Perceptions of Participation and Inclusion Among Adolescents with Disabilities: Experiences from South India

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Declaration

I, <u>Gayatri Kembhavi</u>, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

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Abstract

Disability is an issue of human rights and equal opportunity and is no longer focused on impairment and medical intervention. Adolescents with disabilities (AWD) are marginalised throughout the world (UNICEF, 2005), particularly in low- and middle-income countries where they are affected by poor access to resources, and by stigma and local taboos. Poverty has been shown to accentuate the impact of disability. The cycle of poverty and disability is marked by poor access to education, vocational training, and employment. The need of AWD for inclusion and participation in education, health and social life are the same as their non-disabled peers. For many AWD, these needs continue to go unmet (Groce, 2004).

The research question was: 'How do adolescents with physical disabilities perceive the factors that determine their participation and inclusion in their communities in South India?' Quantitative and qualitative techniques were used. Thirty-seven AWD, 25 parents of AWD, and 24 non-disabled adolescent peers participated in the study in Bangalore, India. A background information questionnaire and two measures of quality of life (QOL) were conducted with all participants. Qualitative data was gathered with each participant group using interviews and focus group discussions (FGD). Photography was used with the AWD to facilitate discussions.

Analysis of QOL data revealed no differences between AWD and parent-proxy scores. Differences exist in QOL scores between AWD and their peers. Analysis of interview and FGD data revealed three key themes that influence the perception of Participation and Inclusion among AWD. These are: 1) Personal Factors; 2) Interpersonal Relationships; and 3) External Factors. Belief in themselves and parental support were two key facilitators of participation. Negative attitudes of others, physical barriers, and poorly implemented legislation were significant barriers to participation. Recommendations are suggested to enhance the participation and inclusion of AWD and to facilitate success in adulthood.

Dedication

This thesis is dedicated to my parents, for allowing me the freedom to explore new avenues of knowledge, and for their unconditional support of my many and varied endeavours; and to Clarence, for his love and support through the journey of this PhD, and for his unwavering belief in me.

Acknowledgements

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Chapter 1 – Introduction

The study of disability has undergone dramatic changes in the past 50 years and continues to evolve. It has moved from a concentration on body function towards living with disability. No more is the field of disability studies the exclusive domain of medical practitioners who sought to prevent or change disabling conditions. Disability is now viewed as an equal opportunity and human rights issue, not only a medical one (Barnes & Mercer, 2001). Changes in the definitions of disability over time reflect this shift. Disability was once defined in terms of the physical, cognitive and sensory impairments that prevented people from achieving daily tasks and fulfilling social roles. Researchers and disability advocates now suggest that disability should be defined as 'a difficulty in functioning at the body, person, or societal levels, in one or more life domains, as experienced by an individual with a health condition in interaction with contextual factors' (Leonardi, et al. 2006, p.1220). The work of organizations representing people with disabilities has increased public awareness of their needs and rights. For people with disabilities throughout the world, the emphasis now is on inclusion, participation and the realisation of their rights.

Children and adolescents with disabilities are marginalized throughout the world (UNICEF, 2005). This is particularly true in some communities in developing countries, where there are great discrepancies in access to services for different groups of people, and local taboos about disability and its causes. Traditionally, children with disabilities have been the recipients of medical and rehabilitative services, the aim of which was to 'normalise' function and reduce their disability. As the focus of the disability movement changes, so too does the view of rehabilitation services for children. The underlying focus of rehabilitation services has shifted from a disease-based model to a paradigm that is consumer-driven and focused on maximising the capacity of the consumer (Condeluci, 1998).

While these issues are important in every country, the added factor of poverty experienced by children and adolescents with disabilities (AWD) in some communities compounds the impact of their disability (Anonymous, 2002; Department for International

Development, 2000). The vicious cycle of poverty and disability is accentuated by poor access to health services, education, vocational training, and employment. The needs of AWD for inclusion and participation in education, health and social life are no different than the needs of their peers, but they cannot participate in these life roles in the same way that their non-disabled peers and siblings do. 'What distinguishes this large group of youth are not their common needs, but the fact that these needs continue to go so largely unmet' (Groce, 2004). The research presented in this thesis aims to determine the extent to which specific groups of AWD in Bangalore, India participate in meaningful life roles and to understand what they perceive to be the barriers to and facilitators of participation in their communities.

1.1 Research Question

How do adolescents with physical disabilities perceive the factors that determine their participation and inclusion in their communities in South India?

1.2 Objectives

a) To examine the quality of life (QOL) of adolescents with physical disabilities from their perspective and from the perspective of their parents/caregivers.

b) To examine the QOL of adolescents with physical disabilities as compared to the QOL of their non-disabled peers.

c) To explore the views of adolescents with physical disabilities about their levels of participation within different sectors of their communities.

1.3 Proposed Outcomes

The proposed outcomes of this study are:

1) To determine if differences exist in perceived QOL between AWD and their parents/caregivers.

2) To determine if there are differences in perceived QOL between AWD and their non-disabled peers.

3) To describe the perceptions of AWD about their participation and inclusion in their communities and establish if there are differences between disabled and non-disabled adolescents.

4) To describe differences in aspirations for the future (specifically related to education and employment) between AWD and their parents/caregivers.

5) To establish factors that determine levels of participation among AWD.

1.4   Thesis overview

Chapter 2 reviews current research and knowledge about relevant facets of this topic. A brief history of the disability rights movement around the world is provided, with a focus on the UK and India. Models of disability and disablement are reviewed, along with their impact on approaches to intervention and service provision for people with disabilities. The prevalence of disability is also discussed, with a discussion of the pervasive methodological issues that have thus far prevented an accurate understanding of how many people are affected by disability around the world. Disability and poverty are often said to be part of a vicious cycle. Poverty is thought to both cause and perpetuate disability. Disability is also thought to cause poverty and keep people in impoverished circumstances. These issues are examined with specific focus on the theoretical impact of poverty on the lives of children and AWD. The focus of this research study is on adolescents with physical disabilities. The socio-political construct of adolescence is reviewed. The current research literature surrounding the particular concerns of AWD is also reviewed, including the issues of transition to adulthood. As QOL is a specific objective of this study, the literature about QOL in children and AWD is critically reviewed. Specific methodological challenges in the measurement of QOL are also included. Chapter 2 concludes with a detailed review of the construct of participation in view of disability and adolescence.

Chapter 3 provides details about the methods used in this research study. A mixed methods approach was employed to collect

data for the study. Data were collected in Bangalore, India through contacts in three local non-governmental organisations (NGO). Thirty-seven AWD, 25 parents or caregivers of AWD, and 24 non-disabled adolescent peers were recruited to participate in the research. A background information form and two measures of QOL were undertaken with each participant. Focus group discussions (FGD) were held with the non-disabled peers, interviews were conducted with parents, and both FGD and interviews were held with the AWD. The AWD also participated in a photography task as a means to facilitate communication and elicit information about their lives. The local NGOs provided assistance with translation, usually by a community health worker who accompanied the researcher (GK) during all interviews and FGD.

Results of the quantitative data analysis (background information and QOL measures) are presented in Chapter 4. All quantitative data was analysed using SPSS 15.0 software. Qualitative data analysis of the interviews and FGD is presented in Chapter 5. Qualitative analysis was conducted using a phenomenological approach. Data analysis was aided by the use of NVivo 7 software. Key themes that emerged from the data are presented in the Model of Inclusion and Participation, and are highlighted with examples from interview transcripts and AWD photographs. Finally, the discussion of key findings is presented in Chapter 6.

Chapter 2 – Literature Review

2.1 Disability

2.1.1 Models of disability and disablement

The concept of disability has evolved from one informed entirely by the medical tradition to the much more encompassing social model of disability and the rights-based approach. For some, this shift has been slow to come. For others in the fields of medicine and rehabilitation, it challenges the fundamental theories that underpin approaches to treatment and intervention. The early medical model viewed disability as a condition arising from illness or disease. This model suggested that people with disabilities were 'abnormal' and in need of a cure. Descriptions of people with disabilities as having a chronic illness arose from the theory that a health condition or disease was a direct cause of disability. Terminology used in the study of disability and rehabilitation informed by the medical model is steeped in references to 'fixing', 'healing' or 'normalising' the person with a disability. There was a need for the person with a disability to conform to socially defined norms of behaviour, movement or productivity. An inability to conform to these societal norms resulted in exclusion and discrimination.

Although research based on the medical model of disability has resulted in many positive gains for people with disabilities, the issue now is 'not one of life-expectancy but expectation of life' (Oliver, 1990, p.48). Although there are entirely good reasons why members of the medical profession are involved in the lives of people with disabilities, some viewed practitioners and researchers in the medical and rehabilitation fields as oppressors and contributors to the marginalisation of people with disabilities (Bricher, 2000). The synergy between people with disabilities, disabled persons' organisations (DPOs), and service delivery organisations, to name a few, has brought about dramatic changes in the views toward disability. The paternalistic, top-down approach of the medical model has been replaced with various approaches that emphasize participation and basic human rights (Rioux, 1997). Since the early 1970s, the social model of disability has developed, in part, as a reaction to the dominance of the medical profession in the lives of people with disabilities (Bricher, 2000).

The development of the social model is usually traced to a proposal forwarded by the Union of the Physically Impaired Against Segregation (UPIAS) in 1976; one that was adopted by Disabled People's International (DPI) (Siminski, 2003). The focus on the individual and his/her limitations in function was displaced by the idea that there are external barriers and attitudes that are disabling (Barnes & Mercer, 2001). The social model emphasizes that it is not the fault of the person with the disability that s/he faces discrimination and exclusion (Tregaskis, 2002). Where the medical model individualised disability (Bricher, 2000), the social model proposes that disability is caused by environmental, social, economic and other barriers that restrict the ability of people with disabilities to participate fully in society (Burchardt, 2004; Thomas, 2002). Within the social model, disability is not inherent to the individual (Rioux, 1997). Rather, people are disabled by the failure of society to accommodate their needs (Barnes, 2002). Moving away from the client-expert driven medical model, the social model of disability is interactive in nature, and believes disability is a shared responsibility amongst multiple parties (Dewsbury, Clarke, Randall, Rouncefield, & Sommerville, 2004). Barton (2001) believes that people with disabilities '…are not arguing for sameness, or to become as normal as possible…. They are desirous of the establishment of alternative definitions and perceptions based on a dignified view of difference' (p.10).

In a similar vein to the social model of disability, the rights-based approach to disability emphasises the need to protect people with disabilities from discrimination that arises from social structures and policies (Ellis, 2005). This approach looks at disability issues as an extension of human-rights (Barnes & Mercer, 2001). Political lobbying by disability-rights advocates and the work of organisations such as DPI have brought about significant changes in the last 30 years. People with disabilities are fighting against the domination of the biomedical model. They refuse 'to accept the view that they are victims of defective bodies or that they need care, cure or charity' (Hughes, 2002, p.65).

While the introduction of legislation designed to ensure non-discrimination and equal access to employment and education is laudable, the measures by which these laws are enforced in most countries are inadequate. Implementation of declarations such as the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (United Nations, 2006) may not occur widely in societies where resources are scarce and the cultural norm is to eschew individual needs in favour of the collective good. Lack of awareness among people with disabilities about existing legislation may also result in slow implementation of policies and poor enforcement (International Disability Network, 2005). Box 1 (overleaf) illustrates some examples of the progress of disability rights over the last 30 years internationally, in the United Kingdom (UK) and in India (Government of the United Kingdom, 1995; Government of the United Kingdom, 2005; International Disability Network, 2005; United Nations, 1993; Government of India, 2006). Changes in international policies and legislation, primarily brought about by the United Nations (UN), are meant to affect disability policy at the national level. Examples from the UK are provided as a comparison to those from India.

1975	The UN General Assembly adopts the Declaration on the Rights of Disabled Persons
1981	International Year for Disabled Persons (declared by UN)
1981	Formation of Disabled Persons International (DPI) by disabled activists whose goal was the empowerment of people with disabilities through political action; DPI achieves consultative status with the UN on disability rights issues
1983-92	United Nations Decade of Disabled Persons
1993-2002	Asian and Pacific Decade of Disabled Persons
1993	UN General Assembly adopts the Standard Rules on the Equalization of Opportunities for Persons with Disabilities, considered to be the most influential document on disability rights in its time
1994	Salamanca Declaration endorsing inclusive education for children with special needs and declaring inclusion as an essential human right; India is one of 92 signatories to the declaration
1995	Disabilities Discrimination Act (DDA) passed in the United Kingdom, after 15 attempts and 13 years after it was first initiated
1995	India passes the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act (PDA) which, like the DDA, enforces non-discrimination of and equal access for persons with disabilities in education and employment
1999	The National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act passed in India
2005	Disabilities Discrimination Act 2005 passed in the United Kingdom which builds on and extends legislation found in the DDA of 1995
2006	UN adopts the Convention on the Rights of Persons with Disabilities which has **137** signatories (including India and the United Kingdom) and **48** ratifications to date (including India)

Box 1. Key dates in the struggle for disability rights

It is interesting to note that India adopted legislation to protect the rights of people with disabilities (the PDA) at the same time as the UK passed the first version of the DDA, and before the UN adopted the UNCRPD in 2006. The work of disability advocates, organisations such as DPI, researchers, academics, governments, and NGOs has resulted in increased public awareness of the needs and rights of people with disabilities. Growing visibility in the news, movies, and other media has

contributed to the recognition that people with disabilities are entitled
to full and meaningful inclusion in the communities in which they live.

2.1.2 Conceptualising disability

Since the early 1950s, scholars from various fields have attempted to
conceptualise disability and to visually represent the relationship
between illness and disease and the consequent disability or handicap.
Models have been put forward by the World Health Organization (WHO),
the National Center for Medical Rehabilitation Research (NCMRR) in the
United States, and scholars such as Saad Nagi, Alan M. Jette, and Patrick
Fougeyrollas. The following section provides a brief overview of the
evolution of models of disablement and the contribution of these
scholars.

In 1965, the sociologist Saad Nagi developed a model of disability
(Mitra, 2006). Nagi's model was not a taxonomy to classify the impact of
disease on disability. Rather, Nagi's model was informed by sociological
theory (Verbrugge & Jette, 1994). Figure 1, below, provides a schematic
of Nagi's model.

Active→ pathology	Impairment→	Functional→ limitation	Disability
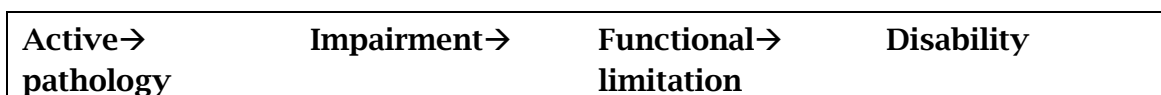
Figure 1. Nagi's scheme of disability (1965)

The classification of impairments, disabilities and handicaps
(ICIDH) developed by the World Health Organization (WHO) in 1980
(World Health Organization, 1980) drew heavily on the medical model of
disability. The ICIDH viewed the process of disablement as fixed and
unidirectional (Figure 2). Impairments were a direct consequence of a
disease process or illness, and disability was thus a consequence of
impairment. All three concepts of impairment, disability and handicap
were considered to be deviations from normal (World Health
Organization, 1980). Under the medical model, medical and
rehabilitation practitioners and researchers aimed to decrease the
prevalence of a disability or to find ways to decrease the impairment
which was felt to cause the disability (Rioux, 1997). By reducing the

degree of impairment, it was believed that the extent of the disability and the handicap, and therefore exclusion from societal roles, would be diminished. For example, an unborn child exposed to an infection in-utero ('disease or illness') might be born with increased muscle tone in his lower extremities ('impairment') that would result in an inability to walk ('disability') and prevent him from attending school ('handicap').

| Disease or illness → | Impairment → | Disability → | Handicap |
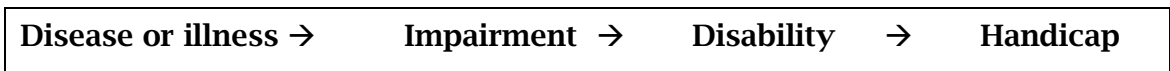
Figure 2. International Classification of Impairments, Disabilities, and Handicaps (ICIDH) (1980)

The ICIDH was heavily criticized, and disability advocates saw its linear construction and the implication that 'handicap' arose directly from 'impairment' as another reason for the discrimination of people with impairments (Masala & Petretto, 2008). The influence of external factors, such as the environment, in creating handicap was not acknowledged. Although the two models described above were developed from slightly different perspectives, they both outline a linear process from illness or pathology to handicap or disability. Neither model accounts for external factors which might modify, or add a dynamic element to the progression from illness to disability.

In the early 1990s, Verbrugge and Jette (1994) published their model of disablement, which incorporated both the ICIDH and Nagi's model, but with dynamic elements. Maintaining the linear process from pathology to disability as the main pathway, they added 'extra-individual factors', 'intra-individual factors' and 'risk factors' as elements that feed into and can alter the disablement process. This model of disablement was developed primarily to describe chronic illness in later life, such as arthritis or atherosclerosis, but the authors claimed that it could also be used for 'youth-onset' conditions (Verbrugge & Jette, 1994).

It was also at this time that the NCMRR (part of the National Institutes of Health) in Washington, DC, conceptualised the 'disablement process.' Unlike the ICIDH and the models by Nagi and Jette, the NCMRR model incorporated bi-directional arrows and added a fifth element of

'societal limitations' (NCMRR, 1993). This model, as illustrated in Figure 3, below, incorporated the criticisms of the previous models and responded to the growing disability movement in the United States that had been made more prominent by the introduction of the Americans with Disabilities Act (ADA) in the early 1990s. The use of this model emphasises that societal attitudes, for example, are just as likely to cause disability as the original pathophysiology or impairment.
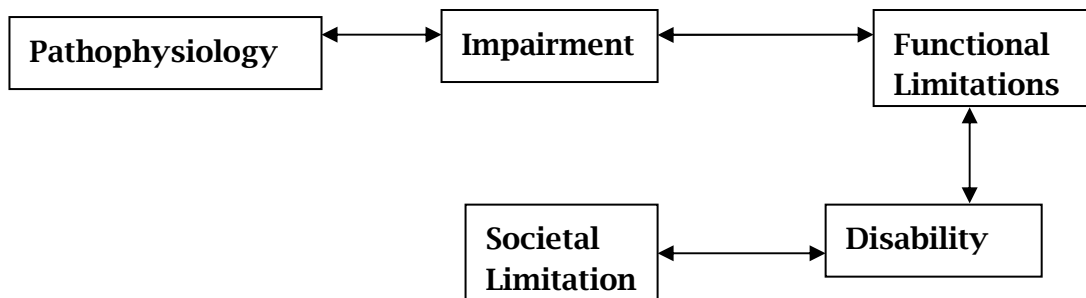
Figure 3. NCMRR disablement process (1993)

With the growing influence of the social model of disability and increasing concerns about the uni-directional and fixed nature of the ICIDH, the WHO began work towards revising the ICIDH, in order to more adequately address these criticisms. In particular, critics noted that the ICIDH failed to recognize the role of the environment in either reducing or emphasising the degree of a disability (Simeonsson, Lollar, Hollowell, & Adams, 2000).

One of the groups involved in the revision of the ICIDH was based in Quebec, Canada. The group, led by Patrick Fougeyrollas, published the Quebec Classification in 1999, now known as the Disability Creation Process (Fougeyrollas, Cloutier, Bergeron, Côté, & St Michel, 1999). This model, unlike the models that came before, was not based on the medical model, but on a model of human development. The origin of disability was not in illness or impairment; rather, disability was the consequence of interactions between multiple factors both within, and external to, the person. Figure 4 presents a simple schematic of the Disability Creation Process (DCP) (Fougeyrollas et al., 1999). In a dramatic departure from the other models illustrated above, the DCP is not linear, and moves the focus of disability away from the individual.

Another significant difference is that the DCP emphasises 'human development', including capabilities, not just disabilities (Fougeyrollas et al., 1999).
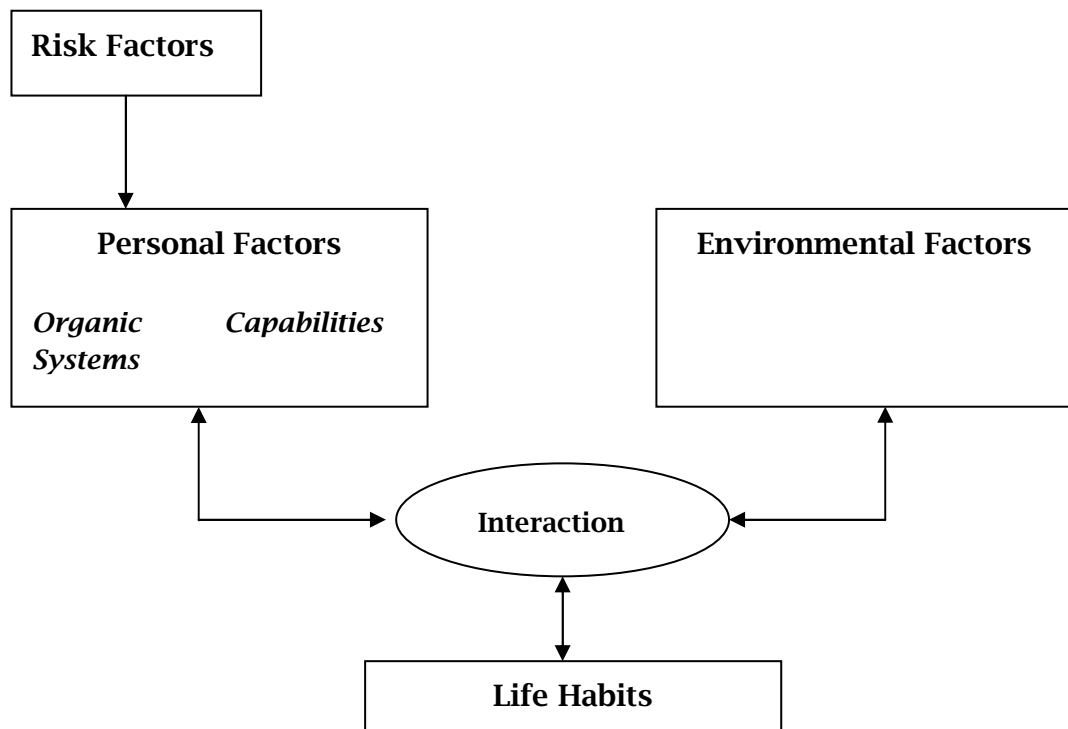
Figure 4. The Disability Creation Process (1999)

The revision process of the ICIDH culminated in the adoption of the International Classification of Functioning, Disability, and Health (ICF) (World Health Organization, 2001). The ICF provides a universal language to describe health and health-related states and establishes the 'basis for the scientific standardization of data on health and disability world-wide' (World Health Organization, 2001). Unlike its predecessors, the ICF is built upon the social model of health and disability. It describes the process of disablement as the negative interaction of an individual with a particular health condition and his/her environment. The ICF is not limited to a negative viewpoint, and describes 'functioning' as the positive interactions of an individual with his/her environment (Masala & Petretto, 2008). The ICF pays particular attention to the impact of both environmental and personal factors on the process of disablement.

The interactions of the components of the ICF are illustrated in Figure 5 below. The two major parts of the ICF are 1) functioning and disability and 2) contextual factors (World Health Organization, 2001). Functioning and disability encompass the middle row of the model: body structure and function, activities, and participation. Contextual factors, given equal importance in this model, are divided into environmental and personal factors. The umbrella term of 'disability' is used to describe problems with body structure and function (impairment), activities (activity limitation) or participation (participation restriction). Neutral aspects of health are grouped under the umbrella term of 'functioning.' Functioning and disability are considered to be an interaction between the health condition (illness, disease, disorder, etc.), and the contextual factors.
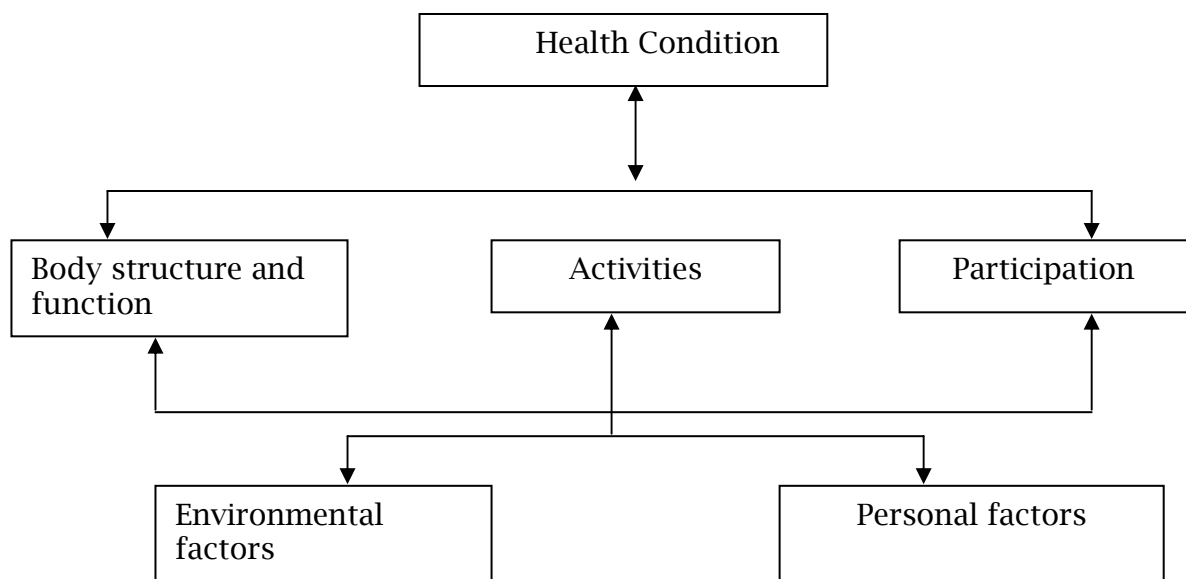
Figure 5. Components of the ICF (2001)

The definitions of the components of the ICF, as provided by the WHO (World Health Organization, 2001, p.10) are as follows:

- body function: physiologic functions of body systems, e.g. respiration
- body structure: anatomical structures, e.g. muscles, bones
- activity: the execution of a task or action, e.g. walking, eating
- participation: involvement in a life situation, e.g. attending school, playing

- environmental factors: physical, attitudinal and social environments in which people live, e.g. stairs, legislation
- personal factors: attributes of the person, e.g. motivation, age, gender, coping skills

The WHO provides detailed descriptions of each component in the ICF publication as well as coding guidelines that are meant to be used if the ICF is employed as a statistical tool.

The ICF enjoys world-wide recognition and wide-spread implementation. Unlike the early conceptualisations of disability, both the ICF and the DCP use the social model of disability as their theoretical base. Both models acknowledge the impact of external factors in what is a dynamic and multi-dimensional, not static and linear, process. Critics of the ICF claim that the model does not truly capture the dynamic nature of disablement, and that other models, such as the DCP (Fougeyrollas et al., 1999), are more effective at demonstrating the holistic and complex nature of disability. Perhaps no model can ever effectively capture the subtleties and nuances of disability and the disablement process. The two models illustrated above, however, provide a much-improved framework from which researchers can explore the nature of disability and better understand the process of disablement.

2.1.3 Prevalence of Disability

The global prevalence of disability is frequently said to be approximately 10% of any given population. This oft-quoted figure was first reported by Helander and subsequently by the WHO in 1976 (Helander, 1993). Little evidence in the research literature substantiates this figure. Data gathered through research and from census reports since the publication of this figure suggest that a prevalence of disability of 10% may by inaccurate and inflated. It is now felt to range anywhere from 0.2 – 21% of the world's population (Helander, 1993). The United Nations Children's Fund (UNICEF) report, 'The State of the World's Children 2008' (UNICEF, 2008) provides childhood disability statistics for 22 countries. The data is the most recent available between

1999 and 2006. Reported prevalence rates vary from 1% in Algeria to 35% in Djibouti (UNICEF, 2008).

The UN Disability Statistics Database (DISTAT) provides access to the UN Disability Statistics Compendium, which was published in 1990 (United Nations, 2008). The compendium provides disability statistics for 55 countries, along with detailed information about the methods used to collect the information. The website also provides figures for prevalence of disability from national census reports, as well as the question(s) asked on the census to collect information about disability. Examples of census questions from several countries are provided in Table 1.

Table 1. Examples of census questions about disability from UN DISTAT

Country	Census Questions
UK (1991)	Does the person have any long-term illness, health problem or handicap which limits his/her daily activities or the work he/she can do? Include problems which are due to old age.
Bangladesh (1982)	Type of disability a) Blind b) Crippled c) Deaf and dumb d) Mentally handicapped e) Others
Zambia (1990)	Is .... Blind? Yes No Deaf/dumb? Yes No Crippled? Yes No Mentally retarded? Yes No

Some countries such as Canada, the United States, and Egypt, asked more than ten questions pertaining to disability (United Nations, 2008). These questions covered a large spectrum of disabilities, including vision, hearing, mental health, physical disabilities, and learning disabilities. Despite the fact that this is the first comprehensive database of disability statistics from multiple countries, the data is not necessarily up-to-date for many countries. The only census data available on DISTAT for India is from 1981. In fact, India completed a census in 2001 and collected more detailed information about disability. This information will be discussed in more detail below.

It is difficult to ascertain precise estimates of disability for several reasons. First, the definition of disability varies between countries and among cultures. A primarily agrarian culture which relies solely on farming for its livelihood may not consider an adolescent with a mild cognitive deficit to have a disability. This same adolescent in a highly industrialised urban setting may encounter far more obstacles to participation, thus be considered to have significant limitations. The inclusion of so-called 'hidden' disabilities, such as mental illness, is inconsistently reported in prevalence figures. This is particularly an issue in countries where data on mental illness is not routinely collected or mental illnesses are not recognised. Attempts at documenting trends of disabilities in children and adolescents by comparing epidemiological studies were hampered by varying definitions of disability throughout the world as well as between different regions of the same country (Suris, 1995).

Second, the stigma associated with disability and attitudes toward disabilities in some cultures may also prevent complete and accurate reporting. Beliefs about causality, valued attributes and perception of adult roles in the community will determine how a particular cultural group views disability (Groce, 1999). These varying interpretations about disability can have a more significant impact on the life of a person with the disability than the original biological impairment. Indeed, the very concept of 'disability' must be viewed with caution. In some communities, '…one cannot be "disabled" for the simple reason that "disability" as a recognized category does not exist' (Whyte & Ingstad, 1995, p.7). In the state of Karnataka in southern India, for example, the terms for 'impairment', 'disability' and 'handicap' do not exist in the local language of Kannada (Murthy, Chatterji, Chandrasekar, & Sekar, 2001). In terms of causality, Room et al. (Room, Rehm, Trotter II, Paglia, & Üstün, 2001) state that, 'People in cultures that maintain a strong belief that bad outcomes reflect bad behaviour somewhere in the past, whether by the affected person or by the person's family, are far less sympathetic to people whose disabilities have been present from birth' (p.252). In such cultures, reporting a disability, particularly of a child,

may bring added stigma to one or more members of the family. Negative consequences for future employment and the ability to marry and have children can also prevent families from reporting disability. The accuracy of prevalence figures can be significantly distorted for these reasons.

Third, large variations in data collection methods may contribute to the inconsistent and inaccurate prevalence rates. Reported figures may be extrapolated to a country's population from birth and other records kept at hospitals in urban settings. Some countries use self-reporting of disability as part of national census data (Government of India, 2006). While this may be a step in the right direction for countries that have no previous history of documenting disability, census data is felt to be incomplete and likely under-identifies the prevalence of disability (Durkin et al., 1994).

The first Indian census since the country's independence to collect information on disability was conducted in 1981, but this practice was discontinued until the 1991 census. The reason given for discontinuing the collection of information about disabilities was that it was difficult to define disability (International Disability Network, 2005). Data gathered from the national census in India in 2001 indicates that the national prevalence of disability is approximately 2% (Government of India, 2006). This rate varies from state to state, as illustrated in Table 2.

Table 2. **Sample data from the Indian Census 2001**

State	Prevalence of Disability (%)	Literacy Rate (%)
India	**2.1**	**64.8**
Jharkhand	1.7	53.6
Karnataka	1.8	66.6
Kerala	2.7	90.9

When comparing certain states, it is interesting to note that the prevalence of disability increases as literacy rates improve, as in the case of Jharkand and Kerala. One possible explanation could be that

states with higher literacy rates, and thus presumably higher levels of education, are better equipped at identifying disability. Awareness of disability may also be higher in these states, as well as access to services for people with disabilities.

The Indian census conducted in 2001 included only 5 categories of disability: visual, hearing, speech, locomotor and mental. The International Disability Rights Monitor (2005) provides several reasons why the collection of this data may have been flawed:

1. The questions about disability were included towards the end of the census, and thus not usually asked.
2. The enumerators were not trained adequately to ask sensitive questions about disability.
3. The enumerators were biased and uninterested in disability.
4. The stigma attached to disability in India could have led to dishonest answers by respondents.
5. The respondents were not aware of the importance of collecting information about disability and thus did not answer the questions.

The possible flaws in the census data on disability were further underscored when the National Sample Survey Organization reported the disability prevalence to be lower than that reported in the 2001 census (International Disability Network, 2005). As a further critique, information is unavailable about the number of respondents who answered the question about disabilities, or if the question was asked to each member of a household or to only one respondent. Additionally, it is not clear how people with multiple disabilities would answer the census question.

Closer examination of the census data from India indicates a higher prevalence of disability in states with higher literacy rates such as Kerala. This finding is similar to that reported by Helander (1993), where the reported prevalence of disability in Canada was 13.3% as compared to 3% in Mali. He hypothesizes that this disparity may be a result of varying definitions of disability, inconsistent reporting, or higher infant mortality and lower life expectancy in a country such as

Mali (Helander, 1993). Under-reporting of disability rates may also be due to illiteracy, attitudes towards disability, or local perceptions of disability. The demographic composition of a country with higher life expectancy and a growing population of older adults can also lead to discrepant prevalence rates. These hypotheses may explain the variations in the prevalence of disability among the states of India. In general, inconsistent reporting, varying definitions, cultural associations and other social variables associated with disability lead to wide variances in prevalence figures around the world. The UN database website, DISTAT, contains a disclaimer that discourages the comparison of prevalence data across countries because of inconsistencies in data collection and reporting methodologies. Although the prevalence of disability is most often reported as 10%, it is clear that we have a poor understanding of the true prevalence of disability world-wide. Until definitions and data collection methodologies become standardized, it will be difficult to know just how many people with disabilities there are in the world.

2.2   Poverty

2.2.1 Disability and poverty

The connection between disability and poverty is one that is generally recognized and acknowledged by researchers and writers from many disparate fields. While it is frequently stated that poverty is both a cause and consequence of disability (ILO, UNESCO, & World Health Organization, 2004; World Bank, 2003; Anonymous, 2002; Dodd & Munck, 2002), there is little research evidence about the relationship between socioeconomic status (SES) and disability, particularly in low- and middle-income countries. The impact of poverty on disability is evident throughout the world. Poverty is seen as a cause of disability. Living in poverty compromises nutritional status. Poor maternal nutrition in expectant women has a direct impact on foetal development, raising the risk of both maternal and newborn morbidity and mortality. Poor nutrition in early infancy and childhood has direct links to certain disabilities. These will be discussed below.

Poverty is also seen as a factor in perpetuating disability. Lustig and Strauser (2004) suggest that living in poverty puts people in socially devalued roles. This results in limited access to employment, education and other opportunities to change their SES. They believe that limited access to opportunities can, and does, put people at increased risk of disability or raises the severity of pre-existing conditions (Lustig & Strauser, 2004). The notion of poverty resulting in limited access to education and employment is echoed by others (World Bank, 2003; Anonymous, 2002; Dodd & Munck, 2002). 'Lack of access to health care, rehabilitation, education, skills training, and employment contributes to the vicious cycle of poverty and disability' (ILO et al., 2004). Nagata (2007) describes this cycle of poverty and disability further, suggesting that it begins with the 'underdevelopment' of a society. Underdevelopment leads to economic poverty, which in turn brings about malnutrition and disease, leading to impairment and disability, which finally cause low levels of human development and productivity (Nagata, 2007).

Oliver (1990) believes that the approaches to disability under the medical model have resulted in a focus on changing the impairment at the expense of focusing on the economic independence of people with disabilities. Under the social model of disablement, poverty is seen as an expression of institutional discrimination, and therefore a contributor to the disabling process (Beresford, 1996). Discrimination and exclusion can lead to impairment, which in turn can lead to disability. Nagata (2007) echoes the call for disability to be viewed as an issue of social development, not just an issue of social welfare.

2.2.2 Disability, poverty, and children

The specific relationship between poverty and physical disability in children is a poorly reported topic. A search of the allied health database CINHAL using the terms 'disability', 'poverty', 'physical' and 'child*', combined with the Boolean operator 'AND', and searching only those articles published in English, revealed 19 records. Of these, only one study was based in a low- or middle-income country. The study, based in Guatemala, examined family resources as one of several factors

when examining the overall experience of families with an adolescent with a disability (Saetermoe, Gómez, Bámaca, & Gallardo, 2004). Families interviewed in the study indicated that their lack of financial resources had a negative impact on the health and function of their adolescent.

Two other studies about childhood disability focused on the prevalence rates of disability and the relationship to poverty or 'distressed' neighbourhoods in the United States (Msall, Avery, Msall, & Hogan, 2007; Parish & Cloud, 2006). Both studies showed that children with disabilities were more likely to live in impoverished circumstances than their non-disabled peers. Msall et al. (2007) used data from the census completed in 2000 to examine the relationship between rate of disability and neighbourhood distress. 'Distress' was defined using cut-off points for male employment, number of households headed only by females, high school drop-out rate, and the number of children living in poverty. The authors found that the rate of disability increased proportionally with the level of distress. Disability rates in the least distressed neighbourhoods were 11/1000, while rates in the most severely distressed areas were 37/1000 (Msall et al., 2007). The limitation of this study was that it did not include children with impairments of memory, learning or attention due to problems with census data in this area. Although the authors acknowledge the 'complex relationship between neighborhood disadvantage, family poverty,...access to health service, and injury' (Msall et al., 2007, p.814) the study does not attempt to examine this relationship in detail.

Parish and Cloud (2006) suggest that financial well-being and parental employment are influenced by factors such as parental education and skills, access to employment, availability of affordable and adequate childcare, and transportation. It seems to be universally assumed, in countries such as the United States, that the cost of raising a child with severe impairments is greater, thereby pushing poor families further into poverty. Another assumption is that having a child with a disability negatively impacts maternal employment (Parish & Cloud, 2006). Research findings in this area are inconsistent, however, and the link between disability and maternal employment is tenuous at

best. Finally, there is little to no research about the ability of parents to access appropriate childcare for a child with a disability. This brings into question the assumption that parental employment is adversely affected by the lack of childcare, thereby increasing poverty.

More generally, studies have examined the impact of nutritional status on child health. It is widely accepted that maternal nutritional deficiencies result in increased infant and child morbidity and mortality (Black et al., 2008). Poor maternal nutrition during pregnancy increases the risk for pre-term birth, low birth weight, and intra-uterine growth retardation. Iron deficiency in very young children has been reported to have adverse effects on neurodevelopment, leading to poor school performance and decreased motor activity (Zimmerman & Hurrell, 2007). Zinc deficiencies lead to increased susceptibility to infectious diseases, particularly diarrhoea, and possible growth retardation in children (Fischer Walker, Ezzati, & Black, 2008). Corneal scarring leading to blindness is directly attributable to vitamin A deficiencies (Black et al., 2008). Poor maternal and child nutritional status can be viewed as a direct consequence of poverty. The burden of disease and disability due to malnutrition is significantly higher in low-income countries, and in communities of a lower SES.

Bauman et al. (2006) examined the effects of social and economic factors on child health. They found that the cumulative effects of poverty, poor parental education, and living in a single-parent family increased a child's risk of having a chronic condition or an activity limitation. Although this study did not discuss children with physical disabilities specifically, it did lend support to the argument that poverty and health are closely intertwined, and that the perpetuation of poverty and chronic illness can span multiple generations. Weinreb et al. (2002) examined the impact of hunger on children's health. Hunger was assumed to be a direct consequence of poverty, and the study found that hunger had a direct impact on chronic illness and behaviour. Disability, however, was not investigated in this study.

Except for the study by Saetermoe et al. (2004) discussed above, there is no research into the relationship between childhood disability

and poverty in low- and middle-income countries. Social and cultural factors must be taken into account in this discussion, making it inappropriate to apply findings from the United States and Europe to the situation of children and adolescents with disabilities in the developing world. More research is required to validate the belief that disability and poverty are inextricably linked, and to determine the manner in which poverty impacts on disability in childhood.

2.3   Adolescence

2.3.1 Defining adolescence

Adolescence is both a biological and social phenomenon. The first documented use of the term was in 1430, and it is defined in the Oxford English Dictionary as 'the process or condition of growing up; the period which extends from childhood to manhood or womanhood; ordinarily considered as extending from 14 to 25 in males and from 12 to 21 in females' (OED, 1989). Other sources define adolescence as beginning with the onset of puberty and ending at the age of majority (Webster, 1961). If the political definition of 'age of majority' marks the end of adolescence, then depending on the country in question, it will occur anywhere between 18 and 21 years of age. The overlap of biological and socio-political constructs contributes to the differing views of adolescence throughout the world and the variable use of the word 'adolescence' to describe older children. UNICEF states that adolescence begins roughly at 10 years of age, and ends at about 19 years (UNICEF, 2002). It further defines 'youth' as the period extending from 19 to 25 years of age (Groce, 2004). It is estimated that there are approximately 1.2 billion adolescents between the ages of 10 and 19 in the world, and that 80% of them live in low- and middle-income countries (UNICEF, 2002).

This definition of adolescence is not necessarily applicable to all cultures and communities. In India, for example, the marriage of a girl of 14 years can move her directly from childhood to adulthood. Conversely, a child with a disability can be forever entrenched in 'childhood' if she does not assume adult roles in the community such as

marriage or bearing children. The 'western' view of childhood and adolescence has influenced how children and adolescents are viewed in the developing world, perhaps inappropriately (Ansell, 2005).

The construct of adolescence and its distinction from both childhood and adulthood is a relatively recent one. The 'Western' concept of adolescence did not emerge until the industrial revolution when families no longer required older children to work in order to supplement the family income (Hall, 1904). Similarly, other authors believe that the concept of adolescence as the phase between childhood and adulthood is '…an epiphenomenon of modern industrial societies' (Mensch, Bruce, & Greene, 1998, p.4). Even today in low-income countries with very low life expectancy, 18 years can be middle age, thereby eliminating the phase of adolescence. In some cultures, adolescence is subsumed under the broader label of 'youth', a period which only ends with a significant event marking the entrance into adulthood, such as marriage (Brown & Larson, 2002). Adolescence is not considered a distinct period of development in these cultures, and thus adolescents are not afforded particular rights (UNICEF, 2002).

The belief that the period of adolescence is marked by increasing independence is prevalent in Western cultures. Coleman (1980) states that 'independence is much more likely to mean freedom within the family to make day-to-day decisions, emotional freedom to make new relationships, and personal freedom to take responsibility for one's self in such things as education, political beliefs and future career' (p.64). This 'negotiation of autonomy…[is] central to Western adolescence' (Brown & Larson, 2002, p.2). Regardless of whether or not adolescence is seen as a distinct phase of development, it is a period of transition from childhood into adulthood, and one in which young people begin to acquire the skills they will require to function as productive adult members of the society in which they live (Brown & Larson, 2002; UNICEF, 2002).

Whether they are referred to as 'children', 'adolescents', or 'youth', the period between the ages of 10 and 19 years is one that is particularly influenced by three main factors of family relationships,

education and peer groups. In a Western culture, the adolescent period is marked by the establishment of autonomy within the family, while at the same time remaining dependent on parents or caregivers for financial and emotional support and security (Coleman, 1980). By contrast, adolescents in an Indian family must balance this struggle for independence with the inherent interdependence of family members and the absolute authority of the head of the household (Verma & Saraswathi, 2002).

