Enabling Healthier Living through Group Empowerment:
A Critical Ethnographic Study of
Adolescents with Disabilities in the Urban Slums of North India

by

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Abstract

Given the importance placed on participation and empowerment in global health initiatives, the perspective of young people with disabilities has emerged as a vital field of study. This critical ethnographic study gained insight into the perspectives of adolescents with disabilities aged 12 to 18 years who were affiliated with a community-based rehabilitation program in the urban slums of North India. The purpose of this research was to highlight the collective voices of adolescents with disabilities about their rehabilitation challenges, to explore how the culture influenced the rehabilitation challenges faced by adolescents, and to support collaborative work among adolescents with and without disabilities that would inform organizational activities. Fieldwork was conducted from January to May 2005 and October 2006 to March 2007 with 21 adolescents with disabilities, 11 adolescents without disability, and 10 community-based rehabilitation team members. Multiple data collection methods were utilized to ensure that participants could comfortably express their views.

A conceptual framework called the ‘Adolescent Group Empowerment Pyramid’ was developed that illustrates one process for empowering adolescents with disabilities and their peers without disabilities within a community setting. Group empowerment involves adolescents with disabilities working towards assuming greater ownership over their rehabilitation while collaborating with their peers. The ‘group’ concept provided the foundation for the framework because adolescents viewed the group setting as enjoyable and effective. Three areas associated with meaningful group empowerment included: group participation, group demonstration, and group recognition. Three external support factors and ten areas for nurturing the group empowerment process are
also described.

Participants promoted a more liberal approach to empowering adolescents that embraced the notion of collaboration (rather than competition), interdependence (rather than independence), shared benefits (rather than individual gain), and the interaction of community groups. This approach promotes a harmonious balance between empowerment and the community, rather than an aggressive approach to gaining power over or from other marginalized individuals. Group empowerment, achieved through enabling group-centered occupations, encourages adolescents to collectively work for social and occupational justice. To ensure the sustainability of community-based rehabilitation initiatives, programs must be aware of personally meaningful factors that empower and maintain the interest of the target population.
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I dedicate this thesis to ASTHA and all those participants who openly welcomed me into their lives, homes and hearts. I will never forget all the stories, laughs and tears that we shared. I hope that I was able to represent your voices well. Your commitment to this study was truly commendable. I hope that you continue to work with your peers in order to capitalize on the supports and resources that are available in your community. You made me realize that regardless of how different our lives may appear, we all share the basic essence of being human. Thank you for embarking on this wonderful journey with me.

It is hard to believe that after several years of preparation and fieldwork, I have finally put this dissertation together. My doctoral experience helped me to grow both personally and professionally, and strengthened my dedication to the field of international health. Carrying out a project of this magnitude was no easy task. I could not have done it without the support of many individuals.

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Chapter 1

Introduction

In 2001, I volunteered with a community-based rehabilitation (CBR) program in South India as a student occupational therapist. This volunteer initiative was organized by Queen’s Project on International Development (Ontario, Canada) and the Association of People with Disability (Bangalore, India). I was responsible for educating CBR team members about occupational therapy interventions aimed at helping young people with disabilities living in rural villages. Through informal interactions with adolescents, I became aware of the lack of attention that was being given to their unique rehabilitation, developmental and socio-cultural issues. Adolescents played a minimal role in shaping CBR services. I wondered whether my concerns held merit within the broader field of disability in India. I began to explore the literature on adolescents with disabilities in the developing world, which gradually led me to pursue doctoral work on CBR in India. I developed a genuine curiosity to explore the perceived rehabilitation challenges of Indian adolescents with disabilities, the subculture of adolescents within the larger Indian culture, and the extent to which adolescents would be able to advocate for their rehabilitation challenges. I never imagined that my volunteer experience would make me so passionate about working in the field of international development, health and rehabilitation.

I believed that the most feasible way to conduct research with adolescents with disabilities in India would be to engage a local CBR program that focused on child and adolescent health. After examining several community organizations, I selected ASTHA’s CBR Program situated in the urban slums of Lal Kuan in New Delhi, India for this study. Although I was born and educated in Canada, I am fluent in Hindi, Punjabi
and Urdu -- the languages primarily spoken in North India. I selected North India as my site for data collection because I was familiar with the cultural context, language and working conditions. This decision proved to be very valuable, as my cultural background and experience allowed me to establish strong rapport with the research community (i.e., the CBR program and community members in Lal Kuan) in order to gather rich data.

1.1 Justifying the Need for Research with Adolescents with Disabilities

There are approximately 1.5 billion individuals between 12 to 24 years of age worldwide; 1.3 billion of them live in developing countries (World Bank, 2006). According to the World Bank (2006), this is the best time to invest in young people in the developing world because they are the next generation to lead our communities (Singal, 2008). There is growing awareness of the potential for young people to build more democratic and economically promising societies (Herrera, 2006). However, little attention is placed on the potential role of young persons with disabilities. There are approximately 650 million persons with disabilities globally; 80% of whom live in developing countries (United Nations, 2006). The rate of disability continues to rise, especially as a result of population growth in developing or underdeveloped areas (Cameron, Nixon, Parnes, & Pidsadny, 2005). Persons with disabilities are viewed as the largest minority in the world (United Nations, 2006).

Approximately 180 million individuals between 10 to 24 years of age are living with physical, developmental, sensory or mental health disabilities that have a significant

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1 Developing countries are generally characterized by the following: in transition from uneven development to more constant economic conditions; lower income per capita; lower industrialization; extreme poverty; less advanced social, health and education systems; higher rates of illiteracy; higher rates of infant mortality; and lower life expectancy (Library of Congress, 2000). I used the terms ‘developing/developed countries’ rather than ‘low/middle/high income countries’ or ‘majority/minority world’ in order to highlight the need for further ‘development’ to improve the living and health conditions of millions of individuals.
impact on their daily life; an estimated 150 million of them live in developing countries (Groce, 2003, 2004; United Nations, 2008b). Adolescents with disabilities in developing countries are one of the most disadvantaged groups in the world because they are often excluded from educational, occupational, social and cultural opportunities (Groce, 2004). A review of disability literature suggests a focus on young children and adults with disabilities while adolescents tend to be placed into one of these two groups (Groce, 2003). Adolescents experience physical, cognitive, emotional and social issues that differ from those in child or adulthood (Lerner & Galambos, 1998). With the numerous challenges facing developing countries, few resources are invested in exploring the perceived rehabilitation issues of adolescents with disabilities (Stone, 1999). The perspectives of adolescents are often missing from program and policy initiatives (Groce, 2003). Failure of adolescents to assume greater control over their rehabilitation may prevent them from benefiting from similar opportunities as their peers. Investigation of adolescents with disabilities may also promote greater insight into their growth and resilience. CBR programs are one strategy for adolescents’ perspectives to be sought and included in program and local policy initiatives.

By 1982, the World Health Organization recognized “CBR [as] an appropriate, feasible, and economically viable approach to provide the most essential rehabilitation to the disabled population in developing countries” (p. 4). CBR is defined as:

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2 In 1980, the World Health Organization presented the International Classification of Impairments, Disabilities and Handicaps (ICIDH) that defined disability as “any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being” (p. 28). However, in 2001, the World Health Organization introduced the International Classification of Functioning, Disability and Health (ICIDH-2, ICF) in which disability serves as “an umbrella term for impairments, activity limitations or participation restrictions” (p. 1).

3 The World Health Organization (2000) defines young people as those individuals between 10 to 24 years of age, youth as those individuals between 15 to 24 years of age, and adolescence as the period from 10 to 19 years of age.
[A] strategy within community development for the rehabilitation, equalization of opportunities and social integration of all people with disabilities. CBR is implemented through the combined efforts of disabled people themselves, their families and communities, and the appropriate health, education, vocational and social services. CBR empowers persons with disabilities to take action to improve their own lives, and contribute rather than drain or deplete whatever scarce resources that are available, thereby benefiting all the community (International Labour Organization, United Nations Educational, Scientific and Cultural Organization, & World Health Organization, 1994, p. 1).

CBR is built on the concept of health promotion and community development (Fransen, 2005). Health involves a state of overall physical, social, psychological and economic well-being, and not merely the absence of illness or impairment (Hammell, 2008; VanderPlaat & Teles, 2005). The capability perspective or human agency view of health addresses people’s capacity and freedom to live a life they see as meaningful (Ruger,

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4 Community development is a process by which people work together to define shared problems, discuss strategies for change, make decisions, and take steps to act and evaluate their decisions (Peat, 1997).

5 The World Health Organization (2007) reports that “rehabilitation of people with disabilities is a process aimed at enabling them to reach and maintain their optimal physical, sensory, intellectual, psychological and social functional levels. Rehabilitation provides disabled people with the tools they need to attain independence and self-determination” (para. 1).

6 The principle aim of social integration is to build “a society for all, in which every individual, each with rights and responsibilities, has an active role to play” (United Nations, 2008a, para. 3).

7 A review of CBR has lead to several inquiries into the meaning of community within CBR (Boyce & Lysack, 1997; Miles, 1990). A community has been described as the physical and social space in which people live and feel united by a sense of belonging and common needs (Crishna 1999; Wade, 2003).

8 Empowerment refers to helping people who have been restrained by social or political forces to gain strength and capitalize on resources in order to assume greater control over their lives and lead what they interpret as a good life in their society (Twible & Henley, 1993). Empowerment facilitates the process of individuals advocating for themselves and making changes on their own behalf (VanderPlaat, 1995).
The right to health is related to the attainment of other human rights as described in the International Bill of Human Rights, including the right to basic needs, education, vocation, access to resources and information, and dignity (VanderPlaat & Teles). Human rights are a collection of universally adopted principles founded on social justice and equality that consider two fundamental issues -- freedom and well-being (Hammell; Kallen, 2004). Human rights reject discrimination on the basis of social class, race, religion, culture, gender, age, sexual orientation, disability or health.

The CBR approach, which is linked to the concept of human rights, is consistent with the discipline of occupational therapy and its aim of occupational justice (Kronenberg & World Federation of Occupational Therapists CBR Project Team, 2003). CBR can assist in working towards occupational justice, which addresses access to opportunities and resources required to participate in daily life sufficient to satisfy one’s personal development and citizenship (Kronenberg & World Federation of Occupational Therapists CBR Project Team, 2003; Pollard & Sakellariou, 2007). India is well known for implementing CBR to reach its disabled population (Crishna, 1999; M. Thomas, 1992).

The population of India is 1.1 billion people. Approximately 51% of the population is under 25 years of age (Registrar General and Census Commissioner of India, 2001). Nearly 82% of the population in India is Hindu, and Hindi is the official

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national language while English is considered the associate official language (Maps of India, 2004). The 2001 Census data from India reported the prevalence of disability at 2.13% (21.91 million people) based on five types of disabilities (Registrar General and Census Commissioner of India, 2001; Singal, 2008). This estimate is significantly below the World Health Organization’s global prevalence rate of 10% (Singal). Other leading Indian non-governmental organizations have argued that almost 41% of the population lives in impoverished conditions and an estimated 60 million people are disabled (Dube, 1994; National Centre for Promotion of Employment for Disabled People & National Association for the Blind, 1999). Almost half of the world’s blind population and nearly 30% of persons with orthopedic disabilities live in India (Dalal & Pande, 1999). It is difficult to collect reliable data on the prevalence of disability in India given the discrepancy in defining disability, untrained field investigators, social stigma, and the challenges of obtaining data from the streets, slums and villages (Department of Women and Child Development, Ministry of Human Resource Development, & Government of India, 2002; Singal). Nevertheless, of the estimated 60 million persons with disabilities in India, about one-third of the disabled population is assumed to be children between 0 to 18 years of age (Asia-Pacific Development Centre on Disability, 1991; National Centre for Promotion of Employment for Disabled People & National Association for the Blind, 1999). Of the approximately 400 million children in India, up to 40 million may be disabled and up to 10% may have special needs (Department of Women and Child Development, Ministry of Human Resource Development, & Government of India, 2002; CRY, Child Rights and You America, 2007).

