" participants in this study focused on their disability and health problems and saw themselves primarily in terms of all the things they could not do. They seemed filled with sadness and regrets that they could not walk like "normal" people and their accounts revealed an absence of data regarding their abilities and accomplishments.

b) Perceptions of Social Competence

In their accounts, participants in this study also revealed two different perceptions of their social competence. The four "able" participants generally perceived themselves to be friendly and well liked and felt that they made friends easily.

P: I'm an outgoing guy. Like it'll only take me five minutes to meet anybody and be their, you know, be a really good friend.
R: So you're not shy or --

P: No, not at all.

R: So would you describe yourself as popular or not popular, or well liked or disliked, or whatever at school?

P: In between. Yes, middle class. Um, middle class. Well, like I'm popular for like being in the "news" and all that junk. Then there's all these people who say hi to me and stuff like that, and I'm going I wonder who that was ...

P: Yeah, I used to be always talking. Constantly talking and people told me to shut up.

R: You were constantly talking?

P: Yeah, I used to be that way.

R: You were a real chatterbox?

P: My grandmother used to say that. I used to talk about anything -- to anyone. School -- anything.

R: You're not as much of a chatterbox anymore?

P: Not really. I talk a lot to some people ... I don't want to overdo it. People get bored. So I don't talk as much.

R: Have you got a best friend at school?

P: I don't really know. I've got lots of friends at school ... I, ah, I'm friends with mostly all the girls in my class. I'm friends with all the girls in my class.

P: I talk a lot too. You should hear me on the phone sometimes ... I was talking to one of my friends a couple, I guess, a couple of months ago and I thought we were only talking for 5 minutes. My mom says "Are you ever going to get off that phone?" and I says, "What do you mean? I've only been on for 5 minutes." "No, you've not. It's been 20 minutes."

R: So you spend a fair bit of time on the phone talking to your girlfriends?

P: Once in a while. When I phone them or they phone me.
In contrast, the "disabled" participants did not perceive themselves to be socially competent.

P: ... I've always had difficult times with people.

R: How were the teachers and your fellow students? How did you get along with them?

P: I got along with them until -- well, I never did really get along with them. I had to fight. I kind of used my wheelchair as a weapon 'cause I was so angry at them ...

As discussed earlier, both participants described themselves as having great difficulty in initiating and maintaining relationships with others. In addition, their accounts revealed a real lack of awareness of their role and responsibilities in maintaining a friendship. Instead, they seemed to expect others to make all kinds of special allowances for them and few demands because of their physical disability.

R: So you've had lots of people disappoint you?

P: Disappear, disappoint, yeah. And I don't know if it's just because of me. People tell me it's not me but it certainly looks like me when everybody sort of disappears like that.

R: It must feel that way.

P: Yeah, you go, what have I done now? Why have they walked out of my room? Or why have they walked out the door? What have I done? (uh huh). Tell me so I can correct it. That's what makes me so mad. I get into these bad habits and people correct me for a while and then they go she ought to know better than that ... That's what makes me so mad. 'Cause, just 'cause I do something and they walk out the door. I'm sitting there going "Why, why? What have I done?"

P: Sometimes I get really angry here (at school) and I start swearing ... And they (other students and teachers) understand so I -- they don't know what the problem is but they recognize that I am frustrated or angry so they overlook it. They let me do it and I come back to my work, usually.
P: ... or if you’re really upset and you’re just in your own world, it doesn’t matter who -- your best friend could be there and you’d be spaced out ... The most important thing, I think, when that happens is just to know that they are there. And you can look at them and say -- what I normally say a thousand times is "I love you." Basically because I want to hear it back a thousand times. Cause I’m really unsure of myself ... And there’s not a whole lot of people to talk to.

Thus, the "able" participants perceived themselves to be socially competent. They described themselves as well-liked and able to make friends easily whereas the "disabled" participants described themselves as having difficulty in initiating and maintaining relationships with others. The participants in the "disabled" group seemed to lack a real awareness of the part they played in a relationship and seemed to expect others to make special allowances for them because of their disability.

c) Perceptions of Cognitive Competence

In their accounts, participants also revealed two different perceptions of their cognitive competence. Although all participants described varying degrees of difficulty with learning, the "able" participants perceived themselves to be "quite smart" and were pleased with their progress at school.

P: ... and ever since then, from Grade 3 on, I’ve been flying. And then I got a computer in Grade 4 and then I found out that I wasn’t stupid, I just had trouble with dyslexia -- a little bit of reading and writing (uh huh) and ever since then I’ve been flying, so -- because I’ve gone all the way through high school and wrote all the government exams --

R: ... And academically, how did you do in relation to the other students?

P: A’s, B’s, C’s so --

R: Do you do well at school?

P: Uggh, um --

R: Is it hard? Do you have to struggle hard? Study hard?
P: Oh, it's one of the things I'm not good at -- studying ... Math is one of my hard ones (uh huh). Um, spelling is easy for me. Art -- I just have to learn how to turn in assignments. I get started on one and um ... Social studies -- so so. I dropped my last one two grades but first time I got a "B". So actually, that was one of my best. Best ones for social studies. A "B" ... In spelling, I dropped from an "A" to a "B". But actually a "B" is not that bad ...

P: Back then, it took me forever to get through six questions.
R: Mmmm. So is school hard for you?
P: Not really.

P: Actually what happened was, when I first went into the school, they set up this handicapped program called (name) and there were other disabled people that came in at the same time I did (oh yeah) but because I was a real pusher, right, they weren't going to do it otherwise, but I just -- And then they figured well, I'm going to need this class, right? But then I proved them wrong and I was in there for like a year and then I went in the mainstream with a little bit of help from the aide. So that made me feel really good too -- when I started out in this (special) class and I could just kind of walk away from it and -- into the regular mainstream.

Some of the "able" participants' difficulties at school appeared related to their physical limitations while others seemed related to their intermittent absences from school as a result of repeated hospitalizations and surgery.

P: ... I'm no different than they (able-bodied peers) are. I'm just slower at writing and it takes a little bit longer to get it through -- the message through. And it takes a bit longer to write it down cause I have strength problems but that's about it. Otherwise, I'm just like the next guy.

R: So talking is not a problem for you but writing is?
P: No -- yeah, but writing is. I'm really, really slow at writing and it's quite messy too. Like I can read it but for anybody else it's --

R: Did you ever have to lie around and recuperate at home for periods of time after surgery?
P: I was supposed to but I never bothered ... I can recuperate at school. Otherwise I get too far behind and I get all sick cause I'm worried about getting so far behind and then I got to get all caught up again and it's just not worth it.

R: What do you think about all the operations that you have to have and stuff? Do you think it interrupts --

P: Yeah!!

R: -- going to school and --

P: Yeah, it does actually. I think that's one of the reasons why I didn't do well in school.

R: The time away from being in school?

P: Yeah. And then you probably get to spend about 2 weeks away from school. I don't really spend that much time in the hospital. I mean, after um, when I had my back surgery, I was out of there in 5 days but I still had to like stay home and do nothing.