Second, '[e]ducation is a key to the fulfilment of other human rights and the catalyst for realizing human potential' (UNICEF, 2002, p.13). Access to education is a basic right stated in Article 28 of the United Nations Convention on the Rights of the Child (UNCRC) (United Nations, 1989). Many countries have mandated primary education, with some extending this to secondary education. The statistics, however, tell a different story. Increasing demand for education, a lack of trained teachers and lack of infrastructure mean that access to schools is limited for many children, particularly in low- and middle-income countries (Fussell & Greene, 2002). India has the largest number of children who are not enrolled in school, with more than half of those who are enrolled dropping out before the age of 14 years (Verma & Saraswathi, 2002). Children living in rural areas, those from lower socio-economic groups or lower castes, children from tribal communities and girls are particularly affected by the disparity in access to education in India.

Finally, the influence of peers on the social and emotional development of adolescents can be far-reaching, particularly when parents do not have the ability to meet all their child's needs (UNICEF, 2002). The effect of peers on social development in adolescence is variable in different cultures. In India, it is very much dependent on social class. Adolescents whose families occupy the upper socioeconomic classes tend to have more leisure time and more financial resources, and thus are influenced more by a 'distinct peer culture' as compared to their contemporaries who occupy lower socio-economic strata (Verma & Saraswathi, 2002).

It can be argued, however, that interaction with peers also shapes the lives of adolescents from lower socioeconomic groups. Although they may not have a peer group independent of their parents, adolescents from lower socioeconomic groups may live in high-density housing or slums. These living circumstances dictate that they spend large amounts of time with their peers. This interaction can still have a significant impact on their social and emotional development. In addition, increasing numbers of adolescents are migrating from rural areas to cities in search of employment. These adolescents do not live with their families, but live and socialise with peers. Marginalised adolescents in urban centres, such as street children, are also heavily influenced by their peers, almost to the exclusion of adults.

The picture of adolescence around the globe is changing rapidly with globalisation and urbanisation, particularly in low- and middle-income countries (UNICEF, 2002; Fussell & Greene, 2002). More adolescents are growing up in urban centres, where exposure to ideologies, attitudes and products from 'western' countries is significant. Experimentation with these new ideologies can cause stress and conflict between adolescents and their families. In India, for example, the move from rural to urban areas can mean greater access to education and health services for adolescents with disabilities. It can also mean, however, a concurrent loss of community support and strain on family finances due to a reduction in wages and a higher cost of living. No less significant on the lives of adolescents throughout the world are the impact of gender and disability. Adolescent girls are more frequently denied access to education, marry and begin child-bearing earlier than their brothers or male peers, and experience double-standards in such areas as sexuality and employment (Fussell & Greene, 2002; Mensch et al., 1998; UNICEF, 2002; Verma & Saraswathi, 2002).

2.3.2 Adolescents with disabilities

Adolescents with disabilities (AWD) are further disadvantaged, and their challenges can be increasingly compounded by socioeconomic circumstances. The needs of AWD for education, vocational training,

employment, inclusion in recreational and spiritual activities, and participation in family life are no different than the needs of their peers without disabilities. 'What distinguishes this large group of youth are not their common needs, but the fact that these needs continue to go so largely unmet' (Groce, 2004, p.14). These needs are not just unmet, but largely unrecognized and unknown. Little has been said about AWD in the disability and rehabilitation literature. The majority of research with AWD has been conducted in North America or Europe. As Groce (2004) points out, there has been little to no research on AWD as distinct group in low- and middle-income countries.

Lack of access to education and marginalisation in society makes AWD a particularly vulnerable group. Yousafzai et al. (2005) found that AWD were unable to access information and education about HIV/AIDS, particularly those with barriers to communication. In addition, misconceptions about the sexuality of AWD excluded them from HIV services and, particularly for adolescent girls, made them more vulnerable to sexual exploitation. AWD are frequently left out of sexual education opportunities. In some cultures, people with disabilities are not viewed as sexual beings, thus not in need of sexual health education programmes.

The findings of Yousafzai et al. (2005) echoed those of Stevens et al. (1996) who found that AWD were less likely to receive information about birth control, sexual abuse or sexually transmitted infections. This vulnerability is compounded by lower educational aspirations, which can subsequently lead to economic challenges and further barriers to participation. This same group concluded that '…adolescents with disabilities are less oriented toward the future educationally, vocationally, and hence, economically' (Stevens et al., 1996, p.163). It is difficult to determine whether the lower educational aspirations and future-orientation are due to parental and societal influence, or are inherent to AWD.

Many studies about AWD from high-income countries focus on their self-esteem or perceived self-worth, or on issues of transition into adulthood. When compared to their non-disabled peers, research shows

that AWD score similarly on measures of self-esteem (Stevens et al., 1996; Manuel, Balkrishnan, Camacho, Smith, & Koman, 2003). The same was true for adolescents with spina bifida when compared to those with spinal cord injuries (Antle, 2004), or in adolescents who were extremely low birth weight and born prematurely (Saigal, Lambert, Russ, & Hoult, 2002). Another common finding was the decrease in self-esteem scores in older adolescents (Antle, 2004), and the lower self-esteem scores in girls compared to boys, both with and without disabilities. Although AWD did not report having fewer friends, their friendships were found to be less intense (Saigal et al., 2002; Antle, 2004).

2.3.3 Transition from adolescence to adulthood

The issue of transition from adolescence to adulthood is one of great interest in the fields of health and education. Much of the current work in this area focuses on adolescents without disabilities. The few studies which have investigated transition of AWD were conducted in North America and Europe, giving the findings a 'Western' bias. Saigal and colleagues (2006) used four key markers to determine successful transition to adulthood of adolescents who were extremely low birth weight. These markers were: 1) educational attainment; 2) marriage; 3) parenthood; and 4) independent living (Saigal et al., 2006). Only 27% of their sample, however, had identified disabilities. The transition to adulthood for AWD is complex and challenging (Stewart, Law, Rosenbaum, & Willms, 2001; Beresford, 2004). Young adults with disabilities defined success in adult life as 'being happy' (King, Cathers, Polgar, MacKinnon, & Havens, 2000). Thematic analysis of semi-structured interviews conducted by King et al. (2000) revealed that the key factors to success were being believed in by others, believing in yourself, and acceptance by others.

Two factors were found to be critical in improving the process of transition to adulthood for AWD. First, AWD and their families need to be key players in the decision-making process during transition, and require appropriate support from professionals during this time (Beresford, 2004). A study in the UK found that service provision becomes increasingly fragmented after children with cerebral palsy

leave school (Stevenson, Pharoah, & Stevenson, 1997). Poor service provision increases caregiver stress, makes information about assistance difficult to obtain, and results in decreased inclusion of young adults with cerebral palsy in their communities. Second, the lack of opportunities and experiences afforded them during childhood to make choices and decisions hampered their ability to be fully involved in these processes during adolescence (Stewart et al., 2001; Beresford, 2004). Without these opportunities, AWD are ill-prepared for their adult roles. A review of the literature by Liptak (2008) found that adults with cerebral palsy are limited in their activities (such as mobility) and less able to participate in their communities (finding meaningful employment, for example) than adults without disabilities. Their decline in physical health, access to services, and decreasing participation begins to occur during adolescence. AWD require sufficient support during this period of transition to ensure optimal participation in meaningful activities as they enter adulthood.

Despite the fact that the issues of AWD in low- and middle-income countries are recognized to be many and complex, there is astonishingly little research investigating their unique needs, and more importantly, the delivery of appropriate services that will allow them to participate fully in their communities. Existing research on AWD and the transition to adulthood has focused on the issues of young people living in North America and Europe. Models of service delivery for both children and adults in these regions differ vastly from those in low- and middle-income countries. Recommendations on service provision for transition planning may not be relevant in contexts where there is a lack of services in general. Much more research is needed into the lives of AWD in developing countries if we are to design meaningful and appropriate services that will enhance their participation and inclusion.

2.4   Quality of Life

2.4.1 Defining quality of life

As a concept, it is widely agreed that quality of life (QOL) is ill-defined (Moons, Budts, & De Geest, 2006; Rosenbaum, Livingston, Palisano,

Galuppi, & Russell, 2007; Muldoon, Barger, Flory, & Manuck, 1998; Albrecht & Devlieger, 1999; Hak, 2001; Brown & Brown, 2003; Bowling, 2005). There are increasing numbers of articles about QOL published annually. The measurement of QOL is becoming more popular for use in evaluating medical and rehabilitation interventions, in programme-planning, and in the formulation of health policy. Under the medical model of disability, interventions were evaluated strictly in terms of their impact on reducing the 'disabling' condition. With the advent of the social model of disability and the use of the ICF to guide practice, researchers and clinicians alike are interested on the impact of interventions and programs on the overall quality of a person's life and well-being. In spite of the growing use of the concept, QOL remains an imprecise term. The issue becomes further complicated when the term 'health-related quality of life' is used.

Health-related quality of life (HRQOL) is defined as the impact of a disease, illness or medical condition, and the subsequent impact of its treatment on perceived satisfaction with life (Muldoon et al., 1998; Ronen, Rosenbaum, Law, & Streiner, 2001). Albrecht & Devlieger (1999) argue that QOL is a broader concept than HRQOL, and this is especially important to remember when discussing the lives of people with disabilities. Definitions of QOL vary, and include: 'satisfaction with life' (Moons et al., 2006); 'holistic well-being' (Rosenbaum et al., 2007); a concept which includes social, spiritual and psychological well-being (Albrecht & Devlieger, 1999); the interaction between a person and his/her environment (Brown & Brown, 2003); or individual perceived health status and well-being (Muldoon et al., 1998). The WHO's definition of health as 'a state of complete physical, mental and social well-being, and not merely the absence of disease or infirmity' (World Health Organization, 2006) is often used as a starting point for defining and measuring QOL. Whilst this definition of 'health' may seem all-encompassing, questions arise when considering people with disabilities. Can a person who is physically disabled due to polio, and thus is not in a 'state of complete physical well-being', still have good QOL?

It is important to delineate health status as a unique entity and not merely a synonym for QOL. Research to date has not made this distinction clearly, although most people view the two as independent, but overlapping, concepts. When the term HRQOL is used for research or outcome evaluation, the waters are further muddied. A meta-analysis of QOL literature revealed that patients did not equate health status with QOL (Smith, Avis, & Assmann, 1999). Mental health and emotional well-being were most closely correlated with QOL, while health status was more closely related to physical function, pain and energy/fatigue. The concept of HRQOL can be viewed, then, as a separate concept subsumed within the broader model of QOL (Bjornson & McLaughlin, 2001).

Quality of life is partially dependent on health status, but it also encompasses the much broader issue of an individual's perception of their life and health (Muldoon et al., 1998). Cultural norms dictate certain differences in the approach to QOL but there are some similar values across cultural groups. Bowling (2005) outlines some of these values:

- Psychological outlook and emotional well-being
- Good physical health
- The physical ability to do what they want
- Good social relationships, including family and friends, and the ability to participate in social activities and recreation
- Safe living conditions
- Having enough money to meet needs and being independent

Schalock et al. (2005) propose that cultural differences account for differential values being placed on various aspects of QOL. In general, however, they believe that QOL has eight core domains that are common across cultures (Schalock et al., 2005). These domains are:

- Emotional well-being
- Interpersonal relations
- Material well-being
- Personal development
- Physical well-being

- Self-determination
- Social inclusion
- Rights

Research using these eight core QOL values with adults with mental retardation in North America, China, South America and Europe, supported the hypothesis that cultural differences are reflected in the relative importance given to each of the core values by professionals, parents and user groups (Schalock et al., 2005). Quality of life, then, can be broadly defined as an individual's perceived satisfaction with his/her life, including physical, psychological and social domains. This definition includes, but is not restricted to, HRQOL. This is the definition adopted in the study reported in this thesis.

2.4.2 Quality of life and adolescents with disabilities

People without disabilities, including members of the public, service providers, researchers, and policy-makers have long assumed that the presence of a disability results in a lower QOL. Using some definitions discussed above, these groups have argued that any type of disability would result in a state of less than complete well-being and thus reduced QOL. On the contrary, research has shown that people with disabilities experience good QOL (Albrecht & Devlieger, 1999). Although their health status was compromised in various ways, 54.3% of people included in a study reported a good to excellent QOL (Albrecht & Devlieger, 1999). The researchers found that for people with disabilities, good QOL came from doing well within the constraints of the disability, and that pain and fatigue were the factors that most often negatively impacted QOL. '[People with disabilities] are satisfied with who they are and are able to reach their life goals despite or even because of their disabilities, despite society's tendency to view disability as a continuing tragedy' (Weinberg, 1988, p.152). A reduction in environmental constraints and barriers, increased social support and the use of assistive devices all lead to a higher QOL.

Little is known about the QOL of AWD, particularly in low- and middle-income countries. The past eight years have seen a sudden

increase in the number of research articles published about the QOL of children and AWD, primarily in North America and Europe. In order to summarise the current state of knowledge about QOL and children with disabilities or AWD, a search of relevant databases (CINAHL, PubMed, EMBASE and PsychINFO) was performed for the years 2000 to 2008. When limited to physical or developmental disabilities (excluding autism, learning disabilities, or other cognitive disabilities), 20 papers were found that either reviewed QOL issues in children and AWD, or directly investigated their QOL. The search also excluded articles that described the development of tools and outcome measures to evaluate QOL of children with disabilities. A brief discussion of measurement issues in QOL follows in the next section. The 20 retrieved articles are summarised in Table 3.

Table 3. Summary of research (2000 – 2008) about QOL and children or adolescents with physical or developmental disabilities

Study	Population/Place of study	Methods	Dimensions measured	Results
(Ronen et al., 2001)	• Children aged 6 – 12 years with active epilepsy • Parent focus group • Canada	• Qualitative methods using focus groups	• Investigated HRQOL • Primary aim was to determine the feasibility of using a focus group technique with children	• Determined that the main facets of HRQOL fell into 5 main themes: 1) experience of epilepsy; 2) Life fulfilment/time use; 3) Social; 4) Impact of epilepsy; and 5) Attribution
(Bjornson & McLaughlin, 2001)	• N/A	• Review article which focuses on outcome measures used to assess HRQOL in children with cerebral palsy	• HRQOL	• Calls for measures specifically designed for children with cerebral palsy • Provides recommendations for measures that would be appropriate for children
(Padua et al., 2002)	• 12 adolescents (14-18 years) with spina bifida • Italy	• Participants were asked to complete the SF-36 • Detailed clinical examination on each participant • Disability assessments using the FIM (measure of function) and the Barthel Index (a scale of capacity in reference to daily activities)	• HRQOL – used the SF-36 to measure QOL and examined the correlation with measures of disability and clinical measurements • The SF-36 provides a measure of general health status in 8 categories: physical functioning, role-physical, bodily pain, general health, vitality, social functioning, role-emotional, and mental health • Scores are summarized into a Physical Composite score and a Mental Composite score; low scores indicate increased impairment	• Significant correlations between the physical aspects of the QOL measure (SF-36) and the Barthel Index and walking ability • Low physical disability was correlated with low Mental Composite scores, indicating higher levels of psychological distress and emotional problems • Minimal correlations between clinical assessments (muscle strength, reflexes, etc.) and QOL scores

Study	Population/Place of study	Methods	Dimensions measured	Results
(Edwards, Patrick, & Topoloski, 2003)	• 2801 students between 12 and 18 years of age • 21% reported have disabilities (physical, learning or emotional) • United States	• Youth Quality of Life Instrument (YQOL) • Tool was administered to all students who participated in study	• QOL • Self-rated health, depressive symptoms and contextual variables	• 46% of adolescents with disabilities reported an activity limitation • Adolescents with disabilities had significantly lower QOL than non-disabled adolescents • Self-rating of health, depressive symptoms and contextual factors predicted significant proportion of the variance in QOL between disabled and non-disabled adolescents • Depressive symptoms accounted for the largest variation in QOL scores • When controlling for these factors, there was no significant difference in QOL between disabled and non-disabled groups
(Jirojanakul, Skevington, & Hudson, 2003)	• 278 children of construction workers and 220 urban children • Children between ages of 5 and 8 years • Bangkok, Thailand	• Developed a child's QOL tool based on the WHOQOL-100 • Self-report measure that can be adapted for children with lower levels of literacy • Can be administered individually or in groups • Also administered a 'carer's form' to ascertain the child's QOL from the carer's perspective	• Aim of study was to investigate determinants of a child's QOL • Hypothesized that there were a number of factors that would determine the QOL • Collected data on 23 independent variables that may contribute to QOL	• Health (mild to chronic ill health) was not a significant determinant of QOL • Single most significant determinant of QOL in both groups of children was father's income, particularly for children of construction workers • Almost all other social-environmental factors (e.g. housing, education, transportation) were significantly related to QOL

Study	Population/Place of study	Methods	Dimensions measured	Results
(Wake, Salmon, & Reddihough, 2003)	• 80 children and adolescents between 5 and 18 years with cerebral palsy • Australia	• CHQ-PF50 • Questionnaires were sent to 118 eligible families • Families were asked to complete the form and return it by post	• HRQOL • CHQ-PF50 measures aspects of health which are important to children (physical, social, emotional, and family dimensions) through a parent-report • Scales include: physical functioning, role/social-emotional, role/social-physical, bodily pain/discomfort, behaviour, mental health, self-esteem, general health, parent impact-emotional, parent impact-time, family activities, family cohesion, change in health	• CHQ-PF50 scores for children with cerebral palsy were significantly lower on all scales compared to the normative sample • When comparing children with mild and severe cerebral palsy, those with severe disabilities scored significantly lower on the Physical Summary score (and most of the physical health scales) • Children with mild cerebral palsy had significantly lower scores on the behaviour scale compared to those with severe disabilities • Authors conclude that the CHQ is a reliable and valid tool for children with cerebral palsy and one that provides a 'snapshot' view of parents' perceptions of their child's health and well-being
(Houlihan, O'Donnell, Conaway, & Stevenson, 2004)	• 198 children, 5 to 18 years of age, with moderate to severe cerebral palsy • Canada	• CHQ-PF50	• Influence of frequency of pain on HRQOL • Also measured influence of pain frequency on participation and function	• Frequency of pain was significantly higher in children with cerebral palsy than the normative sample on the CHQ-PF50 • Pain frequency had an impact on QOL and participation (more days of school missed, impact on usual activities and family activities) • Pain frequency was higher in children with increasing severity of cerebral palsy

Study	Population/Place of study	Methods	Dimensions measured	Results
(Bier, Prince, Tremont, & Msall, 2005)	• 34 participants with myelomeningocele between 4 and 27 years of age (mean age 13 years) • United States	• Aim was to determine the predictors of HRQOL • HROQL measured using rating scale – participants had to assess the HRQOL of 5 hypothetical individuals with varying health conditions, then assess their own HRQOL using same scale • Parents of 28 participants completed all tools; 6 adolescents and young adults completed the study themselves	• Measured functional independence using the WeeFIM • Social Functions Scale (parental need for assistance); Family Support Scale; Amount of Assistance Scale (AAS); Health Utilities Index (HUI-II) • Intelligence of participants assessed using KBIT	• AAS scores were the most highly associated with HRQOL • The combination of AAS, WeeFIM (Self-care) and the HUI-II has the most significant association with HRQOL • Children who required less assistance with activities of daily living had higher HRQOL scores
(Vargus-Adams, 2005)	• 177 children with cerebral palsy between 3 and 18 years of age (mean age 8.5 years) • United States	• CHQ-PF50 administered to parents/guardians of children	• HRQOL • Investigated the relationship of HRQOL and severity of cerebral palsy as measured by the Gross Motor Function Classification System (GMFCS)	• Overall, children with cerebral palsy had CHQ-PF50 scores of >1 SD below the normative mean score • Most CHQ-PF50 subscales had significant correlation with severity of cerebral palsy as measured on GMFCS, particularly subscales concerned with physical functioning • Mental health, emotional-behavioural and self-esteem subscales were not significantly correlated with GMFCS scores

Study	Population/Place of study	Methods	Dimensions measured	Results
(Chow, Lo, & Cummins, 2005)	• 72 adolescents between 11 and 18 years of age with physical disabilities in special schools • 510 students between 11 and 18 years of age without disabilities • Hong Kong	• Student version of the Comprehensive Quality of Life Scale (ComQoL) • Adolescents in both groups completed the ComQoL independently in their classroom settings, with assistance provided to those with disabilities only if it was required for filling in the responses	• ComQoL has 7 objective domains: 1) material wellbeing; 2) health; 3) productivity; 4) intimacy; 5) safety; 6) place in community; and 7) emotional wellbeing • Each objective domain consists of 3 items • For each of the 7 domains, the respondents also indicated a subjective rating, consisting of 2 questions – level of satisfaction and degree of importance of that domain	• Adolescents with physical disabilities had significantly lower objective QOL scores compared to the control group, but there was no difference in subjective QOL scores • In particular, the objective differences were in the health, intimacy and safety domains of the ComQoL • When adjusted for the gender imbalance in the group with disabilities, there was a significant difference in the subjective QOL ratings for the domain of safety • There was a significant drop in subjective QOL for the adolescents without disabilities with increasing age • There was no significant correlation between subjective and objective QOL for either group

Study	Population/Place of study	Methods	Dimensions measured	Results
(Schoenmakers, Uiterwaal, Gulmans, Gooskens, & Helders, 2005)	• 122 children with myelomeningocele, between 1 and 18 years of age • Netherlands	• Spina Bifida Health Related Quality of Life Questionnaire (proxy parental report for children, adolescents complete questionnaire themselves) • Functional abilities measured by the PEDI (Pediatric Evaluation of Disability Inventory) • Other measures of impairment also included (e.g. muscle strength, intelligence)	• HRQOL • Investigated which functional abilities were determinants of HRQOL	• HROQL was significantly associated with functional ambulation (child was a household or community walker) and having independent mobility • Independence in self-care was not significantly associated with higher HRQOL
(Varni et al., 2005)	• 148 children with cerebral palsy between 5 and 18 years of age (mean age 10 years) and/or their families • United States	• Pediatric Quality of Life Inventory Version 4.0 (PedsQL 4.0) • Administered by interview to children who could not read or write • Other children completed tool independently • Parents of children with cerebral palsy also completed the tool	• HRQOL • Study investigated if children with cerebral palsy were able to self-report on HRQOL	• 69 children were able to self-report on HRQOL • HRQOL in children with cerebral palsy was significantly lower than children without disabilities • Children with more severe impairments had lower HRQOL • Extremely low correlations between child-report and parent-proxy report on Emotional Functioning and School Functioning subscales

Study	Population/Place of study	Methods	Dimensions measured	Results
(Dickinson et al., 2007)	• 818 children with cerebral palsy between 8 and 12 years of age • part of the Study of Participation of Children with Cerebral Palsy Living in Europe (SPARCLE) • Europe	• Kidscreen (generic HRQOL measure for children between 8 and 18 years) • 500 children self-reported • 318 children were unable to self-report because of intellectual impairment (parent-proxy report)	• HRQOL • HRQOL scores were correlated with impairments, pain and compared to the general population	• Children with cerebral palsy had similar QOL to children in the general population except in the domain of school environment (children with cerebral palsy had a higher QOL) • Pain was significantly associated with several domains of the Kidscreen
(Rosenbaum et al., 2007)	• 203 adolescents with cerebral palsy (mean age 16 years) • Canada	• QOL measured using the Quality of Life Instrument for People with Developmental Disabilities • HRQOL measured using the Health Utilities Index, Mark 3 (HUI3) • QOL self-reported by adolescents (or proxy if participant had communication difficulties) • HRQOL reported by proxy	• QOL • HRQOL • Looked at relationship between QOL and HRQOL • Measured gross motor function using the GMFCS	• No interaction between GMFCS levels and QOL scores • In 2 of 3 QOL domains and overall QOL scores, proxy scores were lower than self-report scores • Weak correlations between QOL and HUI3 scores • HUI3 scores decreased significantly with increasing severity of impairment

Study	Population/Place of study	Methods	Dimensions measured	Results
(Young, Rice, Dixon-Woods, Colver, & Parkinson, 2007)	• 28 children with cerebral palsy aged 8 to 13 years • 35 parents • part SPARCLE • Europe	• Qualitative methods using individual interviews with children and parents • Purpose of study was to determine how well children's priorities are represented by the Kidscreen	• Investigated children's priorities about what they think is most important for their HRQOL	• Four main themes emerged from qualitative data analysis: 1) social relationships; 2) home and school environments; 3) self and body; and 4) recreational activities and resources • Authors conclude that the Kidscreen maps well to the priorities of children, but does have some limitations and does not cover certain areas, such as home life, inclusion in relationships with other family members, access to recreational resources (not including finance) and free time
(Livingston, Rosenbaum, Russell, & Palisano, 2007)	• N/A	• Review article	• QOL and HRQOL • Reviewed literature pertaining to QOL in children, adolescents and adults with cerebral palsy	• 20 articles reviewed • variety of measures utilized in literature, including measures of health status, QOL, and condition-specific measures • people with cerebral palsy had decreased health status compared to those without disabilities • little relationship between function and QOL or well-being in people with cerebral palsy • highest correlations were between physical function and measures of physical well-being • few studies that looked specifically at QOL in adolescents with cerebral palsy • one study determined that QOL measures designed for adults were not appropriate for use with adolescents with disabilities

Study	Population/Place of study	Methods	Dimensions measured	Results
(White-Koning et al., 2007)	• 500 children with cerebral palsy between 8 and 12 years • parents of children • part of SPARCLE study • Europe	• Used the Kidscreen to evaluate the agreement between parent-proxy and child self-reports of HRQOL • Evaluated the factors that influence agreement between 2 groups	• HRQOL	• Agreement between parent-proxy reports and child self-report was generally low • In 8 of 10 domains, children reported higher HRQOL than their parents • Only in domain of 'Finances' did parents report higher scores • No disagreement in domain of 'Emotions'
(Muller-Godeffroy et al., 2008)	• 50 children with myelomeningocele between 8 and 16 years of age • Germany	• Children and parents completed the KINDL-R (HRQOL) • Limitations on activities of daily living measured by the Child Health Assessment Questionnaire (CHAQ)	• HRQOL • Examined impact of impairment and limitations of activities of daily living on HRQOL	• No significant associations between level of impairment and HRQOL • No significant associations between limitations of activities of daily living and HRQOL • Children with myelomeningocele had significantly lower overall HRQOL scores than non-disabled children • Adolescents with myelomeningocele had similar HRQOL scores to non-disabled adolescents except in the friends scale (lower HRQOL)
(Shelly et al., 2008)	• 205 parents of children with cerebral palsy (aged 4-12 years) • 53 children aged 9-12 years with cerebral palsy • Australia	• Both groups completed the Cerebral Palsy Quality of Life Questionnaire for Children	• QOL • Examined association of QOL and functioning • Functioning was measured by the GMFCS	• In the parent-proxy reports, all domains of QOL were significantly related to functioning level • In the child-report, the domains of 'feelings about functioning', and 'participation and physical health' were associated with functioning

Study	Population/Place of study	Methods	Dimensions measured	Results
(Arnaud et al., 2008)	• 818 families in the SPARCLE study • children between 8 and 12 years of age with cerebral palsy • Europe	• child's QOL evaluated through a parent-report using the KIDSCREEN	• HRQOL • Examined the relationship between severity of impairment, family social, psychosocial and economic characteristics influenced parent-report of QOL	• Greater severity of cerebral palsy was not always associated with poorer QOL • Lower IQ scores were correlated with poor QOL scores on the social support domain • Increasing severity of gross motor impairment was associated with higher QOL scores on the social acceptance and school environment domains • Lowest mean score for all children was in the social support and peers domain

Of the 20 articles summarised above, 15 measured HRQOL of children with disabilities or AWD. The majority of the articles focused on children and adolescents with cerebral palsy, although other impairments, such as myelomeningocele, were represented. The tools used to measure HRQOL varied from study to study, although most were generic measures of HRQOL. Only two studies examined QOL using qualitative approaches. Due to the large variation in tools used and methodologies employed, it is difficult to compare findings across studies. The studies that used the Child Health Questionnaire – Parent Form 50 (CHQ-PF50) tool all suggest that children and adolescents with disabilities have lower HRQOL than the non-disabled population. In contrast, the findings from the SPARCLE study (Colver & SPARCLE Group, 2006; Dickinson et al., 2007) suggest that children with cerebral palsy have similar QOL to children in the general population.

Similarly, findings about the relationship between QOL and severity of physical impairment and function were inconsistent across the literature summarised in Table 3. Several studies demonstrated a significant correlation between pain, increasing levels of physical impairment or activity limitations and lower QOL scores when comparing children with varying degrees of impairments (Houlihan et al., 2004; Padua et al., 2002; Schoenmakers et al., 2005; Vargus-Adams, 2005; Varni et al., 2005; Wake et al., 2003). By contrast, other research suggests that severity of impairment, level of function, or health status has no relationship to QOL (Arnaud et al., 2008; Muller-Godeffroy et al., 2008; Rosenbaum et al., 2007).

Some of the 20 articles summarised in Table 3 reported on the issue of agreement between parent-proxy reports of QOL and children's self-reports. This is an important issue to consider, as the assumption has long been held that children and AWD are not capable of independently completing standardised QOL tools or providing accurate information for an evaluation of their QOL. Longitudinal research that followed extremely low-birth weight (ELBW) infants into adolescence and young adulthood has shown that health-care providers and parents rated QOL of hypothetical health states significantly lower than

adolescents who were ELBW (27% with a disability) (Saigal, 2000). Of the four studies that analysed the relationship between parent-proxy and child self-report on QOL tools, all four reported low to poor correlations between the two groups (Rosenbaum et al., 2007; Shelly et al., 2008; Varni et al., 2005; White-Koning et al., 2007). In some cases, the disagreement was in particular sub-scales or domains, while other studies showed overall disagreement between parents and their children. This underscores the importance of seeking the views of AWD wherever possible in order to ascertain the most accurate measure of their QOL.

2.4.3 Measurement of QOL

Measurement of QOL is fraught with methodological issues, not the least of which is the lack of a consistent definition. There are nearly as many measures of QOL as there are definitions, leading to difficulties comparing studies and populations. Measures of QOL are either generic tools, such as the Child Health Questionnaire, SF-36 or Kidscreen, or condition-specific, such as the Spina Bifida Health Related Quality of Life Questionnaire and the Cerebral Palsy Quality of Life Questionnaire for Children. An additional challenge in the measurement of QOL in children with disabilities and AWD is the paucity of tools available that are appropriate for use specifically with this population. The majority of generic QOL tools were designed for use with adults. One study suggests that it is inappropriate to use generic QOL tools (designed for use with adults) with AWD (Vitale et al., 2001).

Measurement issues are further compounded with the use of tools that are not culturally appropriate or sensitive. There is a clear lack of research into the QOL of AWD outside the 'Western' context. The information provided in Table 3 shows that of the 20 articles summarised, only two studies were conducted in countries outside North America and Europe. Of these two studies, one used a tool designed to measure QOL in a 'Western' setting (Chow et al., 2005). The other study, located in Thailand, used a measure based on the WHO Quality of Life tool (WHOQOL), but modified it for use with children and

adolescents (Jirojanakul et al., 2003). The context of many questions in QOL tools designed in a Western setting make them inappropriate for use in other settings. In a review of the issues surrounding translation and adaptation of generic QOL measures for use in non-Western settings, findings suggested that only the WHOQOL tool can provide reliable interpretation of QOL in a variety of settings (Bowden & Fox-Rushby, 2003). It is apparent that the accurate measurement of QOL is burdened with a variety of challenges. This is particularly true in the accurate assessment of QOL in AWD in non-Western, low- and middle-income settings.

In summary, the accurate assessment of QOL, particularly for children and AWD is hampered by several factors. First, the majority of generic QOL scales were developed and validated for use with adults with disabilities. Although there are some condition-specific tools that can be used for children and AWD, their use is limited in a wider population. Second, the majority of QOL tools were validated in a 'Western' setting, limiting their use and applicability in other settings, particularly low- and middle-income countries. Third, research has indicated that there are significant differences between proxy-reports and self-reports of QOL. This underscores the importance of administering the tool to AWD themselves if we are to understand QOL issues from their perspective. Few tools have been developed for self-reporting of QOL with AWD. The need for a generic, self-report tool with applicability in a wide variety of settings that can be used with children and AWD is clear. The QOL measure that most closely fits these requirements is the WHOQOL, which will be discussed at length in Chapter 3.

2.5   Participation

Two of the studies discussed in the preceding section on QOL found that AWD were primarily concerned with issues around social relationships and support, friendship, and recreational activities (Arnaud et al., 2008; Young et al., 2007). Within the ICF framework, these issues are related to activity limitations and participation rather

than body function and impairment. 'For persons with disabilities, issues such as living independently, finding meaningful work, and an accessible physical environment are more important than looking normal' (Darrah, Magill-Evans, & Adkins, 2002, p.542). Simply put, for AWD, and all people with disabilities, participation is a more pressing issue than focusing on ameliorating their physical impairments.

2.5.1 Key principles and definitions

The WHO defines participation as involvement in a life situation (World Health Organization, 2001). In the context of AWD, life situations can include recreational activities (including sports, play, and creative endeavours), education, work and family activities (Law et al., 2005). Participation implies a degree of autonomy and control over life situations even if the person is not directly physically completing an activity (Perenboom & Chorus, 2003). Article 12 of the UNCRC states that participation is a right that should be afforded to all children and adolescents: 'States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child' (United Nations, 1989). In addition, Article 23 states that children with disabilities 'should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community' (United Nations, 1989). Two of the key guiding principles of the UNCRPD, found in Article 3, are 'full and effective participation in society', and 'respect for the evolving capacities of children with disabilities…' (United Nations, 2006).

The principle of participation covers multiple areas in the life of a person with a disability. First, participation is a strategy to be employed in programme development and planning (Commonwealth Secretariat, 2005; ILO et al., 2004). Second, participation is recommended as an outcome of intervention and development programmes and thus an indirect indicator of inclusion (World Health Organization, 2001). A review by UNICEF indicated that programmes aimed at AWD that were

deemed to be successful were those where AWD were involved in planning, oversight and evaluation (Groce, 2004). Third, the guidelines for community-based rehabilitation (CBR) programmes, as set out in a joint paper by the International Labour Organization (ILO), the WHO, and UNESCO, stipulate that participation of people with disabilities is a key tenet of CBR (ILO et al., 2004). Surprisingly, a review of the literature on CBR found that of 128 articles published between 1978 and 2002, only five papers even mentioned participation (Finkenflügel, Wolffers, & Huijsman, 2005). Both the implementation and the evaluation of participation as an outcome of programmes designed for and by people with disabilities, including AWD, is yet to become common practice.

2.5.2 Measuring participation

Guided by the medical model of disability, interventions for people with disabilities focused on eliminating impairment. The need for intervention programmes to move the focus away from impairment and enhance and facilitate participation is critical. The growing adoption and use of the ICF has brought about an increasing recognition of this need. In order to determine the success of strategies aimed at increasing participation of AWD, adequate measures are required to evaluate this concept. Measuring participation, as defined by the ICF, is not straightforward. There is a blurring of lines between the definitions of activity and participation in the ICF. The transition from the 'execution of a task or action' (*activity*) to 'involvement in a life situation' (*participation*) is not immediately obvious. Using dressing as an example for an AWD, is the ability to dress independently merely the execution of a task (dressing), or involvement in a life situation (given that adolescents without disabilities are able to dress without the assistance of others)?

When providing detailed information about what constitutes the components of activity and participation, the ICF manual combines them into nine chapters (World Health Organization, 2001). These are:
1. Learning and applying knowledge
2. General tasks and demands

3. Communication
4. Mobility
5. Self care
6. Domestic life
7. Interpersonal interactions and relationships
8. Major life areas
9. Community, social and civic life

In addition to the lack of a clear delineation between activity and participation, there is also significant overlap between the domains of each component. For example, an activity limitation in the domain of mobility can have significant implications for participation in the domain of community, social and civic life.

Two recently published papers have reviewed the issues surrounding the measurement of participation for children with disabilities (Coster & Khetani, 2008; McConachie, Colver, Forsythe, Jarvis, & Parkinson, 2006). McConachie et al. (2006) suggest that participation for children and adolescents falls into four themes:

1) participation that is required for survival (eating, sleeping, etc.);
2) participation as it relates to child development;
3) discretionary participation (situations that are not essential but ones in which children choose to engage); and
4) educational participation.

Not all the themes of participation listed above fit into the ICF definition of participation. For example, eating and sleeping are found under the ICF component of body structure and function. Similarly, child development skills are found either in body function or activity.

Coster and Khetani (2008) go on to suggest that tools designed to measure participation could define the concept in three different ways:

1) with a focus in one sphere (e.g. leisure activities);
2) according to the four themes defined by McConachie et al. (2006); or
3) by life or social role.

As they point out, the measurement of participation by social role is problematic for children and adolescents, as 'there is no agreed upon

list of social roles...' (Coster & Khetani, 2008, p.641). Social roles are also culturally defined, thus measures of participation that focus on social roles would have to ensure cultural sensitivity.

Coster and Khetani (2008) caution against tools that measure purely objective aspects (those that can be observed) of participation, as opposed to subjective aspects (those experienced by the child or adolescent). Observed participation does not imply enjoyment by the child or adolescent, nor does it suggest a perception of inclusion. In most cases, but particularly in regards to participation, quantity does not equate to quality. Measures of participation should include observed (objective) and experienced (subjective) elements. Both papers also point out the need to distinguish between capacity (what the child is capable of doing in an ideal environment) and performance (what the child actually does in a given situation or setting) (Coster & Khetani, 2008; McConachie et al., 2006). Contextual factors, both environmental and personal, will influence performance and participation.

A review of measures that partially or completely focused on the evaluation of participation using the ICF definition, was conducted in 2003 (Perenboom & Chorus, 2003). Eleven instruments were found in a search, but only nine were reviewed closely due to availability. None measured participation exclusively. While the questions on most measures dealt with issues in the ICF domains of activity or participation, response categories included choices in all domains of the ICF. None of the instruments reviewed were developed for use with children or adolescents. Some of the instruments are generic and have potential for use with children or AWD, but would require further testing. The question-response categories, however, may not be appropriate or relevant.

Another review of instruments to measure both components of activity and participation focused on those tools suitable for use with children with cerebral palsy (Morris, Kurinczuk, & Fitzpatrick, 2005). More specifically, Morris et al. (2005) were interested in tools that could be completed by postal surveys of parents and did not require trained interviewers. Of the seven instruments reviewed, not all focused

exclusively on activity or participation, three were measures of QOL, and one was a measure of health status. It is debatable whether a tool developed for evaluating QOL or health status would truly capture the issues pertinent to participation for a child with a disability. In addition, few of the seven tools were validated for use with adolescents. The issues of AWD, particularly in terms of participation, are likely to be quite different from those of children with disabilities. Appropriate measures should capture these differences, and ideally, should ask the AWD themselves and not rely on proxy reports.

Three of the measures reviewed by Morris et al. (2005) were also reviewed by McConachie et al. (2006). These were the Assessment of Life Habits (LIFE-H) (Fougeyrollas et al., 1998), the Activities Scale for Kids (ASK) (Young, Williams, Yoshida, & Wright, 2000), and the Lifestyle Assessment Questionnaire (LAQ-CP) (Mackie, Jessen, & Jarvis, 1998). In addition, McConachie et al. (2006) reviewed the Children's Assessment of Participation and Enjoyment (CAPE) (King et al., 2004). The LIFE-H has its theoretical basis in the DCP (see Figure 4) (Fougeyrollas et al., 1999) and focuses on the dimensions of participation included in the DCP. It divides participation into Daily Activities and Social Roles. A validation study of the LIFE-H for children (five to 13 years of age) demonstrated good inter- and intra-rater reliability and validity (Noreau et al., 2007). The LIFE-H asks parents to rate the difficulty experienced by their child in completing tasks and the degree of assistance required to complete them (Noreau et al., 2007). The LIFE-H also has a second scale relating to satisfaction with the accomplishment of each item (McConachie et al., 2006; Noreau et al., 2007). In this way, the LIFE-H encompasses both observed and experienced aspects of participation. The drawback to the LIFE-H is that it has only been validated for proxy-reports by parents or caregivers of children with disabilities. In addition, it is only validated for use with adults, or children up to the age of 13 years. Use with AWD will require further validation, particularly for a self-report version. McConachie et al. (2006) also suggest that while it is a comprehensive measure of participation, it is quite complex, even for adults with high levels of literacy, to complete with accuracy.

The ASK (Young et al., 2000) was developed for use with children from five to 15 years of age with musculoskeletal impairments. The ASK uses the child as a respondent, not a parent or caregiver. It focuses on frequency of participation (observed), and has two versions with different response options. One option asks what the child can do (capacity), the other asks what they usually do (performance). The ASK covers most activity and participation domains, but is missing questions about communication, and learning and applying knowledge (Morris et al., 2005). In addition, the ASK is based purely on observed aspects of participation and does not cover satisfaction or feelings of inclusion.

The LAQ-CP (Mackie et al., 1998) was developed initially for children with cerebral palsy and their families. The developers subsequently developed a generic measure (the LAQ-G) for any child with a health condition or impairment (Jessen, Colver, Mackie, & Jarvis, 2003). The LAQ-CP and the LAQ-G are based on parent reports, and do not cover all the domains contained within the ICF activity and participation components. The LAQ-G was tested and developed for young children (five to seven years) (Jessen et al., 2003), and the LAQ-CP is reported to be valid for children up to ten years of age (Morris et al., 2005). The LAQ-G focuses on the measurement of observable participation. Given the limited ages for which it is validated, and that it is a measure using proxy report, it would not be suitable for use with AWD in its current format.

The CAPE was developed specifically to measure participation by children (ages six to 14 years) with physical impairments in everyday activities outside of mandatory school activities (King et al., 2004). Using the themes suggested by McConachie et al. (2006), the CAPE measures discretionary participation. This is a self-report measure, and covers the diversity of participation (number of different activities), the frequency with which children participate in these activities, and their enjoyment of activities. The CAPE thus measures both observed and experienced elements of participation. Research with the CAPE suggests that it has good reliability, validity, and the ability to discriminate between children with differing levels of impairment (Imms, Reilly, Carlin, & Dodd, 2008;

King et al., 2007; Law et al., 2006). Table 4 provides a summary of the four measures discussed above.

Several issues arise when considering measures of participation for AWD. First, of the tools discussed above, only the LIFE-H, ASK and CAPE have been validated with older children. None have been validated specifically for use with AWD. Second, when measuring participation of AWD, it is ideal to use self-report tools whenever possible, rather than relying on proxy-reports from parents and caregivers. Only the ASK and the CAPE are currently validated as self-report measures. Third, both observed and experienced aspects of participation should be evaluated. Only the LIFE-H and the CAPE include both areas.

Table 4. Summary of selected participation measures for children and AWD

Name	Validated population	Respondent	Objective	Subjective
Assessment of Life Habits (LIFE-H) (Fougeyrollas et al., 1998)	Adults, children 5-13 years with disabilities	Parent-proxy	√	√
Activities Scale for Kids (ASK) (Young, et al., 2000)	Children with musculoskeletal impairments 5-15 years	Child	√	
Lifestyle Assessment Questionnaire (LAQ-CP) (Mackie et al., 1998)	Children 5-10(?) years with cerebral palsy	Parent-proxy	√	
Children's Assessment of Participation and Enjoyment (CAPE) (King et al., 2004)	Children 6-14 years with physical impairments	Child	√	√

McConachie et al. (2006) stress the importance of giving special consideration to the needs and viewpoints of AWD when developing appropriate measures of participation. They suggest that qualitative research with AWD should be the basis for determining the most appropriate content of participation measures (McConachie et al., 2006). When considering the participation of AWD in low- and middle-income countries, none of the tools discussed above, reviewed by Perenboom and Chorus (2003) or Morris et al. (2005), are appropriate. All the tools have been developed and validated either in North America or Europe. Cultural values and differing social attitudes are both facilitators of and

barriers to participation. As such, measures of participation must be culturally sensitive and appropriate.

2.5.3 Patterns of participation

There has been a recent growth in the literature examining issues of participation for children with disabilities. This literature examines both the patterns of participation for children as well as the factors that influence participation. Research investigating the patterns of participation has used a variety of measures, some of which have been discussed above. Most of these studies examined observable aspects of participation, such as frequency and diversity activities. Few research studies used a qualitative approach in the exploration of participation, or examined experienced (subjective) participation.