An effort to study the field of rehabilitation in India has been evident since the
latter half of the 20th century (Reddy, 1991). The tendency to migrate to the city in the hopes for economic, vocational or educational growth has resulted in a dramatic increase in the number of individuals settling in urban slums (Kenkre, 1994). Urban slums are areas within a city with substandard living conditions. Slum districts are highly populated areas characterized by poor physical and social conditions, poverty, poor sanitation, and poor housing (Pothen, 1982; Sheuya, 2008). Approximately 5.7 million people live in the urban slums in New Delhi, the capital city of India (Dube, 1994). The health and rehabilitation situation in the urban slums is a major priority for national health policy (Kenkre; Sheuya). Rehabilitation issues of 70% of the disabled population may be managed at the level of the community while 30% may require higher-level services (M. Thomas, 1992). The United Nations declared the *Decade of Disabled Persons 1983 - 92* in order to highlight the goals of rehabilitation, and the realization that neither charity nor welfare could prevail in a country such as India (Dalal, 2002). The view that interventions should be community-based was receiving greater support (Dalal, 2002). The CBR approach to disability began more ‘formally’ in India in the 1980s (Action Aid India, 2003; Dalal, 2002).

CBR programs in India, for adolescents with disabilities, tend to explore issues from the perspectives of family members, CBR personnel, health professionals and funding agencies (Crishna, 1999; M. Thomas, 1992). Services are developed, implemented and evaluated according to these individuals while the adolescents they intend to serve have little say in the process. Based on the large conservative Hindu population in India, developmental studies indicate that as a child grows up with a natural dependency on the family, separation during adolescence may be met with resentment;
the family has a desire to continue to protect, control and discipline the child (Kakar, 1979a, 1979b; K. Kumar, 1993). Children are brought up with an “affectionate indulgence” and “child-centeredness” (Kakar, 1979b, p. 18). Interactions within the family tend to be unidirectional where parents and adults guide the child’s behaviour (K. Kumar). A child is seldom seen as a separate figure with their own rights, choices, desires and needs from those of their family or “all-powerful parents”; instead, a child may be seen as the couple’s wish coming true (Kakar, 1979b, p. 18). The freedom that may be enjoyed as a young child may be curtailed in adolescence (K. Kumar). Critics have discussed the absence of typical stages of psychological development in Indian adolescents (K. Kumar; Saraswathi, 1999), and greater psychological continuity in the transition from childhood to adulthood, which may suggest that Indian adolescents experience less emotional turmoil (Verma & Larson, 1999). Although such accounts are debatable, Indian adolescents might experience greater psychological continuity and less obvious emotional turmoil because of an ‘unquestionable’ acceptance of family ideals concerning socio-cultural, religious, educational and vocational matters, and the development of a more ‘joint’ rather than independent identity. Nevertheless, whether disabled or non-disabled, Indian adolescents generally have little control over making decisions about their day-to-day affairs and lifestyle choices and may be viewed as dependent, vulnerable or incapable (Dalal, 2002). Adolescents with disabilities are at a double disadvantage because they tend to have a limited peer support network to share their concerns and desires (Doubt & McColl, 2003; Skar, 2003).

Given my understanding of the Indian culture based on the literature, media, interactions with community organizations and personal experience, I believed it would
be unreasonable to assume that the majority of young persons with disabilities living in underprivileged areas, including slum districts, would be empowered in the absence of some catalyst to facilitate the change. The nature of such catalysts in empowering adolescents is not well understood. Thus, I selected ASTHA’s CBR Program in the urban slums of New Delhi to examine how to empower adolescents with disabilities. CBR programs that address the perceived rehabilitation issues of the target population may allocate resources more appropriately and promote sustainability (Kenkre, 1994; Shediac-Rizkallah & Bone, 1998; M. Thomas, 1992; Wirz, 1996).

1.2 Purpose of this Research

ASTHA is a registered charitable trust that was initiated in New Delhi, India in 1993 (ASTHA, 2008a). ASTHA is responsible for implementing several disability programs targeted at young persons with disabilities throughout the city, including the CBR Program in the urban slums of Lal Kuan in August 2001 (ASTHA, 2008b). ASTHA’s activities in the Lal Kuan community included facilitating educational and vocational opportunities; providing equipment and mobility aids; serving as a resource center; developing a disability management kit; organizing events to increase disability and gender awareness; training volunteers; implementing health workshops; developing parent and women’s groups; and organizing film shows (ASTHA, 2008b; ASTHA & Action Aid India, 2005) (see Appendix A).10

ASTHA had briefly explored the issues of young people in Lal Kuan by talking to a few influential community members and parents with little attention given to the perspectives of children and adolescents with disabilities themselves. The purpose of this

10 For the purpose of this study, community refers to individuals who are bound by a specific location and a shared cultural identity.
critical ethnography was to i) highlight the perspectives of adolescents with disabilities about their personal and shared rehabilitation challenges including self-care, productivity, leisure, social, emotional, sexual and mental health, ii) explore how the culture (broader culture and adolescent subculture) influenced the daily lives and rehabilitation challenges faced by adolescents, and iii) support collaborative work among adolescents with and without disabilities in a few agreed upon activities that would inform organizational activities and policies. This research explores how to empower adolescents with disabilities to express their desires, assume greater ownership over their rehabilitation, and become more involved in their community. Adolescent participants were 12 to 18 years of age. ASTHA’s CBR Program integrated this study into their organizational initiatives as little time and few resources had been invested in highlighting the adolescent perspective, and because they viewed the research to have significant pragmatic value for the continuation of their activities with adolescents.

Without knowledge of the local culture, it is highly improbable that any community-based approach will successfully mobilize local participation (Dalal, 2002). My review of ASTHA’s CBR Program indicated that they were inclusive of broader issues affecting the community. Given the low number of individuals with disabilities in any community, disability is often a low priority. CBR programs are more likely to be successful when disability issues are grounded within broader issues affecting community

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11 The concept of ‘voices’ in this study refers to the perspectives, experiences, desires and stories shared directly by adolescents with and without disabilities themselves.

12 Community participation is “a social process whereby specific groups with shared [concerns] living in a defined geographic area actively pursue identification of their [issues], take decisions and establish mechanisms to [address those problems]” (Rifkin, Muller, & Bichmann, p. 933). Community participation is about community involvement, ownership, capacity building, and empowerment.
development (Boyce & Lysack, 1997; Ganguly & Brar, 1993; M. Thomas, 1992), which positions disability in the broader context of social justice (Fransen, 2005). I believed it would be difficult to support the perspectives of adolescents with disabilities in isolation from other adolescents, the system responsible for service provision, and the cultural context in which they lived. The inclusion of non-disabled adolescents in this study did not serve to overshadow the important disabled adolescent voice nor were non-disabled adolescents used to acknowledge or confirm the perspectives of disabled adolescents. I believed it would have been challenging to justify the experiences of adolescents with disabilities without also understanding the experiences and attitudes of ‘other’ adolescents in the community. Although this study focused heavily on adolescents with disabilities, by including peers without disabilities the research might benefit more adolescents and provide greater insight into more meaningful ways to empower young people. When community members are directly involved in making decisions, the process yields a greater sense of control, power, equality and responsibility over project goals (Peat, 1991a, 1991b). Persons with disabilities are often the most disempowered of any groups because they are trapped in a vicious cycle of internalizing negative social attitudes and oppression; the only means to break the cycle is for disabled individuals to initiate the change process thereby emancipating themselves (Coleridge, 1999).

ASTHA has been working hard to ensure the sustainability of their CBR Program upon their gradual reduction of activities in the community by 2008/2009. This is consistent with the philosophy of CBR where the goal is for community members to take greater ownership over activities. This study was not designed to solve all the rehabilitation challenges and problems experienced by adolescents with disabilities.
Instead, the aim was to understand personally meaningful strategies for empowering adolescents with disabilities and to have their views heard by their community. Research techniques that respect the cultural environment, challenge negative attitudes, create awareness and opportunities, and influence changes in the environment are required for adolescents with disabilities to comfortably express their views. This study provides one example of a research partnership that investigated the perspectives of adolescents with and without disabilities, and determined how to present and utilize their views in a meaningful and culturally sensitive manner.
Chapter 2

Literature Review

Over 5,000 voluntary organizations are working in the area of community health in India (Sharma & Bhatia, 1996; M. J. Thomas & M. Thomas, 2002). Despite the extensive community-based work occurring in India, research on community-based initiatives is limited, and is not widely disseminated or readily accessible. I sought literature on community-based research involving adolescents with disabilities in the developing world, especially within the Indian and South Asian context. Where information was limited, I also included literature from the developed world. Little is known about the role of young persons with disabilities in India in informing community-based rehabilitation (CBR) services, and strategies for empowering young persons with disabilities that acknowledge their perspectives and desires.

2.1 Socio-Cultural Context and Response to Disability in India

India is the world’s largest democracy. There continues to be a significant divide between the rich and poor in India (Sen, 2005), despite reports that India has demonstrated steady economic growth and has become one of the fastest growing economies in the world (Canadian Broadcasting Corporation, 2009; International Monetary Fund, 2008a, 2008b). There is an undeniable link between poverty and disability (United Nations, 2006). Poverty and disability must be a priority alongside other pressing global issues such as economic growth, trade, governance, national security and foreign relations.

There are differences in the level of development across and within states in India on indicators of health, education, employment and income (M. J. Thomas & M. Thomas,
India is described as a culture-conscious nation known for its diverse local cultures, religions and strong family ties (Dalal, 2002; Dube, 1994). The onset of disability in childhood may be considered an existence worse than death in India, jeopardizing the lives of the entire family (Ghai, 2002). Many investigations have focused on societal and community or health worker attitudes towards persons with disabilities in South Asia or India (Bakheit & Shanmugalingam, 1997; Coleridge, 1999; Dalal & Pande, 1999; Paterson, Boyce, & Jamieson, 1999; Reddy, 1991). Common views and attitudes towards disability in India are presented in Table 1.

Table 1. Common Views and Attitudes towards Disability in India.

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<thead>
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<th>Common Views and Attitudes towards Persons with Disability in India</th>
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<tbody>
<tr>
<td>A charitable (pity) or philanthropic view of disability.</td>
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<tr>
<td>View of disability may differ across rural and urban communities, castes and religions.</td>
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<tr>
<td>Disability is seen as a punishment from God for a previous life’s sins, and is attributed to bad karma.</td>
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<tr>
<td>Persons with disability may be viewed as possessing some divine traits.</td>
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<tr>
<td>Disability is seen as requiring medical or religious intervention.</td>
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<tr>
<td>Effort is towards finding a cure for the disability rather than rehabilitation.</td>
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<td>External locus of control.</td>
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<tr>
<td>Visible/noticeable disabilities are less acceptable (e.g., physical/developmental vs. learning/psychiatric).</td>
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<tr>
<td>Focus is mainly on the medical model of disability and on the physical or visible aspects of disability.</td>
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<tr>
<td>Disabled persons are seen as sick, inferior, incompetent and shameful in comparison to the general public.</td>
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<tr>
<td>Adults with disabilities are seen as children or incompetent and incapable of making decisions.</td>
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<tr>
<td>Children with disabilities are seen as submissive.</td>
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<tr>
<td>Gender differences are apparent, as it is more tragic to be a disabled male.</td>
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<tr>
<td>Increased blame placed on the mother who gave birth to a disabled child.</td>
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<tr>
<td>Persons with disabilities are a life-long, ethical responsibility of the family.</td>
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<tr>
<td>Confusion regarding sexuality, puberty and fertility of persons with disabilities.</td>
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<tr>
<td>Myths, tradition and scriptures feed into the cultural belief system that shapes negative attitudes.</td>
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</table>


Several of the studies that were reviewed to create the list in Table 1 were based primarily on community-based research that was conducted in under-resourced areas. Some of the beliefs towards disability may or may not be consistent across the Indian culture and different socio-economic groups. The beliefs outlined in Table 1 are those
that appear to have been passed on from person to person, generation to generation, with little or slow change noted in thinking or practices overtime. Negative societal attitudes towards disability heighten discrimination leading to fewer opportunities for persons with disabilities and exclusion from social roles (Bakheit & Shanmugalingam).

Global health research can be a complex task that is at risk for promoting cultural misinterpretations, stereotyping and unintentional prejudice (Bathum, 2007). When conducting an ethnographic study that addresses disability and rehabilitation, the following questions should be considered: does the concept of disability exist within the culture; what does disability constitute; how does the society suggest persons with disabilities be treated; what structures within the culture facilitate the participation and functioning of persons with disabilities; is the notion of disability related to a concept of rehabilitation; and how is rehabilitation conceptualized? (Hershenson, 2000).