However, the accounts of the "disabled" participants revealed a different picture. For these participants, school was a real struggle because of their severe difficulties with learning and concentrating. Neither participant had graduated from high school.

R: What was it actually like on the day to day stuff at school?

P: It was even hard for me to learn.

R: So you had trouble learning?

P: Yeah.

R: So it was a real struggle for you at school then?

P: Yes, and I still have that struggle behind me ...

R: ... What grade did you get to?

P: Grade 2 and that was it.

R: And what did you do afterwards in school?

P: I went on to bigger and better things.
R: And what was that?

P: Like learning the parts of a vacuum cleaner and learning how to cook.

P: ... Sometimes I like to think about sexuality because it's a different subject and away from everything else that is a struggle. Like school and work ... Somedays I'm really bad at concentrating ...

R: What was it like for you going to school?

P: Awful ... I spent a lot of time trying to do schoolwork ... there wasn’t any time for play. There wasn’t any time for anything ...

In summary, participants had different perceptions of their cognitive competence. The "able" participants viewed themselves as having some learning difficulties but seemed quite pleased with their progress at school. The older participant in this group had already graduated from high school and was considering attending university in the near future. In contrast, the "disabled" participants had more severe learning problems and neither had completed high school. They perceived school to be a real struggle and were well aware of their difficulties with learning and concentrating.

d) Perceptions of Self-Worth and Self-Respect

In their accounts, participants in this study also revealed radically different feelings of self-worth and self-respect. Comments made by the "able" participants made it clear that they thought it was "okay" to be disabled. That is, their comments indicated that they were not ashamed of their disability and realized that they were a person of worth regardless of their physical disability. As well, the "able" participants recognized that they were more the "same" than "different" from others.

P: ... so now I know exactly where I am (uh huh) and, you know, a real competent person. I know what I can be and I know how to adapt so that I can do different things.
R: ... What would you see as sort of your personal limitations, or do you have any?

P: There are none.

R: (Laughing) You have none?

P: No. I haven't got any so far and I don't intend to get any!

R: ... how do you describe the impact on a child or a person of growing up with a disability?

P: Well, it's definitely a severe impact (uh huh) until you realize that you are a special person in yourself and you can make happen whatever you want to happen and then as soon as you realize that, nothing's going to stop you.

P: ... Like anybody can meet me, like yourself, and within 15 minutes, you know that I'm a super positive person and I'm willing to do anything, and I can do anything ... I always push myself extra hard and say, "I can overcome this and I'm going to overcome it."

R: ... So when you compare yourself to a lot of people, there's a lot of things you can do a lot better than a lot of people?

P: Yeah, I can. I used to think why bother trying it, I won't be able to do it any way. Why bother?

R: Is it different now?

P: Yup. Now that I've achieved these goals that I set when I was a kid or that I didn't want to try for, now I've achieved it, so I better get going.

P: ... I found out that the only person who's going to help me first, is me. If I initiate things a thousand things will happen but if I just sit back ... and go "Oh, poor me, I'm disabled" and this and that and the other, I'm not going to get anywhere (uh huh). I'm just going to depress myself and depress everybody else so I have to rise above that and go, "I'm a winner and I'm going to be the --, you know, the best that I can for everybody as well as myself."

In contrast, the two "disabled" participants revealed feelings of low self-worth and low self-respect. These feelings were reflected both in their
verbal and non-verbal behavior. During the interviews, both participants spoke in a low monotonous tone of voice and their facial expression was one of extreme sadness. One participant wept at times as she discussed her experience of growing up with a congenital physical disability. In their accounts, these participants revealed their inner struggle with the basic human existential question as to the reason for their existence. Although this is a question faced not only by the disabled, it is in many ways heightened by disability.

P: I feel like why am I alive sometimes. Because of the way people treat me. Makes me wonder why did I go through all this. It makes me wonder why I should live ... And it makes me wonder why people treated me like this when I could've been helped if they didn't put me in an institution to begin with.

P: Sometimes I feel like quitting the thing (life) ... I've even had days where I wanted to commit suicide ... A couple of times I wanted to and my friends say, "Oh, you don't mean that." Oh yeah!! ... I say, "Come over if you don't want me to do it" ...

The accounts of the two participants in the "disabled" group also revealed that they engaged in repeated comparisons of their disability with that of other persons. It seemed that these participants used others in their immediate environment who were "worse off" than them as a means of gaining a clearer sense of their own capabilities and limitations.

P: Like I have a roommate that I go home to everyday. Not knowing how to speak, not knowing how to tell when he has to go to the bathroom or something, not able to feed himself, not able to even converse with a person ... He can't even roll over on a mattress or anything ... He mainly has to be, not babied, but almost treated like, like um, not like a human being, sort of thing ... I still have a difficult time looking at my roommate and saying, "hey, I'm more fortunate than he is."

P: It, as you can see, it (cerebral palsy) affects all sorts of different parts of your body (uh huh) -- like it affects some people, like it affected your speak (sic), you're not able to speak to people. Some
it affected your breathing (uh huh). Some it affected your legs. Some will never be able to walk like I can (uh huh). Some they can't even get all dressed, they go all spastic ...

P: But then, I look at some other friend of mine and go, by the grace of God go I.

R: In what way?

P: Because they're a lot worse. They can't talk, they can't move, some of them can't even move -- so I'm pretty lucky.

R: Uh huh. So when you look at others and look at yourself, you say it could be a lot worse?

P: Yup. Could be a lot worse. I can stand. I can walk if I have to.

R: So tell me a bit about your disability ...

P: Cerebral palsy. Spastic. But not the kind that makes you, you know -- some people really jump and move all the time. Not that kind. Stiff more than anything ...

P: ... They can't even move and it makes me cry everyday because I know I can do it and I know he'll never be able to do it ...

Thus, the participants' accounts revealed two different perceptions of their self-worth and self-respect. Participants in the "able" group reflected their feelings of high self-worth and self-respect in their comments throughout the interview process. In contrast, the two participants in the "disabled" group reflected feelings of low self-worth and self-respect both in their verbal and non-verbal behavior. They engaged in repeated comparisons of their disability and situation with that of others and thus, seemed to gain a clearer sense of their own capabilities and limitations.

In summary, participants in this study had two radically different perceptions of themselves. The accounts of the "able" participants revealed that they perceived themselves to be physically, socially and cognitively
competent and reflected their feelings of high self-worth and high self-respect. In contrast, the "disabled" participants did not perceive themselves to be physically, socially or cognitively competent and their accounts reflected feelings of low self-worth and low self-respect.

Summary

This chapter has presented six participants' accounts of their experience of growing up with a congenital physical disability that confines them to a wheelchair. In the construction of the accounts, participants described three common components to the experience: family life, peer relationships and leisure-time activities. However, the overwhelming feature of the accounts was that there were two radically different perspectives on what this experience is like. These two different perspectives appear related to the participants' perceptions of themselves as either "able" or "disabled".