When comparing levels of participation between children with and without impairment using the CAPE, one study found that children with cerebral palsy had lower levels of participation in formal activities as compared to informal activities (Imms et al., 2008). Although the intensity of participation was lower, children with cerebral palsy reported high levels of satisfaction. In general, patterns of participation for children with cerebral palsy were similar to non-disabled children, but they tended to participate in activities that were closer to home, and with family members rather than other friends (Imms et al., 2008). Another study with children with cerebral palsy also found lower levels of involvement in formal activities (Law et al., 2006). This study, however, did not compare participation between children with and without disabilities.

Research investigating the impact of severity of impairment on participation has variable findings. Imms et al. (2008) found that there was no difference in CAPE scores between children classified in Levels I through IV on the Gross Motor Function Classification System (GMFCS). The GMFCS (Palisano et al., 1997) is a classification system for children with cerebral palsy based on independent mobility and function, rather than muscle tone and impairment. Higher levels on the GMFCS indicate increasing difficulty. In the study by Imms et al. (2008), there was both

reduced diversity and intensity of participation for children classified in Level V of the GMFCS as compared to children classified in the other four levels.

Other findings, by contrast, suggest a decrease in participation with increasing severity of impairment (Lepage, Noreau, Bernard, & Fougeyrollas, 1998; Noreau et al., 2007; Kerr, McDowell, & McDonough, 2006; Simeonsson, Carlson, Huntington, McMillen, & Brent, 2001). Lepage et al. (1998) found that the combination of severity of cerebral palsy, difficulty with comprehension, and the distribution of spasticity (hemiplegia, diplegia or quadriplegia) accounted for 80% of the variance in total LIFE-H scores in children and adolescents between five and 17 years of age. The LIFE-H was also used to examine the differences in participation between children with different diagnoses (Noreau et al., 2007). While there were significant differences between children with cerebral palsy, neuropathy and myelomeningocele in most categories of the LIFE-H, there were no differences between the groups in the category of Interpersonal Relationships. There were no data provided, however, to indicate if the diagnostic categories also represented differing levels of functional impairment.

Kerr et al. (2006) studied the relationship between gross motor function and participation using the LAQ-CP in children with cerebral palsy between the ages of five and 16 years. Motor function was assessed by trained therapists using the Gross Motor Function Measure (GMFM), a tool designed to measure change in gross motor function in children with cerebral palsy (Russell, Rosenbaum, Avery, & Lane, 2002). The results demonstrated a significant negative correlation (-.52) between GMFM scores and LAQ-CP scores, indicating that increasing functional limitations caused decreasing participation. The authors of this paper claim that 'better physical function correlated with a better quality of life' (Kerr et al., 2006, p.25). The authors' conclusions, however, can be queried. First, the conclusions demonstrate a pervasive confusion between QOL and participation. The LAQ-CP is a parent-report measure of participation, not QOL. High rates of observed participation do not imply high QOL, a vastly different, subjective concept. Second,

the LAQ-CP was validated for use with young children only, but was used in this study to assess participation of children up to the age of 16 years. A more appropriate tool for participation in older children would have provided more strength to these findings.

A survey of special education teachers about the participation by students with disabilities in their schools found that participation levels decreased as severity of disability increased (Simeonsson et al., 2001). Teachers were also asked to rank their students' QOL on a scale from 1 (poor) to 5 (excellent). Results indicated that participation levels were positively correlated with QOL scores. Participation was measured using a survey developed specifically for this study, and focused on school-based activities only. Although a large number of teachers responded (1180 surveys were returned), there are questions about the results of this study.

First, it is unclear how severity of impairment was evaluated, but it is assumed that teachers were asked to provide information on the diagnosis and to rate the severity of impairment. Although the teachers had frequent contact with their students, the consistency and accuracy with which they were able to evaluate impairment is unclear. Second, QOL was not measured using a validated measure, but a five-point scale developed by the study authors. Again, no guidelines were given as to how 'poor' or 'excellent' QOL were defined. The authors do recognise the challenges posed by the measuring participation accurately, and have provided interesting survey data about a large number of schools and students. A more in-depth study about school participation by students with disabilities, preferably using self-report measures, would contribute greatly to our understanding of the needs of students with disabilities in the educational system.

Some qualitative research studies have also investigated participation and the meaning of successful participation for children with disabilities and their families. One study used video analysis to investigate the participation of AWD in meal-time conversation with their parents and non-disabled siblings (Saetermoe, Farruggia, & Lopez, 1999). The researchers found that in comparison to their siblings, AWD

participated to a lesser degree in conversations during an evening meal, and demonstrated lower levels of meaningful conversations. Findings were based only on a single meal-time conversation, which may not have been reflective of usual behaviour. There are several possible sources of observer error and bias, and the results may be confounded by the limited sampling of conversations. It is still interesting to note the researchers' conclusions that parents' desires to protect their AWD may in fact lead to reduced participation (Saetermoe et al., 1999).

Another study explored the meaning of successful participation, and barriers to and facilitators of participation for children with disabilities (ages five to 16 years) and their parents (Heah, Case, McGuire, & Law, 2007). Both children and parents were interviewed, separately, although parents were often present during the interview with their child. Four major themes emerged from the data about the meaning of successful participation: 1) Doing and being with others, 2) Having fun, 3) Feeling successful, and 4) Doing things by myself (Heah et al., 2007). The authors emphasise that successful participation is dependent on factors that are both internal and external to the child. In addition, they highlight that '…participation in itself was not always meaningful…but that the shared experience of participation with the right person(s) brought meaning to an activity' (Heah et al., 2007, p.44).

2.5.4 Factors that impact upon participation

A pilot study investigated the participation of young adults with physical disabilities, and involved the participants in determining the study design (Bent, Jones, Molloy, Chamberlain, & Tennant, 2001). Focus group discussions with study participants revealed that self-esteem and physical barriers were of most concern to young adults with disabilities. These discussions determined the tools that were used by the researchers to measure outcomes. Regression analyses illustrated that energy, pain, physical independence and self-efficacy accounted for over 60% of the variability in participation as measured by the London Handicap Scale (Bent et al., 2001).

Environmental impacts on participation have been the focus of several other recent studies. Mihaylov et al. (2004) reviewed the literature to identify the environmental factors which influenced the participation of children with cerebral palsy. They found that there were a number of factors that fell into the ICF category of environmental factors that were both barriers to and facilitators of participation. These included physical barriers, psychosocial pressures, finances, public services and attitudes. Their review led to the conclusion that any research that investigates the environmental barriers to and facilitators of participation of children with cerebral palsy '…must include discussions with children themselves and must focus on those aspects of attitudes, support, and relationships that are important to them' (Mihaylov, Jarvis, Colver, & Beresford, 2004, p.302).

The study by Heah et al. (2007) also investigated barriers and facilitators to participation. Interestingly, it was primarily the parents, not the children, who identified these factors. Environmental barriers and facilitators included: 1) the design of community programs, 2) parental values, preferences and vigilance, 3) social and physical support, and 4) 'keeping up with other kids' (Heah et al., 2007, p.41). Similar themes were found in a study of children with cerebral palsy in northeast England (Lawlor, Mihaylov, Welsh, Jarvis, & Colver, 2006). The four key themes identified by parents in this study were: 1) mobility, 2) transport, 3) support by and to family, and 4) attitudes of others and institutions. Both barriers to and facilitators of participation were discussed within each theme. The study focused on the environmental factors, and did not investigate other possible barriers to and facilitators of participation. The study also focused on parental perceptions and did not include the perceptions of the children themselves.

The relationship between environmental factors and participation has been evaluated using standardised outcome measures (Forsyth, Colver, Alvanides, Woolley, & Lowe, 2007; Hammal, Jarvis, & Colver, 2004; Law, Petrenchik, King, & Hurley, 2007). Impairment, measured using the Health Utilities Index-3 (HUI-3) and five environmental

domains, measured using the European Child Environment Questionnaire (ECEQ), accounted for 48% of the variance in participation scores on the LAQ in children between one and 12 years of age with cerebral palsy (Forsyth et al., 2007). The five domains on the ECEQ were support, physical accessibility, educational provision, transport, and family and friends. The highest correlations with LAQ scores were with the support domain of the ECEQ, and the level of impairment measured by the HUI-3. The authors suggest that some findings may have been affected by the relatively young age of the children in the study. Another study using the LAQ to assess participation found that where children with cerebral palsy lived had as much influence on participation as the severity of their impairment (Hammal et al., 2004). What was not included in this study, however, were the specific features of the different neighbourhoods, and the intrinsic factors in each community that may have restricted or enhanced participation.

Environmental factors were quantitatively measured in a study that investigated the impact of barriers in children of differing ages with a range of functional abilities (measured by the ASK) (Law et al., 2007). This study used the Craig Hospital Inventory of Environmental Factors (CHIEF), a tool that describes environmental factors that are known to be barriers or facilitators to participation for people with disabilities. Developed for an adult population, it was used in this study as a parent-report tool. Key findings were that older children (ages 12 to 14 years) experienced more barriers to participation in some areas as compared to younger children. Overall, children with more functional impairments experienced more barriers to participation. Finally, the physical environment had a far greater impact on participation for children with disabilities than did attitudes at home or in the community (Law et al., 2007). Unlike the findings by Hammal et al. (2004), place of residence did not have any relationship to participation.

The importance of measuring participation in children and AWD is unquestionable. As a key component of the ICF, it should be, and is becoming, a focus of intervention and programmes for people with disabilities. As discussed above, however, lack of clarity about the

definition of participation leads to methodological issues of measurement and evaluation. There are many facets to participation and as such, multiple angles from which it can be viewed and approached. In considering AWD, it would seem that their perceptions are the most important in determining levels of participation. The inclusion of the views of AWD in research has yet to become standard practice. Evaluation of participation of AWD in low- and middle-income settings is further compounded by the lack of appropriate tools. All the measures discussed above have been developed and validated for North American and European populations, and primarily for young children. Given these restrictions, qualitative studies are the preferable option if we are to understand the issues surrounding participation in developing countries, and if we are to develop appropriate measures of participation for AWD.

2.6   Summary and Conclusion

The field of disability studies has come a long way from its inception in the biomedical model. The social model of disability has increased awareness of the needs and rights of people with disabilities, and has brought about changes in legislation around the world. Most notably, the ratification of the UNCRPD provides people with disabilities the legal support they require to hold governments and legislators accountable for ensuring an equitable and accessible society. The ICF (Figure 5) and the DCP (Figure 4) have done much to change the focus of medical and rehabilitation programmes for people with disabilities. The aim is no longer to 'fix' the disability, but to eliminate the barriers that prevent meaningful participation and inclusion in society. Gaps still exist in our knowledge about the prevalence of disability world-wide, with quoted figures as low as 1% and as high as 20%. In particular, little is known about the extent of disabilities in the population of AWD, particularly in low- and middle-income countries.

Adolescence is a time of transition, in both a physiological and social sense. The successful transition to adult roles and responsibilities is enhanced by full and equal access to health care, education,

vocational training and participation in family and societal roles. Definitions and values placed on the importance of adolescence as a distinct phase of development and on people with disabilities can either restrict or facilitate full participation. To date, very little research has been conducted into the lives of AWD in low- and middle-income countries. Although poverty has been said to both cause and exacerbate disability, little research has investigated the effects of poverty on the lives of AWD.

The key outcome for any programme aimed at AWD should be full and meaningful participation. Participation can be limited by factors that are both internal and external to the AWD. Internal factors include motivation, self-esteem, and perceived capability. External factors include elements of the physical environment, as well as attitudes and behaviours of others, and legislation and policies that have a direct impact on inclusion. Fulfilling the rights of AWD can only be brought about through full and equal participation in all life roles. The research described in this thesis concentrates upon this aspect of participation and inclusion for AWD. The WHO recognizes that opportunities for participation must be afforded at every stage of programme planning, implementation and evaluation. Participation is a difficult concept to define and measure as it has different connotations in different cultures and at various life stages. Research has shown the importance of participation in the lives of AWD. Much more research is required, however, to investigate the meaning of participation for AWD and the barriers and facilitators they face to meaningful participation and inclusion if they are to become successful adults, participating and contributing to the societies in which they live.

Chapter 3 – Methods

3.1   Design

This exploratory, descriptive research employed an iterative, mixed methods design. Both quantitative and qualitative methods were used to achieve the study objectives. Ethical approval for the study was received from the University College London Research Ethics Committee and locally from the participating agencies. The final study design was agreed by the researchers after consultation with local partners: Mobility India (MI), Association for Persons with Disabilities (APD) and the Spastic Society of Karnataka (SSK). These meetings occurred prior to the commencement of the data collection period in December 2005 and again in August 2006. Ongoing research support for the study was provided by Dr. Maya Thomas in Bangalore, India.

3.2   Setting

Based on population, India is the second-largest country in the world with a current estimated population of just over one billion people, with the majority (64%) of the population between 15 and 64 years (Central Intelligence Agency, 2006). The state of Karnataka in south India, where the research was conducted, was formed in 1973 and is the eighth largest state in the country (see Figure 6 below, (Compare Infobase Pvt.Ltd., 2003)).

Figure 6. Map of India

According to the national census in 2001, Karnataka has a population of 52 850 562 people (approximately the same population as England) and a literacy rate of 67.04%, above the national average (Government of India, 2006). Of the total population of Karnataka, 34% is urban, again higher than the national average. The reported number of children between the ages of five and 19 years with a physical disability in India is about 1.5 million, but as was discussed earlier, these figures are confounded by several variables. Using census figures collected in 2001 (Government of India, 2006), and extrapolating from total population numbers and disability rates it is estimated that there are approximately 76 000 children between the ages of five and 19 years in Karnataka with a physical disability.

The city of Bangalore, in Karnataka, is India's third-largest city with a population of 6.5 million people. Approximately 10% of the

population of Bangalore live in slums, which are demarcated by the municipal corporation and recognized as distinct areas of the city. The percentage of the population who live in temporary accommodation or sidewalk dwellings is unknown. Bangalore is one of India's fastest growing cities, with a growing population of transient workers and families. Given these unknown factors, the total population of children with disabilities in Bangalore is difficult to estimate.

In addition to being a signatory on all the major UN legislations in regards to disability, India has implemented several of its own policies and documents, listed below in Box 2.

Policy/Legislation	Year Enacted
Mental Health Act	1987
Rehabilitation Council of India Act	1992
National Trust Act for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities	1999
Persons with Disabilities Act (Equal Opportunities, Protection of Rights and Full Participation) of 1995	1996
CPWD Guidelines for Barrier Free Built Environment and Space Standards for Disabled and Elderly	Date unknown

Box 2. Selected policies and legislation in India

These national policies and legislation indicate a concerted effort at a national level to improve the inclusion of people with disabilities. What remains unknown, however, is the extent to which government policy has changed the day-to-day lives of people with disabilities, particularly children. Enforcement of policies and legislation is scattered, at best, and awareness of the existence of these policies among people with disabilities is lacking. A search of the published literature and other sources of gray material indicate little research has been conducted on the lived experiences of people, particularly children, with disabilities in India.

3.3   Study Sample

3.3.1 Participants

The study involved the following three groups of participants:

1) Adolescents with physical disabilities;

2) Parents or caregivers of adolescents with physical disabilities;

3) Adolescents without physical disabilities (reference group).

Group 1: Participants between the ages of 13 and 19 years of age with physical disabilities (AWD) were included in the study. Inclusion criteria included diagnoses of cerebral palsy, myelomeningocele, traumatic brain injury, and other orthopaedic impairments. Adolescents with cerebral palsy who were classified between Levels I and III on the Gross Motor Functional Classification System – Expanded and Revised (GMFCS-E &R) (Palisano et al., 1997; Palisano, Rosenbaum, Bartlett, & Livingston, 2007) were included in the study. Children classified in Levels IV and V of the GMFCS-E&R were included if they were able to participate in group discussions and were able to express themselves verbally or through a translator. Exclusion criteria included children with severe cognitive impairments, children with severe dysarthria leading to unintelligible speech, those with a diagnosis of autism, or children with single sensory impairments (vision or hearing). These exclusion criteria were chosen as the data collection procedures required that subjects were able to participate in group discussions. In addition, the scope of this study was narrowed to adolescents whose primary disability was of a physical nature. Group 1 consisted of three subgroups.

Group 2: The parent(s) or caregiver(s) of adolescents with disabilities (PD) were invited to participate in the study. If the parent(s) was not the primary caregiver(s), then the primary caregiver was interviewed. Group 2 consisted of three subgroups.

Group 3: Gender and age-matched adolescents without disabilities (AC) were included as a reference group. Participants in this group were recruited by asking the AWD to identify siblings, relatives or friends who were interested in being involved in the study. If they were unable to identify a peer who could participate in the study, the agency involved was asked to identify a peer member. This group consisted of three subgroups. Table 5 describes the groups of participants and the specific subgroups that participated from each agency.

Table 5. Participant groups

Agency	Group 1	Group 2	Group 3
	AWD	PD	AC
Mobility India	Group 1-A	Group 2-A	Group 3-A
Association for Persons with Disabilities	Group 1-B	Group 2-B	Group 3-B
Spastic Society of Karnataka	Group 1-C	Group 2-C	Group 3-C

For the purposes of data collection, the participants in Group 1 were divided into adolescent (13 – 16 years of age) and youth (16 – 19 year of age) groups. The data from both groups, however, was analysed together.

3.3.2 Participating agencies

Participant groups were recruited from three NGOs in Bangalore, India. The agencies were: 1) Mobility India (MI); 2) the Association for Persons with Disabilities (APD); and 3) the Spastic Society of Karnataka (SSK). These three NGOs are the largest in Bangalore providing an extensive range of rehabilitation services for children and adults with disabilities. Each of these agencies has a history of collaboration on research and special projects with outside groups. Professor Sheila Wirz and the local supervisor Dr. Maya Thomas have extensive experience working with all three of these organisations.

By choosing participants from these three organisations, access was granted to AWD from varying SES, across a range of ages, and those with differing levels of education. Participants who were recruited from

APD and MI represented a sample of AWD from a lower SES. Due to the rapid economic growth and development in Bangalore in the past ten years, it was important to include a representative group from a middle-income to high-middle-income SES. These were the participants recruited from SSK.

The NGOs were also chosen in order to have a wide range of disabilities represented in the participant group. The majority of adolescents recruited through APD and MI had disabilities due to poliomyelitis infections during early childhood, while participants from SSK had cerebral palsy. This diversity was important to capture a range of experiences among adolescents with different types of physical disabilities.

Table 6 below outlines the services provided by each of the agencies in Bangalore.

Table 6. Services provided by participating agencies

Agency	Services Provided
Mobility India (MI) Est. 1994 Website: www.mobility-india.org	2. On-site rehabilitation services for children with disabilities and their families 3. Community rehabilitation programs in urban slums for children with disabilities 4. Rural outreach programs for people with disabilities 5. Vocational training programs for rehabilitation assistants, prosthetic and orthotic technicians 6. Provision of prosthetic limbs to other rehabilitation sites around India
Association for Persons with Disabilities (APD) Est. 1959 Website: www.apd-india.org	1. Inclusive school for children with and without disabilities (for children up to the age of 12 years) 2. Community rehabilitation programs in urban slums for children (age 0 – 18 years) with disabilities 3. Rural outreach programs for people with disabilities 4. On-site support groups and rehabilitation for children with disabilities and adults with spinal cord injuries 5. Provision of wheelchairs for adults with spinal cord injuries around Bangalore 6. Vocational training programs for youth with disabilities (various disciplines)
Spastic Society of Karnataka (SSK) Est. 1982 Website: www.spasticsocietyofkarnataka.org	1. Segregated school (primary through secondary school) for children with cerebral palsy and other neuro-muscular disabilities 2. On-site diagnostic and therapeutic interventions for children with cerebral palsy and other neuro-muscular disabilities 3. Vocational training for youth with disabilities 4. Community-based rehabilitation programs

3.4   Dimensions Measured

There were two standardised, quantitative measures used in this study to evaluate QOL of all participants, and one quantitative tool to assess

gross motor function of those participants with cerebral palsy. These measures are discussed in detail below. Qualitative methods were employed to explore perceptions of participation and inclusion among the AWD. These are discussed in more detail in the section that follows on data collection.

3.4.1 Quality of life

WHOQOL–BREF

After an extensive search for an appropriate tool to measure QOL of AWD, the WHOQOL-BREF (Appendix II) was chosen as the most appropriate QOL measure to use in this setting. There are no other measures of QOL for use with children or AWD living in a developing country. The WHOQOL-BREF was chosen as it was 'culture-free' and relatively simple to administer, and determined to be the most appropriate for the given setting.

The WHOQOL-BREF was used to measure the QOL of AWD and AC. The tool was also administered to the PD (Group 2) to determine their perception of their AWD's QOL. Research involving the WHOQOL-BREF is ongoing at the National Institute of Mental Health and Neurosciences (NIMHANS) in Bangalore, India. Dr. Prabha Chandra, Professor of Psychiatry, is involved with the WHOQOL group in India, and is currently using the tool in research with women who have HIV/AIDS. Administrative issues about the tool were discussed with Dr. Chandra, who also provided the researcher (GK) with a copy of the WHOQOL-BREF in Kannada, one of the local languages.

The WHOQOL (WHOQOL Group, 1998b) was developed to fill the need for a reliable, valid and responsive QOL measure that could be used across cultures. The development of the WHOQOL involved 15 international centres that field-tested the items on a diverse group of participants. After several iterations, the WHOQOL contained 100 questions that formed 24 facets of QOL contained within four main domains – physical, psychological, social relationships and environment.

The WHOQOL defines QOL as 'individuals' perception of their position in life in the context of the culture and value systems in which

they live and in relation to their goals, expectations, standards and concerns' (WHOQOL Group, 1998b). The WHQOL-100 has been shown to have good discriminant and concurrent validity, and good test-retest reliability (Bowling, 2005). Although the WHOQOL-100 has good psychometric properties, it can be too long and cumbersome to use in some situations, particularly when QOL is only one area of interest. The WHOQOL group developed the WHOQOL-BREF as a shorter and faster to administer version of the WHOQOL-100 (Saxena, Carlson, Billington, & Orley, 2001; WHOQOL Group, 1998a). This version has demonstrated good internal consistency (Cronbach's alpha values ranging from .66 to .84) and good discrimination between well and ill patients. The test-retest reliability ranged from .66 to .87 and multiple regression analyses suggested that each of the four domains contributed significantly to overall QOL (WHOQOL Group, 1998a).

The WHOQOL-BREF retained one question from each of the 24 facets of the WHOQOL-100 as well as two additional questions about overall QOL and general health, for a total of 26 questions, in each of the four domains discussed above. The facets included in each domain are listed below in Table 7 (World Health Organization, 1996).

Table 7. WHOQOL-BREF domains and facets

Domain	Facet
Physical	- Activities of daily living - Medical aids and substances - Energy - Mobility - Pain and discomfort - Sleep - Work capacity
Psychological	- Bodily image and appearance - Negative feelings - Positive feelings - Self-esteem - Spirituality/Religion - Thinking, learning, memory, concentration
Social Relationships	- Personal relationships - Social support - Sexual activity
Environment	- Financial resources - Freedom, physical safety and security - Health and social care - Home environment - Acquiring new information/skills - Participation in recreation and leisure - Physical environment (noise, pollution, traffic, etc.) - Transport

Each question is scored with a five-point Likert response scale. The tool is constructed with both positively and negatively worded questions. A scoring matrix is used to calculate the mean score of items within each domain, and to calculate a domain score. Scores indicate the respondent's perception about their quality of life for that specific domain. Scores for the two general questions of QOL and health status are not included in the total QOL score. The domain scores are scaled in a positive direction, so higher scores indicate a higher perceived quality of life. These domain scores can then be transformed into a score from 4 to 20, or scores from 0 to 100 (World Health Organization, 1996). The first transformation allows for comparison with scores on the original 100-item WHOQOL tool.

EQ–5D

Following discussions with Dr. Chandra, she recommended that her colleague Dr. S. Chaturvedi should be consulted on the EQ-5D, a tool he

was using with adults with disabilities, as a possible measure to use in this study. The EQ-5D (Appendix III) was developed as a standardized tool, non-disease specific tool for the purpose of describing HRQOL (Brooks & EuroQol Group, 1996; Rabin & de Charro, 2001). The authors intended that this measure be completed by the respondent, and thus be kept brief. The purpose of this tool was to be a generic tool that would complement other health-related quality of life (HRQOL) measures.

The EQ-5D has three sections: 1) a self-classifier; 2) a visual analogue scale (VAS) to rate health; and 3) a valuation of health states. The developers suggest that the EQ-5D can be used for three types of research, including clinical studies, economic studies and population-heath studies (Krabbe & Weijnen, 2003). The five dimensions in the first section, the self-classifier, are each divided into three levels which indicate progressively more difficulty in that area. The dimensions are: 1) mobility; 2) self-care; 3) usual activities; 4) pain/discomfort; and 5) anxiety/depression. Respondents choose the level which best describes their *current* health state in each dimension. The resulting five-digit number combination describes overall health state. The second section, the VAS, uses a 20cm 'thermometer' with the end points of '0' indicating worst imaginable health state, and '100' indicating best possible health state. Respondents are asked to indicate where their *current* health state falls on the thermometer. For the purposes of this study, only the first two sections of the tool were employed. The EuroQol Group reports that test-retest reliability of the EQ-5D falls between .73 and .78 (Brooks & EuroQol Group, 1996). The measure has been criticized, however, for large ceiling effects and for its short time reference ('how is your health today?') (Bowling, 2005).

The EQ-5D is being tested in an Indian context at NIMHANS in Bangalore, India. The use of the EQ-5D is also being studied in people with disabilities. After discussions with Dr. Chaturvedi about the EQ-5D, it was decided to include it as an additional measure in this study. Dr. Chaturvedi thought that this tool could be used as an adjunct to the WHOQOL-BREF as it was brief and easy to administer. The decision to

use an additional measure and the relationship between the EQ-5D and the WHOQOL-BREF will be discussed further in Chapter 6. It was used to determine HRQOL with AWD, their peers, and the PD group. There are 60 official translations of the EQ-5D, with an additional 51 translations awaiting official status from the EuroQol Group (EuroQol Group, 2007).

3.4.2 Gross motor function

The Gross Motor Function Classification System (GMFCS) (Palisano et al., 1997) is an internationally recognized classification system developed for children with a diagnosis of cerebral palsy. Previous classification systems for cerebral palsy were based on topography and muscle tone. While providing a clear picture of the child's impairment, these classification systems did not provide any indication of functional abilities. The GMFCS (Appendix VIII) is used to classify children by function rather than impairment and is based on self-initiated movements, with particular emphasis on sitting and mobility. The GMFCS puts the focus on ability, not limitations or capability. Thus the impact of personal and environmental factors on a child's abilities is taken into account. The GMFCS has five levels and incorporates the concepts of the ICF. Level I indicates the highest level of function, while children in Level V are those who are largely dependent on others for mobility and self-care.

The GMFCS was initially designed for use with children with cerebral palsy between the ages of 2 and 12 years. A revised version of the GMFCS, the GMFCS-E & R for use with children from 2 to 18 years of age was validated in 2007 (Palisano, Rosenbaum, Bartlett, & Livingston, 2008). The tool is available through McMaster University on the CanChild website at www.canchild.ca (Palisano et al., 2007). The developers of the GMFCS are careful to point out that it is not an assessment tool, but was developed as a classification system intended to facilitate communication amongst clinicians (Harvey, Rosenbaum, Kerr Graham, & Palisano, 2009). Family reports for the GMFCS were highly correlated with those of professionals, suggesting that parent proxy reports are also a reliable method of using the tool (Morris, Galuppi, & Rosenbaum, 2004). The GMFCS has gained international

recognition and is widely used, particularly in Europe, North America and Australia, with growing use in other countries.

3.5   Data collection

Data collection occurred in an iterative process, with information gathered at each phase of the study informing the following phase (see Figure 7).

Phase 4: Meeting with stakeholders (x 8), including agency representatives, parents, adolescents or youth with disabilities to confirm and validate findings

Phase 1A: Agreement by participating agencies
Phase 1B: Recruitment of adolescents with disabilities (Group 1): MI x 1; APD x 1; SSK x 1 = 3
Recruitment of parents (Group 2): MI x 1; APD x 1; SSK x 1 = 3
Meeting with parents to seek permission, collect basic data and administer QOL measures

Perceptions of participation and inclusion among adolescents with

Phase 3: Introduction of photography task to Group 1 (x 3 subgroups); FGD using photographs (x 3 groups); administration of QOL measures; follow-up interviews if required

Phase 2: Recruitment of peer group (Group 3):
MI x 1; APD x 1; SSK x 1 = 3
FGD with peers and administration of QOL measures

Figure 7. Data collection procedures

3.5.1 Preliminary phase

Prior to the formal data collection period of the study, several preliminary discussions in London and informal visits to India were conducted. The researchers (GK and Professor Wirz) met with MC, a young woman with cerebral palsy living in both London and India. The idea for the project was discussed, and MC provided some feedback. In addition, an informal meeting took place with Dr. RL, a Research Fellow and disability advocate. The input from these two disabled activists during the planning phase was invaluable. Dr. Maya Thomas, who later facilitated meetings with local NGOs in Bangalore, India in December 2005, agreed to act as the local supervisor for the project. Researchers (GK and Professor Wirz) had several meetings with representatives from MI, APD, and SSK to discuss the project and the feasibility of conducting such research in Bangalore.

3.5.2 Phase 1

The first phase of the study began with formal discussions with representatives from MI, APD, and SSK. Study procedures were explained to representatives and consent for participation was provided by the heads of MI, APD and SSK. Representatives were asked to identify a group of AWD and their parents who met the inclusion criteria for the study. Each agency assigned a staff member who would be responsible for assisting with data collection and who would also provide translation for the discussions. It was felt that an external translator may introduce other forms of bias into the study, particularly as this person would be unknown to the participants. The staff member or community health workers had a long-standing relationship with the families and their children, and that level of trust was important to ensure success during the focus groups and interviews.

In preparation for data collection in the urban slum areas covered by MI and APD, the researcher (GK) spent several days with the community health worker in observation sessions. These sessions allowed the researcher to become familiar with the community, and build trust and awareness with families. Upon the completion of the

observation sessions, the health worker and the researcher (GK) visited each family at their home. The purpose of the study and procedures were discussed and opportunities for asking questions were provided for both the AWD and their parents.

Dr. Thomas, the directors of APD and MI, the local CBR project coordinators, and the community health workers all advised that I should not ask parents and caregivers for signed consent. There were several reasons for accepting verbal consent from parents and adolescents rather than demanding signed consent. First, the literacy skills of most parents in the urban slums were limited and I was told that they would be uncomfortable signing a piece of paper that they could not read. Second, the families all had long-established relationships with APD and MI, and trusted the community health workers to safeguard the interests of their child and their family. The health workers indicated to us that it would be seen as a breach of this trust if they were to ask the families to sign a document. Several families were uncomfortable at first when they saw the papers, and asked repeatedly if the researchers were from the government or if I was reporting their activities to anyone. Some families may have been living outside legal society and were afraid that their activities would be reported to the authorities. For these reasons, and in order to respect local customs and cultural norms, it was determined that verbal informed consent for participation from all parents/caregivers living within the urban slums covered by APD and MI would be accepted.

At the first visit, the Background Information Form (Appendix I), the WHOQOL-BREF (Appendix II) and the EQ-5D (Appendix III) were completed by the parent/caregiver. All measures were administered using an interview format. The health worker would ask the questions in the appropriate language (Kannada, Tamil or Urdu) and would translate the response into English. The researcher (GK) would note the responses on the questionnaire forms. Although the EQ-5D is available in Kannada, Tamil and Hindi, the health workers were not always able to read all three languages. More often, the health workers were fluent in speaking all three Indian languages and English, but only able to read English and

one other Indian language. In this case, the health worker would read the questions in English and verbally translate it into the appropriate language. Administration of questionnaires using an interview was necessary due to differing levels of literacy amongst the study participants and their parents/caregivers and because the majority of participants did not speak English. Prior to the first visit, the verbal translations of each measure were checked with Dr. Thomas and the health worker. Each question was reviewed, clarifications on word substitution were made, and health workers were trained about acceptable probes and prompts, if required.

A list of AWD who met inclusion criteria and attended the school program at SSK was compiled by the school principal and the site contact. These families were sent a letter of invitation (Appendix IV) to attend a parent meeting, requested by SSK. The study purpose and procedures were explained to parents/caregivers at this meeting by the researcher. All families that agreed to participate were provided with an information letter (Appendix V) and asked to complete and sign the written consent form (Appendix VI). Parents who could not attend the initial meeting provided verbal consent for their child's participation in the study and were asked to sign the consent form during the individual interview. These procedures were discussed with SSK and approved before the commencement of data collection.

The Background Information Form and the QOL measures were administered during the individual interview with the parent/caregiver. In order to maintain consistency across the study, the Background Information Form, the WHOQOL-BREF and the EQ-5D were completed using an interview format, even with those parents for whom English was the preferred language of communication. For those parents who did not speak English, a staff member from SSK was asked to translate. These translations were checked for accuracy using a similar methodology described earlier.

Eligible AWD between 16 and 19 years of age who were enrolled in the vocational training program at APD were identified by the coordinator of the program. The purpose and procedures of the study

were explained to the students, opportunities for questions provided, and verbal consent attained. Using the same procedure as described above, the Background Information Form, WHOQOL-BREF and EQ-5D were administered in an interview format through a translator.

3.5.3 Phase 2

Each participant or parent/caregiver was asked to identify a peer without a disability (AC) who was willing to participate in the study. Peers (Group 3) were matched on age and gender to the AWD. While this technique of sampling did introduce further bias into the study, previous research experience has demonstrated that this is an effective strategy to employ for populations to which access is difficult (Yousafzai, Filteau, & Wirz, 2003), and when the prevalence of AWD is low. Individual interviews were conducted with AC to complete the Background Information Form, the WHOQOL-BREF and the EQ-5D. This data provided baseline information about the QOL of AC in an urban south Indian population. Using the same procedures outlined in Phase 1, all tools were administered via an interview process. Upon completion of the individual interviews, focus group discussions (FGD) were held with members of Group 3. Using methodology similar to that described by Bent et al. (2001), these discussions determined which questions would be included in the FGD with the AWD. Questions covered the areas of: 1) education; 2) family, including their role within their family; 3) employment and/or volunteer activities; and 4) social and recreational, including information about time spent with friends and preferred recreational activities; and 5) aspirations for the future, including education, employment and family (see Appendix VII for a sample interview script).

3.5.4 Phase 3

Phase three of the study began with an introductory rapport-building session with the AWD. This session provided an opportunity for the participants, researcher and community health worker to establish rapport. Any questions from the participants about the study or their

role were clarified. Participants were reminded that their involvement in the study was voluntary. The initial group meeting also allowed for introduction of the first step of data collection. Photography was used as a data collection tool and as a means to stimulate non-directive discussion.

Use of visual methods, such as photography, is an established method of participatory research (Boyden & Ennew, 1997; Wang & Burris, 1997). Using this technique, participants are provided with cameras and asked to document images that are relevant to the study purposes (Wang & Burris, 1997; Wang, Yi, Tao, & Carovano, 1998). It has been used with youth in deprived neighbourhoods to explore quality of life issues (Morrow, 2001), and through photo diaries with street children in Uganda (Young & Barret, 2001). Photography has also been used with children in rural Bolivia (Punch, 2002). A version of this research technique, called 'Photovoice' has been used successfully with a group of adolescents in an after-school youth centre (Strack, Magill, & McDonagh, 2004). 'Photovoice' is a more structured approach to using photography in research. Photovoice allows people to document specific concerns and provides them with the basis on which to engage in dialogue about these issues. It was also developed as a method through which to reach policy-makers to influence change at the community level. Photovoice is unique because '…it gives cameras to people who might otherwise not have access to such a tool, so that they may record and catalyze change in their communities, rather than stand as passive subjects of other people's intentions and images' (Wang & Burris, 1997, p.370-1).

Participatory research techniques were especially relevant for this study as the primary focus was the participation of AWD in their communities. As underscored by Mihaylov et al. (2004), any research which investigates the barriers and facilitators to participation of adolescents must include them. The study did not adhere completely to the concept of 'Photovoice' as outlined by Wang et al. (1997), but did utilise the general concepts. Drawing is frequently used with children to engage them in discussion about their lives, but it was determined that

drawing would not be an appropriate activity for AWD. Drawing, as a technique to foster discussion, is ineffective when used with children who are too old and self-conscious about their perceived ability (or inability) to draw adequately (Punch, 2002). A manual task such as drawing would not be appropriate for AWD with impaired hand function. Other participatory techniques, such as drama, were not considered due to the language barrier between the researcher and the participants.

For the purposes of this study, each AWD was provided with a disposable camera. Instructions for correct use of the cameras were reviewed at the introductory session. Participants were shown how to use the flash, how to forward the film and some basic tips on effective photography. Participants were asked to take pictures which documented things in their life that:

1) made them happy/ gave them a sense of pride/ that they enjoyed

2) made them sad

3) made them angry or frustrated; and

4) they would have liked to change/make different.

These four broad categories were chosen as they represented specific emotions, rather than being more materially based, for example, 'Things I like/Things I dislike.' The intention was that photographs which represented emotions would lead to more in-depth discussions about broader issues of inclusion and participation.

While some guidelines were necessary, excessive guidance about the types of pictures to take were not provided in order to maintain an open data collection process. The goal was not to influence the subject matter of the pictures, but rather, to allow the AWD to express themselves freely to allow for an open discussion at the subsequent group interview. Adolescents whose disabilities prevented them from being able to use the camera independently due to fine motor or visual difficulty were told that they could ask for assistance from a friend or family member, but that they should specify what they wanted photographed.

Approximately one week was provided to complete the photography task. This length of time was chosen as most participants were in school, and would not able to take many pictures during the evening hours. A shorter time may have prevented some participants from photographing an adequate breadth of topics. Cameras were returned to the researcher for development and printing of the pictures. Once the pictures were developed, a FGD was held with Group 1.

The purpose of the FGD was to use the pictures taken by the participants as a catalyst for a discussion about participation and inclusion. The first part of the FGD began with sharing and discussion of the photographs. Two sheets of chart paper were used. Each was divided into two columns, with the headings 'Happy', 'Sad', 'Angry/Frustrated' and 'Things I Want to Change.' Headings were written in English, and Kannada, as well as a pictorial representation of the title. Photographs were randomly selected by the researcher and shown to the group. The AWD who took the picture was invited to indicate the column in which his/her picture belonged and was provided with the opportunity to explain the meaning behind the picture. Every participant was given the option of discussing at least one of their photographs. Once each participant had shared at least one photograph with the group, the rest of the pictures were spread on the table so the AWD in the group could discuss them freely.

The aim of this participatory research technique was to stimulate a non-directive discussion amongst the AWD and to provide a safe atmosphere in which they could share their perceived barriers and facilitators to participation. Participants were allowed to discuss any topic they chose, with little direction from the facilitator. Participants were able to keep their pictures, while the researcher retained the negatives for further use if required, with the participants' consent. For the duration of the study, select photographs were kept by the researcher to use with other groups as samples, but were returned to the study participants once data collection was completed.

Based on issues raised by the AC (Group 3) in Phase 2 of the study, the interview guide for the second part of the FGD was

developed. Similar to the questions posed to participants in Group 4, this second part of the FGD dealt with issues of education, family, employment, recreation and friends, and future goals and aspirations. The FGD was digitally recorded and transcribed for further analysis, and written notes were kept by the session facilitator/researcher (GK). If issues in the FGD guide were discussed during the sharing of the photographs, they were not repeated during the second part of the FGD. In some cases, the two parts of the FGD had to be split into two sessions. This was usually due to time constraints. Several participants requested an individual interview following the FGD. They were participants who were either too shy to speak in front of the other members of the group, or felt they had more to contribute that they were unable to say during the FGD. These individual interviews were also digitally recorded, transcribed and analysed using the same procedures as the FGD.

Individual interviews with AWD were held to complete the WHOQOL-BREF and the EQ-5D. The Background Information Form was completed by the older AWD from APD as their parents/caregivers could not be not included in the study. All tools were administered using an interview format to maintain consistency in data collection among the three participant groups. In keeping with recommendations for participatory research with children (Boyden & Ennew, 1997), the measures were not administered until the relationship between the researcher and the AWD was established.

3.5.5 Phase 4

Key stakeholders, service providers and other agency representatives, PD, and AWD were invited to a meeting to share draft results of the study. The final group of participants who attended the meeting included representatives from MI, APD and SSK, and AWD from the vocational training program at APD. Other AWD and PD were unable to attend. Attendees were asked to share their experiences when working with AWD, and AWD were asked to verify that the early findings accurately reflected their experiences. Participants were also invited to

share any other issues or concerns related to the participation of adolescents with disabilities in their communities.

3.6   Data Analysis

3.6.1 Quantitative data analysis

Background Information Form

Data from the Background Information Form (Appendix I) was summarised for all participants, and included gender, diagnosis (for adolescents with disabilities), age, and education levels. Parental information including education level and employment status for mothers and fathers was summarised. Household information, including monthly household income and other indicators of socio-economic status was tabulated. Information was summarised by participant group and by service provider (MI, APD and SSK). To determine if there were any differences between the AWD and AC in terms of age and educational levels, an independent samples t-test was used.

QOL measures

As this study was primarily intended to be a qualitative exploration of the perceptions of participation and inclusion among AWD, sample size calculations were not performed. It is acknowledged that the number of participants was small compared to other quantitative studies that investigate QOL using standardised measures. Analysis of QOL data was performed using non-parametric approaches (described below) as initial exploratory information about AWD and their peers. Detailed analysis of the QOL measures was also not an initial objective of this study. However, as the study included two measures that have not previously been used with AWD, it was relevant to examine the properties of each measure in more detail. Findings were interpreted with these limitations under consideration.

WHOQOL–BREF

The median and the range of scores for each of the four domains (physical, psychological, social relationships and environmental) and Q1 (overall QOL) and Q2 (general health) of the WHOQOL-BREF were calculated for the three participant groups, AWD, AC, PD. All inferential analyses were conducted using non-parametric statistical tests. Non-parametric tests were used because the data was not normally distributed and the data were measured at an ordinal level (Fitzgerald, Dimitrov, & Rumrill, 2001; Portney & Watkins, 2000). A Mann-Whitney U test was used to determine if there were any differences between the AWD and the AC in terms of:

1) Q1 (overall QOL);

2) Q2 (overall health); and

3) 4 domain scores.

The Mann-Whitney U test is analogous to the t-test used for parametric analyses, and examines data by using relative ranks of scores (Norman & Streiner, 1999; Portney & Watkins, 2000). In order to examine for differences in domain scores between AWD and PD, the Wilcoxon Signed Ranks test was employed. This method of analysis is used for paired ordinal-level data (Norman & Streiner, 1999; Portney & Watkins, 2000).

To compare WHOQOL-BREF scores of participants from the three agencies (MI, APD and SSK), a Kruskal-Wallis one-way analysis of variance test was used. The Kruskal-Wallis is utilized for three or more groups and ranks scores in order to make comparisons (Portney & Watkins, 2000). If significant differences were found between scores from the three agencies, post-hoc analyses using Mann-Whitney U tests with Bonferroni corrections for multiple tests were used to determine where the significant differences occurred.

In order to determine the association between domain scores and overall QOL score (Q1) and overall health score (Q2) on WHOQOL-BREF scores for AWD, a Spearman rank correlation coefficient (rho) was calculated. This statistical test compares the relative rank of ordinal variables (Norman & Streiner, 1999).

EQ–5D

The median and the range of scores for each of the EQ-5D self-classifier domains (Mobility, Self-Care, Usual Activities, Pain/Discomfort, and Anxiety/Depression) were calculated for each of the three participant groups. A total QOL score was also calculated by adding domain scores to determine a total score out of 15 for each participant. The median and range of the total score were also calculated. Scores on the VAS were reported as a score out of 10, using the median and the range for each of the three participant groups.

To examine for significant differences between the AWD and the AC groups, scores on the EQ-5D self-classifier domains, total QOL scores and VAS scores were compared using a Mann-Whitney U test. To determine if there were differences in EQ-5D scores between AWD and PD, the Wilcoxon Signed Ranks test was utilized. Using a Kruskal-Wallis test with post-hoc analyses, the scores on the EQ-5D were examined for differences between the three participating agencies.