Societal values tend to prioritize physical and medical health issues for persons with disabilities (Tulloch, 1999). Rehabilitation opportunities addressing other determinants of health, including special education, vocational training and peer support are grossly inadequate and reach only a small portion of the population (Groce, 2003, 2004; Reddy, 1991). The Indian milieu offers little understanding and acceptance of the social model of disability, which locates the problem at the level of the society rather than the person with impairment (Ghai, 2002). Many people with disabilities are unable to live a meaningfully occupied life which has little to do with individual factors (Pollard & Sakellariou, 2007). One must attend to the effect of poverty and the role of society in disability (Fransen, 2005). However, the field of disability studies has also criticized the favouring of the social model of disability by interventionists because the model may be
inappropriate given the local circumstances and understanding, may restrict people’s intellectual freedom, and oversimplify their lives (Davis, 2000). Not all the problems experienced by persons with disabilities are a result of negative societal attitudes and impairment cannot be dismissed as a factor in disabling conditions, particularly in communities that do not have access to any health care (Fransen). Nevertheless, globally, for adolescents with disabilities, social, educational and vocational challenges are far more pressing than medical issues (Groce, 2003, 2004). The need to prioritize basic and medical requirements in developing countries is acknowledged. However, due to limited resources and the level of poverty, it is often difficult to directly address primary or basic medical concerns. Thus, if there is any potential to address other issues concerning persons with disabilities, efforts should be made to address those issues to enhance quality of life (e.g., improving employment may lead to greater funds for food).

Societal attitudes appear to play an especially influential role when the person with a disability is a child or adolescent. The attitudes towards children with disabilities in six ethnic communities in Australia were investigated using survey methodology (Westbrook & Legge, 1993). Findings suggested that societal views influenced the child’s self-concept, motivation, social skills, role expectations, perceived needs, participation and integration into mainstream culture. Attitudes towards children and adolescents with disabilities influenced the problems that were identified and prioritized by community members. Disability has been said to be “culturally constituted and socially negotiated” (Mehrotra, 2006, p. 406). The greatest barrier to the lives of young persons with disabilities is injustice, social isolation and discrimination (Davis, 1998). Even with greater awareness about one’s circumstances, people are often not trained to
connect how this new understanding is historically, politically and economically situated (M. Fine & Weis, 2005). The current push towards using ‘politically correct or neutral’ language may turn even the most antagonizing circumstances into more manageable and acceptable conditions; for example, replacing the term poor with low socio-economic status or mental retardation with developmentally delayed. Such strategies may undermine the severity of the problems experienced by individuals in the developing world, and may be counterproductive for receiving necessary interventions, supports and resources. The ‘affected’ person’s voice may be lost in contemporary discourse given the new language used in policies, legislations, and by organizations.

Vasishta (2006) reported that the “attitude [towards disability] may have changed from out-of-sight to full inclusion, but that is mostly on paper and at slogans level only. The inherent attitude is still the same. … Changing attitudes is one of the most difficult things in the world” (p. 31). Poor and disadvantaged persons continue to be excluded from mainstream society due to their powerlessness and voicelessness (World Bank, 2002). Little information could be found on how adolescents with disabilities perceive their socio-cultural context and how they identify with the mainstream culture.

2.2 The ‘Triple Disadvantage’: Poor, Disabled and a Woman

A considerable portion of Indian society is patriarchal (Dube, 1994). The birth of a son in India is celebrated, while the birth of a daughter is often met with a quiet or cold reception (Kakar, 1979b). A female born with a disability would be at increased risk of discrimination and displeasure. The family has been represented as one site of oppression for women in South Asia (Mehrotra, 2006). Adolescents in contemporary India have the added burden of living in co-existing traditional and modern societies,
where the economy and social structures have radically shifted societal roles (Call et al., 2002; Verma & Saraswathi, 2002). The perspectives of adolescents may conflict with their parents due to significantly unique generational experiences (Call et al.; Verma & Saraswathi). The struggle may be heightened for adolescent girls who are trying to balance traditional expectations and kinship networks with new cultures (Call et al.; Verma & Saraswathi). Late childhood and early adolescence is a time when young Indian girls are deliberately conditioned to become women who embody traditional and culturally accepted feminine roles (Kakar, 1979a). Traditional gender roles and expectations in India allow greater discrimination and unequal treatment towards women in comparison to men (Mehrotra, 2006; M. J. Thomas & M. Thomas, 2002). Young women, with disabilities, living in poverty in the developing world, are one of the most disadvantaged and vulnerable groups in the world (Rao, 2005).

Disabled women activists have highlighted that women suffer oppression both because of their gender and disability (Mehrotra, 2006). Activists have accused the disability movement of being preoccupied with men’s concerns while ignoring women’s issues, including social and economic injustice, sexuality, marriage, childbearing and motherhood (Mehrotra). Disability agendas in India advance only a few select issues that predominately concern middle class men or the few very privileged disabled (Ghai, 2002). Historically, women with disabilities have been excluded from Indian feminist and disability movements (Emmett & Alant, 2006; Ghai; M. Thomas, Raja, & Prakash, 2001; Traustadottir, 1992). Ghai, who is a woman with a disability, stressed that simply presenting women in disability movements is insufficient; they must be included in dialogue where different perspectives can be shared and heard. Two quotes from Ghai’s
conversations illustrate the frustration experienced by Indian women with disabilities: “Being a woman is the biggest form of disability” (p. 60) and “Disability is like belonging to the lowest caste possible” (p. 60). Women with disabilities who hold more reputable positions in their community or are well educated may not view their femaleness or disability as a ‘disadvantage’ (Ghai; Thornton, 2006). For the majority of women however, being disabled only exacerbates the problems they experience by their society (Action Aid India, 2003).

The life histories of 21 disabled women in Rural Haryana, Northern India were studied across three age groups -- less than 15 years, 15 to 45 years of age, and over 45 years of age (Mehrotra, 2006). The adolescent women with disabilities (i.e., developmental delay; physical disability; sensory disability) highlighted the challenges they experienced at school, at home and in the community. The young women were ridiculed by other children and had difficulty engaging in physically demanding games. Thus, they often relied on a sibling to be their full-time playmate. Adolescent girls reported dropping out of school due to loss of interest and the inability of teachers to meet their special needs. The young women also experienced difficulty performing housekeeping tasks. The family desired for these women to get married. The burden of care for these women was often transferred to a family member other than a parent. The adolescent women were introduced to disability pensions and certificates. It was concluded that conditions of women with disabilities do change over time and that disability is an additional burden on girls’ already marginalized gender position in society.

Qualitative semi-structured interviews were conducted to understand how 13 South Asian (Muslim and Sikh) physically disabled women aged 17 to 30 years, in
Britain, simultaneously negotiate their disability and ethnicity (Hussain, 2005). Topics investigated included social supports, family relationships, religion and culture, living with a disability, society and disability, services, education, and future expectations. Participants reported little freedom, greater isolation, and greater responsibility over domestic activities; but believed that developing a sense of independence and control did not require them to leave their homes. The findings demonstrated that even when South Asian families emigrate, disabled women experience tensions to be strong and capable, but simultaneously submissive and compliant in order to meet cultural expectations and avoid conflict with family members.

In an effort to empower women with disabilities aged 16 to 25 years in Bangalore, Southern India, the Association of People with Disability and Mobility India recruited nine females with either a mobility or communication disability to participate in a prosthetics and orthotics training program (M. Thomas, Raja, & Prakash, 2001). The women received training over a period of one year and were then assisted in running a collaborative mobility aids workshop. The women were encouraged to live together while training and working. The Association of People with Disability in collaboration with Queen’s University in Kingston (Ontario, Canada) conducted individual and group interviews with the disabled women to study the personal, professional and social developments that evolved from the training experience. The women who were living together during the process appeared to have an advantage in developing skills, mature attitudes and independence. This work provides evidence for how young women with disabilities can be empowered collectively with adequate support.

The empowerment of women in India is essential to improving their status
(Government of India, 2001; Murthy, 2004). Despite some increase in the recollections of women with disabilities about their experiences, barriers, isolation, powerlessness, poverty and achievements (Traustadottir, 1992), these have seldom focused on the perspectives of adolescent women with disabilities living in marginalized or under-resourced areas. Although the policies that govern CBR stress equal rights, opportunities and access for all individuals with disabilities, research still indicates that the distribution of resources continues to favour males (International Labour Organization, United Nations Educational, Scientific and Cultural Organization, & World Health Organization, 2004). The United Nations member states have adopted eight Millennium Development Goals, which they hope to achieve by 2015: 1) eradicate extreme hunger and poverty, 2) achieve universal primary education, 3) promote gender equality and empower women, 4) reduce child mortality, 5) improve maternal health, 6) combat HIV/AIDS, malaria and other diseases, 7) ensure environmental sustainability, and 8) develop a global partnership for development (United Nations Development Programme, 2001). These goals have the potential to improve the lives of billions of individuals in the world’s poorest nations (International Disability and Development Consortium, 2008). However, persons with disabilities are not explicitly mentioned in the goals (International Disability and Development Consortium, 2008). Without accounting for disability, the goals may fail to improve the lives of some of the most disadvantaged and poorest women with disabilities. Discussions about gender equality are especially complex in developing areas where cultural values may conflict with western ideals (Coleridge, 1999).

2.3 Disability and Rehabilitation in India

Disability and rehabilitation as a cultural phenomenon or construct has been
receiving greater attention (Hershenson, 2000). The definition and meaning of disability and rehabilitation differs across cultures and families (Banks, 2003; Devlieger, 2000; Hershenson; Peat & Shahani, 1990). The field of rehabilitation in India has received greater attention since the latter half of the 20th century (Reddy, 1991), with government and non-governmental organizations promoting CBR for the past 15 to 20 years (Action Aid India, 2003). A typical CBR program in India begins with some stimulus external to the community that is interested in implementing a CBR program in a desired area (M. Thomas, 1992). Persons affiliated with the external agency, including health professionals, social workers, teachers or rehabilitation therapists, help to address local rehabilitation, health, social, vocational and educational issues. They help to train local people to work with disabled and non-disabled community members in order to improve the condition of the overall community. Services are often implemented based on funding rather than on the community’s desires (Crishna, 1999; Sharma & Bhatia, 1996). Implementing CBR programs is further complicated by the wide variation in the use of CBR (Lang, 1999; McColl & Paterson, 1997; Swedish Organisation of Disabled Persons International Aid Association & World Health Organization, 2002; M. Thomas, 1992; Wade, 2003; Wirz & M. Thomas, 2002), and by the confusion associated with concepts that define CBR, including community, rehabilitation, disability, empowerment and sustainability. CBR is most needed in urban and rural villages in India where children and adolescents with disabilities face significant barriers to participation in community life (M. Thomas, 1992).

The Rehabilitation Council of India, which was organized in 1986, regulates training programs and policies for professionals in the field of rehabilitation
The Rehabilitation Council of India Act 1992 (amended in 2000) oversees the activities of individuals working with persons with disability, and also enforces disciplinary action against unqualified individuals providing services (Rehabilitation Council of India, Government of India, 2004). The act supports the performance of basic rehabilitation activities by family members or informal workers, and continues to promote medically-oriented rehabilitation interventions with little involvement of disabled persons themselves (Lang, 1999). Further efforts to improve the lives of persons with disabilities led the Government of India to recommend new legislation called the Persons With Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995 (Dalal, 2002; Government of India, 1996; S. Kumar, 1995; Srivastava & Bajpai). The act is guided by the principle of empowerment and the prevention of discrimination. Fines and imprisonment can be imposed on parents or caregivers who willfully neglect, deprive or discriminate against a child with disability, or for those persons who utilize disabled people for profit (S. Kumar). The Ministry of Social Justice and Empowerment has informed procedures for Medical Boards of district hospitals to assess and issue Disability Certificates to persons with disabilities in India (Punarbhava-National Interactive Portal on Disability, 2008). Disability Certificates serve as proof of a person’s disability and as an important document to access rights, resources and benefits, including assistance to obtain equipment, free travel on state buses, education scholarships, loans for self-employment, unemployment allowance for educated disabled persons, grant incentives for marriages between disabled and normal persons, and other financial assistance. The ministry is currently reviewing the certification process because
many individuals continue to experience difficulty in obtaining a Disability Certificate (Punarbhava-National Interactive Portal on Disability, 2008).

A national plan of action for children in India, guided by the United Nations Convention on the Rights of the Child 1989, commits itself to ensure that all rights are given to all children up to the age of 18 years (Department of Women and Child Development, Ministry of Human Resource Development, & Government of India, 2002). Policies for child and adolescent health in India address the promotion of physical and mental health; protection from physical, psychological, social, economic and sexual abuse and exploitation; access to health and resource centers; education; participation in community life; and recognition of special needs (Department of Women and Child Development, 2005; Ministry of Social Justice and Empowerment & Government of India, n.d.). The extent to which policies are enforced for children with disabilities from lower socio-economic backgrounds remains unclear.