Four participants in this study had an image of themselves as "able". These participants viewed life with a congenital physical disability in a positive way and focused on their abilities and assets rather than their physical limitations. They described their family life as harmonious and their relationships with family members as loving and supportive. Furthermore, they were generally satisfied with their peer relationships and were involved in a wide variety of leisure-time activities. Their accounts revealed the particular importance of wheelchair sports in the lives of these participants.

Two participants had an image of themselves as "disabled". That is, they viewed life with a congenital physical disability in a negative way and saw life as a never ending struggle against obstacles that were often overwhelming. To these participants, their disability and their physical
limitations were always in the forefront of their minds. They described their early family life as stressful prior to their institutionalization in their elementary school years. Both participants felt dissatisfied with their peer relationships and had no close friends. In addition, they were involved in very few leisure-time activities outside their home and had no hobbies.

The final section of this chapter presented the differences in participants' perceptions of themselves. The participants who saw themselves as "able" perceived themselves to be physically, socially and cognitively competent and their accounts revealed feelings of high self-worth and self-respect. In contrast, the "disabled" participants did not view themselves as physically, socially, or cognitively competent and revealed feelings of low self-worth and self-respect.

This chapter has presented the accounts of the participants as they were constructed in the process of collecting and analyzing the data. In Chapter 5, the major findings that emerged from these accounts will be discussed in relation to the research literature reviewed in Chapter 2 and evaluated in light of relevant theoretical perspectives.
CHAPTER 5:
DISCUSSION OF FINDINGS

Introduction

This chapter presents a discussion of the major findings of this study in relation to pertinent literature. The purpose of such a discussion is to elaborate upon the key themes that were identified and to compare the findings of this study with the findings of other researchers. Much of the literature reviewed in Chapter 2 is reintroduced for this discussion and additional literature is used as necessary to facilitate interpretation of the findings. The organizing framework for this discussion will follow the themes as they were presented in Chapter 4. The first part of the chapter will, therefore, examine the literature in relation to the findings regarding participants' general perceptions of their experience of growing up with a congenital physical disability and their descriptions of family life, peer relationships and leisure-time activities. The last section of the chapter will discuss the literature in relation to this study's findings regarding participants' perceptions of themselves, that is, their perceptions of their body and physical competence, social competence, cognitive competence, self-worth and self-respect.

General Perceptions

Participants in this study had two dramatically different perspectives on the experience of growing up with a congenital physical disability. That is, some participants had a positive attitude toward life with a congenital physical disability while others did not. This finding has some support in the literature. Thomas (1982) suggests that the child's attitude to his/her
disability is shaped during childhood and that disabled children develop a personal philosophy which enables them to cope. Thomas cites numerous quotes from the autobiographies of many disabled individuals to support this statement but does not go so far as to suggest that there are two radically different perspectives on the experience of growing up with a congenital physical disability. However, Wright (1983) in her work, maintains that people, disabled or able-bodied, do have two vastly different perspectives on the significance of disability. She conceptualizes these two different perspectives as the "coping versus succumbing frameworks". In the coping framework, Wright describes the person as oriented toward seeking solutions and discovering satisfaction in living. The person emphasizes what he/she can do and accomplishments are appreciated. In addition, the negative aspects of life are felt to be manageable and the disabled person lives with his/her limitations although the disability may be regarded as a nuisance.

In the succumbing framework, the emphasis is on what the disabled person cannot do and the negative aspects of life are kept in the forefront. The person views him/herself as a victim of misfortune and accomplishments are minimized. The findings of the present study are consistent with the two perspectives described by Wright (1983), although Wright applies her framework equally to disabled and able-bodied persons, children and adults, persons with acquired and congenital disabilities.

Describing the Experience

Family Life

This study found that the majority of participants perceived their families to be managing or coping well with their disability and their family life to be
harmonious, loving and supportive. Relatively few studies have explored disabled children's or adolescents' perceptions of their family relationships (Thomas, 1982), however, so it is difficult to know if this finding reflects the experience of other disabled adolescents. One early study by Cruickshank (1952) did examine family relationships through a series of sentence completion tasks and he concluded that disabled children generally have a more positive relationship with their mothers than their fathers. The significance of such a finding is questionable, however, as it says nothing about the nature of the parent-child relationship or about family relationships on the whole.

In a more recent study, Wallander, Varni, Babani, Banis, and Wilcox (1986) found that the families of spina bifida children were significantly more cohesive, expressive, organized, controlling and less conflicted than were the control families. This is in sharp contrast to the findings of many other researchers. The prevalent view in the literature is that the presence of a disabled child or adolescent within the family causes problems in marital harmony, family adjustment and coping, and sibling relations (Dorner, 1973; Friedrich, 1977; Kolin et al., 1971; Simeonsson & McHale, 1981; Tew et al., 1977).

It is widely recognized that a disabled child or adolescent places increased emotional, physical and financial stress on the family and exerts enormous pressure on the relationship between husband and wife and between parents and other able-bodied children (Breslau, Weitzman & Messenger, 1981; Darling, 1979; Feder, 1978; Hobbs & Perrin, 1985; Klaus & Kennell, 1983; McDaniel, 1969; Resnick, 1984; Wright, 1983). Theorists agree,
however, that numerous variables besides the degree or severity of the child’s
disability play a role in determining how a family responds to the stress of
raising a disabled child (Feder, 1978; Heisler, 1972). Among these variables
are the internal and external resources of the family and the degree to which
the disabled child is perceived as a threat to the family’s status, goals and
objectives (Feder, 1978; Heisler, 1972). For example, a relatively minor
disability may be totally unacceptable to a parent if it interferes with the child
fulfilling the parent’s particular aspirations for the child while a child with a
more severe disability may be absorbed by another family with less strain
(Feder, 1978).

One theoretical perspective that emphasizes the role of perception in
shaping an individual’s response to matters of health and illness is the
cognitive-phenomenological theory of stress and coping developed by Lazarus
and his colleagues (Folkman & Lazarus, 1985; Lazarus, 1966, 1981; Lazarus &
Folkman, 1984a, 1984b). According to this theory, cognitive factors are central
in determining the impact of stressful events, the selection of coping patterns
and the emotional, psychological and behavioral reactions. As the presence of
a disabled child or adolescent within the family is generally perceived as a
stressful experience, the Lazarus stress theory may provide a useful
framework from which to address the family’s ability to cope with a disabled
child or adolescent.

Lazarus and Folkman (1984b) define stress as a "... particular relationship
between the person and his environment that is appraised by the person as
taxing or exceeding his or her resources and endangering his or her
well-being" (p. 19). Lazarus postulates that two processes, cognitive appraisal
and coping, are critical in mediating the person-environment relationship. Cognitive appraisal is an evaluative process whereby the individual evaluates the significance of what is happening in the environment for his or her well-being. There are two kinds of cognitive appraisal: primary appraisal, through which the significance of an event for one's well-being is evaluated (Is there anything at stake here?) and secondary appraisal, through which coping resources and options are evaluated ("What can I do?"). Primary appraisal involves determining that the event or encounter is irrelevant, benign-positive or stressful. Stressful appraisals are of three types: harm/loss, referring to damage already done; threat, referring to potential for harm and loss; and challenge, referring to an anticipated opportunity for growth, mastery or gain. Primary and secondary appraisals function interdependently and shape the meaning of every stressful encounter.