The Spearman's rho was used to determine the association of the self-classifier domain scores and the VAS scores for the EQ-5D. As for the WHOQOL-BREF, this analysis was performed for scores attained by the AWD from each of the three agencies.

WHOQOL–BREF and EQ–5D

Using a Spearman's rho, the scores on Q1 of the WHOQOL-BREF were compared to the overall QOL scores (/15) on the EQ-5D. Similarly, the scores on Q2 of the WHOQOL-BREF were compared to the VAS scores of the EQ-5D. Domain scores on both tools were also compared using the Spearman's rho for all AWD. Table 8, below, summarises all the quantitative analyses.

Table 8. Summary of quantitative analyses

Measure	Statistical test
Background Information Form	• Descriptive summary • Independent samples t-test
WHOQOL-BREF EQ-5D	• Median and range • Mann-Whitney U test (to examine for differences between groups) • Wilcoxin Signed Ranks test (to examine for differences between pairs) • Kruskal-Wallis one-way ANOVA (to compare scores between agencies) • Spearman's rho (to examine for correlations between domain scores and between measures)

3.6.2 Bracketing assumptions and biases

An integral component of qualitative data analysis is the recognition of the biases and assumptions brought into the process by the researcher(s). The process of acknowledging and then setting aside these assumptions and biases is one way to ensure 'objectivity' during data analysis. As the primary researcher and data collector in this study, I brought several assumptions and biases to the field. First, prior to embarking on this field of study, I spent nine years working with children with disabilities and their families as a physical therapist in Canada. My professional experiences included direct intervention and consultations for children from birth to 19 years. My experiences with AWD, as a result of my clinical career, were limited to those living in a high-income country. I recognised that AWD in South India were likely to be very different in their attitudes, behaviour and expectations, but still carried some preconceived notions about adolescent behaviour with me when I entered the field.

The second source of bias was also related to my professional experience as a physical therapist. Upon learning of my professional background, some families would deviate from the interview to ask about intervention options for their AWD. I had to set aside any desire to provide therapeutic suggestions for the AWD until the data collection phase was completed. In order to be objective about the information

gathered from the FGD and interviews, and to focus on the purpose of the study, it was important that I set aside my therapeutic biases.

Third, and not insignificantly, was my cultural bias. Although I am ethnically Indian, I am culturally 'Western', having been born and brought up in Canada. Frequent visits to India and the influence of my family have given me an appreciation of Indian culture, values, morals and social norms. This understanding, however, has its limitations, and is largely based on visits to India as an 'outsider.' My understanding of the ways in which Indian society views disability was informed primarily by the opinions of relatives and friends in India, and subsequently by academic writing. It was important that these views about disability were recognised and then set aside while I collected the data.

Fourth, related to my cultural bias, was the way in which I was perceived by local partners and participants. My outward appearance of being Indian was both an advantage and a disadvantage. It was a disadvantage because local partners and participants expected me to understand the subtle nuances of culturally appropriate behaviour and norms of interpersonal relationships. I believe it was difficult, initially, to reconcile their expectations for my behaviour, and for the local partners and participants to dismiss their preconceived notions about me. My appearance and my understanding of Indian culture was also an advantage. I believe it was an important factor in allowing me to gain access to local communities, and to develop relationships quickly with AWD and their families. Indian society places a high value on interpersonal relationships. While this facilitated discussions with participants and their families, it was also important that I maintained a degree of impartiality in order to gather thorough and unbiased data.

3.6.3 Qualitative data analysis

All FGD and individual interviews were transcribed verbatim from the audio recordings. Transcripts were checked upon completion through a review of the digital recordings. If there were any recordings in which the English spoken by the translator was unclear or inaudible, the original discussion (in the local languages of Kannada, Tamil or Urdu)

was checked with a native speaker of the language (KR) for accuracy and clarification.

Qualitative analysis was performed using QSR NVivo version 7 software (QSR International, 2006) within the theoretical framework of phenomenology. NVivo 7 software facilitates thematic analysis through the creation of 'free' nodes which are subsequently grouped using the programme to create 'tree' nodes. Using NVivo 7 terminology, the tree node is also referred to as the 'parent node', while the sub-themes within the parent node are called 'child' nodes. It is possible to build several levels of 'children' and 'parents' when using NVivo 7. The software allows the user to further analyse the themes to look for further relationships between parent and child nodes. NVivo 7 also allows for the combination of quantitative and qualitative data for the purposes of triangulation. The specific steps of analysis used in this study are described in detail in Chapter 5.

Chapter 4 – Quantitative Data Analysis and Results

4.1 Quantitative Data Analysis

This chapter presents the results of quantitative data analysis. All quantitative data analysis was performed using SPSS 15.0 for Windows (SPSS Inc., 2006). Quantitative results are presented in three sections: background/demographic information, data from the WHOQOL-BREF and data from the EQ-5D. This is followed by results from the thematic analysis of the qualitative data in Chapter 5.

4.1.1 Background Information Form

Participant Information

In total, there were 37 AWD, 24 AC, and 25 PD who participated in the study. Data collected from the Background Information Form (Appendix I) is summarised and presented in the tables and figures that follow. Table 9 provides information about the gender, age (mean and SD) and years of education (mean and SD) for the adolescents with disabilities (AWD) and the adolescents without disabilities (AC).

Table 9. Age and education of AWD and AC

	AWD (n=37)	AC (n=24)
Gender (frequency)	M = 20	M = 8
	F = 17	F = 16
Mean age in years (SD)	15.6 (2.3)	15.4 (2.3)
Mean years of education completed (SD)	8.6 (3.1)	8.3 (2.7)

Participants from both groups were very well-matched on age and years of completed education. Although attempts were made to match the adolescent participants on gender, it was difficult to find gender-matched peers, particularly those from SSK (this issue will be discussed in more detail in Chapter 6). While there was a good match of female participants from the AWD and AC groups, there were significantly more male AWD than AC. An independent samples t-test revealed no significant difference in age ($t=.364$, $p=.717$) or years of completed education ($t=.442$, $p=.660$) between the AWD and AC.

Table 10 presents the reported diagnoses of the participants with physical disabilities. These diagnoses were provided by the participants' parents or caregivers, and in the case of the participants who were living away from home, by the participant themselves. It was not possible to verify the diagnoses through chart reviews or medical reports, as these were usually unavailable. In most cases, participating agencies did not keep detailed medical records of all the AWD involved in their services. For the participants attending vocational training programs at APD, diagnostic information was limited to what they or their parents provided. Classification on the GMFCS-E&R (Appendix VIII) was determined by the researcher (GK) based on observations and discussions with the community health worker, parent, or vocational training instructor, as appropriate.

Table 10. Diagnoses of AWD

Diagnosis		Number
Cerebral palsy		17
GMFCS–E&R Level	*Level I*	*3*
	Level II	*7*
	Level III	*4*
	Level IV	*3*
Poliomyelitis*		12
Traumatic brain injury		1
Other orthopaedic impairments		7
Total number of participants		37

*These participants were infected with the polio virus as children and all had persistent impairments affecting one or both lower limbs.

Of the 17 participants with cerebral palsy, no participants were classified in Level V (severe limitations of head and trunk control and limited self-mobility) of the GMFCS-E&R. The category 'other orthopaedic impairments' included uncorrected club feet, orthopaedic trauma during early childhood which resulted in a long-term motor disability, and other congenital deformities.

Table 11 provides participant information for each of the three agencies, MI, APD and SSK. Adolescents with disabilities and their peers are included in these figures. As mentioned in Chapter 3, the AWD were

intentionally recruited to represent a range of age and educational levels.

Table 11. Demographic information by service provider

Variable	MI (n=16)	APD (n=26)	SSK (n=19)
Gender	M = 5	M = 12	M = 11
	F = 11	F = 14	F = 8
Mean age in years (SD)	13.9 (1.3)	17.0 (1.9)[b]	15.0 (2.2)[c]
Mean years of education completed (SD)	6.4 (2.3)[a]	8.9 (2.7)[b]	9.6 (3.0)

[a] Significant difference between MI and SSK
[b] Significant difference between APD and MI
[c] Significant difference between APD and SSK

The age of participants from MI, APD and SSK were compared using an analysis of variance (ANOVA) with post-hoc comparisons using the Tukey's HSD. There were significant differences in mean age between participants from APD and SSK (p=.002), and between APD and MI (p<.001). There were no significant differences in mean age between participants in MI and SSK. Similar analyses were performed to determine if there were any significant differences in mean years of completed education between the participants from MI, APD and SSK. Results indicate a significant difference in years of education between participants from APD and MI (p=.017) and MI and SSK (p=.003). There were no differences between participants from APD and SSK. This can also be explained by the younger mean age of the participants from MI. All the participants from MI and SSK were enrolled in primary or secondary school during the period of data collection. Of the 26 participants from APD, 14 were in vocational training, six were enrolled in school, one participant was working, two had dropped out of school, and three were neither in school nor working.

Parental Information

Table 12 summarises the level of education attained by each parent and parental employment status for adolescents in each of the two groups (AWD and AC).

Table 12. Parental education and employment by participant group

		AWD (n=37) Frequency	AC (n=24) Frequency
Mother's education	No formal education	17	11
	≤ 12 years	14	8
	Graduate or post-graduate	6	4
Mother's employment status	Unemployed	20	13
	Employed	14	7
	Self-employed	3	3
	Not applicable	-	1
Father's education	No formal education	8	10
	≤ 12 years	12	8
	Graduate or post-graduate	9	4
Father's employment status	Unemployed	2	1
	Employed	18	15
	Self-employed	9	6
	Not applicable	8	2

The majority of parents of participants in both groups had either no formal education or 12 years or less of education. Basic education in India is provided for ten years. The additional two years (years 11 and 12) are optional pre-university college. A minority of parents had graduate (e.g. BA) or post-graduate (e.g. MSc) education. Professional degrees, such as a bachelor's of engineering (BE) or a medical degree (MBBS) are included in this category. Overall, more mothers were unemployed than fathers in both participant groups. Parents were categorised as 'employed' if they were earning a regular salary and worked for an organisation (public or private) or for the government. 'Self-employed' parents were primarily daily labourers (e.g. construction workers or vegetable sellers) earning wages on a daily basis, or those employed in households as domestic help.

Table 13 highlights some key differences between parents and caregivers among the three participating agencies.

Table 13. Parental education and employment by participating agency

		MI (n=16) Frequency	APD (n=26) Frequency	SSK (n=19) Frequency
Mother's education	No formal education	10	17	1
	Graduate or post-graduate	-	-	10
Father's education	No formal education	7	10	1
	Graduate or post-graduate	-	-	13
Mother's employment status	Unemployed	6	15	12
Father's employment status	Unemployed	1	2	-
Single parent families		3	7	1

The levels of parental education, both for mothers and fathers, was significantly higher for the participants from SSK, with more parents having graduate or post-graduate education. Employment status was generally similar amongst parents from the three agencies, including the fact that more mothers were unemployed than fathers from all three agencies. There were more single parent families from MI and APD than amongst participants from SSK. The majority were single mothers, and the frequency was higher amongst participants with disabilities. The difference in parental education and employment between SSK and the other participating agencies supports the hypothesis that this group represented a higher SES.

Household Information

Monthly household income was analysed by participating agency and by participant group. Monthly household income (in rupees) for the AWD and AC participants is provided in Table 14. The poverty line, as defined by the Government of India for the city of Bangalore, is a monthly per capita income of Rs 475 (Mahapatra, 2008).

Table 14. Monthly household income (Rs) per person by participant group

	Median Income	Range
AWD	620	83 – 13 333
AC	500	83 – 10 000

Table 14 indicates that the median income for both groups was similar. The AWD participants had a median monthly household income which was slightly higher than the poverty line, while the AC participants had a median income which was lower than the AWD, but still slightly above the poverty line.

The monthly per capita income per household from each agency is provided in Table 15.

Table 15. Monthly per capita household income (Rs) by participating agency

	Median Income	Range
APD	396	83-1000
MI	500	130-1250
SSK	3333	459-13 333

Table 15 shows that participants from SSK had a significantly higher median monthly household income than those from APD and MI. The median monthly per capita income for families from APD falls below the national poverty line for urban households in Bangalore. The household income of families from MI was just above the poverty line. This finding also confirmed that participants from SSK represented a higher SES.

Most participants lived in houses with one to three rooms. Household data is summarised by participant group in Figure 8 below, and by participating agency in Figure 9. Hot water was defined as the access to immediate hot water from a tap via an electric water heater or other water heating source.
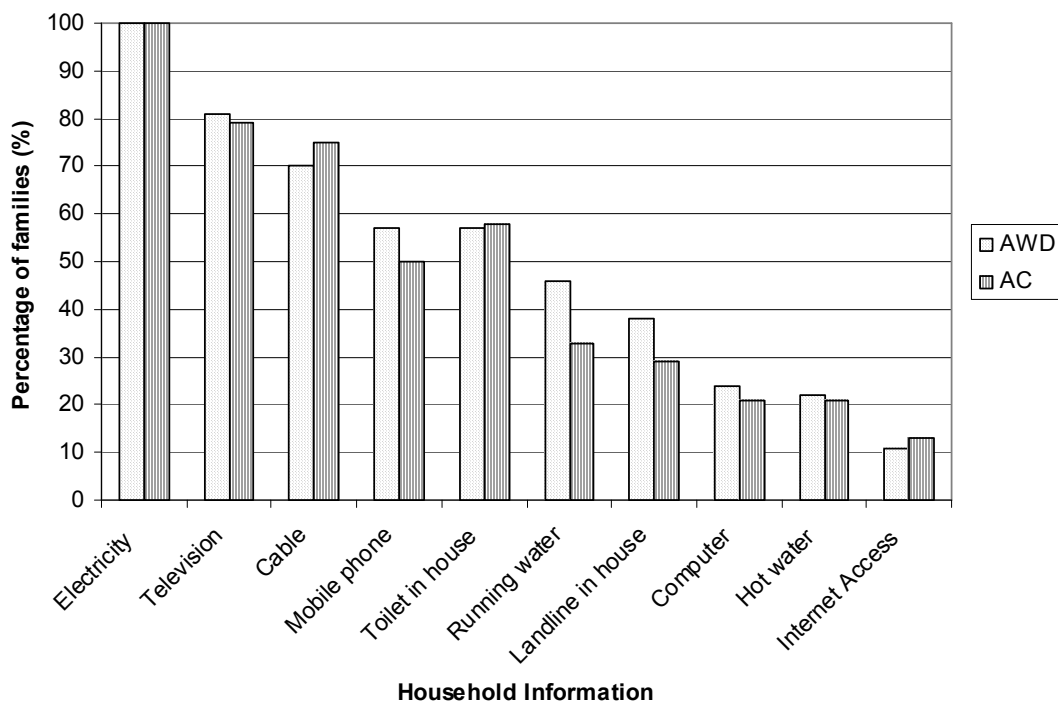
Figure 8. Household information by participant group
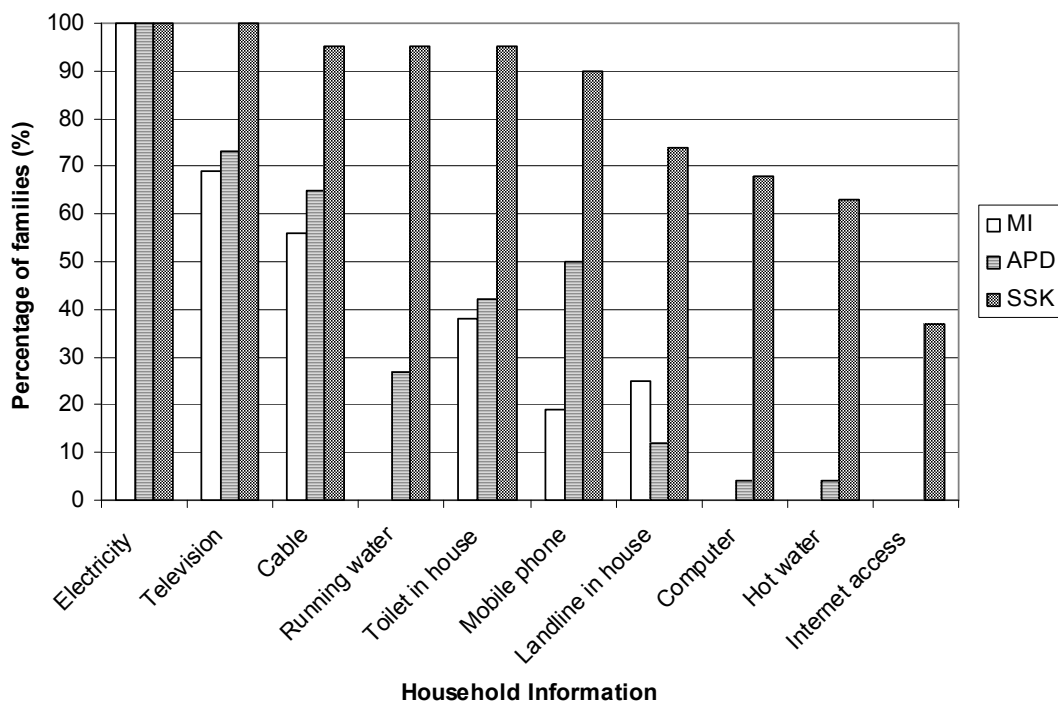
Figure 9. Household information by participating agency

There was very little difference between AWD and AC in terms of material household possessions. Mobile phones were much more common than landlines, which may be explained by the difficulty in getting a landline connection, particularly in urban slum settings. Mobile

phones are also relatively inexpensive and readily available in Bangalore. Nearly every household had a television, and most households with a television had a cable connection. Using parameters such as running water, the presence of a toilet in the house, possession of a computer, and internet access as markers of SES, Figure 9 confirms that participants from SSK were from a higher SES than those from MI and APD. This finding supports the results illustrated in Table 15.

4.1.2 WHOQOL-BREF

As discussed previously, it is recognised that number of participants was small for the QOL analysis that follows in this section. The information is provided as exploratory data.

Data for the WHOQOL-BREF (Appendix II) for AWD and AC is presented in Table 16, below. Data is provided for Question 1 (Overall QOL) and Question 2 (Overall Health), as well as each of the four domains (Physical, Psychological, Social Relationships, and Environmental). As per scoring guidelines (World Health Organization, 1996), domain scores were mathematically transformed to scores out of 100, while scores for Q1 and Q2 were reported out of a total possible five points. Higher scores on the WHOQOL-BREF indicate higher levels of satisfaction.

Table 16. WHOQOL-BREF scores by adolescent participant group*

	AWD (n=37)	AC (n=24)
General Scores (/5)		
Q1 (Overall QOL)	4 (1-5)	4 (2-5)
Q2 (Overall health)	4 (1-5)	4 (2-5)
Domain Scores (/100)		
Physical Domain	69 (44-100)[a]	88 (56-100)[a]
Psychological Domain	69 (19-94)[a]	81 (44-100)[a]
Social Relationships Domain	94 (44-100)	97 (69-100)
Environmental Domain	63 (31-100)	66 (31-100)

*Median scores (range) reported

[a] Significant difference (p=.02) between AWD and AC

There were significant differences (p=.02) between the groups in the Physical and the Psychological domains. There were no other significant differences between domain scores.

Scores for AWD and PD on the WHOQOL-BREF were compared using the Wilcoxon Signed Ranks test for paired data. Results revealed that there were significant differences between AWD and PD on Q1 of the WHOQOL-BREF only, with scores of the AWD being significantly higher than those of their parents. There were no other significant differences between AWD and PD scores in any other domain.

Domain scores on the WHOQOL-BREF for AWD from each participating agency are presented in Table 17, below. Analysis indicated significant differences in domain scores between agencies in all domains except Social Relationships. The Bonferroni correction for multiple comparisons was applied, and the α-level was set at .02.

Table 17. WHOQOL-BREF scores by participating agency*

Domain	APD (n=14)	MI (n=8)	SSK (n=15)
General Scores (/5)			
Q1 (Overall QOL)	3.5 (1-5)	4 (4-5)	4 (4-5)[b]
Q2 (Overall health)	3 (1-5)	4 (3-5)	4 (2-5)[b]
Domain Scores (/100)			
Physical	69 (44-94)[a]	84.5 (63-100)	81 (44-100)[b]
Psychological	63 (19-88)	81 (50-100)	81 (44-100)[b]
Social Relationships	94 (50-100)	94 (44-100)	94 (44-100)
Environmental	56 (31-100)	66 (56-81)	75 (44-100)[b]

*Median scores (range) reported

[a] Significant difference (p=.02) between APD and MI

[b] Significant difference (p=.01) between SSK and APD

When comparing WHOQOL-BREF scores between APD and SSK, the scores reported by participants from APD were significantly lower (indicating less satisfaction) than those from SSK in all domains except Social Relationships. When comparing scores between APD and MI, the scores of participants from APD in the Physical Domain were significantly lower than those from MI. There were no significant differences in reported WHOQOL-BREF scores between participants from MI and SSK.

Correlation analyses were performed to determine the relationship of domain scores with overall QOL (Q1) and overall general health (Q2). Results of the Spearman's rho for all WHOQOL-BREF scores for AWD are presented in Table 18, below.

Table 18. Spearman's rho for AWD WHOQOL-BREF domain scores

	Q1	Q2	Physical	Psychological	Social Relationships
Q2	.39*				
Physical	.46**	.59**			
Psychological	.43**	.37*	.61**		
Social Relationships	.10	.33*	.21	.28	
Environmental	.20	.31	.62**	.65**	.19

*Correlation is significant at p= .05 (2-tailed)
**Correlation is significant at p= .01 (2-tailed)

The strongest relationships between WHOQOL-BREF domain scores for AWD were between the Environmental and Psychological, the Environmental and Physical, and the Physical and the Psychological domains. The relationship between Q1 and the other domains was moderate. The relationship between Q2 and the Physical domain was also moderately strong. Although many of the correlation coefficients were statistically significant, the absolute values indicate relationships that were moderately strong, at best.

4.1.3 EQ-5D

Scores on the EQ-5D (Appendix III) for the two adolescents participant groups (AWD and AC) are reported in Table 19, below. Self-classifier median and range of scores are reported for each domain (Mobility, Self Care, Usual Activities, Pain/Discomfort and Anxiety/Depression), and as a total QOL score out of 15 possible points. Higher scores on the EQ-5D indicate more difficulty with the particular domain. The domain of 'Self-Care' refers to activities such as washing and dressing oneself, whereas 'Usual Activities' includes work, attending school, housework, family and leisure activities. Median scores and the range on the VAS, which asks about overall health, are also reported. The highest possible score

on the VAS is 10 points, and higher scores indicate better self-reported overall health.

Table 19. EQ-5D domain and VAS scores by adolescent participant group*

	AWD (n=37)	AC (n=24)
Domain Scores (/3)		
Mobility	2 (1-3)[a]	1 (1-2)
Self Care	1 (1-3)[a]	1 (1-2)
Usual Activities	2 (1-3)[a]	1 (1-2)
Pain/Discomfort	2 (1-3)	1 (1-2)
Anxiety/Depression	2 (1-3)	1 (1-3)
Overall QOL (/15)	8 (5-12)[a]	6 (5-9)
VAS Score (/10)	7 (5-10)[a]	9.3 (5-10)

*Median (range) scores reported
[a] Significant differences (p=.01) between AWD and AC

Scores for AWD and AC were compared. Overall QOL scores and VAS scores were significantly different (p=.01). Although analyses indicated a trend towards a significant difference between the AWD and the AC group on Pain/Discomfort (p=.03), there was no statistically significant difference in this domain, or in the domain of Anxiety/Depression. There were significant differences (p=.01) between AWD and AC for all other domains. The Wilcoxon Signed Ranks test revealed that there were no significant differences in EQ-5D scores between AWD and their parents.

EQ-5D scores by participating agency are summarised below in Table 20. The median and range of scores are reported for each domain, overall QOL score and the VAS score. The Kruskal-Wallis ANOVA revealed significant differences between scores in the domains of Mobility, Usual Activities, Pain/Discomfort and the VAS scores.

Table 20. EQ-5D scores by participating agency

	APD (n=14)	MI (n=8)	SSK (n=15)
Domain Scores (/3)			
Mobility	2 (1-2)[a]	2 (1-2)	2 (1-3)
Self Care	1 (1-2)	1 (1-2)	1 (1-3)
Usual Activities	2 (1-3)[a]	1 (1-2)	1 (1-2)[b]
Pain/Discomfort	1.5 (1-3)	2 (1-3)	1 (1-2)[b]
Anxiety/Depression	2 (1-3)	1 (1-3)	1 (1-3)
VAS Score (/10)	7 (5-10)[a]	9 (6-10)	8.7 (5-10)[b]

[a] Significant difference (p=.02) between APD and MI
[b] Significant difference (p=.02) between SSK and APD

When comparing the domain scores between APD and MI, participants from MI reported lower scores in Mobility and Usual Activities than those from APD, indicating less difficulty with this domain. The participants from APD had significantly higher scores in the domains of Usual Activities and Pain/Discomfort, as compared to participants from SSK. This indicates more perceived difficulty in those domains for participants from APD. The VAS score was significantly lower for participants from APD than those from MI and SSK, indicating that their perception of their overall health was worse than that of participants from the other two agencies.

The Spearman rho was calculated to examine the relationship between self-classifier scores and the VAS scores. The relationships between individual self-classifier domains were also examined. Results for the correlation analyses are presented in Table 21, below.

Table 21. Spearman's rho for EQ-5D self-classifier domain and VAS scores

	Mobility	Self Care	Usual Act.	Pain/ Discomfort	Anx./ Dep.
Self Care	.32				
Usual Activities	.07	.23			
Pain/ Discomfort	.05	.20	.34*		
Anxiety/ Depression	.07	.28	.15	.45**	
Total VAS Score	-.24	-.21	-.47**	-.43**	-.39*

*Correlation is significant at p=.05 (2-tailed)
**Correlation is significant at p=.01 (2-tailed)

Overall, the correlations between domain scores on the EQ-5D and between domain scores and the VAS were weak. The strongest relationship, with a rho-value of -.47, was between the domain of Usual Activities and the VAS score. Negative correlation coefficients occur as higher VAS scores indicate increasing satisfaction with overall health, whereas higher domain scores indicate more difficulty. There was a moderate relationship between the domain of Pain/ Discomfort and Anxiety/ Depression. In general, there were poor correlations among EQ-5D domain scores and between domain scores and VAS scores for the AWD.

4.1.4 WHOQOL-BREF and EQ-5D

Scores on the WHOQOL-BREF and the EQ-5D were analysed for significant relationships. Scores on Q1 of the WHOQOL-BREF were compared to the total self-classifier scores (/15) on the EQ-5D, and Q2 scores were compared to EQ-5D VAS scores. There were no significant correlations between these two questions on the measures, with the Spearman's rho values ranging between -.031 and .065. Second, domain scores on the WHOQOL-BREF were compared to EQ-5D self-classifier domain scores. There were also no significant correlations between any domain scores on the two QOL measures.

4.2   Summary

A summary of all the statistically significant differences in QOL scores is presented in Table 22, below.

Table 22. Summary of significant results

	WHOQOL-BREF*						EQ-5D*					
	Q1	Q2	P	Ps	SR	E	M	SC	UA	P/D	A/D	VAS
AWD & AC			√	√			√	√	√			√
MI & SSK												
MI & APD			√				√		√			√
SSK & APD	√	√	√	√		√			√	√		√

*Domain abbreviations: P=Physical; Ps=Psychological; SR=Social Relationships; E=Environmental; M=Mobility; SC=Self-care; UA=Usual Activities; P/D=Pain/Discomfort; A/D=Anxiety/Depression

In general, the correlations among domain scores within the WHOQOL-BREF and the EQ-5D were moderate, at best. There were no significant correlations between the two measures of QOL. In addition to collection quantitative data about the QOL of AWD and AC, qualitative data using interviews and FGD was also gathered. This data was deemed to be necessary to provide further understanding of the perceptions of AWD about participation and inclusion. This data is presented in the following chapter.

Chapter 5 – Qualitative Data Analysis and Results

5.1 Qualitative Data Analysis

A key focus of this research was to understand the perceptions of AWD about participation and inclusion. As discussed Chapter 2, current research evidence points to the growing importance of measuring participation rather than impairment for AWD. There is, however, a gap in the knowledge about what participation means to AWD, particularly in developing countries. In order to understand their perceptions about these issues, interviews and FGD were conducted with AWD, their parents (PD) and non-disabled peers (AC). The analysis of the qualitative data collected is presented in this chapter.

5.2 AWD and AC Interviews

Transcripts of FGD and interviews with AWD and AC were analysed using NVivo 7. There was no superimposed thematic structure to the interview transcripts. Analysis occurred in several stages. First, four transcripts from AWD interviews were manually analysed by two researchers (GK and SW) working independently. Each researcher established a list of preliminary themes. The initial list of themes was discussed until agreement was reached on a list of ten themes found in the four interviews. These ten themes were then transferred to NVivo as 'free nodes.'

In the next stage of analysis, six more interview transcripts (AWD and AC) were analysed using NVivo 7 by GK. Free nodes were created for any additional themes that arose in the new transcripts. The ten original nodes and any additional free nodes were reviewed and grouped into a structure of parent and child nodes by GK. Any free nodes that did not seem to fit into the parent-child node structure were kept as free nodes. The parent and child nodes and any remaining free nodes were carefully scrutinised by SW and then discussed with GK. Some free nodes were reclassified into existing child or parent nodes. Any free nodes that represented original and important themes were made into new parent nodes. After a review of the parent and child nodes, the remaining transcripts were analysed using the parent and child node structure.

After all transcripts were analysed using NVivo 7, two parent and related child nodes were chosen at random. The corresponding quotations for these nodes were collated by GK. These were reviewed by SW and any queries about coding were discussed with GK. Parent and child nodes were revised if required or certain passages from the transcripts were reclassified into different parent or child nodes. Finally, all parent and child nodes and the corresponding quotations were reviewed by GK. After a thorough review of all parent and child nodes, there were no remaining free nodes.

The first stage of analysis of the AWD and AC interviews revealed a thematic structure with eight parent nodes and 38 child nodes. The eight parent nodes that emerged were:

1. Me and My Body
2. Education
3. Leisure Activities
4. Aspirations
5. Family
6. Other People
7. External Environment
8. Inclusion

Each of the eight parent nodes contained between two and five child nodes, as shown in Figure 10. Two of the child nodes (Mobility and Feelings about my disability) were further sub-divided into two child nodes (Figure 10). The graphic representation of the parent and child nodes is not proportional, and the size of the circles has no relationship to the relative significance of one parent node as compared to another. This figure was created using NVivo 7 in order to illustrate the parent and child node structure that emerged in the first stage of data analysis.
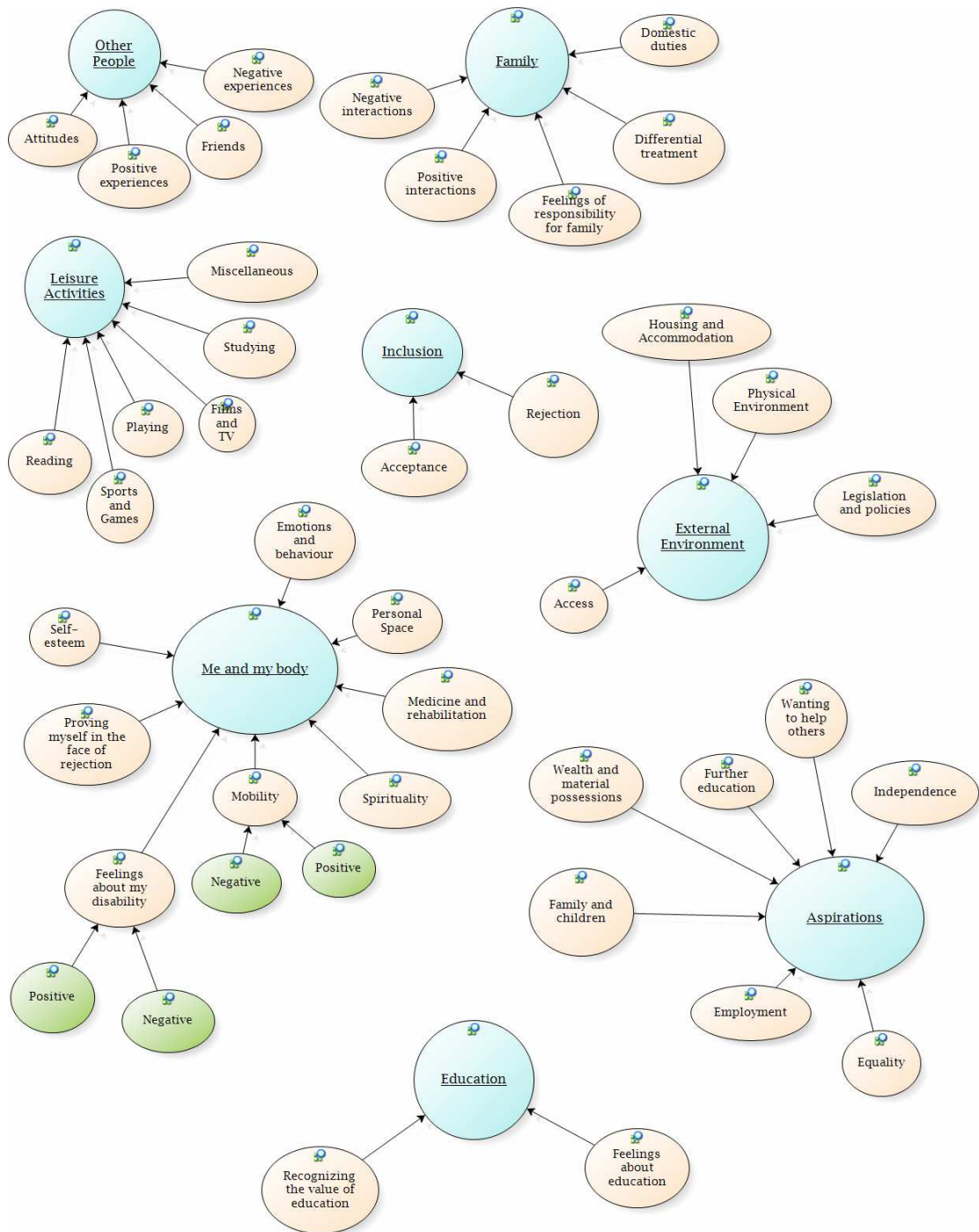
Figure 10. Parent and child nodes from first stage of analysis of AWD and AC interviews

After completion of the first stage of analysis, the parent and child nodes were further analysed. Excerpts for each parent and child node were re-read and changes were made to the coding, if required. Some child nodes were collapsed together if there was felt to be too much overlap. From this second stage of analysis, four primary themes emerged from the data. These four themes are:

- Personal Factors
- Interpersonal Relationships
- External Factors
- Inclusion and Participation

Figure 11 illustrates the process of moving from the eight parent nodes shown in Figure 10 to the four primary themes that emerged from the AWD and AC interview transcripts. The parent node of External Environment remained as a key theme, which was renamed External Factors.

Me and My Body
Education
Leisure activities
Aspirations

Personal Factors

Family
Other people

Interpersonal Relationships

External Environment

External Factors

Inclusion

Inclusion and Participation
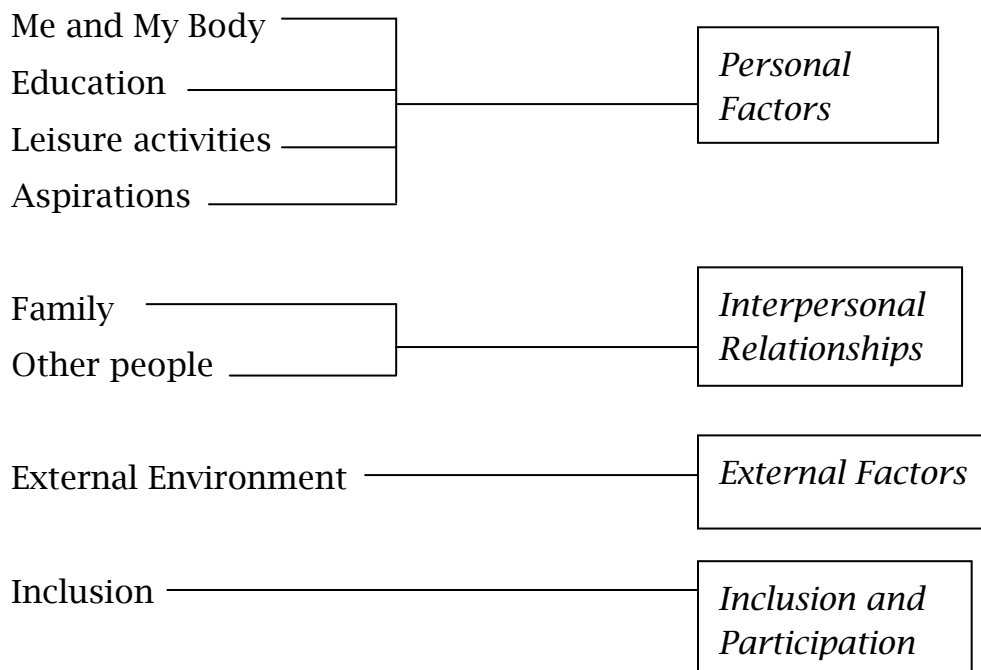
Figure 11. Second stage of analysis

The three themes of Personal Factors, Interpersonal Relationships, and External Factors all directly impacted the theme of Inclusion and Participation. In addition, there were relationships amongst these three themes. The model of the four primary themes and the relationships between them is presented in Figure 12, below.
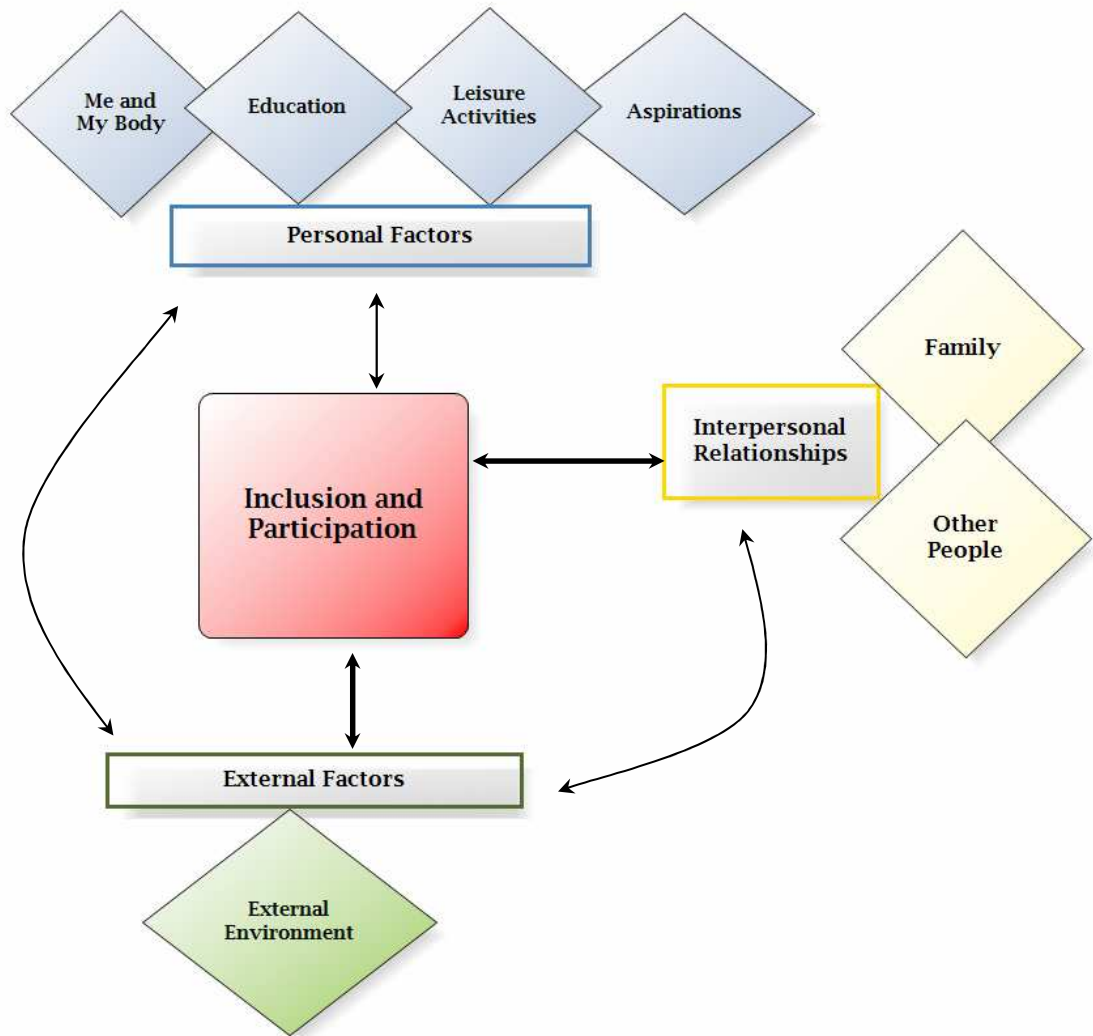
Figure 12. Four primary themes emerging from AWD and AC interviews

Thematic analyses of interview and FGD data show that the primary influences on Inclusion and Participation are Personal Factors (elements that were internal to the AWD or AC), Interpersonal Relationships (with family and non-family members), and External Factors. The heavier arrows in the model above illustrate that the themes of Interpersonal Relationships and External Factors had more of an impact on Inclusion and Participation than Personal Factors, although all three themes affected Inclusion and Participation.

As described in Chapter 3, 37 AWD took photographs that were the catalyst for the interviews and FGD. This chapter includes only a sample of all the photographs taken by the AWD. More pictures taken by AWD are included in Appendix IX. Permission was received from participants to use all the pictures. The themes and the related sub-

themes derived from the interviews and FGD transcripts are illustrated in this chapter by use of these photographs.

Excerpts from interviews and FGD are provided in shaded boxes throughout the chapter to provide supporting evidence for the themes and sub-themes. All names have been changed to protect the privacy of the participants. Passages from the FGD and interviews have not been corrected for grammar in order to reflect the local dialogue, vocabulary and manner of speaking. Unless otherwise specified, the participants all spoke through a translator, thus many responses are in the third person. Explanatory notes about the FGD and interview excerpts, if required, are provided below the quotations.

5.2.1 Personal Factors
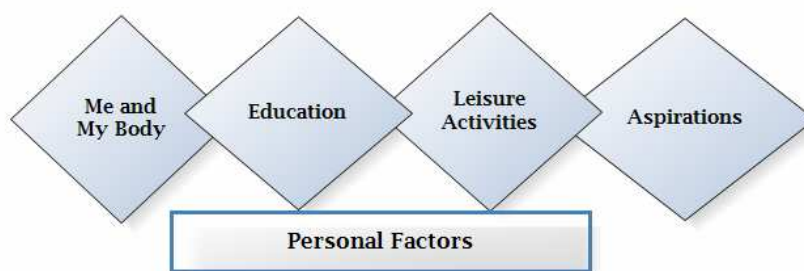
Figure 13. Personal Factors

Personal Factors was one of the primary themes that emerged from the data analysis (Figure 13). The main sub-themes of Personal Factors were Me and My Body, Education, Leisure Activities, and Aspirations. There was overlap among the sub-themes, and within the nodes contained in each sub-theme. Interview excerpts were often designated multiple codes. Multiply coded excerpts are only presented to illustrate one theme, unless they are particularly relevant and necessary to illustrate more than one theme.

Personal Factors/Me and My Body
This sub-theme refers to the thoughts and perceptions that the AWD and AC had about themselves, their disability, and their feelings and emotions. As illustrated in Figure 10, the sub-theme of Me and My Body contained several nodes, including (in no particular order):

- spirituality and personal space
- mobility
- feelings about disability
- proving myself in the face of rejection or exclusion.

Personal Factors/Me and My Body/Spirituality and personal space

Many participants referred to spirituality and religion. The AWD expressed that they found peace and happiness when they went to a place of worship, and that having pictures of gods or other religious icons in their homes give them a sense of calm. Many participants took photographs of the religious posters pictures in their homes that represented Hinduism, Christianity, or Islam. It was often difficult to determine the religious beliefs of many families, as many homes had pictures and posters representing more than one faith on the walls.