According to Stone (1999), disability research globally indicates that most time is invested on outcomes and evaluation of services, and little time is spent on exploring wider issues such as local strategies for rehabilitation, opportunities for persons with disabilities, social expectations and impact of cultural perceptions. There is variation in how rehabilitation issues are determined in the diverse urban slums in Northern India, but epidemiological data tends to be the predominant method for identifying issues (Chaudhury, Menon-Sen, & Zinkin, 1995; Mitchell, Zhuo, & Watts, 1989). Review of previous surveys indicates that they fail to cover important determinants of health, fail to detect mild to moderate disability, are costly, not analyzed adequately, and have little impact on services (Ganguly & Brar, 1993). Another frequent mistake is to select a few
prominent individuals in the villages (village chiefs) to determine issues (Stockman, 1994). ‘Broad-brushed’ and ‘ritualistic’ methods to explore issues may overshadow the perspectives of people (Hawe, 1996). Methods that go beyond quantitative surveys and a limited biomedical framework should be used to capture the diverse challenges of groups (Butler, 1987; Krefting, 1992). Qualitatively, impact drawings, Venn diagrams, social mapping, flow diagrams, and historical timelines have been used to explore community and disabled persons’ problems (Rifkin & Pridmore, 2001).

The degree to which people living in the most disadvantaged regions in India are able to communicate their views due to cultural barriers, illiteracy, education and lack of assertiveness makes access to CBR programs even more difficult. There continues to be a lack of agreed upon indicators to measure the success of CBR programs in India (Wirz & M. Thomas, 2002). Community participation and understanding local needs and values are fundamental for the short and long-term sustainability of CBR (Pollard & Sakellariou, 2008; Turmusani, Vreede, & Wirz, 2002). The link between understanding the perceived issues of disabled people and sustainability of CBR requires further investigation (Peat, 1997). The concept of sustainability itself is disputed. Previously, one means of defining the theoretical success of community-based health programs was to assess the ability of community members to continue the program independent of or with minimal economic, managerial and technical external support (Crishna, 1999; Miles, 1996; Shedia- Rizkallah & Bone, 1998; M. Thomas, 1992). Current reflections on CBR and sustainability argue that it is unreasonable to expect that the majority of programs will become sustainable without external support; thus, the success of programs is reflected in the ongoing commitment of community members to CBR, including training

The International Labour Organization’s review of CBR indicated that CBR may be professionally unsatisfactory, challenging to organize as a self-sustainable program, and is not feasible without major support from outside the community (M. Thomas, 1992). A review of empirical research on CBR initiatives across developing countries questioned the degree to which CBR permitted community participation and people with disabilities to control the CBR process (Lang, 1999; Turmusani et al., 2002). A review of CBR programs in India found that it was not apparent whether CBR initiatives were truly rooted in the community and that knowledge transfer was essential (Ganguly & Brar, 1993). Community ownership of CBR programs is hardly a reality (Fransen, 2005). The International Consultation to Review CBR highlighted the importance of disabled people and their communities assuming power over the CBR process rather than prescriptive interventions targeted by community workers (World Health Organization, 2003). CBR initiatives are seldom integrated into broader national policies and multi-sectoral collaboration is a significant challenge (Fransen). Many promising outcomes of CBR have been noted from informal or unpublished clinical and personal experiences, but statistical evaluation of and research on CBR is generally lacking or seldom available in the larger public domain for critique (Mitchell, 1999; Peat, 1991a; M. J. Thomas & M. Thomas, 2002; Wade, 2003; Wirz & M. Thomas, 2002). CBR will only benefit by moving into the mainstream of reporting, which will draw attention to outcomes and the research methodology used (Mitchell).
2.4 Participation and Empowerment of Young Persons with Disabilities

The majority of CBR programs are initiated and run by larger national and international agencies; thus, community participation can be minimal (Turmusani et al., 2002). Persons with disabilities have little or no participation in day-to-day decisions regarding how CBR unfolds and control remains largely in the hands of non-disabled persons and professionals (Turmusani et al.). A recent joint position paper by the International Labour Organization, United Nations Educational, Scientific and Cultural Organization, and World Health Organization (2004) highlighted that despite all the efforts and progress, many persons with disabilities do not receive equal opportunities to participate in vocational, educational and leisure activities, have limited involvement in their communities and the larger society, and are not enabled to maximize their abilities.

An investigation by the United Nations Children’s Fund (1999) on the status of adolescents with disabilities indicated that only 12% of all disability-related organizations and personnel were able to identify programs that were specifically targeted at adolescents with disability (see also Groce, 2003). The programs that were identified were small in nature, serving less than 100 young disabled persons in countries where millions have disabilities. The Swedish Organisation of Disabled Persons International Aid Association and World Health Organization (2002) described the following strategies as being effective in raising awareness and instilling change in the community: exposure to role models such as persons with disability who are socially and materially successful; dialogue and knowledge transfer at community gatherings and meetings; and empowerment workshops for disabled persons and community members.

The Centre of Excellence for Youth Engagement (2007) in Canada proposed the
Youth Engagement – A Conceptual Model that is meant to guide further research on youth engagement. The centre defines youth engagement as “the meaningful and sustained involvement of a young person in an activity focusing outside the self” (p. 1). The centre highlights both objective (i.e., behaviour, structure and content) and subjective (i.e., feeling, thinking and evaluation) experiences as important aspects of engagement. The centre identified the following factors as important for engaging youth: initiating factors or barriers, sustaining factors or barriers, and positive or negative outcomes at the individual, social or system level. The research conducted by the centre indicates that the meaningfulness of activities is a critical aspect for engaging youth. Youth can experience a range of positive outcomes including a sense of achievement, competence, belonging and control from being meaningfully engaged. Further research is needed to understand the influence of different activities, processes and contexts on meaningful engagement for adolescents.

A concern often raised is whether a conflict, in theory or in practice, exists between an adult’s responsibility to act in a child’s best interest and what the child desires (N. Thomas & O’Kane, 1998). Studies that have investigated the problems of children with disabilities in developing countries from the perspective of the family, aim to meet the family’s problems and facilitate family support (Banks, 2003; McConkey & Mphole, 2000; Werner, 1990). There continues to be greater reliance on caregivers for insight into the child’s experiences (Garth & Aroni, 2003). While the experiences of parents are valuable, they may overshadow the necessary child perspective. All individuals, including young people, should be offered opportunities to learn how to express their feelings and to communicate in more effective ways (Galheigo, 2005).
The social activities of 88 children with epilepsy in a CBR program in rural India and 250 randomly selected controls were obtained through a questionnaire given to the children’s mothers (Pal, Chaudhury, Sengupta, & Das, 2002). The children were aged two to 28 years. Girls engaged primarily in domestic activities while boys were more involved in outdoor activities with their peers. All children and youth with epilepsy had significant social deficits, limited involvement in peer activities, and parents delegated fewer responsibilities to disabled children than to non-disabled children. The causes of poor social integration or the perspectives of adolescents with disabilities were not described. Instead, parents’ interpretation of their adolescents’ social activities was sought. The researchers acknowledged that parental reports may be a source of response bias, but they believed that this concern could be addressed by direct observation of the children.

The perspectives of seven young South Asians with disabilities and their parents living in the United Kingdom were explored using semi-structured in-depth interviews in order to inform services (Patel, n.d.). It was reported that the very act of participating in the research process can be a liberating experience for children. The study highlighted the importance of listening to the perspectives of young people with disabilities; however, it still placed significant focus on the inclusion of parent and caregiver perspectives.

A participatory study by the Swedish Organization of Disabled Persons International Aid Association and World Health Organization (2002) explored the impact of CBR on quality of life from the perspectives of children and adults with disabilities. Ghana, Guyana and Nepal were the preferred sites for data collection. Thirty-three persons with disabilities participated in in-depth interviews; nine focus groups were also
developed which led to the identification of 80 more participants. The study provided insight into the positive influences of CBR on quality of life, including enhanced self-esteem, feeling empowered, greater independence and social integration. Findings also indicated that CBR had limited impact on physical well-being and on society to fulfill its responsibility towards rights for all. Although persons with disabilities reported feeling more empowered, the study provided few details regarding how this change evolved. Information from children and adults was grouped together, which made it difficult to extract the perspectives and issues most relevant to adolescents.

The experiences of 13 adolescents and young adults (aged 15 to 20 years) with a range of disabilities including sensory, physical, psychological or communication were explored in Kenya using observations and interviews (Kisanji, 1995). The accounts of parents, teachers and community-rehabilitation workers were also sought. The findings indicated that the immediate and extended family structure was important for providing care and support. Child-rearing practices that parents used with adolescents and young adults included being overprotective, fulfilling caregiving duties and being nurturing, having expectations, and maintaining partnerships with professionals. Adolescents and young adults highlighted the importance of school effectiveness, social relations and social integration, and problems surrounding harassment and exploitation when discussing their experiences. The ‘meaning of life’ for 80 adolescents with a physical disability in Korea revealed the importance of greater quality of life, good deeds, social adaptation, having relationships, achievement, perception of one’s usefulness, recognition by others and rehabilitation (Kim & Kang, 2003). Both the Kenyan and Korean studies raised salient issues regarding adolescents with disabilities growing up in the developing
world, but provided little insight into how their perspectives were applied.

Recently, there has been greater awareness of the need for children to be involved in decisions that affect their lives, and how to actually put this aspiration into action (Badham, 2004; Cavet & Sloper; 2004; Matthews, 2001; O’Quigley, 2000; Shier, 2001). An increasing number of young people are participating in councils and meetings and presenting information in public forums (Allard, 1996). Although participating in these activities has been shown to be effective, under certain conditions these activities may result in embarrassment for young people or be counterproductive (Allard). There is still significant evidence that indicates that young persons with disabilities are not being listened to (Curtain & Clarke, 2005). A literature review of disabled children’s participation and control over decision-making revealed that they are capable of expressing their views given the appropriate environment, children value participation, children’s role in decision-making requires further investigation, and including disabled children in decision-making results in more successful outcomes (Cavet & Sloper).

The United Nations Convention on the Rights of the Child 1989 Article 12 reinforces that children have the right to express their views and to have their views heard and considered (Davis, 1998; United Nations, 1989). Article 13 highlights contextual issues and states that children should have freedom to seek, receive and provide information in any medium they desire; thus, the issue of providing information in an understandable format is of particular relevance to disabled children (Cavet & Sloper, 2004; Davis, 1998; United Nations, 1989). Article 29 specifies that education should be cognizant of children’s personality, abilities, culture, language and values (Davis, 1998; United Nations, 1989). Although children’s rights are more accepted, there continues to
be greater focus placed on caring for children rather than genuine reinforcement of their rights (Waterson & Goldhagen, 2007). It is no longer sufficient to simply seek the views of young persons with disabilities without indicating how their perspectives and participation will continue to be sought and incorporated into higher-level program and policy initiatives; one must attend to the matter of empowerment versus merely delivering services (Twible & Henley, 1993).

Empowerment has evolved as a desirable construct to create personal and social change (Baistow, 1994). Different cultural and political ideologies are attached to the concept of empowerment, and the term is not easily translated into different languages (World Bank, 2002). The World Bank (2002) defines empowerment as “increasing one’s authority and control over the resources and decisions that affect one’s life” (p. 11). Empowerment is “a mechanism by which people, organizations, and communities gain mastery over their affairs” (Rappaport, 1987, p. 122). It is a process that unfolds gradually from which positive changes may occur in self-determination, ownership, independence, choice, control, decision-making, skills, assertiveness, self-reflection, and voice (Nelson, Lord, & Uchoka, 2001). Zimmerman (1995) suggested that psychological empowerment operates on three levels: i) intrapersonal (perceived control, motivation and belief in oneself), ii) interactional (people’s understanding and relationship to their socio-cultural-political environment, awareness of resources and ways to mobilize resources, and skill development and transfer), and iii) behavioural (actions required to address issues, community and organizational involvement, and coping behaviours). Zimmerman (1995) further distinguishes between empowering processes versus empowered outcomes. The former discusses how individuals, organizations and
communities gain control over issues that concern them (e.g., creating or receiving opportunities), whereas the latter refers to the results of those processes. If empowerment is viewed as an end or outcome, then in theory, one must begin with adequately describing the end in interest and the process leading up to it (Khwaja, 2005). There continues to be debate regarding the best ways to evaluate for empowerment (VanderPlaat, 1995); for example, through internal accounts versus the development of appropriate indicators to measure empowerment (Khwaja).