In Lazarus' framework, coping is conceptualized as "... constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (Lazarus & Folkman, 1984b, p. 141). Lazarus maintains that coping efforts can be anticipatory or reactive in nature and that they function to manage or alter the problem that is causing the distress (problem-focused coping) and to regulate the accompanying stressful emotions (emotion-focused coping). The way in which people cope, however, depends heavily on the resources that are available to them. Some resources which help to buffer the effects of stress include: good health and energy, positive beliefs, good problem-solving skills, good social skills, good social support and adequate financial resources (Lazarus & Folkman, 1984b).
Thus, utilizing Lazarus' theory, one can speculate that the four families in the present study who were perceived by participants to be "coping well" had adequate resources available to them to assist them in their coping. Although it is likely that these parents initially appraised the birth of their disabled child as a loss or threat, their coping efforts appear to have been successful in helping them to deal with this stressful experience and manage their accompanying emotions. In contrast, the two families who were not able to care for their disabled child at home, likely did not have the necessary external and internal resources available to them to assist them in their coping. They seemed unable to manage their emotions concerning their child's disability and their coping efforts appeared unsuccessful in managing the demands of caring for their disabled child.

A second finding in relation to family life was the perception of the majority of participants that their families were encouraging and that their parents fostered their independence. In their comparative study of disabled and non-disabled adolescents, Anderson and Klarke (1982) reported similar findings. They found that two thirds of the disabled adolescents believed their parents did not try to do things for them when they thought they could manage themselves. On the basis of their data, the authors concluded, that the term "overprotection" was frequently applied unfairly to parents of disabled children.

Several other researchers have concluded, however, that there is a tendency toward overprotection on the part of parents of disabled children (Anderson, 1979; Boles, 1959; Feder, 1978; Kemp, 1981; Lairy & Harrison, 1973; Oswin, 1967; Poznanski, 1973; Sandowski, 1979). Sandowski (1979) and
Poznanski (1973) suggest that parental and familial overprotection is the result of parents trying to deal with their guilt feelings toward their disabled child. Although several participants in the current study perceived their parents to feel guilty about their disability, they did not perceive them to be overprotective. Several possible explanations could account for this. Firstly, participants could be incorrect in their perception that their parents felt guilty about their disability. Secondly, it is possible that these participants' parents had resolved most of their guilt feelings so that although they surfaced periodically, they were not the major driving force behind them. Thirdly, it is possible that these parents were aware that overprotection was a risk inherent in parenting disabled children and consciously worked to avoid it. Fourthly, it is likely that parents who felt extremely guilty and overprotective of their disabled children would never have volunteered their children to participate in the present study. Therefore, parents of the participants in this study may not have had strong enough guilt feelings to influence their parenting in an obvious way. Lastly, the literature could be wrong in its assumption that there is a link between parental guilt and overprotection.

**Peer Relationships**

This study found that the majority of participants had two different perspectives on their peer relationships. The four "able" participants were generally satisfied with their peer relationships while the two "disabled" participants were not. Although none of the "able" participants described themselves as having a best friend, all perceived themselves to be part of a large group of able-bodied and disabled friends, either at school or in the community. This finding has some support in the literature. Resnick (1984)
reported that 80 percent of the disabled adolescents in his study stated that they had friends. Similarly, Lorber and Schloss (1973) found that 72 percent of the adolescents with spina bifida in their study had one or more friends.

These findings are in sharp contrast, however, with those of several other researchers (Altman, 1981; Anderson, 1979; Dorner, 1975, 1976, 1977; Minde, 1978; Minde, Hackett, Killou & Silver, 1972; Rowe, 1973). Dorner (1975) reported that about 50 percent of the adolescents with spina bifida in his sample were judged to be socially isolated. Minde and Associates (1972) also found that peer group isolation was the norm. In their study, about two-thirds of the adolescents with cerebral palsy had few meaningful relationships with able-bodied peers. Similarly, Anderson (1979) reported that almost fifty percent of the 119 disabled teenagers in her study led isolated and lonely lives. They had no peer contacts outside school and relied heavily on parents and siblings for companionship. These findings are supported, however, by this study's finding that the two "disabled" participants perceived themselves to be lonely and socially isolated. In their accounts, both of these participants revealed that they had no close friends or confidants.

There are a few possible explanations for the finding of the present study. Firstly, the four "able" participants who described themselves as members of a peer group all attended (or had attended) regular classes in the public school system while the two "disabled" participants had attended special classes or schools for the disabled. One can speculate, therefore, that integration of disabled children and adolescents into regular classes at school may facilitate the development of satisfactory peer relationships. Another possible explanation for the finding of the present study may be, as Dorner
(1975) concluded, that the more mobile the adolescent is, the less social isolation he or she experiences. The four participants in the present study who described themselves as having satisfactory peer relationships were all independently mobile in their wheelchairs. That is, they were able to wheel themselves around their school and neighbourhood as they wished and were not dependent on others except in special circumstances. Therefore, these participants had multiple opportunities for interacting with and developing relationships with able-bodied and disabled peers. However, the findings of the present study would suggest that independent mobility is not the sole factor affecting the development of satisfying peer relationships. In this study, the two "disabled" participants were also independently mobile in their electric wheelchairs and nonetheless, they described feeling lonely and socially isolated. Further discussion of possible factors influencing peer relationships will be presented in the following sections of this chapter.

This study also found that the participants who perceived themselves as "able" were the frequent targets of teasing and ridicule during their elementary and high school years. However, the two "disabled" participants did not describe similar experiences. One can speculate that this may have been because the researcher did not ask them directly about this or perhaps they did not experience teasing and ridicule from their peers as they attended special schools with disabled peers. The literature suggests, however, that teasing is commonly experienced by disabled teenagers whether they are in regular or special schools. Nielson (1966) reported all participants in his study had experienced teasing by their able-bodied peers while Anderson (1979) found that disabled teenagers in special schools were as likely to be
teased as those in ordinary schools. In spite of teasing, Anderson found that all disabled teenagers stated that they preferred ordinary to special school placement. However, Anderson and Klarke (1982) found that adolescents with cerebral palsy in ordinary schools were more likely to report teasing and aggression from able-bodied peers. They noted the high degree of dissatisfaction with social life during and after school and concluded that social separation was reinforced by negative peer-group experiences and caused the adolescent to focus on the disability as his/her primary characteristic. However, in the present study, the "able" participants did not appear overly distressed by their peers' teasing and ridicule nor did it appear to result in a high degree of social isolation. Instead, the "able" participants described various strategies that they used to cope with this teasing and ridicule. These strategies included: ignoring it, humor, sarcasm, and making friends with others. These strategies are representative of the problem-focused type of coping described by Lazarus and Folkman (1984b).