Participant 1: *This is photo of her church. She feels happy when she goes to church. She is able to listen to God's songs and good words. That makes her happy.*

Participant 2: *She says God does good to everybody so He makes her feel happy.*

– excerpt from MI AWD FGD

Figure 14. Spirituality

The belief of disability and illness as a manifestation of the divine was also vocalized by many participants. Some participants seemed to accept that God had given them their disability. Others questioned God,

and said that if they could ask for one thing, they would ask God to take away the disability He had 'given' to them. Not all the references to God and disability were framed in a negative light.

> **Participant 1:** *He's saying that now…he saying that, 'why God has given this disability for me? Why my mother died the day I born? He will think these things…*
>
> **Participant 2:** *She will ask God, change the disability. Make me normal. If you want to reduce my intellectual level that is okay, but physically make me normal.*
>
> **Translator (speaking on behalf of APD participants):** *They feel, in a sense, what mistake have I done in my previous life? Why God is punishing me in this way?*
>
> *–excerpt from APD AWD FGD2*
>
> **********
>
> **Participant 1**: *Some people are there…they blame God for everything. But they are thinking bad about God. God gave us our abilities also. Not only the disability.*
>
> *–excerpt from SSK AWD FGD2*

Box 3. Disability as a manifestation of the divine

Personal Factors/Me and My Body/Mobility

There was significant overlap with the sub-themes of 'mobility' and 'feelings about disability,' as well as with the theme of External Factors. What distinguished this theme, however, was that participants spoke specifically about their mobility or barriers to their mobility, rather than in general terms about access or environmental barriers. The overwhelming number of participants spoke of their mobility in terms of restrictions they faced.

Box 4. Mobility restrictions

As shown in the extracts above, discussion about their mobility emerged when participants were asked to show the photographs they took for the topic of 'Things that make you sad' as well as for 'Things you want to change.' Much of the discussion about mobility was not illustrated by a particular photograph, but emerged in subsequent conversation.

Personal Factors/Me and My Body/Feelings about disability

That is Shobha's walker. Walking with the walker makes her sad because she doesn't want to walk with walker. She feels sad because she's having disability.

Figure 15. Feelings about disability

Participants expressed both negative and positive thoughts about their disabilities. Exclusion from games and sports also made them feel sad about their disabilities. As one participant said, '*We want to play, ma'am, but we cannot play*' (-from APD AWD FGD3).

It was clear from the interviews that the positive manner in which the AWD dealt with their disability came from a variety of experiences when they were younger. When asked what advice they would give a younger person with a similar disability, the theme of a positive attitude toward their disability was again apparent.

Facilitator: And what would you tell other young people who are disabled? What advice would you give them, from your experience?

Participant: *So I would tell those children, take it as…take life as it comes. There is no use feeling sad about the things you can't do. You have to think about the things you can do, and concentrate on whatever you can do.*

–excerpt from SSK AWD Interview1

*****

Facilitator: So if you had to give advice to someone who was younger who was disabled, like say a 7 or 8 year old child, what would you tell them? From your experience, now that you're older and have done more things?

Participant 1: *The first is not to see disability without ability. To see ability and get focused on that.*

Participant 2: *They should see what they can do, what skills they have…and use them.*

–excerpt from SSK AWD FGD2

Box 5. Advice to younger people

Many AWD participants reiterated the need to focus on the positive, to use their abilities rather than dwelling on their inabilities, and to prove their capabilities to others. Needing to prove themselves in the face of rejection was another significant finding under the sub-theme of 'Me and My Body.'

Personal Factors/Me and My Body/Proving myself in the face of rejection and exclusion

Participants shared stories of how other people, neighbours, teachers or distant family members would tell them that they were incapable of doing certain activities because they were disabled. When asked what

they did in response, many AWD expressed that they would prove what they could do. As one participant emphatically declared, '*I will do and show!*' (-from SSK AWD FGD1). The importance of proving themselves in the face of rejection also emerged when asked what advice they would provide to a younger person.

Facilitator: What advice would you give to somebody who is younger with a disability? What would you say is the most important thing that they should know?

Participant: *So if she sees that disabled boy, she tell that people will say a hundred and one things about you, that you can't do, you are like that…So ignore such words, don't believe those words. So if you feel you can do, you go ahead. Before somebody says that you can't do, go and start doing anything and ignore what people say, study well and prove yourself that though you are disabled, you can do the job.*

–excerpt from APD AWD FGD2

Participant: *You show the world what you can do. Never sit quietly. Show the world what you are and what you can do.*

–excerpt from SSK AWD Interview3

Box 6. Proving myself in the face of rejection

Personal Factors/Education

Education and the importance of studying was a key sub-theme of 'Personal Factors.' Many participants said they would use leisure time to do extra studying or to learn new skills. The value they placed on education was also apparent when they spoke of advice they would give younger children with disabilities, things that made them sad or what they would like to change if they had the power or money to do so.

So this photo, she feels very sad to look at this boy. Because though he is young, it is the age for him to go to school. But because his family background is poor, he won't go for the school. He sells this fruit. So she feels sad when she looks at this boy. At this young age, he is working. Who is this boy, she don't know. Still it makes her feel sad.

Figure 16. Recognising the importance of education

> **Participant 1:** *He feels that children have to start working at a young age, because they don't have money. So if he gets the money, he will make them stop going to work, let them go to school. Even the poor families in the villages, they won't have the children in the school because of the financial problem. He gets the money, he'll make sure that everybody goes to school, get educated.*
>
> **Facilitator:** So if you could give any advice to a younger person who has a disability, like you, what would you tell that person?
>
> **Participant 2:** *Take proper education. Join a good school. Study well.*
>
> **Participant 3:** *When he meets with a young disabled boy, he will say that take good education, and then if you go for the work with the knowledge…when he's learning, many skills he is learning…when you go for the job without skills, maybe they will shout at you because you're disabled, but if you have proper skills and go for the job, then they respect you. So take good training, learn well, go for good job. That is his advice.*
>
> *–excerpt from APD AWD FGD1*
>
> ****
>
> **Facilitator:** So you think there's a lot more children who could be coming here [SSK school], but they're not here.
>
> **Participant 1:** *Yeah, because their parents aren't accepting them.*
>
> **Participant 2:** *After they accept the child at home, then they must send the child to the school. Then they can learn to cope.*
>
> *–excerpt from SSK AWD FGD2*

Box 7. Valuing education

Both the AWD and the AC groups indicated that, overall, they enjoyed attending school. They appreciated the support they received from their teachers, being able to interact with their friends, and gain important knowledge that they felt would help to achieve their employment goals. Success in school also gave the AWD and the AC a sense of pride. As one AWD said, '*I am studying better in school than others so I am happy*' (-from MI AWD FGD).

Personal Factors/Leisure Activities

When compared to the AC, the AWD engaged in similar leisure activities. Both groups participated in a variety of games and sports, which they often referred to as 'playing', as well as reading, doing crafts, or singing. Nearly all the adolescents from both groups said that they watched television as a leisure activity. Interestingly, the AWD and the AC from the two urban slum settings (APD and MI) had a difficult time answering the question about what they did in their 'free time.' Many indicated that they only had one day a week of leisure time. Time out of school was spent on household chores or extra studying. In comparison, the AWD and AC from SSK seemed to have more leisure time away from school.

There was one notable difference between the AWD and the AC. A recurring topic of conversation among the AWD was that they were often not able to participate in certain leisure activities, particularly games and sports, because of their disabilities. This restriction in playing games and sports meant that the AWD often participated in more sedentary leisure activities such as reading, playing computer games or studying.

> **Facilitator:** Is there some game you want to play, or something you want to do, or something around the house, but that you are not able to do because you have a disability?
>
> **APD participant 1:** *I want to skip and run.*
>
> **APD participant 2:** *Her friends are running, so she can't run with them, so she will stay on one side and she will feel bad. I can't do that – running.*
>
> **APD participant 3:** *Cricket. He likes to play cricket, but he can't do. This is his wish.*
>
> *–excerpt from APD AWD FGD3*
>
> *****
>
> **Participant 1:** *And also…with one leg they play, no? What they say for that? Hop…*
>
> **Facilitator:** Oh, hopscotch…
>
> **Participant 1:** *Yes, she enjoys that…so she says she can't do because she is disabled. She enjoys watching that one, but she can't do. She feels sad about that. And even here, the girls and boys they play volleyball…they can't because of their disability.*
>
> **Participant 2:** *Running games. When somebody is standing there and they have to run and touch somebody…that kind of play she can't do, no? So she feels sad about that.*
>
> **Participant 3:** *I saw these children playing in the playground. I felt sad. Then I thought, 'One day, I must also play with them.' But I feel happy to see them play. In my dreams, I see myself playing like all the children.*
>
> *–excerpt from APD AWD FGD2*

Box 8. Restrictions to participation in leisure activities

Personal Factors/Aspirations

The AWD and the AC spoke about aspirations in both general and specific terms and were not limited to jobs or careers. Desired vocations included engineers, teachers, doctors, government civil service (a highly coveted and competitive position), and jobs in the computing industry. Interestingly, with few exceptions, only the older AWD and AC (those who were over 16 years of age) were specific about the careers they desired. The younger participants (those between 13 and 16 years)

tended to speak in generalities, and had not yet considered the specific job they would like to have after graduation.

Questions about wealth and material possessions were difficult for many AWD and AC to answer, particularly those from MI and APD. Most participants indicated that they would rather use any money they received, either through jobs or as a gift, to help their families and to improve their lives. Specific material desires for themselves included new clothing, food, school supplies, a nicer house, a scooter or a new car. One participant declared, '*Right now, I am living in middle class. I have aim for a luxury life*' (-from MI AWD FGD)*. Another participant insisted that she did not want anything for herself. Rather, she said, '*I want to be a good girl and want a nice job to help my parents and live in good status*' (-from MI AWD FGD)*.

By far the most common topic of discussion among the AWD was a strong desire to help others, particularly those with disabilities. Many participants were unable to think of what they wanted for themselves, but were very determined that they would use their skills and knowledge to help those with fewer opportunities. This theme was particularly evident among the participants from lower APD and MI.

Participant 1: *If she has money she will build her own building, and there she will give education to poor people.*

Participant 2: *What she says is, now I'm disabled child, so one more disabled child is there it seems. Now he cannot go across the road...I would build the road so he could cross the street.*

Participant 3*: *There is this boy in our hostel. He's always sad and he's always quiet and he just studies a little bit. Our warden tries to make him talk but he doesn't say anything. If she has any anger, she takes it out on him. Everybody pushes him, and they make fun of him and when he cries, we also feel like crying. We feel very sad. His parents live in another town and they can't look after him, so they've left him here in this hostel. ... the hostel people treat him very badly. Only when the parents are coming, they give him a bath, and put on nice clothes and make him look as if he's well cared for. After they go, it's the same story. ... And for nothing they keep beating him. He's about 7 or 8 years old. Actually, his mind is alert and he's intelligent, it's only his limbs that don't function properly. Actually if he studies, he will be alright. He can learn. But they won't let him because he now doesn't know when he wants to go to the toilet and he messes himself up and they scold him. When we talk to him, he responds to us and tries to get up and come to us. We should be able to do something for him. We can help him. The warden just doesn't treat him properly.*

–excerpt from APD AWD FGD2

*****

MI participant 1: *I want to change the beggars.*

Facilitator: What do you mean?

MI participant 1: *I want to change the beggars – for that our India is going to poor condition. There should be no beggars.*

MI participant 2: *She want to give money to people who don't have any.*

–excerpt from MI AWD FGD

* This participant was very upset when relating the story of the little boy in her hostel. She continued to insist to the translator and her teacher, after the interview was over, that they should do something to help this boy.

Box 9. Wanting to help others

5.2.2 Interpersonal Relationships
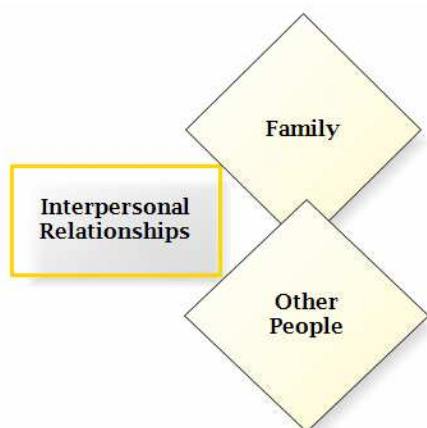
Figure 17. Interpersonal Relationships

Another key theme was Interpersonal Relationships. The main sub-themes within this theme were 'Family' and 'Other People.' The theme of Interpersonal Relationships involved both relationships with friends and family, as well as encounters and experiences with people outside the adolescent's immediate support network.

Interpersonal Relationships/Family

The sub-theme of 'Family' in Interpersonal Relationships referred specifically to interactions the AWD and AC had with family members, both immediate and distant. This sub-theme had several 'nodes', including domestic duties, positive and negative interactions, and feelings of responsibility for family. The majority of AWD and AC participants lived with at least one parent and one or more siblings. The group of AWD and AC participants enrolled in the vocational training program at APD lived in a hostel, away from family. Discussion about their families referred to their experiences when they were living at home or when they returned to their villages during holidays.

Interpersonal Relationships/Family/Domestic duties
Both AWD and AC participants discussed having duties, or responsibilities, at home. The type of task varied from participant to participant. The most common domestic duties for both AWD and AC were preparing meals, cleaning the house, shopping for household

necessities, and washing clothes. The participants from rural villages also spoke of responsibilities for livestock and other agricultural work. The AWD did not have fewer chores to perform, but their assigned tasks were modified by their physical ability. There were also few reported differences on household duties based on gender roles.

Facilitator: So is there anything you want to do at home but other people say you cannot because you have a disability?

Participant 1: *Bringing water.*

Participant 2: *Heavy things, lifting from here to there in the house, people say 'You can't do.'*

–excerpt from APD AWD FGD2

****

Participant 1: *At home they say don't wash the vessels because of height. It is too high for her they say.*

Participant 2: *At home when I carry water bucket they say 'leave that you cannot do, it is too heavy for you.'*

Participant 3: *Same for me. Carrying things, heavy things they won't let me do.*

–excerpt from MI AWD FGD

Box 10. Domestic duties

One of the interpreters, also an instructor in a vocational training program, was quick to emphasise that AWD did not do less than other family members when it came to domestic responsibilities. '*They wash clothes, they cook, everything. To be very frank, no, I have seen all this. We feel the disabled are not able to do work, but when we look really into their families, they are the people who work more*' (-from APD AWD FGD1). Many AWD expressed that they would like to do more at home, but were prevented by others who thought they were not capable. They were anxious to prove that they could. '*Actually, they feel they want to do. Sometimes [their brothers and sisters] take them, but every time they say, "No, you can't do." So they want to do, actually, go work with their brothers and sisters*' (-from APD AWD FGD2).

Differences in domestic duties did appear between AWD of lower and higher SES. Participants from higher SES groups (primarily from SSK) tended to have fewer responsibilities at home. Many said that their only responsibility, according to their parents, was to study and do well in school. Most of the participants from the AC group from SSK referred to doing household work only when their 'maid had taken off' (*–from SSK AC FGD).*

Interpersonal Relationships/Family/ Positive and Negative Interactions

Participant: Yes. And this (pointing to something), I like this very much. My sister said, take a picture of me.

Facilitator: Which is your sister?

Participant: The one sitting in the middle with the bag. She likes to sit here in her little shop. In our Indian culture, it's very rare to see our sisters. So when her sister came and sat in the shop, she was very happy to see her and to visit with her.

Figure 18. Positive family interactions

With few exceptions, all the AWD and AC participants spoke at length about the close relationships they had with their families. This included parents, siblings, uncles, aunts, grandparents and cousins. Those participants who lived far from extended family frequently mentioned visiting family as one of the things that made them happy. Many of the pictures taken by AWD participants in the category of 'Things that make you happy' were of family members.

Participant: No, if I am sad, I think of my aunt. If she was there, she'd make me do everything!

Facilitator: What do you mean, she'd make you do everything?

Participant: She'd make me work.

Facilitator: And does that make you happy, when your aunty makes you do everything?

Participant: Yes.

Facilitator: How come that makes you happy?

Participant: Encourages me. That you can do everything.

– excerpt from SSK AWD Interview2

****

Facilitator: Anything else you want to have? If you could have anything at all, what would you like? What would you wish for?

Participant: Parents have to be with her. She doesn't want anything.

Facilitator: No 'things'. But you want more friends, and you want your family to be with you.

Participant: Yes

–excerpt from APD AC FGD2

****

Participant: He says, this is a photo of his sister's children. About this photo he feels, if they are not there also but he sees this photo and he can feel happy. Earlier he didn't have this photo of these childrens with him. Now he has taken this photo so he is feeling if they are not with me, if I remember them, I can see this photo.

–excerpt from APD AWD FGD1

Box 11. Positive feelings about family

In terms of acceptance, many participants indicated that they felt included in their families. '*Their family consider them family,' and 'Family accepts but outside people don't*' (-from APD AWD FGD2) were typical comments made by many AWD. In response to being asked if they felt involved with their families, and if they participated with their families, one AWD said, '*Yeah! That's why we're all participating now!*' (-from SSK AWD FGD2).

Negative interactions with family fell into several areas. First, many of the female participants expressed frustration at conflicts between their desires for further education and their parents' desires that they should either seek employment or get married.

Participant 1: She is from the rural area, so her parents are not in favour of her…(unclear). So her uncle is supporting her to come here. She wants to study, it seems, but her parents are not in favour of studying, so she is frustrated. After completing this course, what will she do? That is her difficulty now.

Participant 2: See, they have 3 childrens at home, and 3 of them are studying. So her father is in favour of getting her educated for that. But her mother is not in favour because three of them have to get educated at same time, so cannot afford. But she wants to continue her education, but they want to stop after this course…(unclear), after this one year.

Participant 3: Her granny always says, 'What is this? This is enough. Get married soon. So she wants to make her stop.

Facilitator: And you want to study more?

Participant 3: Yes ma'am.

Participant 4: … her mother always goes for stopping study and get married. She's telling that for her, it is only her brother who supports her education and according to her feelings, she doesn't want to get married because she hates marriage.

Participant 1: She belongs to a poor family. So they don't want to send her for further studies because they can't get the fees. She wants to study, but sometimes, because parents are telling because of the money, she should not study. And she wants to study. When she sit and think about that alone, she will feel frustrated. Because she can't see which is right and which is wrong. That kind of thing.

Participant 2: Even she doesn't have bus pass. Every day she has to pay money and come. So we gave from our account to make pass, but she has to pay back that money. So her mother took with lot of trouble. She is coolie, and she brought that money…to give back the money, she pick-pocketed money. Now she has to give back to the office. Parents doesn't have that money. So they say to her, you leave that job, your training, and come and do some work, some working in a house. At least you get some money.

–excerpt from APD AWD FGD2

Box 12. Negative interactions with family

Participants, both AWD and AC, spoke about feeling frustrated with their parents insisted that they stay at home and study, or put restrictions on the things they could do in their free time. For the most part, participants said they did not argue with their parents, but wished that they could do have more freedom. '*She feels, because her parents are very strict, they don't want her to have many friends, go out, all those things. But she feels she needs that independence, the freedom, she needs the freedom where she can go out and have friends…*' (-from APD AC FGD2).

Interpersonal Relationships/Family/Feelings of responsibility for family
The majority of AWD and AC participants indicated a deep sense of responsibility for their parents and siblings. This was particularly true when asked what they would do when they started earning money, or what they felt was important in their future. Many of the male participants felt an obligation to ensure that their sisters married well.

> *Participant 1: He wants to work, be independent, live on his own, and look after his parents, and his sisters. He has to pay money for their marriage.*
>
> *Participant 2: He expects that his family has to be happy. He wants to get his sister a good boy.*
>
> *Participant 3: His sister is not married now. He wants that if she gets married, after marriage, she should be happy.*
>
> <div align="right">– excerpt from APD AWD FGD1</div>
>
> <div align="center">****</div>
>
> *Participant 1: Now as she is disabled her parents are worried. She is a girl, getting boy will be difficult. What will happen to this girl? So they keep worrying about her. So what is her intention, once she completes this training she wants to get job first and live life on her own. Parents should feel that, okay, my daughter is capable of managing herself. They should not worry about me. I should bring them that calm.*
>
> <div align="right">–excerpt from APD AWD FGD2</div>
>
> <div align="center">****</div>
>
> *Participant 1: I want to be a good girl and want a nice job to help my parents and live in good status.*
>
> *Participant 2: I will use money to help my brother and sisters with their education. And I will give money to parents for what they need.*
>
> *Participant 3: My mother has given me big responsibility to look after my sisters after her death.*
>
> <div align="right">–excerpt from MI AWD FGD</div>

Box 13. Feelings of responsibility for family

The sense of responsibility for their parents was not limited to the male participants. Female AWD and AC expressed that any money they earned would go directly to their parents. Participants enrolled in the vocational training program also felt a responsibility for ensuring that their siblings had the same access to education that they had. There was no difference in the expression of this sense of responsibility between the younger (13-16 year old) and the older (16-19 year old) participants.

Interpersonal Relationships/Other People

The theme of Interpersonal Relationships included the sub-theme of Other People. This referred to interactions the participants had with people outside their family unit, including neighbours, teachers, friends, and members of the general public.

Interpersonal Relationships/Other People/Friends

Friendship, and having friends, was a key aspect in the lives of AWD and AC. Participants in both groups discussed the importance of having friends with whom to share happiness and worries.

> ***Participant 1:*** *Everything she can't tell it to her brother, no? So she keeps it in her mind, and she'll discuss it with her best friend.*
>
> ***Facilitator:*** *Anything else you want to have? If you could have anything at all, what would you like? What would you wish for?*
>
> ***Participant 2:*** *Friends, she wants more friends.*
>
> ***Facilitator:*** *So you when feel sad, it's when your parents are very strict, they say don't go out when your friends…*
>
> ***Participant 3:*** *[Her parents] are very strict. When she comes to APD, after finishing her course, she has to directly go to the house. So in between this time, she can't go outside. So she is feeling frustrated because the parents don't understand her feelings. They say she can't go out and have friends, they won't allow it.*
>
> *–excerpt from APD AC FGD2*
>
> ****
>
> **Facilitator**: Anything else that makes you sad or angry?
>
> ***Participant 1:*** *When her friend gets hurt, she feels sad.*
>
> ***Participant 2:*** *When her friends get beating from the teacher, she feels sad.*
>
> ***Facilitator:*** *So what…when you feel frustrated, what do you do? Do you talk to somebody, do you keep things to yourself, what do you do?*
>
> ***Participant 1:*** *They share with their friends.*
>
> *–excerpt from MI AC FGD*

Box 14. Value of friendship

Participants had different friends at school and in their neighbourhoods. Distances from their homes to their schools were often great, meaning that it was not possible to see 'school friends' outside of school hours. The AWD participants from SSK reported that their friends were classmates at school. These same participants said that school holidays were 'boring' because they did not meet their friends. One AWD participant from SSK said that school holidays do not make him sad because, '*We all have email IDs and we keep in touch*' (-from SSK AWD FGD1). In general, all participants said they felt comfortable with their friends, shared feelings, frustrations and joys with them, and wished they had more friends.

Interpersonal Relationships/Other People/Attitudes

The AWD participants spoke at length about their negative experiences with people outside their circle of family and friends. Although some did relate stories of encouragement from teachers or neighbours, most had experienced negative attitudes directed at them because of their disability. In some extreme cases, this negativity led to a complete restriction on participation or exclusion from activities. This particular topic arose when the participants were discussing thing that made them sad, angry or frustrated.

Facilitator: So how does it make you feel when people tell you that you can't do something because you're disabled, but you know you can?

Participant: So when they say, he feels very sad. Though he can do that work, because they say like that, it will make him not to put the effort. If they say he can do, maybe he will put the effort, if they encourage him. Because they discourage him, many things which he can do also he cannot because they discourage him.

– excerpt from APD AWD FGD1

Participant 1: …she still has problems with her hand. In that hand, she has to do all the work. She has to take water, take bath, whatever she has to do, she has to do with one hand. So if she meets some people who understand, then they help. But other people will point to her and say she has to do the work. They don't understand, and they tell her she has to do everything. They don't help. So for that she feels sad.

Participant 2: She says in her village, everybody points to her and says, 'What you can do? You're disabled. You can't do anything. You're fit for nothing. What's the use of her?'

Participant 3: So when they go for their, to the native place [their village], they walk fast. She can't walk fast. They keep telling her, 'Because of you we have to wait. You can't walk fast. Always you will make us wait.' And they tell her like that. … They feel very sad because they can't answer to them also.

–excerpt from APD AWD FGD2

****

Participant 1: In school, when they have sports competition, teacher says 'You can't do because you have a disability' and they won't let her take part in the games.

Participant 2: In school they make her sit all the time. They won't let her stand. If she stands, they tell her to sit down.

Participant 3: In school, they won't allow her to participate in any playing or stand up. They tell her no, because she has a disability.

Participant 4: Outside at school they won't let him participate in sports or play.

–excerpt from MI APD FGD

Box 15. Negative interactions with others

The AWD believed that negative attitudes in others were a consequence of people being poorly educated or ill-informed about disability. The AWD recounted stories of being teased by others, of others dismissing their ability to perform skills or activities, and of being used for their disability.

Facilitator: Okay, is there anything else you want to tell me about your life…?

Participant 1: She says that [other people] should accept that disabled are also like normal. They should not feel that [disabled people] doesn't do anything, [disabled people] can't do anything. They should be aware that even the disabled can do the work.

Participant 2: They should know that if they feel some work cannot be done by the disabled, they should support them. Instead of teasing them and making fun of them, they should accept what they can't do, and what they can do, they should support them.

– excerpt from APD AWD FGD2

****

Participant: Yeah…let me tell you about that. Actually, I like playing chess, Aunty.

Facilitator: Chess? Okay…

Participant: And so we play chess very often. And one day I was playing chess with Arvind. And there were medical students, and they were watching us playing. And they were saying that we didn't know how to play chess and that we were just moving the guys. … I couldn't understand it, Aunty. I couldn't say anything to them…

Facilitator: Why couldn't you say anything to them?

Participant: Because they were medical students.

Facilitator: Oh, so you felt that you had to be respectful, even if they were saying things like that?

Participant: Yeah. And one thing that surprised me was that they are medical students. … So that's why it is hard to believe.

– excerpt from SSK AWD Interview1

****

> *Participant 1: And one more thing – if we go in the auto [rickshaw], and he wants to put gas, and the driver will have to wait in the line for the gas. So he says 'See how he cannot walk', and tells like this so he can move the auto to the front.*
>
> *Participant 2: They have to bring the tube for the gas. So they use him to move in front.*
>
> *Facilitator: So they use you as a reason to go to the front of the line?*
>
> *Participant 1: Yeah.*
>
> *Facilitator: So how do you feel about that?*
>
> *Participant 1: It's frustrating.*
>
> *Participant 2: That is wrong.*
>
> *Participant 1: And one more thing…If we are in the auto [auto–rickshaw], and there is a lot of traffic, the autorickshaw will just turn in the middle of the road and go.*
>
> *Facilitator: Oh, so they'll break the rules if you're in the auto?*
>
> *Participant 1: Yeah, and the traffic police, if they stop him, the auto driver says, 'Look, I have a cripple.' And then he says to me, 'Go walk and show him' and I have to get out of the auto and I have to walk to show the police that I cannot walk.*
>
> *Facilitator: So he makes you get out of the auto to show the police that you can't walk?*
>
> *Participant 1: Yeah…*
>
> *Participant 2: And that makes us frustrated.*
>
> *Participant 3: See, they don't really know what disability is, really. To them, a disabled person means, he can't do anything. That's the attitude.*
>
> *–excerpt from SSK AWD FGD2*

Box 16. Experiencing negative attitudes in others

These attitudes caused frustration on the part of the AWD, and often, as was expressed by one participant, they were unable to stand up for themselves.

Seemingly well-meaning behaviour by other people was also seen to be misinformed or detrimental.

> *Participant 1: Some people overhelp.*
>
> *Facilitator: Overhelp?*
>
> *Participant 1: Yeah…like…uh…they'll be told that we can walk, but they'll lift us anyway.*
>
> *- Some discussion omitted -*
>
> *Participant 1: This is embarrassing to us, when others overhelp.*
>
> *Facilitator: Because it makes you feel completely unable to do anything?*
>
> *Participant 1: Yeah. It makes me feel like I cannot do anything.*
>
> *Participant 2: But it will be uncomfortable for others, that's what they say. To see us…*
>
> *–excerpt from SSK AWD FGD2*

Box 17. Experiencing 'overhelping'

Participants viewed 'overhelping' to also be an extension of the attitude that they were incapable of doing things because they had a disability. It is interesting to note the observation of one participant that 'overhelping' was fuelled by the desire of others to lessen their own feelings of discomfort at seeing someone with a disability, and not necessarily to provide meaningful assistance to the AWD.

When asked if the attitudes of others had changed from their childhood, most agreed that the situation had improved. Any positive changes in attitude seem to be based primarily on changes in physical function. A common story from many AWD participants was that if their physical function had changed since they were children, people generally responded in a more positive manner towards them. In addition, the AWD felt that proving their capabilities through education and employment also altered the perception of disability in others.

Participant 1: So when he was born, people keep telling his parents, what disabled boy, he can't do anything, all those things. But they have ignoring that, he is telling, and now he has come from that and he is in Bangalore and he is studying here. They are telling like that and now their way of looking at him has changed and they respect him. Okay, though he has a disability, he is still able to work.

Participant 2: So when he was four, five years old, he was not able to walk because of his leg. Now he gets therapy, now he's able to walk. So people, that time, people said he's disabled, he can't walk, now he's able to walk. They not looking at him the same, now they respect him, admire him.

Participant 3: So when he was young, he (unclear) wasn't able to walk because he had a lot of disability. With exercises, now he's okay to walk compared to earlier. So neighbour says, compared to that before, now the boy's improved.

– excerpt from APD AWD FGD1

Participant: Uh…many people used to ask me if I had polio or muscular dystrophy, or something like that. I noticed that people didn't know what my problem is. But now I notice that they know what my problem is and they don't ask me anymore. But there are still some people who ask me what my problem is, and all that. There are some people who ask me why I can't walk.

Facilitator: How do you feel people react to anybody in a wheelchair? Do you think it's changed since you were small?

Participant: One thing I have noticed, when I go in my car to places, people don't stare at me so much. But when I go in a wheelchair, they look at me and people will stare. Because of the wheelchair, the stigma is attached to the wheelchair….Actually, I told you that many times earlier in India, they didn't know what spasticity was. And many of the doctors and people would say, 'What is this, and why is he like that?' and all that. So I would get angry and didn't think they should deal with me like that. But now I know that they need to be educated and there is no use feeling bad about it.

– excerpt from SSK AWD Interview1

Box 18. Changing attitudes toward disability

5.2.3 External Factors
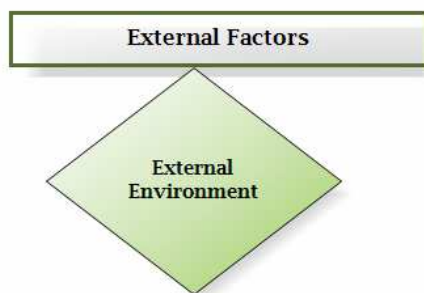
Figure 19. External Factors

The theme External Factors is made up of elements from the external environment. This theme is closely linked to the previous theme of Interpersonal Relationships, in particular the sub-theme of 'Other people.' The nodes within External Environment are physical environment, access, and legislation and policies. Similar to *external factors* in the ICF model (World Health Organization, 2001), the theme of External Factors in this model does not simply refer to the physical environment in which the AWD lived. The attitudes and behaviours of others (found in the theme of Interpersonal Relationships), policies, and social structures can all enhance or restrict participation.

Here is very dirty road and road is not good for her to walk also, so only she took photo.
   –excerpt from APD AWD FGD3

The photo she selected, the road is not good so children cannot walk, disabled peoples cannot walk so only they should clean this road.
   –excerpt from APD AWD FGD3

She's washing this, no? So it's very dirty there.
   –excerpt from APD AWD FGD3

He feels sad because for these two are using wheelchairs and the roads are not proper. So when he sees this picture, he feels the roads are not proper, where they can drive their wheelchairs?
   –excerpt from APD AWD FGD1

Figure 20. Feelings about the physical environment

An overwhelming topic of great concern to the AWD and the AC was the condition of the physical environment in which they lived, travelled, and went to school. Roads in poor condition, dirty and unhygienic surroundings, and the overall inaccessibility of streets and sidewalks were commonly discussed. Most often, these discussions arose when participants were asked about things that made them angry or frustrated, or things they would like to change. Inaccessibility was seeen as a barrier not only for people with disabilities, but for children and the elderly. One participant was using a wheelchair after surgery and was

unable to walk. He said, '*I feel angry when [I see] the road. Every day I go from this place [school] and I can't go from this place, my house. For that I get angry*' (-from SSK AWD FGD1). Participants from APD and MI were particularly frustrated with their physical environment and the seeming lack of priority paid by higher authorities to change conditions.

External Factors/External Environment/Access

Steps...but those steps don't make me angry, but the idea makes me angry. I'll give you an example. Most [arcades] are located at the top of stairs so I get angry because I can't go there.
–from SSK AWD Interview1

Figure 21. Barriers to access

Related to poor physical environment was the major issue of lack of access to buildings, schools, and homes. This theme was common to participants of varying levels of disability, not just those in wheelchairs, or those who used walking aids.

> *Participant: I want to change the sanitary conditions in my place. It is very dirty, and hard to walk. And I want to change my home steps because I cannot walk up them. It is difficult.*
>
> *– excerpt from MI AWD FGD*
>
> ****
>
> *Participant: Let me tell you something. If you see the [name of school], you'll see that things are generally accessible. But if you look at the bathrooms, you will find that there are almost no special facility has been provided like grab bars or hand showers. And it's very difficult for any child to go to use the bathroom on their own. Everywhere else, things are very accessible. But only the bathrooms are not very accessible.*
>
> *–excerpt from SSK AWD Interview1*
>
> ****
>
> *Facilitator: What would you change, if you could?*
>
> *Participant 1: I would change our accessibility.*
>
> *Facilitator: Accessibility? Okay, tell me more about that.*
>
> *Participant 1: Like public places, theatres, shops. Make them easier for us to go.*
>
> *Participant 2: I would make a path for wheelchairs….On the road. On the side, just for wheelchairs.*
>
> *– excerpt from SSK AWD FGD2*

Box 19. Access

The lack of access to public buildings resulted in a participation restriction for the AWD. Poor accessibility also meant a lack of independence for others, who required assistance to go up small steps of curbs. One AWD reported that she was often left in the car when her parents went shopping if the area was inaccessible for her wheelchair. Many AWD participants expressed a desire to participate in similar activities to their AC peers, but were denied this opportunity because of lack of access.

External Factors/External Environment/Legislation and Policies

Lack of access to public buildings was often closely linked to poor implementation of legislation and policies. The majority of the AWD were aware of India's legislation for disability access (contained in the PDA) and the UNCRPD. They were quick to emphasise that the problem lay in enforcement, not lack of policies or legislation.

Participant: If you see the big McDonald's in India, they don't have a ramp. Even though they are supposed to have a ramp. And if you see the restaurants in America, they do have a ramp, because the law there insists on having a ramp. Whereas in India, they don't insist on having a ramp – why would they want to waste money? As long as no one makes them put in a ramp, why would they?

–excerpt from SSK AWD Interview1

****

Participant: [In reference to the government officials] Actually now first, they are working for disabled. They should write rules for disabled. But they won't give them strength. So she will say, before writing rules, make it strict. It has to be followed. She will tell them that. That is the one thing.

–excerpt from APD AWD FGD2

****

Participant 1: I have one more thing, ma'am. In the private buses, there are 2 seats for the disabled, no more. And if we sit there, they say, that's the girls' space, go to the back.

Participant 2: In those buses, no, there's only 2 seats for disabled. But if we go there, the conductor will say, go to the back.

Participant 1: He'll say, they're for girls, not for boys.

Facilitator: So it doesn't matter if those seats are reserved for people with disabilities, you still have to go to the back?

Participant 1: Yeah

Participant 2: And there's only two seats, so if there are already people there, then we have to go somewhere else.

- Some text omitted for clarity -

Participant 1: …normal people will be sitting there.

> *Facilitator:* But they won't make them get up?
>
> *Participant 1: No.*
>
> *Participant 2: And if disabled boys get on, then they just send them to the back of the bus.*
>
> *- Some text omitted for clarity -*
>
> *Participant 1: Yeah! Actually, the first section should be for people with disabilities, not for girls. Then we wouldn't have to go to the back.*
>
> *Facilitator:* So they haven't quite thought about that…
>
> *Participant 1: No, they need to think about that.*
>
> *Participant 2: The private bus people need to do something about this.*
>
> *– excerpt from SSK AWD FGD2*

Box 20. India's disability legislation and policies

5.2.4 Inclusion and Participation

The central focus of this research study was to investigate the views of AWD about participation and inclusion. As illustrated in the model (Figure 12), the three primary themes of Personal Factors, Interpersonal Relationships, and External Factors are all directly linked to the central theme of Inclusion and Participation. While some of the themes and sub-themes enhance participation of AWD, others restrict participation or provide barriers to full inclusion. Although the AWD did not always specifically discuss participation or inclusion, the evidence shows that this is a common thread through the other three themes and their sub-themes.

The evidence suggests that Personal Factors provide the motivation, willingness, and personal skills required for inclusion and participation by AWD in their wider communities. The interaction that the AWD have with their families (a sub-theme of Interpersonal Relationships) was variably positive and negative, but in general, is supportive of their inclusion and participation. Families are inclusive of the AWD as well as providing the necessary supports for participation outside the family unit. Not all family interactions were positive, and some AWD felt that they were left out of activities in which they wished to participate with their family members.

The attitudes, behaviours, and interactions with other people (another sub-theme of Interpersonal Relationships) had a more direct and specific impact on restricting participation. These negative interpersonal relationships, combined with the effect of External Factors, were seen by the AWD to be the most deleterious on their desired levels of inclusion and participation. Most AWD had ideas on how External Factors and some Interpersonal Relationships could be improved to allow more meaningful participation.

5.2 Interviews with parents and caregivers

There were 25 parents/caregivers (PD) who agreed to be interviewed for the study, and provided responses to the questions. Most PD expressed discomfort at having the interviews recorded. To maintain trust between the interviewer (GK) and the parent/caregiver, the majority of the PD interviews were not digitally recorded. Detailed notes were taken during the interview. These notes were then transcribed immediately after the interview, in a different location, with field notes added for each interview. Since there was usually only one interaction with the PD, it was important to maintain trust and openness in order to get the most complete responses to the questions. All interviews with APD and MI PD were conducted with the community health worker acting as a translator. The PD and the health worker had a long-standing relationship, and the PD were comfortable having a known person translate the interview. All but two of the interviews at SSK were conducted in English. The two interviews that were not in English were conducted with a member of the SSK staff, known to the parents, acting as a translator. The responses to these questions were analysed for common themes using a similar approach to that described for the AWD and AC interviews and FGD. NVivo 7 was not used to aid the analysis of PD interviews.

Parents were asked two questions: 1) What are your goals for your child (work, school, future, other) and 2) Do you have any concerns about your child? If so, what are some of your worries/concerns? One of the two most common responses to the first question was further study.

Parents were, in general, pleased with their child's progress school to date, but were keen that they study further. Parents were willing to support their children as much as possible in attaining their educational goals. In some cases, however, there were differences in what the PD thought their child could achieve and the goals of their AWD. One mother was sure that her son's desire to be a computer game programmer was unrealistic.

> *I don't think he can study more. His father will think differently. He will buy him books about computer programming. But then he will let him see on his own that he cannot do something. I wonder what will be a realistic profession for him?*
>
> *– from SSK parent interview 5*

Other parents were willing to support their child's desire for more education, but expressed doubt that this was realistic or possible.

The other common response to the first question was the goal that their AWD would be independent. Specifically, this was a goal that their AWD should achieve financial independence. This was linked to a third goal that their AWD should find appropriate employment. Few PD had specific vocations or careers in mind. Rather, most expressed the hope that their AWD would find a job that provided him/her with enough money to ensure that s/he was not dependent on other family members for support once s/he reached adulthood. The PD of female AWD emphasised that they would not consider marriage for their daughters until they were financially independent. Only one mother said,

> *My daughter spends too much time sleeping or looking at herself in the mirror. She does not help with the housework, unlike her sisters. I want to get her married and send her to her husband's house where she will be his problem instead of mine.*
>
> *– from MI parent interview 7*

In general, PD had few other goals for their AWD's future. Even when prompted, most PD expressed that their only goal was that their AWD should 'do well' in the future in whatever job they desired. Some PD with family land or businesses thought their

AWD could find suitable employment there. Other PD were willing to consider setting up a business if it would provide a source of income for their AWD.

Although not common, several PD expressed a desire that their AWD should become independently mobile, or in one case, '*he should be normal, like before his illness*' (-from MI parent interview 8). These PD did not state how they thought their AWD would achieve physical 'normality', but in the words of another parent, when her son walked, '*[he] should not show any sign of disability*' (-from MI parent interview 5). There was no discussion of any intervention their AWD had already received, or any ongoing intervention to address the physical impairment. It was not clear if the PD thought physical normality would ensure future success for their AWD.

In response to the question about worries or concerns, most PD initially responded by saying they were focused on the present, and were pleased with what their AWD had achieved. When asked about the future, PD expressed a concern about what would happen to their AWD after they died. The PD spoke of saving money to provide for their AWD, but frequently voiced concerns that this would not be adequate for all the needs of their AWD in the future. It was for this reason that the goal of financial independence was so important to many PD.

Another concern, expressed by some PD from SSK only, was the lack of friends their AWD had outside of school. One PD recounted that her daughter '*is happiest when she is at home watching TV and doesn't have any friends near [our] house, and doesn't go out much*' (-from SSK parent interview 4). Another PD was worried that her son '*doesn't have any friends outside school. Other children don't want to play with him*' (-from SSK parent interview 2). These concerns about a lack of friends were not echoed by PD from MI or APD.

The most common responses from the PD were a goals of further education, financial independence and finding suitable employment. The PD were primarily concerned with the future for their AWD after they died, which again emphasised their desire for their AWD to achieve financial independence. Few other concerns were expressed by the PD.

5.3   Summary

In order to maintain objectivity during the analysis of the qualitative data, the assumptions and preconceived ideas held by the researcher (GK) were bracketed. It is a feature of qualitative research, however, that the researcher is an integral part of the process, including analysis. Data gathered during FGD and interviews with AWD, AC and PD were analysed using a phenomenological approach. Transcripts were examined for common themes and sub-themes. NVivo 7 software was used to facilitate data analysis.

Four themes emerged from the thematic analysis of AWD and AC interviews. Three of these themes were: 1) Personal Factors, 2) Interpersonal Relationships, and 3) External Factors. These three themes all had a impact on the fourth theme of Inclusion and Participation. Photographs taken by the AWD were catalysts for discussion during data collection, and supported the themes that emerged during the analysis.

Interviews with parents were analysed using a similar theoretical framework. In regard to their AWD, the PD expressed two main goals of further education and the achievement of financial independence through employment. Related to the goal of financial independence, the PD expressed concerns that they did not want their AWD to be dependent on others, particularly after they (the PD) passed away. What was striking amongst most PD was their determination and desire to support their AWD to achieve education and vocational goals, and to attain financial independence. Goals expressed by the PD were not dependent on the gender of their AWD.

The qualitative data analysis provides some novel and thought-provoking results that require further discussion and consideration. Further discussion is also warranted of the relationship between the QOL results and the outcome of the thematic analysis of FGD and interviews. This discussion follows in the next chapter.

Chapter 6 – Discussion

6.1   Introduction

In an investigation into the perceptions of adolescents with cerebral palsy and their families in Canada, participants 'asked to be listened to, …to be treated with respect and …for equitable access to information with less bureaucracy' (Darrah et al., 2002, p.548). Adolescents indicated frequent occurrences of being spoken about, rather than being spoken to by health professionals and other service providers. Results of the present study show that the desire of AWD for their voices to be heard is universal. The voices of AWD in developing countries are frequently silenced, and thus they are often marginalised from services and programmes. This study gathered exploratory information in order to understand the viewpoint of adolescents with a variety of physical disabilities and in order to redress the oversight that has long been perpetuated in research concerning AWD. The three primary objectives of this research were:

d) To examine the QOL of AWD from their perspective and from the perspective of their parents/caregivers.

e) To examine the QOL of AWD as compared to the QOL of their non-disabled peers.

f) To explore the views of AWD about their levels of participation within different sectors of their communities.