The concept of empowerment was explored in the Sourabha CBR Program in Bangalore, South India using interviews, observations and focus groups (Lang, 1999). Findings revealed that the operationalization of empowerment within CBR was fraught with difficulties. The program had little understanding of the empowerment and social change process, and of the role of participation and partnership. There was little evidence that persons with disabilities felt supported for self-empowerment. Such findings highlight the challenge of translating theory into practice, and suggest the need to further explore the concept of empowerment within CBR (Lang), and empowerment and community development (Coleridge, 1999).

To respect the diversity among children’s perspectives, researchers need to employ several reflexive techniques (Davis, 1998). An empowering research process would motivate young people to become active members in the process, utilize tools which offer opportunity to maximize one’s capacity, and decrease the social distance and power between the child and researcher (Davis, 1998). Community-based researchers can collaborate with youth to generate data to guide local policies and programs (Small, 1996). Parents, practitioners and policymakers can benefit from greater knowledge on
adolescent development and input (Small). Youth are more likely to utilize information that they see as reflecting their reality (Small).

2.5 Significance of this Doctoral Research

Disability represents a life long struggle for young people, especially in poorer neighbourhoods in India. Existing community-based programs in India may have failed to include the important adolescent perspective in the development, implementation and evaluation of services. Limited resources and a negative cultural response to disability have contributed to this issue. Investigating adolescents’ perspectives about local beliefs, expectations and barriers is necessary for understanding the concept of disability and the occupations adolescents find personally meaningful. Participation is seen as an effective means of creating social change in developing countries and allowing oppressed people to express their ideas (Turmusani et al., 2002). Little information is available on effective strategies for enhancing the participation of young persons with disability or illness (Lightfoot & Sloper, 2002). Adolescent health is shaped by every segment of society, and requires international, national, local and state commitment to improve health conditions (Call et al., 2002).

In this study, I utilized culturally sensitive strategies and a range of data collection methods to enable adolescents with disabilities to comfortably share their views. To ensure that the focus remained on adolescents with disabilities, parental, caregiver and professionals’ perspectives were not included. I do acknowledge the critical role of adults in supporting young people with disabilities to be heard and in disseminating research findings. The paramount role of parents, caregivers and family members in caring for young people with disabilities cannot be undermined; however, there are many
studies on parental and caregiver experiences of raising a child with a disability.

Furthermore, the critical examination of CBR as a model of service delivery in the Indian context is not meant to undervalue the extensive amount of work that has been done across the country to help improve the lives of people with disabilities. Further research is necessary to ensure the survival of community-based programs and the vulnerable populations they attempt to serve. Research on disability and CBR in India suggests that little focus is placed on including adolescents in making decisions that affect their lives and rehabilitation activities, a lack of the young persons’ voice is evident, and a need for subjective data is critical. The aim of this study is to provide young persons with disabilities an opportunity to express their perspectives while simultaneously assisting a CBR program to carry out more meaningful activities within a specific socio-cultural and geographical location.
Chapter 3

Theoretical Foundation

No ethnographic study should be carried out without an underlying theoretical framework or model, whether a well-known anthropological theory or an implicit personal theory about how the world works (Fetterman, 1998). Theory helps to describe the problem, provides a framework for how to organize the research questions, and helps to determine which information and observations are important to include (Fetterman; S. Schensul, J. J. Schensul, & LeCompte, 1999). A typical theory for ethnography embraces a multicultural view that appreciates multiple realities and perspectives (Fetterman). When attempting to inform social change, one of two theoretical perspectives appears to dominate: 1) ideational theory proposes that change results from mental or cognitive activity including thoughts, ideas, beliefs, knowledge and interpersonal relationships, and 2) material theory assumes that change results from the re-distribution of and greater control over material conditions including resources, economics, production, environment and social arrangements (Fetterman). It is fundamental to design or utilize a framework that will cover the subject matter in a way that makes sense to participants and allows for the modification of questions to meet situational demands (Agar, 1980). Two theoretical perspectives provided the foundation for this study: i) occupational therapy theory and ii) critical theory and the critical paradigm.13

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13 A paradigm is described as a worldview, a way of looking at and interpreting the world and reality (Denzin & Lincoln, 2000). Paradigms assist researchers in determining what is real and essential, how to proceed in daily research activities, and proposes a set of assumptions, concepts and values about what can be known (Denzin & Lincoln, 2000; Kuhn, 1970; Lincoln & Guba, 1985). A paradigm provides a lens through which to develop, initiate, and continue a particular research tradition (Kuhn, 1970).
3.1 Occupational Therapy Theory

I am a registered and practicing Occupational Therapist. Several occupational therapy (OT) concepts helped to inform this study and influenced my understanding of disability (Devlieger, 2000; Krefting, 1989), culture (Bonder, Martin, & Miracle, 2004; Iwama, 2003; Krefting, 1991a; Litterst, 1985), environment (Dunn, Brown, & McGuigan, 1994; Law et al., 1996), and rehabilitation (Imrie, 1997; McColl et al., 2003; Salvatori et al., 2006; Townsend et al., 1997). OT uses occupation (meaningful activities that one would like to do or need to do) as a therapeutic medium with individuals, organizations and communities (Townsend et al., 1997). Occupation is essential for daily living, health, well-being and development (Polatajko et al., 2007). OT theory embraces the concepts of client-centeredness, collaboration, active participation, self-determination and empowerment (Townsend et al., 1997).

The effort to ensure that OT concepts are culturally sensitive has received considerable attention (Dyck, 1991; Krefting, 1991a; Kronenberg & World Federation of Occupational Therapists CBR Project Team, 2003; Skawski, 1987). Developed world occupational therapists have transferred OT theory and practice models to developing countries to identify the magnitude and nature of rehabilitation issues (Krefting, 1992). It is important to determine the appropriateness of developed world OT concepts in CBR in developing countries (Krefting, 1992; Sakellariou, Pollard, Fransen, Kronenberg, & Sinclair, 2006). Persons with disabilities should be studied within the context of their daily lives in order to truly conceptualize their real world and understand their rehabilitation issues (Spencer, 1993).

The Canadian Model of Occupational Performance (CMOP) -- “a conceptual
framework that describes occupational therapy’s view of the dynamic, interwoven relationship between persons, environment and occupation that results in occupational performance over a person’s lifespan” (Townsend et al., 1997, p. 32, 180) -- guided research activities in this study, facilitated the development and modification of data collection protocols, and provided further understanding of disabling conditions (see Figure 1). The CMOP describes the areas to consider in enabling occupation (M. Egan & Townsend, 2005). Empowerment is the basis for the model (Fransen, 2005).

The CMOP is viewed as an appropriate framework to understand the context and perceived rehabilitation issues of a population. The model provides a holistic view of the person, their environment, and their required and desired occupations. The flexibility of the model allows investigators to focus on a specific area (e.g., leisure) or look at issues broadly. The concepts underlying the CMOP have been used widely with diverse populations and allow for the collection of subjective data. The CMOP allows for knowledge to be organized around issues important to the community. I believe that the model’s conceptual base illustrated concepts that would be relevant to and easily understood by the research population. The holistic tenets of OT theory make it especially appealing for ethnographic research (Krefting, 1989). Since there is no consensus on how best to explore the perceived issues of young persons with disabilities, a variety of methods may be used to determine their effectiveness in seeking the perspectives of young persons with disabilities across diverse communities.

The connection between enabling occupation, empowerment, social inclusion and occupational justice has been made more explicit in recent years. From a critical perspective or worldview, OT aims to achieve greater social inclusion of persons with
**Occupational Therapy:** A health profession that uses occupation as a therapeutic medium to facilitate occupation with individuals, organizations and communities (p. 182).

**Canadian Model of Occupational Performance:** A 1997 conceptual framework that describes occupational therapy’s view of the dynamic, interwoven relationship between persons, environment and occupation that results in occupational performance over a person’s lifespan (p. 32, 180).

**Occupation:** Groups of activities and tasks of everyday life, named, organized, and given value and meaning by individuals and a culture; occupation is everything people do to occupy themselves, including looking after themselves (self-care), enjoying life (leisure), and contributing to the social and economic fabric of their communities (productivity); the domain of concern and the therapeutic medium of occupational therapy (p. 181).

**Occupational Performance:** The result of a dynamic, interwoven relationship between persons, environment, and occupation over a person’s lifespan; the ability to choose, organize, and satisfactorily perform meaningful occupations that are culturally defined and age appropriate for looking after oneself, enjoying life, and contributing to the social and economic fabric of a community (p. 181).

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Figure 1. Canadian Model of Occupational Performance (CMOP).  
Copyright © Canadian Association of Occupational Therapists (CAOT), 1997.  
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disabilities, facilitate changes in people’s environment, and helps people to re-adapt to their environments (Galheigo, 2005). For OT researchers to adopt a critical worldview, they must enable people to be the agents of social change and help them to inform changes at local, national and international service delivery levels (Townsend, Cockburn, Letts, Thibeault, & Trentham, 2007).

More recently, some authors have proposed that working for occupational justice should be the fundamental purpose of OT, which can be achieved through people-centered approaches (Townsend & Polatajko, 2007; Townsend & Whiteford, 2005). Occupational apartheid refers to situations where individuals are deliberately segregated or denied from participating in daily occupations due to oppressive political practices and forces; resulting in social, cultural and economic consequences that may jeopardize their health and well-being (Kronenberg & Pollard, 2005; Pollard & Sakellariou, 2008). Occupational injustice occurs when people’s participation in meaningful occupation is restricted, underdeveloped, marginalized, exploited or otherwise devalued (Townsend & Whiteford). Thus, occupational injustice occurs within the context of occupational apartheid (Kronenberg & Pollard). Wilcock and Townsend (2000) describe occupational justice as “equitable opportunity and resources to enable people’s engagement in meaningful occupations” (p. 85). Four forms of occupational injustice have been identified: i) occupational alienation (prolonged experiences of isolation and emptiness), ii) occupational deprivation (prolonged exclusion from participating in necessary and meaningful occupations due to external factors outside one’s control), iii) occupational marginalization (excluded from occupations due to living on the fringe of society), and iv) occupational imbalance (being un-occupied, under-occupied or over-occupied;
occupational segregation or discrimination on the basis of disability, gender, race or other differences) (Townsend & Wilcock, 2004). Describing these injustices suggests four occupational rights: the right to engage in personally meaningful and fulfilling occupations; the right to participate in diverse occupations that promote health and social well-being; the right to have choices in occupations and to participate in decision-making in everyday life; and the right to equal benefits from a range of occupations (Townsend & Wilcock).

Three fundamental aspects of OT knowledge include “participation in occupations (everyday life), enabling client-centered approaches (empowerment), and occupational justice (social inclusion)” (Townsend & Whiteford, 2005, p. 111). Empowerment is the process that links participation in daily life to the concept of occupational justice. Research on understanding the concept of empowerment both in theory and in practice is essential for achieving occupational justice. Having choice and control in occupations forms the basis of empowerment for individuals and is a key determinant of health (Townsend & Wilcock, 2004).

The concept of occupational justice broadens the understanding of social justice by offering new perspectives on injustices related to occupational participation and denial (Townsend & Wilcock, 2004). Social justice often concerns issues surrounding the unequal distribution of resources, human rights, and punishment for acts that violate social standards (Townsend & Whiteford, 2005). Occupational justice emphasizes moral and civic concern for people’s right to participate in daily occupations, which contributes to their health and quality of life (Townsend & Whiteford). A global vision of justice should be connected with local social, cultural, political and economic values that may
produce unfair restrictions to pursue occupations (Townsend & Whiteford).

Occupational therapy researchers may implement a variety of critical theories or methods to investigate people’s experiences of occupational justice and injustice in order to inform changes in social policies and structures (Townsend & Wilcock).

3.2 Critical Theory and the Critical Paradigm

Critical theorists are concerned with how historical and political contexts of a country, state or system directly or indirectly dominate the socio-cultural expressions of individuals including minority and marginalized groups (LeCompte & J. J. Schensul, 1999b). A number of theorists have contributed to the development of contemporary critical theory, including Freire (see Freire, 1970; Freire & Shor, 1987), Habermas (see Brand, 1990; Habermas 1984, 1987), and Foucault (see Rainbow, 1994; Tremain, 2005). Critical theory, within broader social theory, is concerned with how social issues such as power, justice, equality, rights, cultural tenets, language, ethnicity, class, gender, ability, and sexual orientation interact to form a social system (Kincheloe & McLaren, 2003; LeCompte & J. J. Schensul, 1999b).