**Leisure-Time Activities**

In this study, participants revealed dramatic differences in their involvement in leisure-time activities. The four participants who perceived themselves as "able" were involved in a wide variety of leisure-time activities such as swimming, going to the movies and wheelchair sports which brought them together with both able-bodied and disabled peers. However, many of their leisure-time activities were also pursued with their parents and siblings and included: fishing, camping, gardening and watching television. In contrast, the two "disabled" participants were involved in very few activities or hobbies outside the home. The activities in which they did participate
were generally those that could be done alone and at home, such as reading, watching television and listening to music. This is congruent with the findings of other researchers (O'Reilly & Elliot, 1971; Margalit, 1981; Resnick, 1984) as to the type of leisure activities engaged in by disabled children or adolescents.

Margalit (1981) compared the leisure activities of children with cerebral palsy with those of a healthy peer group. She found that disabled children rarely went to movies, usually because they had no one to go with, and were much more likely to read books than were the controls. She found no differences, however, in the frequency or amount of time spent watching television or listening to the radio. Similarly, Resnick (1984) found that of the 60 adolescents with cerebral palsy in his study, over 75 percent stated that they had some hobby or activity in which they regularly engaged — 15 percent named participation in sports; 15 percent named listening to music; 7 percent cited watching television; 18 percent listed writing or drawing and 15 percent cited collecting objects. Resnick noted that those individuals with hobbies viewed themselves as more popular and happier than those without hobbies.

The literature supports the notion that the use of leisure time has an important socializing component and, thus, has a major impact on the lives of children and adolescents (Resnick, 1984). Together with the family, the peer group is central to the socialization process and frequently provides the structure for leisure time activities (Altman, 1981). Peers fulfill three crucial roles in the use of leisure time: support and communication; companionship and conversation; and fun and socializing (Hedin & Simon, 1980). Thus, in
this study, the leisure-time activities of the "able" participants provided them with numerous opportunities for companionship, conversation, fun and peer support. However, the two "disabled" participants who were involved in very few leisure activities outside their homes, generally missed out on these opportunities for peer support, fun, companionship and conversation. It would appear, therefore, that involvement in leisure-time activities outside the home is another factor positively influencing the development of satisfying peer relationships for disabled children and adolescents.

A second finding of this study related to leisure-time activities was the perception of the "able" participants of the importance of wheelchair sports in their daily lives. In their accounts, the "able" participants revealed that wheelchair sports provided them with positive role models, increased opportunities to interact with their peers, as well as opportunities to compete and be successful. Thus, for these participants, wheelchair sports seemed important in the development of a positive self-image as they provided opportunities to develop feelings of physical and social competence, self-worth and self-respect.

The literature reflects strong support for organized competitive sports and physical activity programs for disabled individuals (Anderson & Klarke, 1982; Brown, 1975; Huberman, 1976). Disabled individuals who engage in such exercise have been found to experience tremendous benefits in both the physical and psychological domains (Berg, 1970; Brown, 1975). Berg (1970) also found that a structured training program was helpful in raising the disabled adolescent's activity level and along with it his/her sense of well-being. Resnick (1984) concluded that sports can be viewed as activities
that help normalize the lives of children and youths with disabilities. In his study, he found that a key issue in playing sports was the sense of involvement or belonging each individual felt with his/her peers and others. One can speculate, therefore, that in this study the "disabled" participants' lack of involvement in competitive sports and physical activity programs may have had a negative influence on their physical and psychological well-being. That is, their lack of involvement in sports limited their opportunities to develop feelings of physical and social competence, self-worth and self-respect.

**Perceptions of Self**

This study also found that participants had different thoughts and feelings about their physical characteristics, capabilities and self-worth. Overall, the four "able" participants viewed themselves in a positive way while the two "disabled" participants viewed themselves in a negative way. This is consistent with the findings of other researchers that some disabled children and adolescents have a positive self-image while others do not (Anderson & Klarke, 1982; Feder, 1978; Haraguchi, 1978; Harvey & Greenway, 1984; Hayden, Davenport & Campbell, 1979). The following section will discuss the differences in participants' self-perceptions in greater detail.

a) **Perceptions of Body and Physical Competence**

This study found that participants had two different perceptions of their body and physical competence. The participants who perceived themselves as "able" minimized their disability and focused on their physical abilities and assets. These participants regarded themselves as physically competent in spite of their physical disability and were proud of their physical accomplishments. This finding contrasts with the widely held assumption
that individuals with disabilities are endlessly preoccupied with their
disability, their defectiveness and the tragedy of their life (Weinberg &
Williams, 1978; Wright, 1983). Wright argues that this discrepancy between
the way the disabled view their situation and the way the non-disabled think
about disability can be understood in terms of the "insider versus outsider"
perspective or the "mine versus thine" problem.

Examining the insider perspective, Wright (1983) claims that for the
disabled who accept their physical deficits, other goals and values become
more important than being physically able or physically intact. That is, they
do not perceive their life as a tragedy because there are still many things that
they can do and many things to be achieved. The able-bodied outsider,
however, generally views physical ability and appearance as highly significant.
Therefore, from the outsider perspective, life for the disabled must be most
unhappy as there is so much that they cannot participate in or achieve.

Thus, the finding of the present study may, therefore, reflect the "able"
participants' acceptance of their deficits and the valuing of qualities other than
physical ability and intactness. One can speculate, therefore, that this study's
finding that "disabled" participants focused on their disabilities, physical
limitations and health problems, suggests that these participants had not come
to terms with their deficits and, instead, valued being physically able and
physically intact.

Several authors argue that the adolescent's attitude to his/her disability
is shaped during childhood (Feder, 1978; Haraguchi, 1978; Heisler, 1972;
Thomas, 1982). Feder (1978) claims that we cannot understand what a
particular child's deficit means to him/her unless we understand the feelings
and values of the parents with whom this child is growing up.

Heisler (1972) states that the parents' feelings about the child and his/her handicap will be a major determiner of the child's self-image. The findings of the present study suggest that the parents of the participants who perceived themselves as "able" had a positive attitude toward their disabled child and his/her disability while the parents of the participants who perceived themselves as "disabled" had a negative attitude toward their disabled child and his/her disability. Thus, positive parental attitudes may have contributed to the positive self-concepts of the "able" participants while negative parental attitudes may have contributed to the negative self-concepts of the "disabled" participants.

In addition, Freeman (1970) argues that the child's concept of him/herself and his/her "body image" are related to the ways in which he/she experiences success or failure in using his/her body and to the meaning he/she attaches to the attitudes of others towards him/her and his/her handicap. One can speculate, therefore, that the "able" participants' many personal accomplishments and successes in wheelchair sports contributed to their feelings of physical competence and their positive body image. In contrast, the "disabled" participants' lack of involvement in wheelchair sports and other leisure-time activities limited their opportunities for developing feelings of physical competence and may have contributed to their feelings of low self-worth and self-respect.