Quantitative data was collected to meet the first two objectives, and qualitative data from FGD and interviews were collected to meet the third objective. Analyses of the data were presented in the preceding two chapters. This chapter examines the results in light of the proposed study outcomes presented in Chapter 1. The results of the study will also be discussed in consideration of the literature that was critically reviewed in Chapter 2. The strengths and limitations of the study, suggestions for future research, and recommendations arising from the results conclude this chapter.

6.2   Quality of life

The results of the QOL analysis raise several interesting issues. Due to the small number of participants, these full data should be considered

illustrative in an arena where there is little published material. Results provide possible directions for future investigations into the QOL of AWD in low- and middle-income countries.

6.2.1 Quality of life of AWD - what do the results tell us?

There were no differences in EQ-5D scores, or most of the WHOQOL-BREF domain scores between AWD and parent proxy scores. These results are contrary to those found in the literature. Four studies reviewed in Chapter 2 that specifically assessed the correlation between parent-proxy scores and child-report QOL scores all found poor relationships, with children's scores being higher than parent-proxy scores (Rosenbaum et al., 2007; Shelly et al., 2008; Varni et al., 2005; White-Koning et al., 2007). The only result that is supported by the research literature was the difference in scores between AWD and PD on Q1 of the WHOQOL-BREF with AWD scores being significantly higher than parent-proxy scores.

There are several explanations for the difference in the findings between this study and the literature. Compared to the reviewed papers, this study had a small number of participants in each group. Differences between scores may have been masked by an insufficient sample size. Additionally, social and cultural reasons may provide an explanation for the difference in results. The QOL literature reviewed in Chapter 2 focused specifically on children or AWD and their parents in Europe or North America. Differential family dynamics and less independence of AWD in India, as compared to Europe or North America, may play a role in the results. Parents of AWD in India might have a closer relationship with their children and thus be able to provide a more accurate estimation of their child's QOL. Cultural differences underscore the inability to transfer research findings between different contexts.

In contrast to the findings between AWD and PD, there were more differences in QOL scores between AWD and their non-disabled peers (AC). On the WHOQOL-BREF, the AWD had significantly lower scores on the Physical and Psychological domains, which is in keeping with other QOL research. Interestingly, there were no differences between the AWD

and AC on the Social Relationships or Environment domains. The Environment domain includes the physical environment, participation, safety and security, access to health care and finances. For this cohort of AWD, it appears that QOL scores in the Environmental domain are not necessarily related to their physical impairment. The broad range of factors represented in the Environment domain of the WHOQOL-BREF may explain the similarity between AWD and AC. The majority of AC were from the same communities as the AWD. Both groups would thus be equally affected by finances, issues of safety and security, and unhygienic living conditions. The reasons for the lack of differences in the Social Relationship domain are likely due to measurement and methodological issues, to be discussed later.

On the EQ-5D, there were significant differences between the AWD and the AC in the domains of Mobility, Self-Care, Usual Activities, and the visual analogue scale (VAS) score of overall health. Scores indicated that AWD had more difficulty with activities in these domains compared to the AC, and reported poorer overall health. The lack of difference between the groups in the domains of Pain/Discomfort and Anxiety/Depression contrasts with the results of the WHOQOL-BREF, where there were significant differences in the Psychological domain. This domain on the WHOQOL-BREF contains items about anxiety and depression. The findings also contradict published research. One study found a correlation between decreasing physical function in AWD and increasing psychological distress and emotional difficulties (Padua et al., 2002), and another found that depressive symptoms accounted for the largest difference in QOL scores between AWD and their non-disabled peers (Edwards et al., 2003). The reviewed studies used different QOL tools, however, and the study by Edwards et al. (2003) included adolescents with a wide range of disabilities.

The difference between AWD and AC in this study on the EQ-5D domains is not surprising considering that the questions focused on difficulty completing tasks. The questions are objective in nature and do not ask about the person's satisfaction in various QOL domains. Although a physical disability may pose difficulties in completing

everyday tasks, satisfaction with performance of the tasks is often unrelated. The only subjective aspect of the EQ-5D relates to the VAS, where respondents have to indicate their health status. Scores on the EQ-5D were also affected by methodological issues, which are discussed in the following section.

6.2.2 Measuring quality of life – measurement and methodology

The initial intent of this study was to use the WHOQOL-BREF only to measure QOL. A review of the literature and currently available tools suggested that it was the only one applicable for the study setting. Although the WHOQOL-BREF is not formally validated for use with AWD, it was the most relevant and appropriate measure to use, and was being validated for use with adults with disabilities in India. Following discussions with local academics, the decision was made to include the EQ-5D in the data collection process. The relative ease of administration of this measure, and the fact that was being validated in India for adults with disabilities contributed to the decision. The sample size of this study was too small for the purposes of a concurrent validity analysis. The discussion that follows covers specific issues of each measure, the relationship between them in reference to the QOL of AWD, and methodological issues that pertain to both tools.

The WHOQOL–BREF and the EQ–5D – are they measuring the same thing?

The developers of the EQ-5D promote it as a tool to assess HRQOL, while the WHOQOL-BREF was developed for use as a measure of QOL across diverse cultures and settings. By using both tools in this study, it was possible to consider if they measure the same concepts. It is expected that there would be some degree of relationship between the measures. Similar domains exist in each tool, and each has a distinct question addressing health status.

Analyses of the data revealed that there were no significant correlations between the measures in any domain or overall QOL scores. A study that investigated the relationship of the two measures in

patients with psychiatric disorders found statistically significant but moderate correlations between the domains on the WHOQOL-BREF and the EQ-5D total scores (van de Willige, Wiersma, Nienhuis, & Jenner, 2005). In addition to the small sample size, other factors might also be responsible for the lack of correlations between the tools in this study.

The tools were developed within very different theoretical constructs. The WHOQOL-BREF was based on the ICIDH model of disability and handicap. The inclusion of items about the attitudinal environment, social relationships, access to services, and psychological well-being, among others, supports the basic premise that QOL is not merely a matter of health. Conversely, the EQ-5D is entrenched in the medical model. The absence of illness or impairment results in better QOL scores. The EQ-5D should more accurately be viewed as a measure of health, not QOL. If the WHOQOL-BREF measures QOL, but the EQ-5D in practice measures health, it is not surprising that there was no correlation between the tools.

Methodological issues of the WHOQOL–BREF

The developers of the WHOQOL-BREF report that it has good internal consistency (Cronbach alpha values between .66 and .84) and that each domain contributed significantly to QOL (WHOQOL Group, 1998a). The internal consistency of the tool was also verified by researchers investigating the validity and reliability for patients with rheumatoid arthritis (Taylor, Myers, Simpson, McPherson, & Weatherall, 2004). Other research has shown that the tool has good convergent validity (Skevington, Lotfy, & O'Connell, 2004), and that correlations between the domains are high (Wang, Yao, Tsai, Wang, & Hsieh, 2006). In contrast, the results from this study indicate that the relationship among the four domains, and the relationship between domains and overall QOL was moderate at best. Possible reasons for this discrepant finding could be small sample size, the population itself (adolescents), and issues of administration.

A Bangla version of the WHOQOL-BREF has been validated in Bangladesh with adolescents (Izutsu et al., 2005). Researchers found it

had 'reasonable reliability and validity' when used with older children and adolescents (Izutsu et al., 2005, p.1787). There were significant gender differences in QOL scores and differences between adolescents living in slum and urban areas. It was unclear if any participants had disabilities as the only variable reported was the presence of 'disease', which was not further defined (Izutsu et al., 2005).

Several questions on the WHOQOL-BREF proved to be problematic during administration in this study. First, the question about finances, 'Have you enough money to meet your needs?' was difficult for many AWD and AC to answer. As is typical of most adolescents in similar settings in India, few participants had money of their own, and were dependent on their parents for financial support. Many participants wondered if they had to answer this question from the perspective of how much money they personally had, or in reference to general household income. Many recognised that their needs were met by their parents, but were unaware if financial hardships were encountered in the process.

Second, the question 'How much do you need any medical treatment to function in your daily life?' was difficult for many participants. While some viewed the need for bracing or other mobility devices as 'medical treatment', others interpreted medical treatment as the need for medication or frequent visits to the doctor for other health issues. The guidelines for the WHOQOL-BREF do not clarify what is intended by 'medical treatment', an issue that is particularly problematic when dealing with people with disabilities. Explanations of 'medical treatment' were not given by the researcher, but notes were made regarding the interpretation used by respondents. The majority of AWD and PD considered 'medical treatment' to be the need for medication or medical care.

The third poorly understood question was, 'To what extent do you feel your life to be meaningful?' Most AWD and AC found it difficult to know what was meant by the term 'meaningful'. The issue of translating this concept into local languages was discussed with the health workers and Dr. Maya Thomas in the initial training phase of the study. Despite

the availability of the official translation of the WHOQOL-BREF in Hindi, it was still difficult to translate the concept of 'meaningful' into Urdu, Kannada or Tamil, as required. Although most participants answered this question after requesting clarification, it is difficult to determine whether it was interpreted and answered consistently by all participants.

Finally, of the three questions in the Social Relationships domain, the question referring to sexual relationships ('How satisfied are you with your sex life?') had to be omitted for use with AWD and AC. Cultural and societal norms dictate that this is an inappropriate question to ask adolescents. Premarital sexual relationships are not condoned in much of Indian society. The Social Relationships domain thus only had two answerable items, compared to the other three domains, which had at least seven items each. The imbalance of items would have affected the results of the study. The overall lack of emphasis on Social Relationships in the WHOQOL-BREF can be criticised, particularly because social support and relationships have been found by many researchers to be key factors in determining QOL across cultures (Albrecht & Devlieger, 1999; Bowling, 2005; Schalock et al., 2005).

In general, the wording of many questions on the WHOQOL-BREF proved to be confusing for all three respondent groups. The questions discussed above, as well as the question that asked about access to information ('How available to you is the information that you need in your day-to-day life?') required frequent clarification. In order to maintain as rigorous an approach to data collection as possible, clarification and explanation of the questions was kept to a minimum. The experiences from this study, however, indicate that the difficulties of administration were due to the complex wording of several questions, and this affected all participants equally regardless of age.

Methodological issues of the EQ–5D
Similar to the findings with the WHOQOL-BREF in this study, the strength of correlations between domains of the EQ-5D were poor to

moderate. The strongest correlation was between the domain of Usual Activities and the VAS (general health). The lack of significant correlations between any of the QOL domains on the EQ-5D is interesting and worthy of further investigation.

Challenges with administration were also experienced with the EQ-5D. In the domain of Anxiety/Depression, the terms 'anxious' and 'depressed' often had to be defined for respondents, particularly AWD and AC. Although it was important to differentiate feelings of sadness from 'depression', it is unclear if the developers of the EQ-5D would view them as equivalent. When asked about pain/discomfort, many participants queried if the question referred to pain during the performance of a particular activity, or pain that was experienced on a continuing basis. Again, the administrative guidelines do not delineate the nature of pain/discomfort that is intended by the question, but only state that it is in reference to the respondent's current health state.

The EQ-5D has previously been criticised for the use of the current day as a frame of reference (Bowling, 2005). In this study, participants in all three groups had to be frequently reminded that their responses had to be limited to the current day. This was especially problematic as the two tools were administered during the same interview and had different frames of reference. This again highlights the fact that the EQ-5D is more a measure of health than QOL. Asking participants about the current day or week is appropriate for evaluating health status. When considering QOL of people with disabilities, however, a longer time frame is more appropriate.

The most problematic question for the AWD was about Mobility. This question provides three statements, and asks the respondent to choose the one that best describes their health state. The choices are: 1) I have no problems in walking about, 2) I have some problems in walking about, or 3) I am confined to bed. The wording of the EQ-5D implies that non-ambulatory mobility is the 'health' equivalent of confinement to bed. This underscores the theoretical construct of the EQ-5D as a tool embedded in the medical model, with disability equated

with poor health. The domain of 'Mobility' in the EQ-5D should more accurately be termed 'Ambulation'.

The AWD who used wheelchairs questioned how they were to respond. They were advised to replace 'walking' with 'moving', and respond accordingly. Although this may have changed the intent of the tool slightly, it is grossly inaccurate to represent wheelchair mobility with confinement to bed. The experience with this particular question brings into question the utility of the EQ-5D for people with disabilities. Although the developers state that it is a tool to measure HRQOL, it is more accurately a measure of health, not QOL. Any tool used to measure QOL in people with disabilities should be framed within the social model of disability, not the medical model.

Measuring QOL – some general considerations

An overarching issue was the general comprehension among all participant groups about the concept of QOL. Defining QOL has historically been problematic, as discussed in Chapter 2. The definition of QOL employed in this study was 'an individual's perceived satisfaction with his/her life, including physical, psychological and social domains.' The translation of the concept of QOL into local languages was challenging. Care had to be taken to ensure that 'satisfaction' was not translated or interpreted by participants as 'happiness.' The first question on the WHOQOL-BREF asks, 'How would you rate your quality of life?' It had to be clarified that this was not the same as asking 'How good is your life?' or 'How happy are you?' It was challenging to explain the question without providing specific examples. The subjective nature of QOL means that respondents need to answer with as little bias and input from the researcher as possible.

The issue of administering QOL tools when the general concept is new or unclear to respondents requires further investigation. Different cultural groups assign varying degrees of importance to the core domains of QOL(Schalock et al., 2005; Bowling, 2005). The developers of the WHOQOL-100 initially incorporated importance ratings into the measure (WHOQOL Group, 1998b). These importance ratings were

dropped from the final version. Importance ratings are essential to understanding what facets contribute to overall QOL scores. They would provide valuable information for service providers who design programmes to increase QOL. Researchers found that importance ratings in only five of the 24 facets of the WHOQOL-100 were correlated with overall QOL scores when comparing people with scores in the lowest two quintiles (Skevington, O'Connell, & WHOQOL Group, 2004). These were mobility, practical social support, financial resources, negative feelings, and work capacity. The five facets were very similar to the themes and sub-themes that emerged from the qualitative analysis of the AWD interviews in this study.

The data collected in this study can be viewed as preparatory to a larger study of validity and feasibility of QOL measures now that many of the methodological issues have been clarified. In terms of administrative ease, the EQ-5D was faster to complete, and had greater ease of understanding. By comparison, some WHOQOL-BREF questions were awkwardly worded and difficult to understand. These difficulties affected all three groups equally. Previous studies that used the WHOQOL-BREF to examine the QOL of adults have not reported any comprehension challenges. Further study with larger numbers of participants can illuminate whether this issue was unique to this study or if it occurs in other populations.

Overall the WHOQOL-BREF is a better tool to measure the QOL of people with disabilities than the EQ-5D. The theoretical construct is aligned with the social model of disability. The cross-cultural applicability of the WHOQOL-BREF makes it more appealing as a generic measure of QOL. It would be important to further understand the importance of each facet of QOL for AWD, and how each one contributes to overall QOL scores. It is interesting to note that many of the facets of the WHOQOL-BREF are similar to the themes and sub-themes that emerged from the qualitative data analysis in this study. There is a significant connection between perceived QOL and perceptions of participation and inclusion, which warrants further discussion.

6.3 Perceptions of AWD about participation and inclusion

The main focus of the qualitative interviews and FGD in this study was to determine the perceptions of AWD about participation and inclusion in various aspects of their lives. 'Participation' as defined by the ICF remains under-researched in most populations of disabled persons, but particularly in AWD. The factors that both enhance and restrict participation and inclusion for the AWD in this study formed three key themes, illustrated in Figure 12, presented in detail in Chapter 5. The three themes are Personal Factors, Interpersonal Relationships, and External Factors. The themes are inter-related, and together they have an impact on perceptions of Participation and Inclusion. The names of the themes that emerged from this study are similar to the names of the ICF components. In order to distinguish between the two, the ICF components will be referred to in the text that follows using italics. The themes from this study will be written using capital letters. Each of the three themes in this study will be discussed in turn, and select sub-themes from each will be highlighted to illustrate how they impact Participation and Inclusion.

6.3.1 Personal Factors – characteristics that influence participation

The ICF makes a distinction between *'capacity'* and *'performance.'* *Capacity* is what the person would be able to do in an ideal environment whereas *performance* is what the person actually does in the environment in which they live (World Health Organization, 2001). The gap between *capacity* and *performance* leads to poor participation and inclusion, and is thought to be the result of *personal* and *environmental* factors. There were several key characteristics inherent to the AWD that influenced participation and enhanced inclusion. Under the ICF, factors such as motivation, goals, and self-esteem are captured in the component of *personal factors*. The theme of Personal Factors in this study included facets that had an impact on Participation and Inclusion. These were Spirituality and Self-Esteem, and Mobility and Leisure Activities.

Spirituality and Self–Esteem

Although participants did not discuss spirituality extensively, the majority demonstrated a strong belief in God and religion. They also believed in fate, and that their disability was 'God's will.' With origins in Hinduism, the quality of fatalism is deeply embedded in much of Indian society. Not all participants in the study were Hindu, but their belief in fate and destiny played a large role in their lives. When asked what they would like to change, few AWD made reference to their disability without several prompts. They were more likely to make the comment that their disability was intended by God, and thus something that was out of their control to alter. This sentiment was echoed by the PD. They also believed that they would succeed in life if God intended for it to happen.

Spiritual beliefs were also a factor when responding to certain questions on the measures of QOL. One question on the WHOQOL-BREF asks, 'To what extent do you feel your life to be meaningful?' Many participants found this question difficult to answer, saying that all life had meaning. The PD also believed that in spite of their wishes and support, it was in God's hands to decide if their child would make a meaningful contribution in life. Although the question itself is ambiguous in many regards, the intent behind it is not thought to be the potential for someone to make a meaningful contribution in life. The comments from the PD, however, were recorded, and illustrate their spirituality and belief in fate.

The attitude of AWD towards their disability may have been influenced by the notions of fate and destiny, but they also demonstrated a strong belief in themselves and their capacity for success in daily life. The determination to prove themselves to others was clear and common across participants. In a study of young adults with cerebral palsy, the researchers found that a factor leading to success in life was 'believing in yourself' (King et al., 2000). Another study echoed these results, and found that 'feeling successful' was one of four key elements in determining successful participation (Heah et al., 2007). In the present study, the AWD believed strongly in disproving

those who thought they were incapable of achieving their goals by demonstrating their capabilities. The AWD were keen to provide similar advice to other AWD and children with disabilities as they felt this was a positive way in which to overcome negative attitudes. Their strong belief in themselves included proving their physical capabilities, as well as their capabilities in education and employment. In this, they were largely supported by their parents. These findings contrast with other research in India with children with physical disabilities, which found that the most common response to negative societal reactions was to avoid interactions and stay quiet (Singh & Ghai, 2009). The AWD in this study demonstrated a more assertive, confident attitude when faced with negativity.

If the AWD are to achieve their full potential, the gap between *capacity* and *performance* needs to be bridged by adequate *environmental factors*, as well as *personal factors*. It is possible that positive *personal factors*, such as motivation, self-esteem and a healthy self-image are particularly important in facilitating participation and inclusion for the AWD if the *environmental factors* are restrictive. The AWD from the urban slums had fewer environmental (physical and financial) facilitators compared to their peers from SSK. These include accessible roads, pavements, buildings, as well as adequate financial resources, and freedom from financial stress and worry. Reliance on their own abilities and the need to prove their capabilities may have been more important for AWD who lacked environmental facilitators. For the most part, the AWD from SSK had more severe physical impairments, but had more environmental facilitators compared to their peers from MI and APD. What both groups had in common, however, was strong emotional and social support, particularly from immediate family.

One key *personal factor* in ensuring successful participation and inclusion is a healthy self-esteem. Research into self-esteem of children and adolescents with disabilities is fraught with methodological issues (Llewellyn, 2001), resulting in inconsistent findings that cannot be easily

compared. One study investigating issues of adolescents with cerebral palsy demonstrated that only adolescents' perceived impact of disability had a significant association with self-esteem scores (Manuel et al., 2003). No other factors, such as a medical assessment of impairment severity, functional status, social support, or measures of maternal optimism had a significant association with self-esteem. Studies to date have not investigated the relationship between self-esteem and participation or inclusion for AWD. It can be hypothesised that positive self-esteem would be a key facilitator to participation and perceived inclusion.

The self-esteem of the AWD in this study was not measured using a standardised tool. Current tools available for this purpose are culturally inappropriate or inapplicable. The discussions with the AWD indicated they had strong convictions about their own abilities. Their deep-rooted faith may have allowed them to focus on their *capacity* rather than their disability. As one participant was careful to point out, '*God gave us our abilities also. Not only the disability*' (-from SSK AWD FGD2). The involvement with agencies such as APD, MI and SSK also provided the AWD with a supportive environment in which they could realise their *capacity*. Their healthy attitudes toward their disability and toward their capacity for success were enhanced by support from family, friends, and external agencies.

A finding that warrants further investigation is the hierarchy of attitudes toward differing impairments that seems to exist among the AWD. Researchers point out that it is not only people without disabilities who hold a hierarchical attitude toward different impairment groups, where certain impairments are seen to be more 'desirable' than others. A study that investigated the attitudes of elite disabled athletes on the United States Olympic team found they held a hierarchical attitude that closely mirrored that of the non-disabled population (Mastro, Burton, Rosendahl, & Sherrill, 1996). Other authors also contend that people with disabilities have varying attitudes toward people with different impairments (Deal, 2003). After some prompting, a few of the AWD indicated that they would like to be able to walk

'normally', or be more mobile. Several AWD, however, stated that they were grateful that they were able to study and learn, and that they did not have 'worse' disabilities, such as 'mental' disabilities. One AWD said that his disability made him sad, but when he saw other children with more impairments than he had, his disability made him happy. Further research would be interesting to shed light on whether this hierarchy is mitigated by society, parental influence, or the experiences of the AWD in their wider communities, including school.

Mobility and Leisure Activities

Another important theme of Personal Factors was Mobility and Leisure Activities. The value placed on mobility, in particular the ability to walk, was clear when the AWD discussed leisure activities. The AWD and AC were superficially very similar in the manner in which they spent their leisure time. All participants from APD and MI had less 'free' time than their peers from SSK. Popular leisure activities included playing games, reading, spending time with friends, watching television, or 'roaming around.' Compared to the AC, the AWD were engaged in more sedentary activities. The AC participated in a mix of active and sedentary pursuits. Active games included cricket, volleyball, running (playing 'chase'), and hopscotch. Interestingly, the opportunity to participate in organised games or sports was rarely provided at school. Games were usually played in the participants' neighbourhoods or organised independently by participants at school during lunch breaks. Even the special school setting of SSK did not provide formal games or sports opportunities for students.

The AWD spoke frequently of their physical impairments and lack of mobility as a barrier to participating in games and sports. The AWD felt unable to participate as much as they wished, whether these activities were 'semi-organised', such as cricket matches with friends, or merely 'roaming around' their neighbourhoods. It is difficult to determine whether the AWD chose sedentary leisure activities after experiencing challenges when attempting to participate in more active pursuits, or if they were directed to sedentary activities by parents and

teachers. The possibility for adapted sports or activities was not discussed, and there did not appear to be any opportunities for such activities for most of the AWD.

Participants from SSK, in general, had more mobility restrictions than the AWD from APD or MI. They did not express dissatisfaction with the lack of opportunities for sports and similar leisure activities, and spent more time in sedentary activities. As opportunities for participation in organized games and sports was rare for most students at SSK, they were less likely to be dissatisfied. Unlike their peers from APD and MI, however, the AWD from SSK had more access to computers, video games and other similar forms of entertainment. The active games they engaged in at school were limited to more informal 'play' with classmates, such as 'chase' or impromptu games of cricket. Only AWD who could walk or used ambulation aids participated in these games. If a child with severe mobility limitations has never been provided with the opportunity to participate in games or sports, then perhaps by adolescence, they are less desirous of those opportunities. The AWD with more mobility impairments in this study found leisure activities in which they could participate with success, and their perceptions were that they were satisfied with their level of inclusion.

6.3.2 Interpersonal Relationships – how other people can enhance participation

The ICF includes relationships with family, friends, and other people under the component of *external factors*. This also includes attitudes and behaviours, be they overt or implied. In the model of Inclusion and Participation from this study, Interpersonal Relationships were an independent theme. The effect of other people's attitudes and actions, including those of family and friends, was felt to be significant enough to warrant an independent theme, and not be subsumed under *external factors*. While Personal Factors largely facilitated participation and inclusion, Interpersonal Relationships were perceived as both facilitators and barriers. Other research has found that from a child's perspective, successful participation was partially defined by being with

and doing activities with other people (Heah et al., 2007). The primary Interpersonal Relationships were with parents and siblings, with friends, and with other people encountered in daily life.

Parents and siblings – relationships with family

In the study by King et al. (2000), a key factor leading to success in life for AWD was being believed in by others. Similarly in the current study, supportive relationships with parents and other family members were important facilitators to participation and inclusion. The positive and supportive nature of family relationships were highlighted in interviews with all participant groups. More importantly, the AWD were aware that their parents believed in their ability to succeed, and were willing to support them in their endeavours. The perception of the AWD that they were included and able to participate fully with their families was a result of having strong family support and being aware of this support. Without this parental support and belief in their abilities, the AWD may not have been able to achieve the same level of participation and inclusion.

All AWD and AC discussed close relationships with siblings. For example, those who lived at home spoke of playing with younger siblings, and sharing domestic duties. Contrary to common belief, the AWD were neither sidelined from domestic responsibilities, nor were they burdened with more tasks than their siblings. The division of labour amongst siblings seemed to be based on ability, contrasting with the findings of Singh and Ghai (2009). The AWD were given tasks that their parents or siblings thought were more realistic and not more difficult jobs, such as lifting heavy pots or working in the fields. Some AWD considered that their family members underestimated their abilities, and wanted to prove they were capable of more. They perceived their participation in domestic chores to be restricted. In some cases, the division of labour was along more traditional gender roles, for example girls were involved with cooking and meal preparation, whereas boys performed manual tasks.

An interesting finding was the sense of responsibility the adolescent participants (AWD and AC) felt for their parents and younger siblings. Male participants felt a need to contribute towards the family finances, particularly to ensure that their sisters found good husbands. Both male and female participants expressed a desire to ensure their younger siblings were given access to education. Finally, the AWD and AC discussed the need to find jobs in order to contribute to the family income. The sense of obligation towards their family was particularly keen amongst AWD and AC from lower SES (MI and APD). This finding contrasts with the 'Western' conceptualisation of adolescence as a time of increasing independence from the family unit (Brown & Larson, 2002). Verma and Saraswathi (2002) refer to the 'inherent interdependence' of members within a family unit in Indian culture. The findings of this study support that interdependence, and show that it is not differentially affected by disability. It would be interesting to investigate if this sense of interdependence is more acute among AWD compared to their non-disabled peers, or if it varies by SES.

'Friends, I want more friends!' – matters of friendship and social isolation
Children with disabilities are thought to have less intense friendships than their non-disabled peers of the same age (Antle, 2004; Saigal et al., 2002). The influence of a peer group is one of the main elements of emotional and social development during the adolescent years. If AWD experience less intense friendships than their peers, it will have an important impact on their social and emotional development. Good social relationships are a core domain of QOL, the assumption being that more intense and positive relationships with friends and family lead to better QOL. The findings of this study do not support this relationship.

The influence of peers on the lives of adolescents in India has been discussed by Verma and Saraswathi (2002). They contend that the effect of peers on adolescent development varies by SES. Adolescents in higher SES experience more contact with peers than those in lower SES. The findings of this study did not entirely support this belief. All the

AWD and AC spoke positively of their friends. They spoke highly of the need for camaraderie and emotional support. Friends were seen as facilitators to participation and inclusion. The participants from lower SES had different groups of friends at school and where they lived, but still spoke frequently of the time spent with friends.

Contrary to Verma and Saraswathi's work (2002), the AWD from SSK (the highest SES) seemed to be socially isolated in comparison to their peers from MI and APD. It was difficult to recruit non-disabled peers for this group. Their friendships were largely limited to other students with disabilities at SSK. Many reported feeling bored during school holidays when they had little or no contact with their friends. Some PD from SSK expressed concern that their children had no friends near their homes, with several stating that local children refused to play with their child.

There are several possible reasons for the relative social isolation of the AWD from SSK. Unlike the suggestion of Verma and Saraswathi (2002), increasing SES could lead to social isolation. Families from lower SES lived in crowded neighbourhoods in a 'communal' setting. Interaction with neighbours is almost inevitable. During the data collection process, it was observed that people often wandered in and out of neighbour's houses. By contrast, the participants from a higher SES lived in independent houses or flats. The lack of adequate social and environmental support to facilitate peer contact would likely increase the effort required, particularly for an AWD with more severe impairments. Only one mother discussed taking her son to play cricket with his friends from their old neighbourhood. Living in small nuclear families and in independent housing appears to increase the degree of social isolation.

A second possible explanation is the barriers posed by the impairment. The AWD who were independently mobile, particularly those who could walk, were likely to meet friends without requiring parental or other assistance. Independent mobility was difficult for the AWD with more severe impairments. These AWD reported spending more of their leisure time alone at home, playing video games or reading

or playing with siblings. Time with friends was limited to school hours. A study in Australia also found that children with disabilities were more likely to participate in activities close to home, with family members rather than friends (Imms et al., 2008). The severity of their impairment, as well as difficulties encountered with transportation and the extra resources required to facilitate relationships with local peers may explain the limited social contact amongst the AWD with more severe physical limitations.

From the perspective of the AWD from SSK, they were not socially isolated. Rather, they expressed a desire for more opportunities to meet school friends outside school hours. School holidays were reported to be 'boring' as they were unable to see their friends from school. The lack of friends without disabilities, particularly for the AWD from SSK, was not perceived as a participation restriction. Negative experiences with non-disabled peers might have culminated in a lack of willingness to seek out friendships with people outside their school environment.

Other people – how attitudes impact upon participation
A major barrier to participation for AWD was the attitude of other people, including, but not limited to neighbours, extended family, teachers, and peers. Negative attitudes and ignorance about disability were frequent topics of discussion. All AWD had experienced varying levels of negative attitudes that created participation restrictions. Misconceptions among extended family and neighbours about disability resulted in the belief that the AWD were incapable of being productive members of their families or society in general. Negative attitudes in school meant that the AWD were less able to participate in both curricular and extra-curricular activities. Access to transportation and other public services were also limited due to both physical barriers and uninformed attitudes and beliefs.

The attitudes of neighbours and extended family seemed primarily based on visible disabilities. This was particularly clear when the AWD discussed how an improvement in their physical abilities following medical or rehabilitative intervention often led neighbours to

comment that they were now 'better than before.' There also seems to be a common misconception that a visible physical disability implies an inability to learn or work. In the words of one participant, '*...they don't know what disability is, really. To them, a disabled person means, he can't do anything*' (-from SSK AWD FGD2). The older AWD discussed how the attitudes of neighbours and extended family only improved once they had achieved success in school and moved on to vocational training or employment. Attitudes had improved since they were young children, but the AWD also acknowledged that they had to continue to prove their capabilities in order to effect further attitudinal changes.

Participation restrictions in the realm of education were also due to attitudes of teachers and non-disabled peers. The AWD from SSK related experiences of being ignored by teachers, of having to sit at the back of the classroom, and being similarly ignored by non-disabled classmates. The AWD from MI and APD did not speak of such experiences in the classroom. Participants from SSK had comparatively more severe physical impairments. The misconception about the link between physical impairments and other disabilities may also extend to the belief that severity is directly proportional. If teachers hold these views, it would then follow that AWD with more severe physical impairments would experience more participation restrictions in the classroom.

The AWD from MI and APD were not immune to misinformed attitudes at school. Many were restricted by teachers from participating in sports days and other extra-curricular activities because of their disabilities. While the AWD were able to '*do and show*' to prove themselves to neighbours and extended family, they were more restricted in the educational environment. The hierarchy within Indian schools and the belief that adults in positions of authority cannot be contradicted prevented the AWD from effectively overcoming the restrictions placed by the attitudes of their teachers.

Inclusion and participation in education is a direct consequence of the attitude of educators. Regardless of whether inclusive or integrated

education is mandated by legislation, the reality for children and AWD can be much different. In a study of mainstream teachers in Hong Kong, the attitudes of teachers towards integration of students with disabilities varied by the type of impairment (Pearson, Lo, Chui, & Wong, 2003). More favourable attitudes were found towards students with physical disabilities, but even those teachers who had extra funding, training and support found integration to be a burden. In another study, school administrators' attitudes towards inclusion were found to be more positive if they previously had positive experiences with students with disabilities and exposure to the concepts of inclusion and integration (Praisner, 2003). A study of attitudes towards disability and inclusion amongst teachers in Mumbai, India, found that the primary influence on attitudes of educators was acquaintance with a person with a disability (Parasuram, 2006). Younger teachers and those with less teaching experience were also more likely to hold positive attitudes toward inclusion. In general, however, the attitudes of all teachers surveyed were neither in favour nor opposed to inclusion. If the principle of inclusive education is mandated by legislation, as it is in the PDA in India, then more education and exposure is required for teachers and school administrators for it to become a reality for children and AWD. Participation and inclusion in education is a key factor for AWD to ensure success in achieving goals and independence in adulthood.

Participation was restricted due to attitudes of the general public. The attitudes held by people such as bus drivers, rickshaw drivers, shop-owners and others, directly impacted on the inclusion and independence of AWD. Access to transportation was denied if bus drivers or rickshaw drivers did not want a 'crippled' passenger. In some cases, rickshaw drivers exploited the AWD to jump queues at petrol stations or dodge fines for violating traffic rules. The independence of the AWD was also limited by pity when other people provided unnecessary and unwanted assistance with tasks such as crossing the street. The AWD found it less difficult to deal with 'overhelping' than to deal with being exploited because of their disability. Feelings of frustration ensued, but equally and perhaps more importantly, the AWD

were unsure of how to change these attitudes. They recognised that ill-informed attitudes were a major factor in restricting their participation. In their opinion, attitudes of the general public in South India have changed over the last 15 years, but much more needs to change if they are to achieve full and equal participation.

Attitudes have been found to be a significant facilitator of and barrier to participation in other countries for people with disabilities. In a study investigating the effect of *environmental factors*, specifically the social and attitudinal environment on the participation of adults with cerebral palsy in Sweden, most participants identified attitudes of family members, friends, peers and colleagues as significant facilitators to participation (Jönsson, Ekholm, & Schult, 2008). In contrast to the present research with AWD, attitudes of other people were not found to be major barriers. A study of children with varying physical disabilities in Canada found that attitudes and support posed significant barriers to participation (Law et al., 2007). The impact of attitudes on participation was most significant for older children (12-14 years) compared to younger children. The study did not evaluate whose attitudes created the most barriers. A qualitative research study in the UK of children with cerebral palsy found that attitudes of family were perceived as facilitators, while 'staring or patronising attitudes of strangers' (Lawlor et al., 2006, p.223) were reported by parents as barriers. Another UK-based study of young adults with physical disabilities found that negative attitudes were a major barrier to employment (Doyle, Moffatt, & Corlett, 1994). The authors believe that '…attitudes at every level from senior political through to local agency are still entrenched against addressing disabling environments' (p.1491). Despite the varying methodologies used to assess attitudes, the studies discussed above and the findings of this research support the conclusion that attitudes of others pose a significant barrier to participation. Negative attitudes have a particular impact on education, employment, and independence.

Negative attitudes also lead to marginalisation. The theory of social liminality purports that the prejudice and stigma faced by people with physical disabilities can result in an undefined societal role

(Murphy, Scheer, Murphy, & Mack, 1988). People with disabilities are neither actively involved nor intentionally removed from society, but rather, are 'nonpersons' in the eyes of society. The research by Murphy et al. (1988) focuses on periods of transition and rites of passage, and the authors suggest that people with disabilities are often suspended between two stages. The application of this theory to AWD would suggest that AWD are suspended in a state between childhood and adulthood, and are unlikely to achieve full status as adults because of their disabilities. Certainly, the limited access to education and employment could preclude the AWD from fulfilling socially accepted adult roles.

The AWD in this study, however, did not perceive their social role as liminal. In spite of the barriers caused by Interpersonal Factors and other Environmental Factors (to be discussed in the following section), they were determined to prove their capabilities. In this, they were supported by family and friends, an important asset in facilitating successful adulthood. The scope of this study does not allow an evaluation of the ability of the AWD to achieve their goals, nor does it provide the opportunity to determine whether they will be marginalised in the future. Further research is needed into the realities of everyday life for young adults with disabilities in similar settings. In particular, research is needed into the transition between adolescence and adulthood, and the ability of AWD and young adults to fulfil expected social roles and responsibilities.

6.3.3 External Factors – how the world around them influences participation

The themes of External Factors emerging from this study included similar sub-themes to the elements found in the *environmental factors* component of the ICF. The ICF component is sub-divided into five categories: 1) Products and technology (including household income and financial assets), 2) Natural environment and human-made changes to environment, 3) Support and relationships, 4) Attitudes, and 5) Services, systems and policies. *Environmental factors* can act as barriers or

facilitators by their presence or in their absence (World Health Organization, 2001). The findings of this study demonstrate a similar theoretical construct to the ICF whereby elements in the external environment have an impact on participation and inclusion. Unlike the ICF, issues related to support, relationships, and attitudes in this study are included in the theme of Interpersonal Relationships that emerged from the data analysis. The other three categories (Products and technology, Natural environment, and Services, systems and policies) however, all appear in the theme of External Factors. Poverty, the physical environment, and policies and legislation will be discussed below in light of how they affect perceptions of Inclusion and Participation.

Poverty, disability, and participation – is there a link?
The rate of urbanisation in India is increasing, and by 2030, it is projected that 41% of the population will live in urban areas, compared to the current level of 28% (Ministry of Housing and Urban Poverty & United Nations Development Program, 2009). With increasing numbers of people moving from rural areas to urban centres, an already strained infrastructure is experiencing further stress. Although the numbers of people living in urban slums has risen, particularly in larger Indian cities, not all people in slums live below the poverty line. As the report points out, slum dwellers are often '…part of the "other" India because of poor city planning,…poorer urban land management and legislation' (Ministry of Housing and Urban Poverty & United Nations Development Program, 2009). Slum dwellers experience limited access to adequate housing, transportation, health care services, and education, among other things. The United Nations Development Program (UNDP) in India points out that women and children are particularly vulnerable to poverty and lack access to basic needs (UNDP, 2009). People with disabilities are not explicitly mentioned, but should be considered to be a vulnerable segment of the population.

The poverty line in India is variably defined as monthly per capita income per household, or as minimum daily caloric intake. In a recent

announcement by the Government of India, they announced that the poverty line would continue to be defined as a per capita monthly income of Rs 454 in urban areas and Rs 328 in rural India (Mahapatra, 2008). According to the Government of Karnataka, people are deemed to be living below the poverty line if they have a monthly income of less than Rs 327 or if they consume less than two meals per day (The Hindu, 2007). The national government's definition of poverty varies among urban centres. Data is not available for Bangalore, but using the closest city in a similar region (Chennai), people with a monthly income of less than Rs 475 are considered to be below the poverty line. Using the government's definition of poverty, the average person living in urban India would be 9% short of the recommended daily caloric intake of 2400 calories (Guruswamy & Abraham, 2006).

Data gathered in the Background Information Form provided evidence that most of the participants in MI and APD were living below the poverty line. The median household income per capita was Rs 396, Rs 500, and Rs 3333 for APD, MI and SSK respectively. If Rs 475 per person is used as the threshold for poverty in Bangalore, the majority of families from APD and most from MI were living below the poverty line (see Figure 9).

The Government of India has been criticised for using commodity prices from 1999 – 2000 to set the poverty levels (Mahapatra, 2008). Given the economic climate in 2009, the purchasing power, particularly for food, is not fairly represented by official poverty levels. Information about daily caloric intake by the participants and their families was not gathered. Other household information that was collected, however, does support the evidence that families from MI and APD lived in relative poverty compared to those from SSK. More families from SSK had access to running water, hot water, indoor toilet facilities, computers and internet access. Interestingly, having legal access to electricity and the ownership of commodities such as televisions and mobile phones did not distinguish between the groups as they all had them.

Current literature on the relationship between disability and poverty suggests that families with a child with a disability are at higher risk of financial stress (Msall et al., 2007; Parish & Cloud, 2006). The results of this study do not provide evidence for a link between disability and poverty. The AWD in this study were not affected to any greater degree by poverty than their non-disabled peers. In fact, the median per capita household income for the AC was slightly lower than the AWD. Access to running water, electricity, toilets, and ownership of televisions, mobile phones and computers did not differ between the two groups. Maternal employment, another indicator of possible financial stress, was not analysed statistically, but in general, more mothers of AWD were employed than in the AC group. The only difference between the two groups that may have an impact on financial stress and poverty were the greater number of single female parent-led families amongst the AWD group compared to the AC.

Poverty and financial stress can also lead to perceptions of lower QOL. Higher QOL scores have been linked to increased social support and reduction in environmental barriers (Albrecht & Devlieger, 1999). Two of the core cross-cultural values of QOL, as outlined by Bowling (2005) and Schalock (2005), are material well-being and having enough money to meet needs. The results from this study support the link between poverty and QOL. As discussed earlier, the AWD from SSK were from a relatively higher SES. When comparing WHOQOL-BREF scores, participants from SSK reported higher QOL scores in most domains compared to the other two groups. The only domain in which there were no differences was Social Relationships. Results of the EQ-5D were more variable, with participants from SSK reporting better QOL in two of the five domains. The participants from APD did, however, have significantly lower self-reported health scores on the VAS compared to AWD from MI and SSK.

The data in this study (with relatively small numbers of subjects) indicate a relationship between QOL and poverty. Participants from SSK tended to live in nuclear families, outside urban slums, had better access to transport (including privately owned vehicles), education and

health services. Based on the items included in the WHOQOL-BREF and the EQ-5D, the AWD from APD and MI who lived in crowded houses, with poor access to transportation and health services, unhygienic surroundings, and whose parents may have been burdened with financial concerns, were more likely to report poorer QOL scores. More research is required to determine the nature of the relationship between QOL and poverty. While not directly part of the study, an experience during data collection highlighted the relationship of poverty and QOL (Box 21).

> *When walking through one of the urban slums with a community health worker, A and I were called to the home of a family whose disabled son had just died. The boy was approximately nine years old, and had cerebral palsy. A told me that he had been ill for a few days, and she was planning on checking in with the family after I'd left. I noticed a brand–new wheelchair with custom seating inserts outside the house. When A asked a relative what had happened, she said his cold had become worse. His mother wanted to take him to a doctor, but she was unable to access adequate health care in time. Transportation to the closest medical clinic was the primary barrier. He was difficult to carry because of his size and muscle tone, and although he had a wheelchair, she could not use it because of the road conditions in their community. She was not strong enough to carry him alone, and her daughter was also not strong enough to help. Her husband had left her when it was apparent that their son had a disability, and was living with another woman. The little boy's death from a respiratory infection may have been entirely preventable, and was attributable in no small way to poverty, lack of access to medical facilities, and the poor condition of the roads. Was it his disability that led to his death, or poverty, or both?*

Box 21. Excerpt from field-notes

The AWD and AC did not specifically mention money and issues of poverty as a direct barrier or facilitator to participation and inclusion. It was, however, an underlying element in most discussions. Some AWD discussed the desire to improve the amount and the quality of food they

and their families consumed. When asked what they would like to change, the AWD often spoke of improving the condition of their homes, or moving away from the area in which they lived. Their long-term ambitions were often to improve the 'status' of their families. Dirty roads, unhygienic conditions in their neighbourhoods, and poor access into their homes also featured prominently in their discussions. These issues were primarily brought up by AWD from APD and MI, but were also mentioned by some SSK participants. In the thematic analysis of the qualitative data, these matters were captured under the sub-theme of 'physical environment.' The ability of AWD, particularly in urban slums, to play outside their homes was limited, and transportation was often an issue, particularly for those with mobility issues. Thus, poverty was a barrier to participation.