Critically-oriented research is not just about increasing knowledge (Horkheimer, 1972), but aims to inform change and make public those forces that pose as obstacles for individuals to actively participate in making decisions about their lives (Kincheloe & McLaren, 2003). The fundamental purpose of critical social research is social justice, which is accomplished by empowered individuals working to achieve societal changes (Bathum, 2007). Change involves conditions taking a different direction or approach, or the process of transformation leading to an altered state (Townsend, Beagan, et al., 2007). The concept of social justice has been associated with the desire for a well-ordered
society, the right to basic equal liberty and opportunities, social and economic disparities that benefit the least-advantaged individuals, and offices and positions that are accessible to all under fair and equitable conditions and opportunities (Rawls & Kelly, 2001).

Empowerment is the desired outcome of critically-oriented research activities.

The theory of communicative action informed by Habermas (1984, 1987; see also Brand, 1990) provided greater understanding of two distinct forms of oppression: 1) lack of power and inequality results from unequal distribution of and access to material resources, and 2) lack of power and inequality results primarily from the privileging of certain public discourse and process of rationalization; power struggles are grounded in poor dialogue; resolving communication barriers is a strong starting point for developing new knowledge to inform social change (E. Chambers 1985; VanderPlaat, 1995).

The critical paradigm, informed by critical theory, promotes the idea that the world and reality are socially constructed and influenced by the socio-cultural and political context (LeCompte & J. J. Schensul, 1999b). Within the context of this study, I established working definitions for the socio-cultural and political contexts. The socio-cultural context concerns how a community’s values, beliefs and expected norms explicitly or implicitly inform how people interact or behave. The political context concerns how groups of people interact to make decisions, controlling or oppressive practices, the struggle for power and cooperation, the government, and ‘other’ activities that ‘govern’ people’s actions. Post-modern critique strengthens emancipatory projects by including groups who had previously been excluded because of race, class, gender (Kincheloe & McLaren, 2003), or in the case of this study, age and disability. Given modern society where many human situations require change (Spradley, 1980), I believed
it was insufficient to present the stories of a group of individuals as if they live in an isolated system. Instead, one must make visible the power and social relations that exist within groups (M. Fine & Weis, 2005). In this study I explored how adolescents with disabilities existed in relation to their peers, culture and community, and I facilitated a platform for adolescents to express their opinions and issues. Critically-oriented researchers act as intellectual advocates and determine through research, discourse, intervention, action or policy change, ways to promote change in power, values, resources and activities (LeCompte & J. J. Schensul, 1999b).
Chapter 4
Methodology

Entering the Urban Slums of Lal Kuan in New Delhi, India

I got up at 6:00am to prepare for my first field visit in the urban slums of Lal Kuan in New Delhi, India. I carefully placed my camera, tape recorder, notebook, pen, snacks and water bottle in my knapsack, and placed a tiny, almost unnoticeable lock on the large pocket of my knapsack because I did not want to offend anyone. I showered in my private bathroom and got ready in my private room. I put on a simple traditional Indian suit and secured my scarf across my chest by placing a safety pin on each shoulder; I wanted to ensure that I looked appropriate.

Since it was my first trip to the slum area, the organization I was affiliated with had sent me the disabled children’s mini-bus to take me to their Community-Based Rehabilitation (CBR) Program until I made alternative arrangements to go via an auto-rickshaw or taxi. The bus arrived outside my house at 8:00am and we were off. The co-ordinator of the CBR Program had described the area to me on several occasions. However, I did not know what to expect. I did not see any photographs of the area and I had not met the other CBR team members. Given all the preparation I had to do to get to this point, I knew I wasn’t going in with a ‘clean slate,’ but I wanted to keep an open mind. I felt a little anxious, a little weak in my stomach; I wasn’t sure if I was just nervous about embarking upon this new journey or if I was actually getting sick.

As the bus drove off, I looked excitedly out the window and suddenly it hit me -- I had just left one of the most posh areas in New Delhi (Greater Kailash II) and was about to conduct a study in one of the worst areas in Delhi (or so I had heard). After only a 25-minute bus ride, my bus stopped outside the entrance into the slum area. The bus driver had to fight his way through massive amounts of traffic in order to enter one slum area of Lal Kuan (i.e., Chungi No. 2). Vehicles were coming at us from all directions, and I felt as though our bus would get struck at any moment. The bus driver said, ‘Ma’am don’t worry, we are used to doing this daily!’ I gave a half-smile; I guess I was supposed to feel relieved.

When we finally made our way through the traffic, we drove down a very narrow and bumpy semi-dirt road. Here I was, finally, after months of preparation, in Lal Kuan. It took us approximately a couple of minutes to get to the CBR Program’s office. As the bus drove down the narrow road, I continued to look outside the window. I saw several people walking in the opposite direction. It appeared as though they were going towards the entrance of the secluded slum area in order to go to work or school. There were several small shops on either side of the narrow dirt road. I saw a shoe shop, a small eatery filled with men only, and a photography and video-recording studio. I saw a few women walking with veils covering their head. There were cows and dogs roaming around everywhere. I saw teenagers playing volleyball. I didn’t see any disabled children, but then I had just arrived. The most gruesome site I saw was a shop surrounded by a flock of dead chickens, and what seemed like tons of live chickens jammed in a metal cage ready to be slaughtered.

I did not write complete fieldnotes until I reached home, but I did write down a few words in my notebook while I was on site. As soon as the bus came to a stop outside the office, I quickly pulled out my notebook. Although it was a little chilly in the morning, it was a pleasant and sunny day; it was ironic how on such a bright day, the first word that I jotted down in my
Fieldnotes/Memos notebook was the word “dark”. It felt as if I had crossed over into another world, everything seemed so different. I was flooded with feelings about being very vigilant about how I presented myself and about the stories that I shared. I took a deep breath and for a moment I couldn’t help but think -- what have I gotten myself into!

The bus stopped at the CBR Program’s main base and I stepped out of the bus at approximately 8:30am. The immediate surroundings were loud, busy and very filthy. There was garbage everywhere and I could see feces all along the lanes next to the gutter. The foul smell was very strong. The CBR team members were sitting around and gave me one of the warmest welcomes that I had ever received. I was able to comfortably communicate with the five team members in Hindi, and it felt as though I had known them for a very long time. I was looking forward to spending the next few months with them, learning from them and seeking their assistance so that I could smoothly fit into their community in order to work with adolescents with disabilities and their peers without disabilities.

After the informal conversation with the CBR team, I tagged along with one of the team member’s on a community visit. The team was currently in the process of conducting a survey with parents who had children with disabilities. It gave me an opportunity to walk through the area. For the most part, families consisting of five, six or seven individuals were living in tiny ‘homes’ consisting of a small bedroom, a little living area, and a tiny kitchen; I did not see a bathroom, but then again, on our walk, I had seen several children going to the bathroom in the fields along the dirt road. Many questions ran through my mind: How and where did the adults and adolescents go to the bathroom? What about the girls? What about disabled children and teenagers who might need more assistance? Although it was only my first day, I began to build a picture about what daily life was like for the people living here.

As I walked back to the CBR Program’s main base, I saw a few young girls, approximately five, six, seven years old wearing tiny knapsacks either going to or returning from school. So I guess there were some things that seemed more promising in the area. After only a glimpse and taste of the area, one thing became very certain to me, it was fundamental for me to understand this environment and culture if I was going to have any chance of helping to inform change here for adolescents with disabilities. And so my journey began…

Excerpt from Researcher’s Fieldnotes & Memos, February 7, 2005

From the onset of this study, there was little argument against the notion that adolescents with disabilities who live in disadvantaged neighbourhoods in India have had little opportunity to express their perspectives, challenges and desires. The views of adolescents are rarely sought, often neglected, suppressed or excluded from program and policy initiatives. I raised concern about the efficacy of community-based rehabilitation (CBR) services when they fail to include the perspectives of adolescents.
4.1 Research Tradition: Qualitative Critical Ethnography

Critical ethnography, informed by critical theory and the critical paradigm, is an applied form of ethnography that is in search of knowledge to inform change (Creswell, 1998). Ethnography is the art and science of investigating and describing a social group, culture, subculture or cultural scene that includes the daily lives, routines, behaviours, values, beliefs, norms, dress, language, artifacts and attitudes that create a describable pattern in the lives of groups of people, communities or organizations (Fetterman, 1998; Germain, 1993; LeCompte & J. J. Schensul, 1999b; Morse & Field, 1995; Spradley, 1980). The interpretation of culture deals with three fundamental characteristics of human experience: 1) actions of people (cultural behaviour), 2) knowledge of people (cultural knowledge), and 3) objects or resources people create and use (cultural artifacts) (Spradley, 1980). It is best to view culture as a series of ‘control mechanisms’ (e.g., rules, norms and strategies) that direct human behaviour and thought, rather than a set of complex and concrete patterns of behaviour (e.g., habits, customs and traditions) (Geertz, 1973). In applied ethnography, the focus has shifted from studying a particular culture to investigating cultural processes and how particular groups associate and negotiate in an attempt to respond to human problems (E. Chambers, 2000).

Critical ethnography began to receive greater attention in North America in the 1980s (Quantz, 1992). Interest in the research tradition grew when anthropologists shifted their attention to studying formal organizations and institutions of work and education in American society, as a significant portion of the day was devoted to interactions and relationships within the realm of work and education (Giroux, 1992; Schwartzman, 1993). Ethnographic inquiry focuses on discovering people’s actions in
‘natural’ settings, learning from the emic or insider perspective through becoming
intimately involved with the cultural group or program under investigation, and critically
appraising actions (LeCompte & J. J. Schensul, 1999b). Many academics have criticized
the idea of the ‘natural setting,’ particularly in the developing world, as settings are
comprised of and sustained through cultural ideology and social strategies (Angrosino,
2005; Hammersley & Atkinson, 1983). What may seem to be common cultural practices
across oppressed persons may in fact be a response to their subordinate status (LeCompte
& J. J. Schensul, 1999b). Critical ethnographies can reveal how marginalized individuals
are situated in social and material relations, and how their social, political and material
disempowerment is manifested in cultural arrangements (Quantz).

To guide this study, I used the critical ethnographic approach as described in the
Critical ethnography as described in the toolkit was appealing for its modern-day view.
Critical ethnography was the most appropriate design for this study because the following
concerns’ that preceded entry into the field, were also reinforced through ongoing
fieldwork: i) an adolescent subculture was apparent within the larger Indian culture in the
slums, but it was inadequately understood; ii) there was limited understanding of the
subculture of adolescents with disabilities and their perceived rehabilitation challenges;
iii) the rehabilitation problems of adolescents were believed to be influenced by the larger
socio-cultural context, but the influence of the context was inadequately understood; iv)
the broader culture and adolescent subculture had to be explored in order to inform
changes in how the perspectives of adolescents were sought and applied, and to empower
adolescents with disabilities to take greater control over their rehabilitation and
community involvement; and v) it was necessary to use a range of strategies in order to comfortably collect data from adolescents. An action or applied component was integrated within the design of this study in order to support adolescents to search for practical solutions to personally meaningful problems; participants worked together to develop three documents that would inform organizational activities for the upcoming year. Post-modern ethnography encourages trying innovative and multiple strategies, and different modes of representation and literary approaches that lack authoritative styles (Van Maanen, 1995). Critical ethnography places significant focus on the nature of participation to improve participants’ abilities to develop new knowledge, create change, and empower themselves (Reason, 2004).

Transformation of social groups through critical dialogue and the demystification of cultural ideology is the fundamental aim of critical ethnography (Quantz, 1992). Critical discourse assumes that culture is a continuous political and social struggle over peoples’ representation within larger social arrangements (Quantz). Critical ethnography provides a means to understand praxis through speaking to daily challenges at a grassroots level (Quantz). Praxis refers to the practical application of new knowledge, applying theory to practice, and translating ideas into action (Greenwood & Levin, 2005). Characteristics of praxis include self-determination, deliberate, creativity, and rationality (Quantz). Praxis is a complex activity whereby individuals become critically aware beings (Quantz).

Giving young consumers a more powerful voice in the area of social and health care is receiving greater attention (Barlow & Harrison, 1996). This study provided a forum for adolescents with disabilities to openly share and reflect on their knowledge and
concerns about disability in their community, and to raise awareness of the social, political and cultural issues that diminish their quality of life. The research aimed to assist adolescents in becoming more aware of how the cultural context influenced the challenges faced by adolescents with disabilities, and how to utilize the research agenda to assume greater control over meaningful issues and occupations.