Another interesting finding of this study was the concern expressed by the three adolescent participants about their physical appearance. It is widely recognized that physical appearance assumes heightened importance during
adolescence and that deviations from normal are not well tolerated (Haraguchi, 1978; Skellern, 1979; Strax & Wolfson, 1984; Wright, 1983).

It was an unexpected finding, however, that most of these participants' expressed concerns were about their hair, height, clothes and the presence of pimples, and not their physical disability per se. Possible explanations for this could be that participants were actually more concerned about physical attributes over which they had some control and ability to change or they may have integrated their physical differences related to their disability into their self-concept in a positive way so that it was not a major source of concern for them. As Wright (1983) notes, "although physique carries a particularly heavy emotional load during adolescence, it is not correct to presume that any single physical deviation will invariably or even probably produce distress. The psychological consequences of deviation will depend on social and individual attitudes towards non-conformity, the strength of intrinsic attitudes of self-acceptance and the possession of compensatory assets, as well as the meaning of that particular deviation for the individual" (p. 248).

This study's finding that all participants felt walking was important and desirable is also contrary to much of the available literature. Travis (1976) notes that some adolescents who have been getting about on crutches may decide to use a wheelchair as they believe the image they project is more normal when sitting than when dragging about a partially paralyzed body on crutches. Haruguchi (1978) also claims that disabled teenagers struggle to be as "inconspicuously different from normal peers as possible" and feel that others give them equipment and special devices to wear that only heighten
their differentness from others (p. 19).

Based on the above information, one would assume, therefore, that disabled adolescents would be reluctant to walk as the scissor gait of cerebral palsy, or the braces and crutches of spina bifida, only draw attention to the physical characteristics they would like to hide. Thus, the present finding challenges the assumption that disabled teens universally find walking with braces and crutches or a scissor gait undesirable. One can speculate that walking was important and desirable for these participants because it made them feel more "able". That is, walking seemed to make participants feel more "normal" and appeared to give them a sense of greater ability because it was yet another thing that they could do.

b) Perceptions of Social Competence

This study found that the four "able" participants perceived themselves to be socially competent. That is, they described themselves as friendly and well-liked and felt that they made friends quite easily. This finding has some support in the literature. Resnick (1984) found that over 80 percent of his sample of disabled adolescents had friends and viewed themselves as popular. Based on self-report, these adolescents had higher self-esteem than those adolescents without friends.

However, other researchers have concluded that approximately 50 percent of disabled adolescents commonly experience severe social isolation, frequent misery and depression (Altman, 1981; Anderson, 1979; Dorner, 1975, 1976; McAndrew, 1979; Minde et al., 1972). This study's finding that the "disabled" participants lacked friends and were socially isolated is congruent with the findings of these other researchers. As Altman (1981) notes, social
isolation results in diminished opportunities for social interaction and impedes the development of social competence. Thus, one can speculate that increased opportunities for peer interaction may be one factor that contributes to the development of social competence in disabled children and adolescents. As social competence has been found to correlate with high self-esteem (Resnick, 1984), this may be another factor which contributed to the feelings of high self-esteem in the "able" participants of the present study.

c) **Perceptions of Cognitive Competence**

This study found that participants had two different perceptions of their cognitive competence. The "able" participants perceived themselves to be "quite smart" while the "disabled" participants perceived themselves to have great difficulty with learning and concentrating.

Although the literature did not reveal any studies of children or adolescents' perceptions of their cognitive competence, learning difficulties and impaired intellectual functioning has been reported in children and adolescents with spina bifida and cerebral palsy (Freeman, 1970; Minde, 1978; Routh, 1988; Travis, 1976). Hunt (1981) reported that of the 100 children born with spina bifida between 1963 and 1972, at a mean age of 10 years, 61 percent scored in the normal range on IQ tests and 39 percent scored below an IQ of 80.

Cull and Wyke (1984) concluded from their investigations that children with hydrocephalic spina bifida showed deficits in their ability to learn, store and retrieve information when compared to children with normal intelligence. As well, Lansdown (1980) reported that while at least 50 percent of children with cerebral palsy are educationally subnormal, the measured intelligence of
one fifth of this group is average or higher.

The findings of the present study may be an accurate reflection of participants’ cognitive functioning or competence and/or it may reflect participants’ feelings of self-worth and self-respect. As discussed earlier, the child’s self-concept is influenced by his/her parents’ feelings and attitudes toward him/her.

In the present study, parents of the "able" participants appeared to feel positive about their child and his/her disability. Therefore, one can speculate that these parents also had a positive attitude toward their child’s cognitive achievements, whatever they might be, and were able to give their child positive feedback about his/her learning and progress at school. Thus, the positive feedback of the "able" participants’ parents may have contributed to their feelings of cognitive competence and feelings of self-worth and self-respect. It is quite likely, however, that the "disabled" participants did not receive positive parental feedback regarding their cognitive achievements. Their accounts revealed many negative experiences throughout their childhood which may have contributed to their feelings of cognitive incompetence and low self-worth and self-respect.

d) **Perceptions of Self-Worth and Self-Respect**

This study also found that participants had two radically different perceptions of their self-worth and self-respect. The "able" participants revealed feelings of high self-worth and self-respect while the "disabled" participants revealed feelings of low self-worth and self-respect. The literature suggests that feelings of belonging and competence contribute to feelings of self-worth and self-respect (Burns, 1979; Felker, 1974). These feelings seem to
develop through a process of self-evaluation whereby the individual examines his/her physical characteristics, abilities, achievements and social relationships according to personal standards or ideals which he/she has internalized from his/her parents or society at large (Mack & Ablon, 1983).

Burns (1979) and Felker (1974) agree that a significant factor in the individual's feelings of belonging involve feeling accepted and valued in his/her relationships with others. They argue that peer acceptance causes the individual to feel respected by others and subsequently, to feel significant and worthy (Burns, 1979; Felker, 1974).

Feelings of competence are thought to develop if the individual perceives that he/she is in control of his/her own behavior and that he/she can successfully perform the behavior required to achieve his/her personal goals and aspirations (Spitzer, 1982). Thus, in this study, the "able" participants' perception of acceptance by their peers and feelings of physical, social and cognitive competence contributed to their feelings of high self-worth and self-respect. By way of contrast, the "disabled" participants' perception of their lack of acceptance by their peers and their lack of feelings of physical, social and cognitive competence resulted in their feelings of low self-worth and self-respect.

**Summary**

This chapter has discussed the major findings of the current study in relation to previous research findings and theoretical literature. Support was generally provided for the findings of the present study although some of the findings differed from those reported in the literature.
This study found that participants had two dramatically different perspectives on the experience of growing up with a congenital physical disability. Four participants viewed life with a disability in a positive way while two did not. Some support for this finding was found in the literature.

This study further suggests that the family may have a profound influence on the disabled adolescent's self-concept and attitude toward his/her disability. Participants in this study who described their family life as harmonious and their family relationships as loving, supportive and encouraging viewed life with a disability in a positive way. They also perceived themselves to be physically, socially and cognitively competent and revealed feelings of high self-worth and self-respect. However, participants who perceived their family life to be chaotic and who described many negative childhood experiences viewed life with a disability in a negative way. They did not perceive themselves to be physically, socially or cognitively competent and spoke in terms that indicated feelings of low self-worth and self-respect.