The physical environment – a barrier to participation and inclusion

The second category in the ICF component of *environmental factors* is the physical environment, whether natural or man-made. Similarly, the physical environment featured prominently as a sub-theme of External Factors in this study. Elements in the physical environment prevented the AWD from accessing their homes and public buildings. Poor road conditions caused further mobility limitations for AWD who used wheelchairs and for those who did not. The awareness of the barriers posed by the physical environment extended to the impact these barriers had on others with physical impairments that were more severe than their own. Some AWD even expressed their concern for animals that had to travel through unhygienic and crowded roads.

The group of AC was not asked specifically about barriers to participation. However, elements of the physical environment are included in the WHOQOL-BREF. The responses to these questions indicated that the physical environment also had an impact on the QOL of AC participants, particularly from APD and MI. Unpaved roads, decreased access to health care facilities, and poor hygienic conditions in the environment have negative consequences for all who experience them, not just people with disabilities. A study to investigate the degree

to which the physical environment affects all people, with and without disabilities would be useful.

There was very little discussion about elements of the physical environment that facilitated participation and inclusion. For the AWD living in the urban slums, physical barriers were faced on a daily basis, both at home and to and from school. Walking was the primary form of transport used by these participants. This proved to be a challenge for those with mobility impairments, particularly in areas with unpaved roads and large open sewers. By contrast, the AWD at SSK and those enrolled in the vocational training program at APD spent much of their day in a comparatively barrier-free environment. Even so, most of these participants discussed the physical environment in terms of barriers, not facilitators. One participant, although praising the accessibility of his school, was still quick to point out the frustration he felt at the lack of wheelchair-accessible toilets.

Environmental barriers not only led to decreased participation, but more importantly, an inability to achieve desired levels of independence. From toileting themselves to being able to walk without restrictions, the physical environment played a major role in the lives of the AWD. The process of gaining physical and emotional independence during adolescence is a key factor in the development of life skills that are critical for success in the adult years. Current research literature points to the fact that participation for adults with disabilities begins to decline during adolescence, leading to decreased ability to fulfil adult roles (Liptak, 2008). The barriers posed by the physical environment discussed by the AWD in this study will have a direct impact on the transition to adulthood, and their ability to experience success in later life.

Policies and legislation – do they really have an impact?
The sub-theme of policies and legislation that emerged from the analysis in this study is also captured under *environmental factors* in the ICF. As discussed in Chapter 2, India has several pieces of legislation that aim to protect the rights of people with disabilities. Most recently,

it has also signed and ratified the UNCRPD. The existing legislation and policies put forward measures through which public buildings, education, and employment are meant to be accessible to all people with disabilities. Policies and legislation are ineffective, however, without careful monitoring and enforcement.

The AWD and the PD were very aware of the existence of these policies. The AWD were equally aware that these policies and laws had little impact on their lives in practice, as most legislation was not enforced. The AWD were unable to participate in desired leisure activities because of poor physical access into public buildings. The lack of ramps was a key concern for participants in wheelchairs, particularly outside large multinational chains, such as McDonald's. The perception amongst AWD was that despite the existence of the PDA and India's signing of the UNCRPD, these businesses have no vested interest in improving access unless they are faced with financial consequences. In a study of young adults in the UK, the researchers found a similar challenge. They state that, '…there is enough legislation to cater for the needs of people with disabilities. What is missing is the will to implement this legislation' (Doyle et al., 1994, p.1497).

Some AWD seemed to face an internal struggle when discussing issues of policies and legislations. They were not keen to point out the failings of the 'system' in India, which they felt had made great strides in becoming more inclusive of people with disabilities since they were children. After some prompting and discussions with the other AWD, they eventually discussed the ways in which good intentions often were not thoroughly planned, or were poorly implemented. An example from several different AWD groups was that of public transport. As part of the disability legislation (PDA), a small number of seats on local buses are designated for use by people with disabilities. A good idea in theory, there are two major limitations in practice. First, the designated seats are at the front of the bus, where all seats are reserved for women. Despite their disability, none of the male AWD were able to use the seats because of their gender. Second, seats were often occupied by non-disabled people, so even female AWD could not use them. This is both

an issue of enforcement and lack of public awareness. The city of Bangalore is slowly making positive changes. The AWD pointed to the newly introduced low-floor buses with disabled access as a move in the right direction.

Application of the disability legislation and the UNCRPD was the topic of an informal discussion with one of the local partners. In the PDA, the Indian government stipulates that a certain percentage of government jobs must be reserved for people with disabilities. The local partner said government offices found ways to circumvent the intent of this law by assigning specific job descriptions for employees with different disabilities. In this way, if the post designated to be filled by someone who was deaf was occupied, then no other person with a hearing impairment would be able to find work in that specific office. The local partner was critical of the way in which employers had found ways to theoretically adhere to the legislation, while still creating barriers to employment for people with disabilities.

Creating stricter guidelines for enforcement and monitoring of policies and legislation were common topics of conversation when the AWD were asked what they would like to change or make different. Most of them, however, stipulated that this desire was largely idealistic, and that change would have to come from higher levels. Few believed they had the power to advocate for change, particularly at a governmental level. One can speculate if this was a matter of age. Perhaps AWD in this context were too inexperienced with self-advocacy to believe they could influence change. Alternatively, this may be an indication of the fact that most AWD in this setting are unused to having their voices heard or taken into account when decisions are made at a higher level. A third possibility is that AWD in this setting focus primarily on the issues that affect them on a daily basis, and less so on matters that seem unattainable or at levels beyond their reach. These findings indicate that AWD need to be given the tools for effective self-advocacy, and need to have their voices heard in a meaningful way, if changes to the lives of people with disabilities in India are to be realised.

6.4 AWD and their parents – are they on the same page?

An objective of this study was to determine the similarities and differences between the AWD and their parents/caregivers, and AWD and their peers. In view of the fact that the majority of research into the needs of AWD is conducted using parent-proxy reports, it is critical to understand if parents accurately represent the concerns of their children. This is particularly important for adolescents as they transition from a state of dependency on parents to more independence in decision-making. Even in countries such as India, where adolescence is not always imbued with the same expectations as in 'Western' settings, it is important to understand any disparities between views of adolescents and their parents. For AWD in particular, service provision and support to facilitate participation should be predicated on their views, not those of their parents. There is also an assumption that AWD are remarkably different than their peers in terms of goals and desires. Previous discussion has examined the subtle differences in leisure activities between AWD and AC. Such differences, however, do not seem to exist when considering goals and ambitions.

6.4.1 The key to a successful future - educational goals

The AWD and the AC held education in high regard and had similar goals to pursue further education. In this, the AWD were supported by their parents. The attainment of a certificate, diploma or even a degree was seen as the path to financial independence and social advancement. This was of particular importance for the participants from lower SES. Data on education for girls in India, and girls with disabilities in particular, suggests that they are denied access to education compared to their male counterparts (Kalyanpur, 2008). In contrast, all female AWD and AC in this study were enrolled in school. The only participants who had dropped out were one male AWD and one male AC who had been sent to work to supplement the family income. The PD all expressed a commitment to ensuring their daughters and sons achieved their educational goals, even if it required sacrifices on their part.

Disagreement between parents and children in terms of education was limited to some AWD and AC female participants from APD. These young women were pursuing vocational training and reported pressure from their parents to discontinue their education and seek employment. In all three cases, financial constraints in the family came into direct conflict with the desire of the participants for self-improvement. The underlying belief in these families was that investment in the education of girls was of lesser value, particularly as they would eventually be married and no longer contribute to the income of their natal family (Kalyanpur, 2008). In all cases, the gender of the participants was the more significant issue, not their disability. This finding was limited to the three participants from APD. One can posit that the supportive attitude of PD towards the education of the AWD was enhanced by the involvement of the agencies (APD, MI and SSK), which work towards the promotion of education for all children with disabilities.

6.4.2 'I'd like to be a...' – employment goals

The employment aspirations of the AWD were detailed and very similar to the AC. Singh and Ghai (2009) found similar results among younger children with physical disabilities in India. By contrast, the desires of the PD in this study were not as specific as that of the AWD. Parents were keen that their child should find a 'good job'. They were either unaware that their AWD had specific employment goals, or were unsure if these goals were achievable. One mother was caught between the desire to support her son's ambitions and her belief that he was being unrealistic. Some PD had specific plans, such as purchasing a small shop for their AWD to manage, or had family land that they envisioned would provide an income for their AWD. In these cases, the AWD appeared to have internalised these plans, and expressed similar desires.

The question that needs to be considered is how realistic are the career goals of the AWD? Statistically, it is unlikely that many AWD will realise their goals of employment. Research about people with disabilities around the world points to high unemployment rates and inability of people with disabilities to access the labour market, which

then contributes to the vicious cycle of poverty and disability (Department for International Development, 2000; Kalyanpur, 2008; Mitra, 2006). The existence of legislation to provide employment opportunities is ineffectively implemented, creating another barrier to participation in employment. The older AWD who had finished their basic education expressed employment goals that were aligned with their physical and academic capabilities. Even some of these participants, however, recognised that their impairments could pose barriers to successful employment. Some who had chosen training courses in physically demanding jobs discussed the discomfort they experienced after a day's training. With limited job adaptations available, it is possible that in spite of adequate training, these AWD may not find appropriate employment. The younger participants seemed more ambitious, and perhaps more unrealistic. Their goals typified those of adolescents within their age group, and were similar to those of their non-disabled peers. In order to determine the exact nature of barriers to employment, longitudinal research is needed to follow AWD from education to employment and beyond.

6.4.3 Looking ahead to marriage and family

Very few AWD or AC mentioned marriage and children as long-term goals. The only female AC who raised the topic did so to declare that she did not aspire to marriage, viewing it as a barrier to achieving her ambitions. Unsurprisingly, there was no discussion about dating or relationships in either group. Western influences have brought the concepts of dating to adolescents and young adults in India, but generally only in urban centres amongst those in higher SES. Traditional values still prevail in most social classes, where appropriate spouses are found by parents or other family, and marriage is seen as inevitable. The inevitability of marriage could explain the lack of discussion about it as a specific future goal by the AWD and the AC. The relatively young age of the participants also meant that their attention was focused on their education and being successful as adults. Marriage was perhaps an

event only to be considered once other goals were achieved for both AWD and AC.

The parents of the AWD, in contrast, did discuss marriage as a significant issue. The PD frequently expressed concerns that it would be difficult to find a spouse for their AWD. One parent had already arranged a marriage for her daughter with a distant relative. This was seen as a safer and more reliable alternative to marriage outside the family. The doubt of PD that their children would find suitable spouses was more pronounced amongst PD of female AWD. Women with disabilities in India are often less attractive to potential spouses because they are seen as financial burdens, and even after marriage can be expelled from their marital home because of failure to live up to expectations (Addlakha, 2007). In India, more women with disabilities are widowed, divorced or separated, compared to men with disabilities (Government of India, 2006). Recognition of this reality is perhaps why the PD were particularly adamant that their AWD should be financially independent before considering marriage.

6.4.4 Caring and over-protectiveness – parents of AWD

Finding a suitable spouse for their AWD was only one of several concerns expressed by the PD. Most parents voiced significant concerns about planning for the future, particularly after their death. The implication was that they were unsure of the ability of the AWD to be independent, both financially and in terms of self-care. Despite these doubts, they were still determined to support their AWD in achieving all their goals. Some PD were hopeful that the AWD would receive support from siblings, while others were keen to provide other means of assistance and reduce the burden on family. Many PD discussed the need to put money aside specifically for their AWD, but were worried that this would not adequately meet all needs.

Research in India with 14 children with physical impairments suggested that parents were worried and overprotective, and in some cases blamed their child for the family's misfortunes (Singh & Ghai, 2009). Research in Puerto Rico also found that over-protectiveness

amongst parents of children with disabilities influenced the development of independence and certain functional skills (Gannotti, Penn Handwerker, Groce, & Cruz, 2001). Over-protectiveness was not perceived by the AWD or their parents in the present study as a particular concern. Nor did the AWD perceive an assignation of blame from their parents, or that their parents were overly worried about them.

From the perspective of the AWD, they experienced frustration at limits placed on them by their parents. For example, one participant wished that his mother would let him 'go out and play' more, instead of telling him to stay home and study. Another participant felt constrained by her mother's reluctance to let her spend more time outside the house with her friends. She perceived this to be a lack of understanding on her mother's part about the importance of her friends, rather than over-protectiveness or worry. These examples can be viewed as typical interactions between parents and adolescent children.

Over-protectiveness can, however, take on different guises. It can be argued that the relative social isolation of the AWD from SSK outside school is one such case. The effort required to facilitate social contact combined with a desire to shield them from discriminatory attitudes may be fuelled by feelings of over-protectiveness by parents. This, in turn, is perceived as a participation restriction by the AWD. The AWD often spoke of being restricted from doing certain household chores that their parents felt were too physically taxing, even though the AWD believed they had the capacity to perform these tasks. Parents may have been protecting their AWD from experiencing failure, but was perceived as a participation restriction by the AWD. Gannotti et al. (2001) speculate that parental over-protection is one factor that can prevent children with disabilities from having the opportunity to achieve certain functional skills. Service providers need to encourage parents to allow AWD to engage in desired activities, while at the same time not denying the importance of cultural and parental values.

6.5   The research study – its strengths and its limitations

<u>6.5.1 The strengths</u>

Methodology

A strength of this study was the methodology, specifically, the photography task used with the AWD. While using photography is not a novel approach to data collection (see Chapter 3 for a complete discussion of this technique), it has not previously been used with AWD in a low – or middle-income setting. The use of photography in this study was an effective method to stimulate discussion with AWD, and was a participant-centred approach.

The intent to use this method was initially met with resistance from some local NGO partners. Concerns were raised that the AWD would not know how to use the cameras due to inexperience with the technology. Other partners felt that the cameras were at risk for theft, or would be sold by participants. A bigger concern for some partners was the possibility that other family members or friends, rather than the AWD, would use the cameras instead, or that the adolescents would not understand the purpose of the task. As an alternative, one NGO partner suggested using drawing instead of photography as it would be better understood by the AWD. Local partners were reassured that the task and use of the cameras would be thoroughly explained to AWD. I was willing to take the risk that some cameras would be lost or not returned, and had planned for such eventualities. I was also confident that the AWD would be serious about the task and that the involvement of family and friends would be minimal. As discussed earlier, drawing was not considered as a suitable alternative because of the potential for physical limitations and because it was not age-appropriate for AWD.

When the task was introduced to the AWD, I was met with more enthusiasm and questions than anticipated. The AWD asked many questions about the intent of the task, the purpose of the study, and how the photographs would be used in the research. Upon receiving technical instructions, the AWD were quick to clarify any questions, and practise with one or two pictures. The AWD were reluctant to let anyone else touch their cameras, including friends and family members who

were present at the meeting. Of the 37 cameras that were distributed, only one camera was stolen when a participant left her bag outside a public toilet, and was immediately replaced. Each camera could take a maximum of 27 pictures. The number of usable photographs taken by AWD varied between six and 18 pictures. Many AWD reported taking more pictures than were developed, but these were unprintable due to poor lighting conditions or inadequate exposure. Three AWD with impaired hand function required assistance to use the cameras, which they sought from their mothers. There was no maternal influence on the subject of the pictures taken.

The discussions about the photographs during the FGD were expected to take no more than 20 minutes. Most discussions lasted between 35 and 45 minutes and had to be concluded by the researcher due to time constraints. The AWD were keen to talk about the photographs that they had taken but had not been developed due to under- or over-exposure. Using photographs rather than directed questions was an effective way to encourage the quieter group members to speak. Using photography also provided AWD with a sense of responsibility for an important piece of data collection. They were diligent in ensuring the task was completed appropriately in order to maintain the rigour of the research.

Some parents initially expressed doubts that their AWD would be able to carry out the task. When the study period concluded, however, the same parents expressed their surprise that their AWD could complete what was required and were be proud of them. Some members of partner NGOs as eager as the AWD to view the photographs and admitted that they did not think the task would be successful. One vocational training instructor requested more information about the cameras and was considering using a similar approach with her students.

<u>6.5.2 The limitations</u>

Recruitment of participants

One limitation of the study was the process used to recruit AWD. All AWD and their parents were recruited through three local NGOs that work specifically with children, adolescents and adults with disabilities. All the participants in the study and their families had been receiving services from the NGOs since the AWD were young children. Services received included medical and rehabilitative interventions, but also advocacy, social skills training, and other support services. Their association with the NGOs would likely have made the AWD and their parents more aware of their rights, and more capable of accessing services to meet their needs. It is questionable how representative the participants in this study are of other AWD in urban settings in south India.

Despite efforts to recruit AWD who represented a range of income levels, there were no families from the highest income brackets. We speculated whether families from higher income brackets avail themselves of services offered by local providers such as SSK. In a discussion with Dr. Maya Thomas, she indicated that her experience suggests that wealthy families with a child or AWD will seek services through private providers, or take their child out of the country for medical and rehabilitation services. Thus, while AWD from transient families remain difficult to identify because of gaps in infrastructure, the AWD from the wealthiest families seem to be the most 'hidden' of children with disabilities.

Finding non–disabled peers

The process of finding peers without disabilities was much less problematic for the AWD from urban slum settings than for those from SSK. The AWD from MI and APD attended community schools and had friends in their neighbourhoods who were able and willing to participate in the FGD and interviews. It was much more difficult, however, to find non-disabled peers for the AWD from SSK. As discussed previously, these participants were more socially isolated in terms of friendship.

This social isolation may have made the AWD from SSK slightly more emotionally immature. The AC group that was interviewed as a 'peer group' was matched on SES, age, and educational variables, but was not identified by the SSK participants themselves.

The setting

Conducting research in non-traditional settings is exciting and provides many new insights into lives of marginalised groups. It does, however, provide challenges that are unlikely to be faced elsewhere. The plethora of state, national and religious holidays, in combination with school holidays posed challenges to scheduling interviews and utilising a consistent approach with all participant groups. Although I attempted to hold FGD with the AWD approximately a week after the photographs were developed, this was not always possible. In one month, in particular, two state-wide strikes, two religious festivals, and one national holiday meant that almost three weeks were lost to holidays and unseen travel restrictions.

Holding FGD and interviews in urban slums was not always straightforward. 'Best practice' for interviews and FGD dictates that a quiet setting with adequate privacy is the ideal. I attempted to find a setting as close to these parameters as possible, but the reality in our study was that the interviews were often conducted in a local home with enough space to accommodate all the AWD, the community health worker and the interviewer (GK). Background noise was often high and there was little to no privacy. Members of the community, the homeowners, other children and relatives would come and go from the meeting place. These were 'real-life' conditions for the participants, however, and it was only my ability as a researcher that was impaired.

Conducting research with translators

My unfamiliarity with the local languages of Kannada and Tamil, and my very rudimentary understanding of Hindi meant that all interviews and FGD had to be conducted with translators. This posed a unique set of challenges. The possibility for misinterpretation grows significantly

(Esposito, 2001). There are two main options available to a researcher when gathering qualitative data in an unfamiliar language. Translation can either occur based on recordings of the interviews, or can occur simultaneously while the researcher is present. Esposito (2001) maintains that simultaneous translation allows the researcher to retain more control over the FGD or interview, and provides opportunity for probing questions and redirection of the discussion.

A good translator must convey the spoken words and the meanings behind those words. It is recommended that a professional translator be used, either alone or in conjunction with a local community translator (Esposito, 2001). Given the financial limitations of this study, and in consideration of ease of access to urban slum communities, this was not a practical option for this study. The majority of participants in this study spoke Kannada, Urdu, or Tamil. For FGD and interviews with these participants, translation was provided by the community health worker, a teacher or other staff member at the NGO. Issues of data analysis become further complicated when there are no words in the source language (Kannada, Urdu or Tamil) for words used in the target language (English) (Twinn, 1997). In the case of one source language in this study (Kannada), words for 'disability' and 'impairment' do not exist.

Some solutions were implemented to minimise the limitations posed by the issue of language and translation in this study. First, all FGD and interviews were conducted with the researcher (GK) present, and translation occurred simultaneously. With some basic understanding of Hindi and growing familiarity with Kannada, I was able to clarify issues if the translation did not seem appropriate at the time of the interview. Second, a random check of three FGD recordings by an external translator (KR) indicated that the community health workers were translating faithfully, conveying meaning and context. In addition, they were not adding their own interpretation or précising the words of the participants. Third, discussions with the translators were held prior to the FGD and interviews to review the purpose and objectives of the study, the intent behind the FGD and interviews, and the theoretical

construct upon which the study was based. Finally, some participants wanted to communicate using English despite having limited skills and vocabulary in this language. They were not discouraged in doing so, but were equally encouraged to use their mother tongue if the researcher felt that they were not able to express themselves as clearly as possible.

Another limitation was that all interviews at SSK were conducted in English. This was the language of instruction at the school, and most parents spoke English fluently. A staff member was present at the initial meeting with the AWD to ensure that the students were comfortable with the language and the study. Subsequent interviews and FGD were conducted without a staff member present. This could have introduced bias into the process of data collection as participant responses may have been followed up by more probes and prompts than were possible in interviews and FGD at APD and MI, resulting in more complete answers.

6.6   Suggestions for future research – what more do we need to understand about the lives of AWD?

The findings of this study point to other areas that warrant further research.

1. An in-depth investigation of the facilitators and barriers found in this study and the role they play in successful transition to adulthood for AWD would provide valuable information. Knowledge of the specific facilitators, particularly those that aid in the achievement of educational and employment goals, would be important information for service providers and families of AWD. The support perceived by the AWD from their parents is a key facilitator to inclusion and participation. Other factors, however, are likely to be necessary in order to ensure that the AWD realise success in later life.

2. More research is required into the relationship of poverty and disability. As discussed in previous chapters, the connection between poverty and disability is widely acknowledged but poorly researched. Evidence from this study indicates that poverty did not negatively

influence the perceived participation and inclusion of AWD. Issues of poverty may have a larger role to play in the transition to adulthood for AWD. The ability to achieve educational goals and find meaningful employment are critical in breaking the cycle of poverty and disability. The relationships between poverty and some facets of QOL found in this study also deserve closer examination.

3. The area of QOL and its measurement with AWD in similar settings has not been extensively studied. This study provides initial data, but research with a larger sample size is required. In general, the question of whether the measurement of QOL in this population provides valuable information needs to be asked. Currently, the tools available to measure QOL in developing countries have not been validated with adolescents. Tools that have been validated for use with children and adolescents with disabilities are not appropriate for this setting. Rather than focusing strictly on QOL, more valuable and interesting information may be gained from examining the importance placed by AWD in this, and similar settings, to the facets of QOL as identified by Bowling (2005) and Schalock et al. (2005). This should employ both quantitative and qualitative approaches. Validation of tools such as the WHOQOL-BREF with AWD is also required.

4. Discussions with participants and representatives from each of the three partner agencies in the final phase of the study identified the area of sexual health education and sexuality as one that required more research and more support for service provision. Community health workers were particularly concerned about the need to provide education to young women with disabilities. Sexuality in the context of disability is gaining increasing recognition in the literature, but remains a culturally sensitive topic in certain countries. Addlakha (2007) suggests that even with the passing of legislation such as the PDA in India, the rights of persons with disabilities to relationships, family and children have been sidelined. The stereotyping of people with disabilities as asexual persists to some degree. Addlakha (2007) also suggests that women with

disabilities in India suffer the double burden of disability and gender discrimination. Research has shown that adolescents with disabilities are vulnerable to sexual exploitation, rape, and abuse, putting them at higher risk for sexually transmitted infections such as HIV/AIDS because of their inability to access education and counselling (Yousafzai et al., 2005). The limited scope of this study did not allow the issue of sexuality and sexual health to be further explored with the AWD, but it is a critical area that should be investigated.

5. A final suggestion for further study is the specific role of mothers of AWD, in the same or similar cultural milieu. Both the AWD and the AC spoke more often of their mothers than their fathers. Further, they spoke more often of interactions with maternal extended family rather than paternal family. Traditionally in India, when a woman marries, interaction with her natal family is reduced in favour of time spent with her marital family. That did not seem to occur with many families in this study. Other research also points to the extra support provided to mothers of children with disabilities by their natal families (Chakravarti, 2008). One possible explanation for this could be the assignation of blame on the mother for the child's disability. One mother in this study felt significant pressure to have a 'normal' male child after giving birth to two daughters (one with a disability) and a son with severe disabilities who died in early childhood. She reported that her mother-in-law threatened to find another wife for her husband if she was unable to have a 'normal' son. Of the eight single-parent families in this study, all but one were led by the mother. In most cases, the husband had left the family because of the child's impairment. It has been argued that 'disabling' elements within the environment that affect children with impairments also affect mothers of these children (Ryan & Runswick-Cole, 2008). The focus to date has primarily been on the negative aspects of parenting a child with a disability, and not on the positive effects it can have for mothers (Ryan & Runswick-Cole, 2008). An Indian study of parents of young people with cerebral palsy also found that although mothers had to shoulder much of the caring

role for the disabled family member, this led to the development of independence and new competencies (Chakravarti, 2008). Chakravarti (2008) suggests that within the rigid gender roles found in Indian society, fathers of children with disabilities need support to take on a bigger caregiving role. Much of the support provided to families of children with disabilities has been focused on young children. More adequate resources are need to assist families of AWD to facilitate independence, skills and the transition to adulthood. The role of parents in creating enabling environments should not be overlooked, but the ways in which they can be supported needs further research.

6.7   Key recommendations – the outcomes of this study

In addition to suggestion for further research, several key recommendations have arisen from the results of this study. These recommendations are specifically in reference to enhancing inclusion and participation of AWD and their families.

1. Provision of parental support: Parental support and encouragement was viewed by the AWD as an important facilitator to inclusion and participation. The PD also felt responsible for providing the necessary supports in order for their AWD to achieve their goals. Historically, agencies such as MI, SSK and APD have provided intervention and community rehabilitation services for younger children and their families, with a focus on minimising impairment and improving function. Parental support is provided when children are very young, but there is little indication that support services are provided to parents of AWD. One parent meeting was observed at MI. This group was initially organised to support parents of young children with disabilities and had grown into a general community support group. All community members were welcome, although the initial focus had been on parents of children with disabilities. Such groups are an effective means of providing support and skills to parents by service organisations, but also through parent-to-

parent interactions. A more concerted effort to facilitate such groups for parents of AWD would be beneficial in ensuring the successful transition of AWD to adulthood.

2. Advocacy skills: A major barrier to participation and inclusion, as perceived by the AWD, were attitudes of the general public. This extended to the ineffective implementation of existing legislation and disability policies. AWD need coaching in self-advocacy skills as a tool to effect change in their communities. They have a keen awareness of the barriers to participation and inclusion but have little opportunity to voice their needs and opinions. Various governmental departments in India solicit input from representatives of DPOs. If existing policies and legislation such as the PDA and UNCRPD are to be implemented and enforced, channels must be provided for people with disabilities, including AWD, to have input into the process.

3. Providing AWD with a means of expression: The results of this study indicate that photography is an effective and useful research and advocacy tool when used by AWD. Photography can not only be employed to gather information, but also for advocacy purposes. If AWD are to be given a voice and a means of drawing attention to their concerns, photography can provide an effective method of expression. This is a more age-appropriate tool than drawing. The results of this study demonstrate that even those AWD with little to no experience with cameras were able to complete the task successfully. Providing AWD with alternative ways in which to express their opinions and needs would promote and support their advocacy skills.

4. Measuring QOL: If the aim of service organisations is to improve the QOL of the children and families to whom they provide support and intervention, then appropriate tools are required to measure this outcome. The results of this study indicate that in this setting, the

WHOQOL-BREF was the most culturally appropriate. It also is aligned with the ICF and the social model of disability, and does not focus exclusively on aspects of impairment like other QOL tools. There are methodological issues with the WHOQOL-BREF, as discussed earlier, which need to be examined more closely. Using validated measures, however, is necessary if service providers are to evaluate whether their interventions have an impact on QOL.

6.8 Conclusion

This is the first study to specifically examine the perceptions of AWD in South India about inclusion and participation at home, school and in their wider communities. The perceptions of AWD in developing countries have previously been omitted from the discourse concerning children and adults with disabilities. The needs of AWD are unique. As such, intervention and services provided by community programs should be tailored to meet their needs, and not be based on programs designed for children or adults. Only by hearing their voices will the inclusion and participation of AWD be realised.

The results of this study indicate that AWD are, in many ways, similar to their non-disabled peers. Scores on many facets of two QOL measures were not significantly different between the two groups. The AWD and AC engaged in similar recreational activities, had similar household chores, and voiced the desire for similar educational and employment goals. There were subtle differences, however, which can be attributed in part to the presence of physical impairments. The AWD perceived barriers to participation in physically active recreational pursuits, and were prevented from doing household tasks that required greater physical ability.

Parental support was a key facilitator of participation and inclusion. Parents of AWD were vocal in their desire to support their children in the pursuit of long-term goals. Parent-proxy scores on measures of QOL were also similar to those reported by the AWD. The parents did, however, have significant concerns about the future. In particular, they voiced worries about providing adequate financial

support for their child and the feasibility of their AWD achieving meaningful independence.

One of the most significant barriers to inclusion and participation for the AWD was the attitudes of others. This included teachers and members of the general public. Negative attitudes prevented AWD from inclusion and participation in school activities, recreational activities, and accessing public services. The AWD were aware of the barriers placed by these attitudes and worked hard to prove themselves and their capabilities. The other significant barrier to inclusion and participation was due to External Factors, including the physical environment and policies and legislation. Despite the existence in India of the PDA and the ratification of the UNCRPD, the AWD were aware that a lack of implementation and monitoring made these policies ineffective in facilitating their participation and inclusion.

The AWD who participated in this study had educational and employment goals that were similar to their non-disabled peers. In order for the AWD to achieve success in adulthood, the barriers they perceive to inclusion and participation need to be overcome. The support they receive from their parents is a facilitator in overcoming these barriers. The parents of AWD require further support as their children transition to adulthood. Services to date have focused on providing families with resources for the development and improvement of function in young children with disabilities. Adolescence is a critical period that requires particular skills and support. Most importantly, the AWD themselves require support and skills to advocate for their needs. In the words of Mahatma Gandhi, '*The greatest lessons of life, if we would but stoop and humble ourselves, we would learn not from grown-up learned men, but from the so-called ignorant children.*'

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Appendices

Appendix I – Background Information Form

Participation by adolescents with disabilities in health, education and social systems: experiences from south India

Child Information:

1. Name:_____

2. Date of birth

   (dd/mm/yyyy):_____

3. Gender: M☐   F☐

4. Medical diagnosis/health condition (please check):

   ☐Cerebral palsy   Level I☐   Level II☐   Level III☐   Level IV☐

   ☐Brain Injury ☐Spinal Cord Injury (Level_____)

   ☐Other (specify):_____

5. Name of school:_____

6. Grade level at school:_____

7. Number of years of school:_____

Family Information:

Mother:

8. Name:_____

9. Highest Level of Education:_____

10. Current occupation:_____

Father:

11. Name:_____

12. Highest Level of Education:_____

13. Current occupation:_____

Household Information:

14. Type of housing:

   Private   ☐   State ☐   Informal   ☐

   Other:_____

15. Details about housing:

   a. Number of rooms in house_____

   b. Running water in house?   Yes ☐   No ☐

   c. Hot water?   Yes ☐   No ☐

   d. Toilet in house?   Yes ☐   No ☐

16. Type of transportation:

Bus ☐   Two-wheeler ☐   Own car ☐

Other:_____

17. Number of people living in house:

    a. Adults_____

    b. Children_____

    c. Age of other children:

    Child 1_____   Child 3_____

    Child 2_____   Child 4_____

Other:

19. Does anyone own a mobile phone?   Yes ☐ No ☐

20. Is there a computer in the house?   Yes ☐ No ☐

21. Is there cable television?   Yes ☐ No ☐

22. What are your plans/hopes for your child after completion of schooling?_____

_____

_____

Name of person completing form:_____

Signature and Date (dd/mm/yy):_____

Appendix II – WHOQOL–BREF

This assessment asks how you feel about your quality of life, health, or other areas of your life. Please answer all the questions. If you are unsure about which response to give to a question, please choose the one that appears most appropriate. This can often be your first response.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the last two weeks. For example, thinking about the last two weeks, a question might ask:

	Not at all	Not much	Moderate-ly	A great deal	Complete-ly
Do you get the kind of support from others that you need?	1	2	3	4	5

You should circle the number that best fits how much support you got from others over the last two weeks. So you would circle the number 4 if you got a great deal of support from others as follows.

	Not at all	Not much	Moderate-ly	A great deal	Complete-ly
Do you get the kind of support from others that you need?	1	2	3	4	5

You would circle number 1 if you did not get any of the support that you needed from others in the last two weeks.

Please read each question, assess your feelings, and circle the number
on the scale for each question that gives the best answer for you.

		Very poor	Poor	Neither poor nor good	Good	Very good
1(G1)	How would you rate your quality of life?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
2 (G4)	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about how much you have experienced
certain things in the last two weeks.

		Not at all	A little	A moderate amount	Very much	An extreme amount
3 (F1.4)	To what extent do you feel that physical pain prevents you from doing what you need to do?	1	2	3	4	5
4(F11.3)	How much do you need any medical treatment to function in your daily life?	1	2	3	4	5
5(F4.1)	How much do you enjoy life?	1	2	3	4	5
6(F24.2)	To what extent do you feel your life to be meaningful?	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	Extremely
7(F5.3)	How well are you able to concentrate?	1	2	3	4	5
8 (F16.1)	How safe do you feel in your daily life?	1	2	3	4	5
9 (F22.1)	How healthy is your physical environment?	1	2	3	4	5

The following questions ask about how completely you experience or were able to do certain things in the last two weeks.

		Not at all	A little	Moderately	Mostly	Completely
10 (F2.1)	Do you have enough energy for everyday life?	1	2	3	4	5
11 (F7.1)	Are you able to accept your bodily appearance?	1	2	3	4	5
12 (F18.1)	Have you enough money to meet your needs?	1	2	3	4	5
13 (F20.1)	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14 (F21.1)	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

		Very poor	Poor	Neither poor nor good	Good	Very good
15 (F9.1)	How well are you able to get around?	1	2	3	4	5

The following questions ask you to say how good or satisfied you have felt about various aspects of your life over the last two weeks.

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
16 (F3.3)	How satisfied are you with your sleep?	1	2	3	4	5
17 (F10.3)	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
18(F12.4)	How satisfied are you with your capacity for work?	1	2	3	4	5
19 (F6.3)	How satisfied are you with yourself?	1	2	3	4	5
20(F13.3)	How satisfied are you with your personal relationships?	1	2	3	4	5
21(F15.3)	How satisfied are you with your sex life?	1	2	3	4	5
22(F14.4)	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23(F17.3)	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24(F19.3)	How satisfied are you with your access to health services?	1	2	3	4	5
25(F23.3)	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to how often you have felt or experienced certain things in the last two weeks.

		Never	Seldom	Quite often	Very often	Always
26 (F8.1)	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	1	2	3	4	5

THANK YOU FOR YOUR HELP

Appendix III – EQ–5D

By placing a tick in one box in each group below, please indicate which statements best describe your own health state today.

Mobility

> I have no problems in walking about

> I have some problems in walking about

> I am confined to bed

Self–Care

> I have no problems with self-care

> I have some problems washing or dressing myself

> I am unable to wash or dress myself

Usual Activities (*e.g. work, study, housework, family or leisure activities)*

> I have no problems with performing my usual activities

> I have some problems with performing my usual activities

> I am unable to perform my usual activities

Pain/Discomfort

> I have no pain or discomfort

> I have moderate pain or discomfort

> I have extreme pain or discomfort

Anxiety/Depression

> I am not anxious or depressed

> I am moderately anxious or depressed

> I am extremely anxious or depressed

We would like you to indicate on this scale how good or bad your own health is today, in your opinion. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your health state is today.

To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

Best
imaginable
health state

100

9 0

8 0

7 0

6 0

5 0

4 0

3 0

2 0

1 0

0

Worst
imaginable
health state
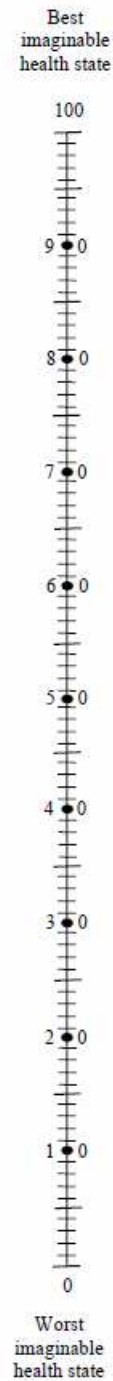
Appendix IV – Letter of Invitation

January 22, 2007

Dear parent,

We would like to invite your family to take part in a research study. The purpose of this study is to help us learn more about the lives of young people in Bangalore who have disabilities. By taking part in this study, you will be helping us to learn what is important to you and your child. We are also interested in learning if your child is the same as or different than other children of the same age who do not have a disability.

You will be asked to come to one group meeting. The meeting will last about ½ an hour. At this meeting, you will be able to meet other parents of children with disabilities. You will meet the researcher and learn more about the study.

You will then be asked to meet separately with the researcher. This meeting will last about 45 minutes to 1 hour and will be at a time that is convenient to you. You will be asked to share some information about your family with the researcher. Everything you tell us will be kept confidential. You will also be asked to fill out some forms which will help us learn more about your child. The answers you give will only be read by the researchers.

If you are interested in taking part in this study, please contact Mr. Rabi Isaac at the Spastic Society of Karnataka at 080-xxxxxxx.

Thank you very much,

Gayatri Kembhavi, MScPT, MPhil/PhD Student, University of London
Mr. Rabi Isaac, Spastic Society of Karnataka

....

Name of family _____
☐ YES I would like to take part in the study

☐ NO I would not like to take part in the study

Appendix V – Information Sheet for Parents

Title of Project: Participation of adolescents with disabilities in health, education, and social systems: experiences from south India

Name of Researchers*:
Gayatri Kembhavi, MScPT, MPhil/PhD Student
Professor Sheila Wirz, PhD
Dr. Rachael McDonald, PhD
Dr. Maya Thomas, PhD
*Centre for International Health & Development, Institute of Child Health, 30 Guilford St., London WC1N 1EH

Dear _____,

Thank you for agreeing to take part in our research study.

Purpose/Description: The purpose of this research study is to help us learn more about the lives of young people in Bangalore who have disabilities. By taking part in this study, you will be helping us to learn what is important to you and your child.

You will be asked to come to one group meeting. The meeting will last about ½ an hour. At this meeting, you will be able to meet other parents of children with disabilities. You will meet the researcher and learn more about the study.

You will then be asked to meet separately with the researcher. This meeting will last about 1 hour. You will be asked to share some information about your family with the researcher. Everything you tell us will be kept confidential. You will also be asked to fill out some forms which will help us learn more about your child. The answers you give will only be read by the researchers.

Risks/Benefits: There are no risks to you being in this study. Anything you tell us will be very important for our research and will help us get the best information we can.

Ability to say no: You can decide not to take part in the study at any time. If you decide to stop taking part, this will not affect you or your child in any way.

Questions: If you have any questions about the study, you can contact Gayatri Kembhavi, Dr. Maya Thomas or _____.

We appreciate your time and what you have to tell us.

This study has been approved by the University College London's Research Ethics Committee. The researchers have undergone a satisfactory criminal records check. The data collected for this study will comply with the UK Data Protection Act 1988. Data will be kept for 5 years after completion of the study.

Appendix VI – Informed Consent Form

Title of Project: Participation of adolescents with disabilities in social, education, and health systems: experiences from south India

Name of Researchers*: Gayatri Kembhavi**, MScPT, MPhil/PhD Student
Professor Sheila Wirz, PhD
Dr. Rachael McDonald, PhD
Dr. Maya Thomas, PhD
*Centre for International Child Health, Institute of Child Health, 30 Guilford St., London WC1N 1EH
**Contact in Bangalore: g.kembhavi@ich.ucl.ac.uk

	Yes	No
Has the project been explained to you by someone?		
Have you been given the chance to ask questions about the study?		
Did someone answer all your questions about the study?		
Who explained the study to you?		
Do you understand that you can stop taking part in the study at any time, and there will be no penalty to you?		
Do you understand that the information we learn from this study might be published in international journals?		
Do you understand that the researchers might take pictures of you during the study?		
Do you understand that these pictures cannot be used without your permission?		

If you have any more questions or concerns about the study at any time, you can discuss these with Gayatri Kembhavi or Dr. Maya Thomas.

Full Name (printed): ....

Signature: ....

Date: ....

Appendix VII – Sample Interview Script

Participation by adolescents with disabilities in health, education and social
systems: experiences from south India

```
Agency:_____                    Group
Code:_____
Number of Participants:_____
Number of males/females:_____(m)_____(f)
```

- *Introduce self and project*
- *Discuss reasons for interview*
- *Goals and objectives*
- *Review confidentiality, recording, freedom to not answer*

1. Education

Let's start by talking about school/education. Please tell me about school/the training program you are in. (Probes: What are you training for? How long is the program? What did you do before you came here for this program?)

2. Social/Recreational/Hobbies

What do you like to do in your free time/ for fun? What hobbies do you have? (Probes: How much free time do you have during the week? How much free time do you have on weekends? Who do you spend your free time with? What kinds of things do you enjoy doing: sports/computer games/internet, movies, reading, activities in community, with family, religious activities, etc.)
Are there things you would like to be doing in your free time that you cannot?

3. Housing

Where are you living right now? (Probes: Do you live alone, with family or with other people? What chores/responsibilities do you have in your house – e.g. cooking, cleaning, etc.?

4. Employment/ Finances

Have you ever had a paying job? (What was it? If not, how do you look after your expenses?)

5. Future Aspirations

What are your goals after you finish this training program? Where would you like to work? What other goals do you have for the future? (Probes: housing, employment, career, family, etc.)

6. Other Information

Is there any other information that you think would be important for me to know to better understand the things that are important to you?

Appendix VIII – GMFCS – E&R

Gross Motor Function Classification System – Expanded and Revised

INTRODUCTION & USER INSTRUCTIONS

The Gross Motor Function Classification System (GMFCS) for cerebral palsy is based on self-initiated movement, with emphasis on sitting, transfers, and mobility. When defining a five-level classification system, our primary criterion has been that the distinctions between levels must be meaningful in daily life. Distinctions are based on functional limitations, the need for hand-held mobility devices (such as walkers, crutches, or canes) or wheeled mobility, and to a much lesser extent, quality of movement. The distinctions between Levels I and II are not as pronounced as the distinctions between the other levels, particularly for infants less than 2 years of age.

The expanded GMFCS (2007) includes an age band for youth 12 to 18 years of age and emphasizes the concepts inherent in the World Health Organization's International Classification of Functioning, Disability and Health (ICF). We encourage users to be aware of the impact that environmental and personal factors may have on what children and youth are observed or reported to do. The focus of the GMFCS is on determining which level best represents the child's or youth's present abilities and limitations in gross motor function. Emphasis is on usual performance in home, school, and community settings (i.e., what they do), rather than what they are known to be able to do at their best (capability). It is therefore important to classify current performance in gross motor function and not to include judgments about the quality of movement or prognosis for improvement.

The title for each level is the method of mobility that is most characteristic of performance after 6 years of age. The descriptions of functional abilities and limitations for each age band are broad and are not intended to describe all aspects of the function of individual children/youth. For example, an infant with hemiplegia who is unable to crawl on his or her hands and knees, but otherwise fits the description of Level I (i.e., can pull to stand and walk), would be classified in Level I. The scale is ordinal, with no intent that the distances between levels be considered equal or that children and youth with cerebral palsy are equally distributed across the five levels. A summary of the distinctions between each pair of levels is provided to assist in determining the level that most closely resembles a child's/youth's current gross motor function.

We recognize that the manifestations of gross motor function are dependent on age, especially during infancy and early childhood. For each level, separate descriptions are provided in several age bands. Children below age 2 should be considered at their corrected age if they were premature. The descriptions for the 6 to 12 year and 12 to18 year age bands reflect the potential impact of environment factors (e.g., distances in school and community) and personal factors (e.g., energy demands and social preferences) on methods of mobility.

An effort has been made to emphasize abilities rather than limitations. Thus, as a general principle, the gross motor function of children and youth who are able to perform the functions described in any particular level will probably be classified at or above that level of function; in contrast, the gross motor function of children and youth who cannot perform the functions of a particular level should be classified below that level of function.