4.2 Research Questions and Objectives

Utilizing a critical ethnographic approach, this study highlighted disabled adolescents’ personal and shared rehabilitation challenges, explored how the broader culture and adolescent sub-culture influenced the daily lives and rehabilitation challenges faced by adolescents, and supported adolescents with and without disabilities in collaborating on a few agreed upon activities that would inform organizational activities and policies. The study provided greater insight into positive aspects associated with adolescents with disabilities, including the concepts of resilience and coping. My goal was to determine personally meaningful strategies that would make it more likely to empower adolescents with disabilities to i) take the initiative to express their concerns and desires, ii) assume greater control over their rehabilitation activities, and iii) become more involved within their community. The research problem in applied ethnographies is concerned with increasing understanding of socio-cultural and political problems and using the increased awareness to create positive change in groups, communities or organizations (S. Schensul, J. J. Schensul, et al., 1999). The research questions and objectives that guided this study are presented in Figure 2. An overview of the five-phases of this study is presented in Table 2. The study purpose and activities were integrated directly within ASTHA’s CBR Program initiatives. The central research
question implies how disempowering and controlling community practices may prevent adolescents with disabilities from embarking on meaningful rehabilitation occupations. Thus, the central research question focused on discovering personally meaningful strategies or processes for empowering adolescents with disabilities to assume greater control over their lives and rehabilitation activities.

**Figure 2. Central Research Question, Sub-questions and Objectives.**
Table 2. Five-Phases of Qualitative Critical Ethnographic Study.

| RESEARCH PHASES | PHASE I Pilot Testing Adolescents with Disabilities | PHASE II Adolescents with Disabilities | PHASE III Adolescents without Disabilities | PHASE IV Community-Based Rehabilitation (CBR) Team Members | PHASE V *Action/Applied Component* Participants from Phase II, III & IV
<table>
<thead>
<tr>
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</thead>
<tbody>
<tr>
<td><strong>Research Question</strong></td>
<td>How can an understanding of cultural influences and the subculture of adolescents help community-based rehabilitation programs to empower adolescents with disabilities to exercise greater control over their rehabilitation activities and become more vocal within their community?</td>
<td>To determine the utility of interview and observation protocols with young persons with disabilities.</td>
<td>To explore the culture and perceived rehabilitation challenges of adolescents with disabilities.</td>
<td>To describe a) the CBR program, and b) the role of the CBR team members in the lives of adolescents with disabilities.</td>
<td>1. To member check and do follow-up interviews. 2. To disseminate preliminary findings to adolescents, caregivers, and CBR team. 3. To use the preliminary findings and help adolescents to work together on agreed upon organizational activities (i.e., informing documentation/reports, annual plans, and local CBR policy). 4. To disseminate the three organizational documents developed by adolescents. 5. To explore the process of adolescents engaging in activities together.</td>
</tr>
<tr>
<td><strong>Objective(s) of each Phase</strong></td>
<td>To determine the utility of interview and observation protocols with young persons with disabilities.</td>
<td>To explore the culture and perceived rehabilitation challenges of adolescents with disabilities.</td>
<td>To investigate a) the culture and occupations of adolescents without disabilities, and b) the attitudes of young persons towards adolescents with disabilities.</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Sample Size</strong></td>
<td>2</td>
<td>21</td>
<td>11</td>
<td>5</td>
<td>30 Adolescents</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td>2 male</td>
<td>14 male; 7 female</td>
<td>5 male; 6 female</td>
<td>2 male; 3 female</td>
<td>17 male; 13 female</td>
</tr>
<tr>
<td><strong>Age Range</strong></td>
<td>12 - 16 years</td>
<td>12 - 18 years</td>
<td>12 - 17 years</td>
<td>35 - 39 years</td>
<td>13 - 20 years</td>
</tr>
<tr>
<td><strong>Sampling Method</strong></td>
<td>Convenience</td>
<td>Criterion, Purposive &amp; Opportunistic</td>
<td>Criterion, Purposive &amp; Opportunistic</td>
<td>Criterion</td>
<td>Criterion</td>
</tr>
<tr>
<td><strong>Fieldwork</strong></td>
<td>Jun-Aug 2004 Canada</td>
<td>Jan 2005-May 2005 - Trip #1 to India</td>
<td>Oct 2006-Mar 2007 - Trip #2 to India</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Location</strong></td>
<td>Community, Toronto</td>
<td>ASTHA’s Community-Based Rehabilitation (CBR) Program in the urban slums of Lal Kuan, New Delhi, India</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td><strong>Examples of Disabilities</strong></td>
<td>Polio, speech impairment, cleft lip/palate, visual impairment, hearing impairment, seizure disorder, mild down syndrome, spinal muscular atrophy, physical disability of the upper extremity, cognitive disability, and affected appearance.</td>
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<tr>
<td><strong>Strategies to Collect Data</strong></td>
<td>Demographic profiles, informal/casual interactions, daily observations and unobtrusive measures/outcroppings, semi-structured in-depth interviews, participant observation, focus groups, participatory development techniques, document review, photography and videography.</td>
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</tbody>
</table>

*Note.* Pilot testing is not normally completed as part of an ethnographic study. Pilot testing was completed for this study in order to prepare for activities that were going to be undertaken in India. Details regarding pilot testing are not presented in this doctoral dissertation, but may be requested from the author.
4.3 Study Site

Preferred settings for critical ethnographic studies are those that impede community development and prevent public expression (LeCompte & J. J. Schensul, 1999b). I selected ASTHA’s CBR Program in the urban slums of Lal Kuan in New Delhi, India for this study. New Delhi, the capital city of India, is a part of the union territory of Delhi. The population of Delhi is approximately 14 million people, making it the second largest metropolitan region in India (Maps of India, 2004). Lal Kuan is situated on the outskirts of New Delhi. Lal Kuan is a hilly area with deep quarries and narrow lanes spread over six square kilometers, and is divided into 11 blocks with a population of about 35,000 people. The majority of people are of the Hindu faith and Hindi speaking. There are an estimated 500 young persons with disabilities in the area (ASTHA, 2001).

4.4 Participant Recruitment

This section describes the process of recruiting participants by approaching appropriate gatekeepers; the sampling methods used; and the inclusion/exclusion criteria.

4.4.1 Gatekeepers

Ethnographic studies typically start with a gatekeeper who helps the researcher to initiate contact with potential informants (S. Schensul, J. J. Schensul, et al., 1999), be accepted by the research population (Hammersley & Atkinson, 1983), and gain access to information (LeCompte & J. J. Schensul, 1999b). ASTHA staff approached adult CBR team members to participate in this study, and I confirmed their willingness to participate. In collaboration with the CBR team, I recruited adolescents that agreed to participate in a long-term study. The CBR team helped me to recruit an exceptional case -- an adolescent with disability who was more involved in the community -- to compare and validate data.
4.4.2 Sampling Method

In an ethnographic study, informants who are knowledgeable or sensitive about the area of concern and who are eager to reveal information are most appealing (Hammersley & Atkinson, 1983). Criterion sampling which involves establishing criteria for studying select individuals that possess characteristics central to the study (Creswell, 1995; LeCompte & J. J. Schensul, 1999b), and purposive or opportunistic sampling which involves selecting appropriate participants while moving through the community and interacting with individuals (Agar, 1980; Germain, 1993), were the most appropriate sampling methods for this study.

4.4.3 Inclusion/Exclusion Criteria

The inclusion/exclusion criteria for this study are described in Table 3.

Table 3. Inclusion/Exclusion Criteria Based on 10 Areas.

<table>
<thead>
<tr>
<th>Domain</th>
<th>Criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>Adolescents had to be between 12 to 18 years of age at the time of recruitment.</td>
</tr>
<tr>
<td>Disability</td>
<td>Adolescents with disabilities had to identify themselves as having a disability or with the concept of disability, but not necessarily as being disabled.</td>
</tr>
<tr>
<td>Gender</td>
<td>Both male and female adolescents were included to remain consistent with the organization’s goal of promoting gender awareness.</td>
</tr>
<tr>
<td>Comprehension</td>
<td>Adolescents had to be able to demonstrate an understanding of the study.</td>
</tr>
<tr>
<td>Communication</td>
<td>Adolescents had to be able to verbally communicate.</td>
</tr>
<tr>
<td>Family Members</td>
<td>Once an adolescent was recruited, no opposite gender sibling or extended family member was recruited because it was believed that it might be uncomfortable for two siblings or cousins of the opposite gender to participate together.</td>
</tr>
<tr>
<td>Severe Disabilities</td>
<td>Adolescents with severe multiple impairments and/or severe developmental delay were excluded, as these individuals would likely present with significant challenges that were beyond the scope of this study.</td>
</tr>
<tr>
<td>Marital Status</td>
<td>Adolescents had to be unmarried. Participants who were in pre-marital romantic relationships at the time of recruitment were acceptable. Adolescents who were married and/or had children were excluded, as these individuals would likely present with issues/challenges that were beyond the scope of this study.</td>
</tr>
<tr>
<td>Consent</td>
<td>Primary caregiver(s) had to willingly consent for the adolescent to participate independently with little/no parental supervision. Adolescents had to willingly (without coercion from parents/CBR team) consent to participate. Verbal consent in the presence of another individual other than the investigator was sufficient.</td>
</tr>
<tr>
<td>Community-Based Rehabilitation (CBR) Team Members</td>
<td>All CBR team members were invited to participate. CBR team members had to demonstrate an adequate understanding of the study and provide written consent. CBR members were re-assured that failing to participate or choosing not to participate would have no impact on their role within the organization.</td>
</tr>
</tbody>
</table>
4.5 Participant Socio-Demographics

Twenty-one adolescents with disabilities, 11 adolescents without disabilities, and 10 adult CBR team members participated in this study. A summary of the socio-demographic data is presented in Table 4. Of the 32 adolescents who participated, 14 acted as key informants. Participants reported that this was the first time they comprehensively discussed their lives, experiences and culture, and were included in a research study.

All adolescent participants in this study were living at home with their immediate family members. The average age of adolescents was 14.3 years. There were more male than female participants. Both adolescent women and men appeared enthusiastic about participating in a research study. Adolescents were primarily of the Hindu faith and all participants communicated verbally with me in Hindi. Adolescents with disabilities had to identify themselves as having a disability or with the concept of disability.¹⁴ Nineteen participants with disabilities had visible or noticeable disabilities, while two participants had less obvious disabilities including a speech and hearing impairment. Participants with disabilities more often reported feeling dissatisfied with their appearance. Roughly half of the participants with disabilities reported or demonstrated difficulty with reading and writing in comparison to only one non-disabled adolescent. All adolescents without disability were going to school in comparison to only half of the adolescents with disabilities. Participants with disabilities who were not going to school or working reported greater boredom and lack of meaningful occupation in their lives.

¹⁴ I used the term ‘with disability’ or ‘disabled’ when discussing adolescents with disabilities, and the term ‘without disability’ or ‘non-disabled’ when referring to adolescents without disability. I seldom used the term ‘able-bodied’ for adolescents without disabilities because many adolescents with disabilities also considered themselves to be very ‘able’.
Table 4. Socio-Demographic Data.