This study also found that not all disabled adolescents are socially isolated and lonely. The majority of participants in this study described themselves as a member of a peer group and perceived themselves to be quite well-liked. Although this finding is in sharp contrast with the findings of many researchers, some support was found in the literature.

In addition, this study found that the participants who perceived themselves as "able" were the frequent target of teasing and ridicule during their elementary and high school years. However, these participants who had
positive self-concepts and feelings of high self-worth and self-respect appeared to be able to cope with this teasing and ridicule.

This study further found that all participants described walking as desirable and important to them, even if it required the use of braces and crutches. This finding is contrary to much of the available literature.

Lastly, this study found that the "able" participants identified strongly with wheelchair athletes, such as Rick Hansen. These participants seemed to look to these individuals as role models and there appeared to be a positive psychological benefit of seeing other individuals in wheelchairs succeeding in their personal endeavors. As a result of their successes, the "able" participants appeared to gain a sense of hope and possibility for their own future.

In the following chapter, a summary of the study is presented, major conclusions are drawn and implications for nursing practice and research are suggested.
CHAPTER 6:
SUMMARY, CONCLUSIONS AND IMPLICATIONS FOR NURSING

This final chapter presents a summary of the study reported in this thesis. In addition, major conclusions are drawn and implications of the study's findings for nursing practice and research are provided.

Summary

This study was designed to explore and describe the adolescent's experience of growing up with a congenital physical disability that confines him/her to a wheelchair. The impetus for this study came from the researcher's observation of the numerous discrepancies in the literature regarding the impact of a congenital physical disability on the adolescent's self-concept. It was recognized that a study was needed to address this lack of knowledge in order to provide direction for the provision of health care to these individuals and their families.

The methodology that directed this study was the phenomenological paradigm of qualitative research. This methodology was seen as most appropriate because of the lack of knowledge about the adolescent's experience of growing up with a congenital physical disability and the effect this has on self-concept development. This method seeks to describe human experience as it is lived and assumes that, through the research process, the informants and researcher can construct accounts of the phenomena that describe reality with a richness and depth unobtainable with other research methods.

The data for this study were collected by way of indepth interviews with a total of six participants ranging in age from 12 to 23 years. Three of the
participants had spina bifida and three had cerebral palsy but all required a wheelchair for mobility. A total of 13 interviews took place over an 11 month period. Interviews were audiotaped and transcribed verbatim immediately following their collection. Data collection and data analysis occurred simultaneously using the analytic process described by Giorgi (1975). Although each participant's account of his/her experience was unique, common themes representing the shared aspects of their experience were readily discernable. Thus, over time it was possible to construct accounts of the participants' experience of growing up with a congenital physical disability. The accounts that were constructed during the research process revealed three major components to the experience. The three components were: family life, peer relationships and leisure-time activities. The overwhelming feature of the participants' descriptions was the two radically different perspectives on what it is like to grow up with a congenital physical disability. These two different perspectives appear related to participants' perceptions of themselves as either "able" or "disabled". Four participants in this study viewed themselves as "able" and viewed living with a congenital physical disability in a positive way. These participants saw life as a challenge and believed that they had much to offer in spite of their physical disability. They focused on their abilities and assets not their limitations and were proud of their physical accomplishments. They perceived themselves to be physically, socially and cognitively competent and spoke in terms that revealed feelings of self-worth and self-respect. This researcher interpreted these findings to indicate that the "able" participants had positive self-concepts and high self-esteem. In addition, they described their family life as
harmonious, loving and supportive and were generally satisfied with their peer relationships. They also participated in numerous leisure-time activities, both with their families and able-bodied and disabled peers.

In contrast, two participants viewed themselves as "disabled" and saw life as difficult, a never ending struggle against obstacles that were often overwhelming. To these participants, their disability and all the things they could not do were first and foremost in their minds. Both participants had been institutionalized during their elementary school years when their families were no longer able to manage them at home. They were unsatisfied with their peer relationships and had no close friends or confidants. They did not perceive themselves to be physically, cognitively or socially competent and in their accounts, they did not reveal feelings of self-worth or self-respect. Thus, this researcher interpreted this to indicate that these participants had poor self-concepts and low self-esteem. As well, these participants engaged in very few leisure-time activities outside their home and generally spent time alone in solitary activities.

**Conclusions**

On the basis of this study's findings a number of conclusions have been drawn:

1. Disabled informants perceive their families to have a profound influence on their self-concept and attitudes toward their disability.

2. Disabled informants perceive their families to be an important source of support and companionship.

3. Disabled informants with positive self-concepts and high self-esteem seem to be able to cope with their peers' teasing and ridicule.
4. Many of the concerns of disabled adolescents are similar to those of able-bodied adolescents. Their concerns regarding physical appearance center around height, hair, clothes, the presence of pimples and attractiveness to members of the opposite sex.

5. Walking, even if it requires the use of special devices or equipment, seems to be important to disabled informants for a number of reasons. These reasons may include: making them less conspicuous to others, making them appear more "normal" and increasing their sense of "ability".

6. Disabled informants do not necessarily lead lives that are unhappy, socially isolated and lonely.

7. Disabled informants with positive self-concepts and high self-esteem perceive identification with other disabled individuals who are successful in their personal endeavors as important in the development of a positive self-concept.

8. Disabled informants with positive self-concepts and high self-esteem perceive that wheelchair sports and other leisure-time activities provide increased opportunities for mastery and opportunities to interact with their peers. As a result, participation in these activities may facilitate the development of feelings of physical and social competence, self-worth and self-respect.

9. Disabled informants with positive self-concepts and high self-esteem perceive participation in leisure-time activities outside the home as a positive influence in the development of satisfying peer relationships.
Implications for Nursing Practice

The findings of this study suggest a number of implications for nursing practice.

Firstly, nurses need to assess family attitudes toward the presence of a disabled child or adolescent within the family. The findings of this study suggest that family attitudes may be an important influence on the disabled child’s or adolescent’s self-concept and attitude toward his/her own disability. Therefore, nurses need to foster or promote positive attitudes and feelings toward the disabled child and adolescent in all family members.

Secondly, nurses must assess families of disabled children and adolescents to determine their level of functioning or coping. As some families may have difficulty coping with life that includes a disabled child or adolescent, nurses must determine what problems, if any, the family is experiencing. As the family appears to be an important source of support and companionship for disabled children and adolescents, nurses must intervene when problems are identified in order to facilitate coping among all family members. The findings of the present study support maintaining disabled children and adolescents at home whenever possible. However, if families are unable to cope with the presence of a disabled child or adolescent, a loving alternative home must be provided.