OPERATIONAL DEFINITIONS

Body support walker – A mobility device that supports the pelvis and trunk. The child/youth is physically positioned in the walker by another person.

Hand-held mobility device – Canes, crutches, and anterior and posterior walkers that do not support the trunk during walking.

Physical assistance – Another person manually assists the child/youth to move.

Powered mobility – The child/youth actively controls the joystick or electrical switch that enables independent mobility. The mobility base may be a wheelchair, scooter or other type of powered mobility device.

Self-propels manual wheelchair – The child/youth actively uses arms and hands or feet to propel the wheels and move.

Transported – A person manually pushes a mobility device (e.g., wheelchair, stroller, or pram) to move the child/youth from one place to another.

Walks – Unless otherwise specified indicates no physical assistance from another person or any use of a hand-held mobility device. An orthosis (i.e., brace or splint) may be worn.

Wheeled mobility – Refers to any type of device with wheels that enables movement (e.g., stroller, manual wheelchair, or powered wheelchair).

GENERAL HEADINGS FOR EACH LEVEL

LEVEL I - Walks without Limitations
LEVEL II - Walks with Limitations
LEVEL III - Walks Using a Hand-Held Mobility Device
LEVEL IV - Self-Mobility with Limitations; May Use Powered Mobility
LEVEL V - Transported in a Manual Wheelchair

DISTINCTIONS BETWEEN LEVELS

Distinctions Between Levels I and II - Compared with children and youth in Level I, children and youth in Level II have limitations walking long distances and balancing; may need a hand-held mobility device when first learning to walk; may use wheeled mobility when traveling long distances outdoors and in the community; require the use of a railing to walk up and down stairs; and are not as capable of running and jumping.

Distinctions Between Levels II and III - Children and youth in Level II are capable of walking without a hand-held mobility device after age 4 (although they may choose to use one at times). Children and youth in Level III need a hand-held mobility device to walk indoors and use wheeled mobility outdoors and in the community.

Distinctions Between Levels III and IV - Children and youth in Level III sit on their own or require at most limited external support to sit, are more independent in standing transfers, and walk with a hand-held mobility device. Children and youth in Level IV function in sitting (usually supported) but self-mobility is limited. Children and youth in Level IV are more likely to be transported in a manual wheelchair or use powered mobility.

Distinctions Between Levels IV and V - Children and youth in Level V have severe limitations in head and trunk control and require extensive assisted technology and physical assistance. Self-mobility is achieved only if the child/youth can learn how to operate a powered wheelchair.

BEFORE 2ND BIRTHDAY

LEVEL I: Infants move in and out of sitting and floor sit with both hands free to manipulate objects. Infants crawl on hands and knees, pull to stand and take steps holding on to furniture. Infants walk between 18 months and 2 years of age without the need for any assistive mobility device.

LEVEL II: Infants maintain floor sitting but may need to use their hands for support to maintain balance. Infants creep on their stomach or crawl on hands and knees. Infants may pull to stand and take steps holding on to furniture.

LEVEL III: Infants maintain floor sitting when the low back is supported. Infants roll and creep forward on their stomachs.

LEVEL IV: Infants have head control but trunk support is required for floor sitting. Infants can roll to supine and may roll prone.

LEVEL V: Physical impairments limit voluntary control of movement. Infants are unable to maintain antigravity head and trunk postures in prone and sitting. Infants require adult assistance to roll.

BETWEEN 2ND AND 4TH BIRTHDAY

LEVEL I: Children floor sit with both hands free to manipulate objects. Movements in and out of floor sitting and standing are performed without adult assistance. Children walk as the preferred method of mobility without the need for any assistive mobility device.

LEVEL II: Children floor sit but may have difficulty with balance when both hands are free to manipulate objects. Movements in and out of sitting are performed without adult assistance. Children pull to stand on a stable surface. Children crawl on hands and knees with a reciprocal pattern, cruise holding onto furniture and walk using an assistive mobility device as preferred methods of mobility.

LEVEL III: Children maintain floor sitting often by "W-sitting" (sitting between flexed and internally rotated hips and knees) and may require adult assistance to assume sitting. Children creep on their stomach or crawl on hands and knees (often without reciprocal leg movements) as their primary methods of self-mobility. Children may pull to stand on a stable surface and cruise short distances. Children may walk short distances indoors using a hand-held mobility device (walker) and adult assistance for steering and turning.

LEVEL IV: Children floor sit when placed, but are unable to maintain alignment and balance without use of their hands for support. Children frequently require adaptive equipment for sitting and standing. Self-mobility for short distances (within a room) is achieved through rolling, creeping on stomach, or crawling on hands and knees without reciprocal leg movement.

LEVEL V: Physical impairments restrict voluntary control of movement and the ability to maintain antigravity head and trunk postures. All areas of motor function are limited. Functional limitations in sitting and standing are not fully compensated for through the use of adaptive equipment and assistive technology. At Level V, children have no means of independent movement and are transported. Some children achieve self-mobility using a powered wheelchair with extensive adaptations.

BETWEEN 4TH AND 6TH BIRTHDAY

LEVEL I: Children get into and out of, and sit in, a chair without the need for hand support. Children move from the floor and from chair sitting to standing without the need for objects for support. Children walk indoors and outdoors, and climb stairs. Emerging ability to run and jump.

LEVEL II: Children sit in a chair with both hands free to manipulate objects. Children move from the floor to standing and from chair sitting to standing but often require a stable surface to push or pull up on with their arms. Children walk without the need for a handheld mobility device indoors and for short distances on level surfaces outdoors. Children climb stairs holding onto a railing but are unable to run or jump.

LEVEL III: Children sit on a regular chair but may require pelvic or trunk support to maximize hand function. Children move in and out of chair sitting using a stable surface to push on or pull up with their arms. Children walk with a hand-held mobility device on level surfaces and climb stairs with assistance from an adult. Children frequently are transported when traveling for long distances or outdoors on uneven terrain.

LEVEL IV: Children sit on a chair but need adaptive seating for trunk control and to maximize hand function. Children move in and out of chair sitting with assistance from an adult or a stable surface to push or pull up on with their arms. Children may at best walk short distances with a walker and adult supervision but have difficulty turning and maintaining balance on uneven surfaces. Children are transported in the community. Children may achieve self-mobility using a powered wheelchair.

LEVEL V: Physical impairments restrict voluntary control of movement and the ability to maintain antigravity head and trunk postures. All areas of motor function are limited. Functional limitations in sitting and standing are not fully compensated for through the use of adaptive equipment and assistive technology. At Level V, children have no means of independent movement and are transported. Some children achieve self-mobility using a powered wheelchair with extensive adaptations.

BETWEEN 6TH AND 12TH BIRTHDAY

Level I: Children walk at home, school, outdoors, and in the community. Children are able to walk up and down curbs without physical assistance and stairs without the use of a railing. Children perform gross motor skills such as running and jumping but speed, balance, and coordination are limited. Children may participate in physical activities and sports depending on personal choices and environmental factors.

Level II: Children walk in most settings. Children may experience difficulty walking long distances and balancing on uneven terrain, inclines, in crowded areas, confined spaces or when carrying objects. Children walk up and down stairs holding onto a railing or with physical assistance if there is no railing. Outdoors and in the community, children may walk with physical assistance, a hand-held mobility device, or use wheeled mobility when traveling long distances. Children have at best only minimal ability to perform gross motor skills such as running and jumping. Limitations in performance of gross motor skills may necessitate adaptations to enable participation in physical activities and sports.

Level III: Children walk using a hand-held mobility device in most indoor settings. When seated, children may require a seat belt for pelvic alignment and balance. Sit-to-stand and floor-to-stand transfers require physical assistance of a person or support surface. When traveling long distances, children use some form of wheeled mobility. Children may walk up and down stairs holding onto a railing with supervision or physical assistance. Limitations in walking may necessitate adaptations to enable participation in physical activities and sports including self-propelling a manual wheelchair or powered mobility.

Level IV: Children use methods of mobility that require physical assistance or powered mobility in most settings. Children require adaptive seating for trunk and pelvic control and physical assistance for most transfers. At home, children use floor mobility (roll, creep, or crawl), walk short distances with physical assistance, or use powered mobility. When positioned, children may use a body support walker at home or school. At school, outdoors, and in the community, children are transported in a manual wheelchair or use powered mobility. Limitations in mobility necessitate adaptations to enable participation in physical activities and sports, including physical assistance and/or powered mobility.

Level V: Children are transported in a manual wheelchair in all settings. Children are limited in their ability to maintain antigravity head and trunk postures and control arm and leg movements. Assistive technology is used to improve head alignment, seating, standing, and and/or mobility but limitations are not fully compensated by equipment. Transfers require complete physical assistance of an adult. At home, children may move short distances on the floor or may be

carried by an adult. Children may achieve self-mobility using powered mobility with extensive adaptations for seating and control access. Limitations in mobility necessitate adaptations to enable participation in physical activities and sports including physical assistance and using powered mobility.

BETWEEN 12TH AND 18TH BIRTHDAY

Level I: Youth walk at home, school, outdoors, and in the community. Youth are able to walk up and down curbs without physical assistance and stairs without the use of a railing. Youth perform gross motor skills such as running and jumping but speed, balance, and coordination are limited. Youth may participate in physical activities and sports depending on personal choices and environmental factors.

Level II: Youth walk in most settings. Environmental factors (such as uneven terrain, inclines, long distances, time demands, weather, and peer acceptability) and personal preference influence mobility choices. At school or work, youth may walk using a handheld mobility device for safety. Outdoors and in the community, youth may use wheeled mobility when traveling long distances. Youth walk up and down stairs holding a railing or with physical assistance if there is no railing. Limitations in performance of gross motor skills may necessitate adaptations to enable participation in physical activities and sports.

Level III: Youth are capable of walking using a hand-held mobility device. Compared to individuals in other levels, youth in Level III demonstrate more variability in methods of mobility depending on physical ability and environmental and personal factors. When seated, youth may require a seat belt for pelvic alignment and balance. Sit-to-stand and floor-to-stand transfers require physical assistance from a person or support surface. At school, youth may self-propel a manual wheelchair or use powered mobility. Outdoors and in the community, youth are transported in a wheelchair or use powered mobility. Youth may walk up and down stairs holding onto a railing with supervision or physical assistance. Limitations in walking may necessitate adaptations to enable participation in physical activities and sports including self-propelling a manual wheelchair or powered mobility.

Level IV: Youth use wheeled mobility in most settings. Youth require adaptive seating for pelvic and trunk control. Physical assistance from 1 or 2 persons is required for transfers. Youth may support weight with their legs to assist with standing transfers. Indoors, youth may walk short distances with physical assistance, use wheeled mobility, or, when positioned, use a body support walker. Youth are physically capable of operating a powered wheelchair. When a powered wheelchair is not feasible or available, youth are transported in a manual wheelchair. Limitations in mobility necessitate adaptations to enable participation in physical activities and sports, including physical assistance and/or powered mobility.

Level V: Youth are transported in a manual wheelchair in all settings. Youth are limited in their ability to maintain antigravity head and trunk postures and control arm and leg movements. Assistive technology is used to improve head alignment, seating, standing, and mobility but limitations are not fully compensated by equipment. Physical assistance from 1 or 2 persons or a mechanical lift is required for transfers. Youth may achieve self-mobility using powered mobility with extensive adaptations for seating and control access. Limitations in mobility necessitate adaptations to enable participation in physical activities and sports including physical assistance and using powered mobility.

Appendix IX – Sample of Photographs Taken by AWD

Things that make me happy

Innovations for the disabled

Friends

Things that make me sad

Poor road conditions

Lack of a good kitchen

Things that make me frustrated/angry

Water being wasted

Inaccessible roads

Things that I want to change/make different

Dirty living environment

Stairs into the house

Appendix X – Sample interview transcript

The following appendix provides a sample interview script. Where appropriate, all names have been changed to maintain confidentiality. In cases where more than one participant responded to the same question, or spoke at the same time, participants have been designated with numbers (e.g. 1, 2, etc). The numerical designation was not consistently allocated to the same participant throughout the interview, and merely indicates multiple responses.

> **Interview: SYDGI**
> **Date: April 5, 2007**
> **Facilitator: Gayatri**
> *Names have been changed to maintain confidentiality*

GK: Okay, so, first question is, what year of school are you all in?

Participant: We are studying in 12th year.

GK: Which year? Are you all doing 12th?

Participant: Right now we're in 12th.

GK: All of you?

Participant: Yeah.

GK: And then after 12th, what happens?   I don't know the school system here so that's why I'm asking you.

Participant: Basically we are doing the Open School system. So we're taking it for 2 years. Five years is the maximum.

GK: Okay.

Participant: *More description of how the Open School system works.* Three of us are completing 12th, and two of them are in first year.

GK: Okay, so which two are in first year?

Participant: *Participants indicate themselves.*

GK: So you two. And the three of you are in the second of 2 years?

Participant: Yeah.

GK: So what are you going to do when you finish then?

Participant: I've also done my animation course.

GK: Oh wow! Where?

Participant: *Unclear – mentions name of company.* So I'm getting a job.

GK: Oh, you're going to start working?! We have a working man amongst us!

Participant: *Laughter*

GK: Okay, who else? What are you going to do?

Participant: Trying to get a job. And if I don't get a job, then I'll go for more qualifications.

GK: And what about you?

Participant: I'm in first year. So one more year I have left.

GK: And then?

Participant: And then I'll go for more studies**.**

GK: You're going to study more? What do you want to study?

Participant: BCom or MBA.

GK: Okay, wow…and what about you?

Participant: I'd like to be a *unclear*.

GK: Like your own business?

Participant: Yes.

GK: Okay, so you want to be an animator, that's what you are going to do. And you want to get a BCom or MBA, and you want to some kind of business, something….And what kind of job are you looking for?

Participant: After, I plan to do *unclear*.

GK: Ah, okay. So *unclear…?navy?* And you, what kind of job do you want?

Participant: I think a computer job.

GK: A computer job, okay. And you?

Participant: I haven't decided yet.

GK: Okay. So when you're not studying, what kind of things do you do in your free time?

Participant 1: See TV.

Participant 2: Read books.

Participant 3: Read the newspaper.

GK: Anything else?

Participant: Play games.

GK: What kind of games?

Participant: Caram board, chess, etc.

GK: Etcetera, etcetera…

Participant: *Laughter*. Going out, roaming around…

GK: But it's too hot to roam! How do you roam right now?

Participant: *Laughter*. Right now we don't roam. After April!

GK: Ah! So what else do you do in your free time? What kinds of things do you do at home with your family?

Participant: Do jobs. *General discussion.*

GK: Do you do anything special with your family?

Participant: *General discussion but no answers given.*

GK: Okay, how many of you have brothers and sisters?

Participant: *Indicate by show of hands.*

GK: So all of you except you? So you're an only child? So are all of your brothers and sisters younger or older than you?

Participant 1: Older.

Participant 2: Younger.

Participant 3: I have one elder and 2 younger.

Participant 4: I have 2 elder and 2 younger.

GK: Okay, so do you do anything with your brothers and sisters?

Participant: Play games.

GK: Are they all living at home?

Participant: *Nods.*

GK: And you?

Participant: He has a dog, also.

GK: He has a dog, and some brothers and sisters? Some people like their pets better than their brothers and sisters.

Participant: *Laughter*

GK: So do you do anything with your brothers and sisters?

Participant: We go out.

GK: Go out and…?

Participant: Play games. We play a lot.

GK: Yeah? And you?

Participant: Play games and go out.

GK: So do you get along with your brothers and sisters?

Participant: Yes

Others nod their heads. One Participant doesn't say or do anything.

GK: I don't think you do!

Participant: No. We play some games. *Unclear*

GK: So everyone does their own things?

Participant: Yeah.

GK: So what responsibilities do you have in your house?

Participant: None.

Some unclear talking and laughing.

GK: Sandeep has none, so he goes home and does nothing…

Participant: *Laughter.*

GK: So what about you? Do you have any jobs you do in the house?

Participant: Nowadays, just studying.

GK: But anything your parents say you should do?

Participant: No.

GK: Do they ask you to clean anything, or look after anything?

Participant: *Shakes his head*

GK: No? Nothing?! How about you?

Participant: Nothing.

GK: Nothing?! Lucky all of you!

Participant: No. They say, first, do your own work.

GK: Ah, okay, so your primary job is to study and do well?

Participant: Yes.

GK: And what about you? No jobs?

Participant: Sweeping.

GK: And what about you?

Participant: No jobs. Studying.

GK: Hmm…how many of you have sisters?

Participant: *Indicate by show of hands.*

GK: So do your sisters have jobs around the house?

Participant: *General discussion, some nods.*

GK: So do you think you don't have to do jobs because you're boys, or…?

Participant: No, it's not like that.

GK: No?

Participant: I'm not allowed to do what my sisters do.

GK: No? What do your sisters do?

Participant: Cooking.

GK: And they won't let you cook, or you don't know HOW to cook?

Participant: I don't know how.

GK: Ah, okay. So they probably think there's no point asking you to do it then.

Participant: No.

GK: Okay, so what kinds of things make you frustrated or angry in life?

Participant 1: Nothing.

Participant 2: My mother.

GK: Your mother? Why does your mother make you angry?

Participant: She doesn't let me buy anything from the shop. If my father allows me to buy anything also, my mother says, 'No, first you can stay here, then only you can buy.'

GK: So first you have to study…

Participant 1: Yeah.

Participant 2: If he studies nicely, then only she'll let him buy things.

GK: Oh.

Participant: But my father, my father lets me do…

GK: He lets you buy things?

Participant: Yeah. If I go out with my father, there are a lot of things he lets me buy, but if I go out with both parents, then I can't buy things.

GK: Because my mother will say 'No.'

Participant: Yes.

GK: So your mother makes you frustrated?

Participant: Yeah.

GK: And what about you? What makes you frustrated?

Participant: I never get frustrated.

GK: You never get frustrated? Or angry?

Participant: Because I stay calm.

GK: But do you feel it inside? When you get frustrated?

Participant: No.

GK: No? Okay, Sandeep? Well, you always look happy, so nothing must make you frustrated!

Participant: No!

GK: Okay, your turn…

Participant: Nothing.

GK: Nothing? So you're calm, happy all the time?

Participant: Yes.

GK: I don't know if I believe you! But I will!

Participant: *Laughter*.

GK: Okay, how about you?

Participant: Nothing. *Laughs*

GK: So nothing makes you frustrated? Not even when you can't go somewhere, or do something?

Participant: Yeah, that does. *Rest of comments cannot be heard because Participant is laughing*.

GK: Oh so now we're getting somewhere! Sandeep, what makes you frustrated?

Participant: *More laughter from all Participants and no response to question.*

GK: Okay, let me give you an example. I get frustrated when I'm trying to walk down the footpath, and all of a sudden there's a huge hole and if I weren't looking down, I'd fall into that hole. So I get frustrated because I have to walk slowly and look down all the time, and I almost get run over by autos because I'm too busy looking down at the hole so I don't see them. So those kinds of things make me frustrated. Does anything like that make you frustrated?

Participant 1: *General comments, no specific answers…walking…*

Participant 2: I don't get frustrated.

Participant 3: I also don't get frustrated.

Participant 4: And one more thing, ma'am.

GK: Yes?

Participant: If I go out, my mother will always say, 'Don't eat this. Don't do that. Don't do that.' Everything. My mother stops me from doing everything.

GK: Ah…so your mother would be happiest if you stayed in the house?

Participant: Yeah.

GK: That would be frustrating.

Participant: Stay in the house and always study.

GK: Well, now you have holidays coming up for 2 months, right?

Participant: We get frustrated when power goes off.

GK: Yes!

Participant 1: No TV, no tapes.

Participant 2: No television, no tape recorders.

GK: Okay, so that's a good thing that would make you frustrated. What do you wish could be made different? About anything around you. What would you change, if you could? If you could change anything at all, what would you change? You can change other people, you can change the environment, you can change...anything.

Participant: I would change our accessibility.

GK: Accessibility? Okay, tell me more about that.

Participant: Like public places, theatres, shops. Make them easier for us to go.

GK: Okay, so accessibility is a big one?

Participant: I would make a path for wheelchairs.

GK: One the street?

Participant: One the road. On the side, just for wheelchairs.

GK: Yeah, that's a great idea. They have that in some countries. They have a separate path for bicycles and other things.

Participant: They have that here, for walking.

GK: I don't know what you're talking about!

Participant: (*In agreement*) There's no place to walk, also!

GK: I almost got run over by a scooter on the sidewalk...on the footpath, which is supposed to be for people.

One Participant steps out to speak to a teacher.

Okay, so you want to improve accessibility? Do you find that to be a big problem?

Participant: Also the behaviour of people.

GK: How so?

Participant: Because they try to prevent us from doing things...they don't help.

GK: They don't?

Participant: Some do, but not all.

GK: So have you encountered some people who...

Participant: Some people overhelp.

GK: Overhelp?

Participant: Yeah...

GK: Like how?

Participant: Like...uh...they'll be told that we can walk, but they'll lift us anyway.

GK: Hmm...okay, so they do TOO much for you.

Participant 1: And one more thing –

Participant 2: Too much helping!

Participant 3: If we go there in the shop, they'll just look at our wheelchair, and say, 'Oh, see how he doesn't walk.' And we can, but they'll just think like this.

GK: Hmm…because they think you have a disability so you must have a chair.

Participant: Yeah.

GK: How about you? Have you had any experiences?

Participant: Yes, I have. One man, he thought I just couldn't talk…

GK: So the problem is sometimes that people help too much…

Participant 1: Yeah, they should understand how much to help.

Participant 2: They're all doing it the wrong way.

GK: So it should be down the middle somewhere, right?

Participant: Yeah.

GK: Anything else that they should be considering?

Participant 1: And one more thing - if we go in the auto (*rickshaw*), and he wants to put gas, and the driver will have to wait in the line for the gas. So he says 'See how he cannot walk', and tells like this so he can move the auto to the front.

Participant 2: They have to bring the tube for the gas. So they use him to move in front.

GK: So they use you as a reason to go to the front of the line.

Participant: Yeah.

GK: So how do you feel about that?

Participant 1: It's frustrating.

Participant 2: That is wrong.

GK: It is wrong…

Participant: Yeah, and one more thing…

GK: Yes?

Participant: If we are in the auto, and there is a lot of traffic, the autorickshaw will just turn in the middle of the road and go.

GK: Oh, so they'll break the rules if you're in the auto?

Participant: Yeah, and the traffic police, if they stop him, the auto driver says, 'Look, I have a cripple.' And then he says to me, 'Go walk and show him' and I have to get out of the auto and I have to walk to show the police that I cannot walk.

GK: So he makes you get out of the auto to show the police that you can't walk?

Participant: Yeah…

GK: That's…that's not right!

Participant 1: No…

Participant 2: And that makes us frustrated.

Participant 3: And if person don't know also, they show and say, 'this person is disabled.'

GK: So what other things…what else have you experienced about other people's attitudes being a problem for you?

Participant 1: I don't know how many other people know, about being disabled. My friends know…

Participant 2: See, they don't really know what disability is, really. To them, a disabled person means, he can't do anything. That's the attitude.

Participant 3: One more thing – if a normal person walks, no one will see. But if a disabled person walks, then everybody sees and look.

Participant 4: And wonder…

GK: Yeah – so what were you saying?

Participant: If there's anything wrong in a person, they'll show a hand and laugh at that person.

GK: So do you think that's the biggest problem for you? The way other people think and act?

Participant: Yeah…more than anything.

GK: So how do you think you can change that?

Participant: How…?

GK: If somebody says, 'Oh, you're disabled, you're in a wheelchair, what can you do?' then what do you say to them? Do you say something, or do you just stay quiet?

Participant: I just let it go.

GK: Yeah? What about you?

Participant: I give them an example. I show them.

GK: Well, that's a good way – to just do what you want to do and prove to them…

Participant 1: That's more interactive.

Participant 2: But they will not see it, no?

Participant 3: Like other schools – students from other schools. They try to interact. Like last year, last school year, different schools were coming, doing activities in our school. There were lots of them.

GK: Do you think that helped?

Participant 1: Yes.

Participant 2: Some students it didn't help.

Participant 3: Right now it might not help, but as they grow up, they'll think differently.

Participant 4: Some of them, they won't come afterwards, when we say hello to them.

GK: But maybe you have to make that change in small steps, right?

Participant: Yeah.

GK: If you can change the attitude of two or three people, then you've done a good job. But you can't expect to change the attitude of everybody...

Participant: No, it takes time.

GK: So if you had to give advice to someone who was younger who was disabled, like say a 7 or 8 year old child, what would you tell them? From your experience, now that you're older and have done more things?

Participant 1: The first is not to see disability without ability. To see ability and get focused on that.

Participant 2: They should see what they can do, what skills they have...and use them.

GK: Use those skills...okay...do you have any advice?

Participant: I don't know.

GK: So if someone younger came up to you and said, 'You look like you're doing well in life, what should I do to be like you?', what would you say?

Participant: I don't know...

GK: How about you?

Participant: If two boys are same age, and one is not disabled. But he's having some problem inside, like heart attack, or something like that, that will not be shown outside. But they have more problems than us. For them, no one will see. They will only put medicine and they will live their life. But for us, everyone will see. But that's not a big problem for us.

GK: So people think that because they can see your disability, that you have a bigger problem that for the people who you cannot see their...health problem. So they assume you can do less than you can, just because you *look* like you can do less.

Participant: Yes. And on the street, they will stare at us and laugh and say things.

GK: Because they can see?

Participant: Yes.

GK: So what do you say to them, people your own age who say things, who laugh...?

Participant: Not our friends!

GK: No, no...not your friends, but other people, outside. Do you say something to them?

Participant: We just ignore it.

GK: Yeah? But how do you feel, then, when they...

Comment and laughter from a Participant – difficult to hear.

Participant: They're bad people...

GK: Yes...

Participant: If our parents are also with us, no, then they'll advise – go and do some operation, this, that, go do this, this...if they do that, we also have more problems. I had an operation, so what? The problem stayed.

GK: Was it your parents' friends who recommended that you go?

Participant: No, no...

GK: Somebody else?

Participant: Yeah. They said, plenty of people were alright, so you also go and do it. So my dad took me. And he has done a good job, but it has failed.

GK: But part of that is that people think you can be cured, right? That you have something that can be fixed. But if you're happy with the way you are, and you're able to do the things that you want to, then other people should accept that, and be happy.

Participant: Yeah, but even the government says that...what to do?

GK: But don't you find that most people think they know what's best for you, compared to what you know?

Participant: Yes. And no one can be 100% perfect.

GK: That's right! No one can be perfect.

Participant 1: How can they say what to improve? They can't make out...

Participant 2: The other problem is that there are a lot of bad people who say these things...

GK: There are a lot of bad people in this world...

Okay, so if you could have one thing for yourself, what would you want? If you could have any one thing for yourself.

Participant: One thing?

GK: Yeah, I'm limiting you to one thing. If I gave you an unlimited supply of money, what would you get? Or it could be something that doesn't need money, what would you want?

Participant: Hmm...nothing.

GK: You don't want anything?

Participant: I want to be able to read people's minds.

GK: Oh, that might be a scary thing to have!

Participant: There should be a law to build ramps. There's a problem with not enough ramps.

GK: But you know, there actually is a rule in India that all buildings have to be accessible. So the problem isn't that there isn't a law, the problem is that nobody enforces it, right?

Participant 1: Yeah...*rest is unclear*

Participant 2: Some people are there...they blame God for everything. But they are thinking bad about God. God gave us our abilities also. Not only the disability.

GK: Yes...

Participant: I have one more thing, ma'am. In the private buses, there are 2 seats for the disabled, no more. And if we sit there, they say, that's the girls' space, go to the back.

GK: What?!

Participant 1: In those buses, no, there's only 2 seats for disabled. But if we go there, the conductor will say, go to the back.

Participant 2: He'll say, they're for girls, not for boys.

GK: So it doesn't matter if those seats are reserved for people with disabilities, you still have to go to the back?

Participant 1: Yeah

Participant 2: And there's only two seats, so if there are already people there, then we have to go somewhere else.

GK: So that's it? So there's only 2 seats, and if there are already 2 people with disabilities on the bus, then your bad luck, you have to go to the back.

Participant: No, no...normal people will be sitting there.

GK: But they won't make them get up?

Participant 1: No.

Participant 2: And if disabled boys get on, then they just send them to the back of the bus.

GK: So the problem is that you're not girls, not that you have a disability.

Participant: Yeah! Actually, the first section should be for people with disabilities, not for girls. Then we wouldn't have to go to the back.

GK: So they haven't quite thought about that...

Participant 1: No, they need to think about that.

Participant 2: The private bus people need to do something about this.

GK: If you had to give some advice to places like *name of institution deleted*, what kinds of things would you suggest that they...what *more* things could you suggest that they do for people who have disabilities like you? What other programs would be helpful, what other skills would you like to learn?

Participant 1: I think *name of institution deleted* is doing great – they're going beyond as well.

Participant 2: Yeah.

GK: Yeah? So you're all very happy?

 Participant: *Unclear positive comments about the buildings at SSK.*

GK: So you're all very happy with what they're offering here?

Participant 1: We are all able to do everything to our maximum abilities here.

Participant 2: We can't complain about anything.

GK: That's good then! So is there anything else you think people should know about young people who are disabled in India? This is your chance to express your opinions and feelings!

Participant: All parents should accept them, and send to the school.

GK: So you think there's a lot more children who could be coming here, but they're not here.

Participant 1: Yeah, because their parents aren't accepting them.

Participant 2: After they accept the child at home, then they must send the child to the school. Then they can learn to cope.

GK: Do you all feel that you are involved with your families, that you participate fully with your families?

Participant 1: Yes.

Participant 2: Yeah! That is why we are all participating now!

GK: How about in everyday life? Do you feel that you can do whatever you want to do?

Participant 1: Yes.

Participant 2: Sometimes I feel I cannot. Not exactly what I want to do. Like, I want to play football, and I cannot.

GK: So playing football is one thing. Is there anything else you want to do?

Participant 1: Standing with others and chatting with them.

Participant 2: Satisfy my parents.

GK: You want to satisfy your parents. Okay…I don't think anyone's parents are fully satisfied!

Participant: Yeah. *Laughs.*

GK: So do you all feel that generally you and your parents agree with what you want to do with your lives?

Participant: No, they always say, 'What you want, you do.'

GK: So your parents are all very supportive, and if you say, 'This is what I want' then they'll help you?

Participant: Yeah. *General agreement from all Participants.*

General conversation – Participants joking with each other and trying to get one of the group members to say something, but he refuses to…laughter.

GK: Is there any other message you'd like to give?

Participant: We cannot participate in all the games. With the others. Like basketball, and things.

GK: Do you think there should be more opportunities for you to play games? Like at school, should there be more games, like adapted sports or something?

Participant: There are no games at school.

GK: This school has no games?

Participant: No games.

GK: Maybe they should do something about that.

Participant: They won't do it for us…we're leaving! *Laughter.*

GK: You should start some special boys' teams or something. Or you can come back and be coaches.

Participant 1: One more thing…those who are physically handicapped, they can see that. But those who are mentally handicapped, they cannot see that. So they said, you come support…government should give support for mentally handicapped also.

Participant 2: The government gives support for all people. But awareness should be there also.

GK: I think that's the thing I'm hearing from all of you, is awareness, or lack of awareness is the big problem. Amongst people at all levels…people in the government, everyday people, people outside. Have any of you experienced a situation where somebody has said 'Don't do this because you're disabled.'?

Participant: Yeah, I have. I just go against them.

GK: You go against them? And you just go ahead and do it?

Participant: Yeah.

GK: Okay, so give me an example of when that happened.

Participant: The told me first not to lift anything. So okay, I just did it anyway.

GK: You did that to show them that you could do it?

Participant: Yeah.

GK: And what about you?

Participant: I was crossing the road. And then, someone caught my hand. And I said, 'I don't need help.' And I went and crossed on my own.

GK: So he thought you needed help to cross the road, and you went and did it on your own. That's what you were saying before, right? People who don't know you can walk so they just carry you.

Participant: Yeah.

GK: I don't know if this happened to you, but it happened to some other people I know – people who could push their own wheelchairs, but this person just started pushing them anyway.

Participant: This is embarrassing to us, when others overhelp.

GK: Because it makes you feel completely unable to do anything?

Participant 1: Yeah. It makes me feel like I cannot do anything.

Participant 2: But it will be uncomfortable for others, that's what they say. To see us…

Participant 3: Some schools will not let you go there…some schools.

GK: Actually, somebody else here, one of the younger students told me that he tried to go to another school, his local school, and they looked at him and said no.

Participant: Yeah. Some schools, not all of them.

GK: Has that happened to any of you?

Participant 1: Yeah. It happened to me. In Hyderabad. They said to my parents, 'Like him, people cannot go to this school.' Why this happened?

Participant 2: In my school, they just ignored me in the back of the room.

Participant 3: Yeah, in my school too...they just left me in the corner.

General discussion with all Participants sharing similar experiences of being ignored in the classroom.

GK: So they just ignored you. Teachers or other students?

Participant 1: Both.

Participant 2: For me, the other students. The teachers were okay.

Participant 3: The teachers wouldn't ask any questions. Even if I knew the answers, they wouldn't ask me anything.

More discussion about how they were rarely included in class discussions, even if they knew the answers to questions the teachers would never call them for the responses, etc.

GK: Do you have any other goals in life, besides your jobs? Anything else you want?

Participant 1: I want my diploma.

Participant 2: Me too.

Participant 3: I'd like to create a character with animation, that maybe is in a movie. Just one character.

End of Interview. Discussion about the school production of the Lion King. One of the Participants was the Lion in the Lion King. Other Participants discussing his role, and the play in general.

Field Note:
This interview was done with a group of students who were not part of the initial camera task as they were recruited quite late in the study. At one point in the interview, 4 or 5 of the Participants were teasing one of the other Participants about something which he refused to talk about. I think it may have been about a girl, but I didn't force the issue – his reaction suggested that it wasn't something he felt comfortable discussing. I wonder if this was because of my gender or because boy-girl relationships aren't openly discussed. A cultural issue? This may have nothing to do with disability, but with their age, and the cultural norms.

Appendix XI – Sample interview transcript with coding

This appendix provides a sample of the coding stripes in NVivo for the sample interview provided in Appendix X. Coding stripes refer to the themes and sub-themes of passages of text, and are a visual illustration of themes and the way in which themes overlap. The examples provided herein are screen snapshots from NVivo of a selection of passages. Not all themes are illustrated, and the entire interview has not been included.
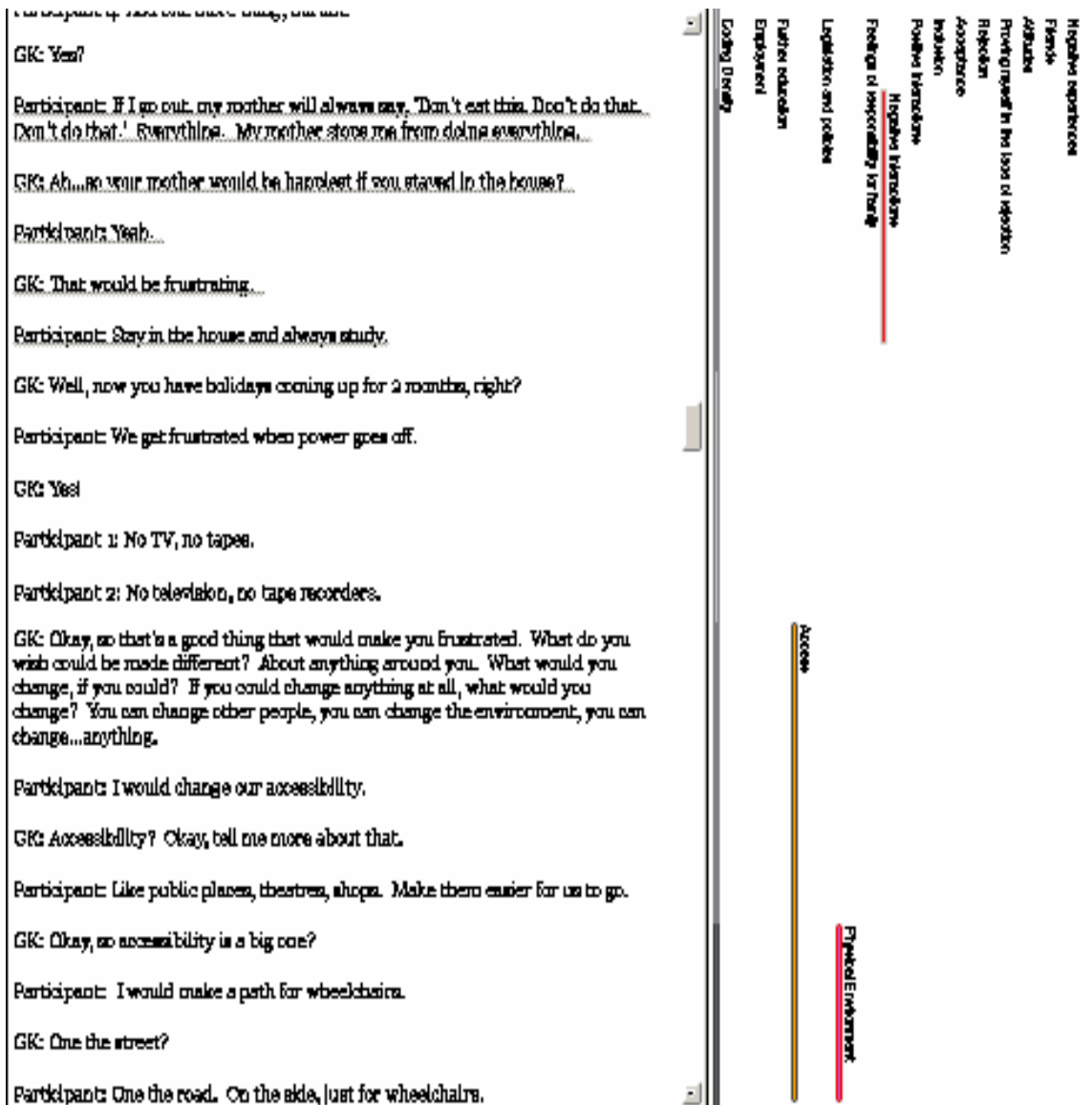
Figure 22. Coding stripes for sample interview – screen capture 1

Participant 1: Yeah...rest is unclear

Participant 2: Some people are there...they blame God for everything. But they are thinking bad about God. God gave us our abilities also. Not only the disability.

GK: Yes...

Participant: I have one more thing, ma'am. In the private busses, there are 2 seats for the disabled, no more. And if we sit there, they say, that's the girls' space, go to the back.

GK: What?!

Participant 1: In those buses, no, there's only 2 seats for disabled. But if we go there, the conductor will say, go to the back.

Participant 2: He'll say, they're for girls, not for boys.

GK: So it doesn't matter if those seats are reserved for people with disabilities, you still have to go to the back?

Participant 1: Yeah

Participant 2: And there's only two seats, so if there are already people there, then we have to go somewhere else.

GK: So that's it? So there's only 2 seats, and if there are already 2 people with disabilities on the bus, then your bad luck, you have to go to the back.

Participant: No, no...normal people will be sitting there.

GK: But they won't make them get up?

Participant 1: No.

Participant 2: And if disabled boys get on, then they just send them to the back of the bus.

GK: So the problem is that you're not girls, not that you have a disability.

Participant: Yeah! Actually, the first section should be for people with disabilities, not for girls. Then we wouldn't have to go to the back.

Figure 23. Screen capture 2

... Do you're all very happy with what they're doing here?

Participant 1: We are all able to do everything to our maximum abilities here.

Participant 2: We can't complain about anything.

GK: That's good then! So is there anything else you think people should know about young people who are dis[...]

[...]

[...]

[...]

[...] then they must send the child to the school. Then they can learn to cope.

GK: Do you all feel that you are involved with your families, that you participate fully with your families?

Participant 1: Yes.

Participant 2: Yeah! That is why we are all participating now!

GK: How about in everyday life? Do you feel that you can do whatever you want to do?

Participant 1: Yes.

Participant 2: Sometimes I feel I cannot. Not exactly what I want to do. Like, I want to play football, and I cannot.

GK: So playing football is one thing. Is there anything else you want to do?

Participant 1: Standing with others and chatting with them.

Participant 2: Satisfy my parents.

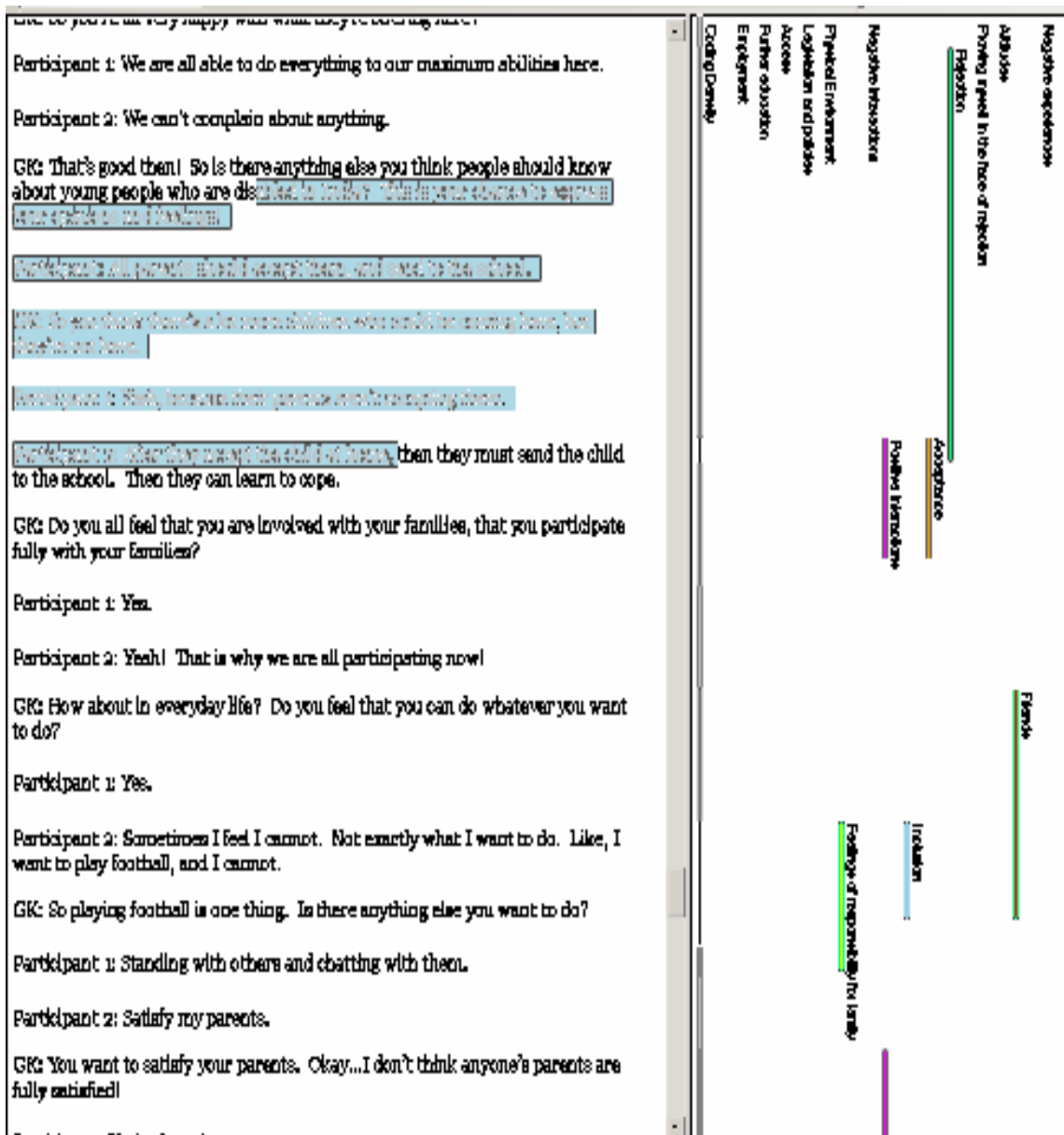GK: You want to satisfy your parents. Okay...I don't think anyone's parents are fully satisfied!

Figure 24. Screen capture 3

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