Thirdly, nurses need to emphasize to parents the importance of promoting diverse forms of leisure-time activities outside the family for their disabled child or adolescent. The findings of this study suggest that these activities provide opportunities for peer interaction and may promote the development of social competence. As well, this study suggests that
participation in peer group activities may facilitate peer acceptance which may result in feelings of belonging and increased feelings of self-worth and self-respect. More specifically, wheelchair sports and other physical activities can provide disabled children and adolescents with positive role models and increased opportunities for mastery. Thus, participation in these activities may promote the development of a positive body image, feelings of physical competence and self-worth which, in turn, may enhance the self-concept and self-esteem of the disabled child or adolescent.

Fourthly, nurses working with disabled children and adolescents must avoid assuming that all disabled children and adolescents are unhappy and having difficulty coping with their disability. The findings of this study suggest that nurses should assess each child or adolescent individually to determine their level of coping and psychological well-being. Nursing interventions should focus on building positive self-concepts and feelings of self-worth and self-respect. Toward this end, disabled children and adolescents may need to be encouraged to express and recognize their feelings about their disability and helped to focus on their strengths and abilities rather than their limitations. As the development of satisfactory peer relationships may be an area of special vulnerability for disabled children and adolescents, nurses may also need to help disabled children and adolescents develop social skills that would facilitate such relationships.

Finally, the findings of this study suggest that nurses should encourage disabled children and adolescents to walk if at all possible. Whether walking requires the use of special devices, such as braces or crutches, seems unimportant. Rather, the ability to walk even a few steps seems to provide
the disabled child or adolescent with a sense of increased "ability" as it is yet another thing they can do. In addition, some disabled children and adolescents may perceive walking, or being upright, as a way to appear more "normal" and be less conspicuous to others. Therefore, nurses should support disabled children and adolescents in their efforts to walk and explain the possible significance of walking to their parents so that their efforts can be encouraged at home.

It is apparent that there are many ways that nurses can intervene to provide care to children and adolescents with congenital physical disabilities and their families. However, it is clear that more research-based knowledge would be necessary before a comprehensive understanding of the adolescent's experience of growing up with a congenital physical disability and the effect this has on self-concept development could be achieved. The following section will discuss the implications for nursing research that emerge from the findings of this study.

**Implications for Nursing Research**

This study has contributed only beginning knowledge to our understanding of the adolescent's experience of growing up with a congenital physical disability and the effect this has on self-concept development. Clearly, more research is needed to guide the delivery of health care to children and adolescents with congenital physical disabilities and their families. However, several suggestions for further research can be generated from this study's findings.

This study's finding that participants had two different perspectives on the experience of growing up with a congenital physical disability suggests a
need for further research. Another study involving larger numbers of participants would be useful to see if this finding reflects the experience of other adolescents with congenital physical disabilities. The difficulties encountered in obtaining a sample for this study suggests that participants may not have been representative of the population of disabled adolescents with congenital physical disabilities and therefore, future research is needed in this area.

This study explored the adolescent's experience of growing up with a congenital physical disability. The accounts of the participants clearly indicated the important role of the family in the adolescent's life experience and his/her self-concept. Therefore, a study which explored the experience of the family that has an adolescent with a congenital physical disability may provide valuable information as to the factors or resources within the family that facilitate family coping and thus, foster the development of a good self-concept in the disabled child or adolescent. In addition, such a study may provide clues as to the impact of the disabled adolescent on family functioning and family relationships and provide direction for interventions needed to lessen the apparent negative effects on the family.

The findings of this study suggest that disabled adolescents may have some of the same concerns about their physical appearance as able-bodied adolescents. The adolescent participants in this study seemed more concerned about their height, hair, clothes and the presence of pimples than their physical disability per se. It would be beneficial to replicate this study with other populations of congenitally disabled adolescents to gain insight into the personal significance of their disability and to enhance our understanding of
how disabled adolescents perceive their physical disability. This study found that the majority of participants viewed living with a disability in a positive way and felt physically, socially and cognitively competent. Longitudinal studies of disabled adolescents could yield valuable data as to the role of attitude and self-concept in long term outcome or quality of life.

A final issue requiring further study is the influence on self-concept of the recent influx of positive role models for disabled children and adolescents. This study's finding of the importance of wheelchair athletes, such as Rick Hansen, to the majority of participants suggests that positive role models may have a significant impact on the self-concept of disabled children and adolescents. Therefore, further studies in this area could provide valuable information that may help to foster positive self-concepts in disabled children and adolescents.

In conclusion, the adolescent's experience of growing up with a congenital physical disability has not yet received the attention it deserves in health care planning and research. It seems particularly urgent to pay attention to this group of individuals as larger numbers of children with congenital physical disabilities are now surviving into adolescence and adulthood. Much more knowledge is required, however, before health care professionals can appreciate the complexities of the life issues of disabled adolescents. The only viable source of this knowledge and information is the disabled adolescent him/herself and it is to these individuals we must turn for the answers.
References


APPENDICES
I have read the above information and agree/do not agree to have the researcher contact me by telephone to discuss the study.

_________________________  ____________________________
Date                                            Signature of Parent/Legal Guardian

_________________________
Telephone Number

The study described above has been explained to me/us and I/we consent/do not consent to have my/our child participate in this study. I/we have received a copy of the information letter and consent form.

_________________________  ____________________________
Date                                            Signature of Parent/Legal Guardian

The study described above has been explained to me and I am willing/not willing to participate in this study. I understand that I have the right to withdraw from this study at any time.

_________________________  ____________________________
Date                                            Signature of Parent/Legal Guardian
Appendix B

Sample Interview Questions

1. How many years have you been in a wheelchair?

2. Has being in a wheelchair affected you in any way? If so, how?

3. What is it like to go to school in a wheelchair? (If clarification necessary) I am especially interested in whether you are able to get around on your own, if you are able to go out at lunch and recess to play with your classmates, what activities you are able to participate in?

4. How well do you do at school? Are you smart? Are you smarter than the other individuals in your class?

5. How do you see yourself physically as compared to other individuals in your class or school? What sorts of things can you do well with your body? What sorts of things do you have difficulty doing physically?

6. Do you have a best friend in your neighbourhood? Who do you consider your best friend? Why? Can you tell me a bit about what this friend is like?

7. Do you make friends easily? Do other people your own age like you?

8. How do you see yourself compared to other people your own age? What sorts of things about your personality make you different from any other person in the world? (If clarification necessary) How would you describe yourself if you had to tell someone what you are like? That is, would you say that you are a friendly person, a happy person, someone with a bad temper or what?

9. How do you think other people see you? (If further clarification necessary) How do you think your friends, family members and
9. How do you think other people see you? (If further clarification necessary) How do you think your friends, family members and strangers would describe you?

10. How do you get along with your parents? Your brothers and sisters? Has your being in a wheelchair affected their lives in any way? If so, how?

11. What kinds of things do you like to do for fun? What are your hobbies or favourite activities?

12. What is a "typical" day like for you? I am especially interested in such things as day-to-day routines, who does what around your house, things you do together as a family.

13. What do you see yourself doing when you are older and have finished school?

14. What is it like for you to talk about the experience of growing up in a wheelchair?