<table>
<thead>
<tr>
<th>ADOLESCENTS</th>
<th>Adolescents with Disabilities</th>
<th>Adolescents without Disabilities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of Participants</td>
<td>21</td>
<td>11</td>
</tr>
<tr>
<td>Gender</td>
<td>14 Males; 7 Females</td>
<td>5 Males; 6 Females</td>
</tr>
<tr>
<td>Age in years at recruitment</td>
<td>Mean Age: 14.8; Range: 12 to 18</td>
<td>Mean Age: 13.7; Range: 12 to 17</td>
</tr>
<tr>
<td>Religious Beliefs</td>
<td>19 Hindu; 2 Muslim</td>
<td>9 Hindu; 1 Muslim; 1 Christian</td>
</tr>
<tr>
<td>Disability</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Note. Some participants presented with multiple disabilities.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Polio</td>
<td>11</td>
<td>N/A</td>
</tr>
<tr>
<td>Speech Impairment</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Cleft Lip/Palate</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Visual Impairment</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Hearing Impairment</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Seizure Disorder</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Mild Down Syndrome</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Spinal Muscular Atrophy</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Other - Physical Disability</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Other - Cognitive Disability</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Other - Appearance</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Attending School</td>
<td>10</td>
<td>11</td>
</tr>
<tr>
<td>Working</td>
<td>6</td>
<td>0</td>
</tr>
<tr>
<td>Not Going to School/Working</td>
<td>5</td>
<td>0</td>
</tr>
<tr>
<td>Communication</td>
<td>Hindi/Urdu Speaking 21 English Speaking 3</td>
<td>Hindi/Urdu Reading 13 Speaking 11 Reading 6 Speaking 10 Reading 8</td>
</tr>
<tr>
<td></td>
<td>Hindi/Urdu Writing 13 English Writing 4</td>
<td>Hindi/Urdu Writing 10 English Writing 8</td>
</tr>
</tbody>
</table>

COMMUNITY-BASED REHABILITATION (CBR) TEAM MEMBERS

| Number of Participants | 10 |
| Gender                 | 4 Males; 6 Females |
| Age in years at recruitment | Mean Age: 33.9; Range: 27 to 42 |
| Religious Beliefs      | 9 Hindu; 1 Muslim |
| Health Status/Disability | Normal/No Disability |
| Educational Background | Masters in Social Work 2 |
| Note: Some participants presented with multiple training. |
| Masters in Business Administration | 1 |
| Master of Arts | 1 |
| Bachelor of Arts | 1 |
| High School (Grade 12) | 4 |
| No Formal Education | 1 |
| Other - Certificate in Adult Education | 1 |
| Other - Certificate of Multipurpose Rehabilitation Therapist | 1 |
| Other - Specific Training Regarding Disability | 6 |
| Role Within Community-Based Rehabilitation (CBR) Program | Co-ordinator 2 |
| CBR Worker (from outside of the slum area) | 2 |
| CBR Worker (from within the slum area) | 1 |
| Community Teacher (from outside of the slum area) | 2 |
| Social Worker | 1 |
| Rehabilitation Therapist | 1 |
| Communication | Hindi/Urdu Speaking 10 English Speaking 6 |
| | Hindi/Urdu Reading 9 English Reading 7 |
| | Hindi/Urdu Writing 9 English Writing 7 |
4.6 Data Collection

This section describes the data collection process including the fieldwork schedule; the instruments and procedures; and the multiple methods for data collection.

4.6.1 Fieldwork Schedule

I made two separate trips to India to collect data. Trip one was from January 2005 to May 2005, and the second trip was from October 2006 to March 2007. I spent eight to nine months in Lal Kuan over a period of two years. I worked four to five days per week for five to six hours per day in order to immerse myself in the community, develop rapport, and gain long-term knowledge of participants and their environment.

4.6.2 Instruments and Procedures

Upon entering the field, I had informal conversations with adolescents about the treatment of adolescents with disabilities in the community, and whether adolescents wanted to discuss issues they deemed important and have a greater say in the issues that affected them. After I conducted the first few interviews with adolescents, I was better able to adapt the study to be relevant to local concerns. I collected data with participants in Hindi. Adolescents’ commitment to the study over two years reflected that the study purpose was important to their aspirations. I did not assume the role of an advocate or more assertive individual until my second trip to India when I was more familiar with the socio-cultural context, aware of adolescents’ views, involved in disseminating information, and able to facilitate adolescents’ working collectively to identify their issues and desires.

4.6.3 Multiple Data Collection Methods

I tried to present my role as the ‘student or learner’ and adolescents’ role as the
‘teacher’ to break down power differences, but many adolescents continued to view me as an authority figure using statements including, “I’m talking too much sister, you should talk now.” Cultural practices appeared to hinder adolescents from speaking their mind or speaking too much in the presence of an authority figure. Considering the socio-cultural context, age, disability, educational qualifications and lack of opportunity, I utilized multiple methods to collect data to ensure that adolescents could comfortably express their views. Data was collected and collated from the strategies outlined in Table 5. See Appendix B to view the 15 data collection protocols and guides for this study.

Table 5. Data Collected and Collated.

<table>
<thead>
<tr>
<th>Data Collection Methods</th>
<th>Description/Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>42 Demographic Profiles</td>
<td>Collected from adolescents and CBR team members.</td>
</tr>
<tr>
<td>57 Individual Interviews</td>
<td>Conducted with adolescents. Each ranged from 45 to 120 minutes.</td>
</tr>
<tr>
<td>25 Follow-up Interviews</td>
<td>Conducted with adolescents. Each ranged from 30 to 90 minutes.</td>
</tr>
<tr>
<td>7 Focus groups</td>
<td>5 focus groups with adolescents approximately 120 minutes each. Regarding adolescents’ collective understanding of disability; the Disability Day Celebration in the community; the CBR Program’s plan for 2007; and designing a page for the organization’s annual report.</td>
</tr>
<tr>
<td>25 Follow-up Interviews</td>
<td>2 focus groups with the CBR team approximately 120 minutes each. Regarding the team’s understanding of and work with adolescents.</td>
</tr>
<tr>
<td>8 Participant Observation Sessions</td>
<td>Observations of adolescents carried during a school day, typical day, Teacher’s Workshop, Arts &amp; Crafts Workshop, Special Olympics practice, and Disability Day Celebration.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>7 Participatory Development Techniques</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>31 Impact Drawings</td>
<td>Drawn by adolescents. Regarding personal understanding of disability.</td>
</tr>
<tr>
<td>27 Typical Day Schedules</td>
<td>Completed by adolescents. Regarding individual daily routine.</td>
</tr>
<tr>
<td>27 List of Problems</td>
<td>Completed by adolescents. Regarding problems faced by adolescents.</td>
</tr>
<tr>
<td>27 Force Field Analyses</td>
<td>Completed by adolescents. Regarding future goals/resources required.</td>
</tr>
<tr>
<td>1 Group Tree Diagram</td>
<td>Completed by a group of adolescents. Regarding their collective understanding of disability.</td>
</tr>
<tr>
<td>1 Group Fishes (adapted to Cars) and Boulders</td>
<td>Completed by a group of adolescents. Regarding their collective understanding of facilitators and barriers.</td>
</tr>
<tr>
<td>Group List of Problems</td>
<td>Completed by a group of adolescents. Regarding their collective understanding of problems experienced by young women and men, and adolescents with and without disabilities.</td>
</tr>
</tbody>
</table>

| 2 Journal Entries | Submitted independently by two adolescents. |
| 16 Client Files | Reports on adolescents with disabilities obtained from CBR Program. |
| 8 Organization Documents | Regarding ASTHA’s CBR Program. |
| 100+ Informal Interactions | With adolescents and CBR team members. |
| Daily Observations | Initiated immediately upon entering field. |
| 682 Photographs and 35 Videos | Facilitated recollection of large amounts of data gathered over a span of two years. Provided greater appreciation of adolescents’ involvement. |
Core or primary data included demographic profiles, individual and focus group interviews, participatory development activities, observational fieldnotes, journal entries, and fieldnotes from informal interactions. Supplementary or secondary data included organizational documents, client files obtained from the program, photos and videos. Not all methods yielded rich information from all participants. Some adolescents preferred to share their ideas via written accounts, while others were eager to talk about their issues. Multiple methods of data collection, a thick description (Geertz, 1973), and verbatim quotation (Fetterman, 1998) can help to contextualize data to see the larger perspective.

Focus should be placed on the quantity and quality of data collected. Collecting endless amounts of data does not ensure high quality data, but research has shown an association between length of time in field/quantity of data and the comprehensiveness of the study (LeCompte & J. J. Schensul, 1999). In the following sections, I discuss the application of some of the data collection methods utilized in this study.

*Participant Observation*

Participant observation is the signature data collection method for ethnographic research (Spradley, 1980). Participant observation may provide insight to the researcher that may normally be denied to the formal or external researcher (Lohman, 1937), may help to corroborate or contradict information provided verbally or in a written manner by participants, and is helpful in studying the perspectives and meaning of occupations for young persons with disability (Spitzer, 2003).

Spradley’s (1980, p. 78) participant observation checklist was used to guide observations in this study (see Appendix B, p. 217). Participants were aware that they were being observed during activities or generally. My role as an observer ranged from
being moderately (i.e., observation of a typical day at school or home) to being actively (i.e., attendance at the Disability Day Celebration in the slums) involved.

*Individual In-depth Semi-Structured Interviews*

Interviewing is a complex act requiring consideration of multiple dimensions of culture, boundaries, ethics and format (Fontana & Frey, 2005). Ethnographic interviews are often semi-structured, one-on-one interactions that may mirror a friendly conversation, but have greater direction (Hasselkus, 1990; S. Schensul, J. J. Schensul, et al., 1999; Spradley, 1979). Foley and Valenzuela (2005) describe the use of a conversational style of interviewing and the sharing of greater personal information than the conventional interviewer as a way to increase participation. I conducted interviews with participants in their first language. I used a semi-structured interview guide to facilitate the conversation. I used broad open-ended questions to generate discussion (e.g., tell me about your friends), and used more direct questions to probe when participants demonstrated difficulty providing details (e.g., how many friends do you have; what do you do with your friends; what do you like about your friends). I encouraged adolescents to share stories that provided greater insight into their views. To ensure that I did not lose data to mechanical malfunction, I used two cassette recorders to tape interviews.

*Focus Groups*

Focus groups elicit information that is difficult to obtain from individual interviews or for which you require a collective understanding (Hoppe, Wells, Morrison, Gillmore, & Wilsdon, 1995; J. J. Schensul, LeCompte, Nastasi, & Borgatti, 1999). Focus groups tend to provide more multivariate accounts of social, cultural and political influences (Kamberelis & Dimitriadis, 2005). Colucci (2007) promoted the inclusion of
fun or productive exercises or activity-related questions within focus groups with young people. These techniques encourage young people to respond more actively and promote depth within discussions. Focus group data must be analyzed considering the group context, as data cannot be separated from the group context (Carey & Smith, 1994).

Focus groups were an important data collection method for this study because adolescents found the group setting to be “fun,” and focus groups elicited information on the group context, group concept and group empowerment. Conducting focus groups was an overwhelming task for me as the sole investigator; I was responsible for attending to several factors simultaneously including body language, communication style, group dynamics, emotions, nature of information provided, probing for further information, and my role as the facilitator. I set several conditions for conducting focus groups in this study. First, the purpose of the focus group determined the number of adolescents to invite. The first focus group had 11 participants, the second had six, the third had seven, the fourth had 11, and the fifth had seven. A large number of participants were invited to any given focus group to ensure that an adequate number of individuals attended; larger focus groups resulted from more participants showing up than was expected. The two larger focus groups involved an introductory session and discussions and activities in smaller groups, where I facilitated small group sessions and then brought together all participants at the end. Second, all groups were mixed gender to remain consistent with the organization’s aim of promoting gender awareness. Third, I shared expectations regarding respect and confidentiality at the beginning of focus groups. Fourth, information collected via written or visual activities was shared, read and explained by participants to ensure that it was interpreted and translated accurately. Fifth, I audio-
taped, video-taped and photographed all focus groups with consent in order to review group dynamics (transcripts alone appeared to de-contextualize the group data). I analyzed data at the group level for sequence of events, activities, behaviours and interactions, collective responses, and response to the group setting. I used primarily focus groups to gather data during the applied/action phase of the study when adolescents worked together to develop three organizational documents (see Table 6).

Table 6. Three Organizational Documents Developed by Adolescents.

<table>
<thead>
<tr>
<th>DOCUMENT #1</th>
<th>DOCUMENT #2</th>
<th>DOCUMENT #3</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Title</strong></td>
<td>Report and Documentation on <em>Disability Day Celebration</em> in Lal Kuan</td>
<td>Comments and Feedback on <em>ASTHA Plans and Budget 2007 Next Steps Project</em> Report</td>
</tr>
</tbody>
</table>
| **Purpose** | - *World Disability Day* is celebrated annually on December 3.  
  - The Community-Based Rehabilitation (CBR) Program held a Disability Day Celebration in the urban slums on December 1, 2006 to raise disability awareness.  
  - Approximately 200 community members attended the day’s festivities/events.  
  - Questions remained as to how young disabled consumers felt about the event.  
  - Adolescents were responsible for documenting the subjective aspect of the event.  
  - Perspectives of young consumers are important to determine the strengths of such events, to improve activities, and to obtain/allocate funding and resources. | - The Community-Based Rehabilitation (CBR) Program prepared a document about its core beliefs and upcoming activities. The 15-page document was entitled: *ASTHA Plans and Budget 2007 Next Steps Project*.  
- Perspectives of young people were overlooked in the development of such documents due to the complexity of the documents, time restraints, lack of support, and cultural views that questioned their abilities.  
- There was consensus that i) adolescents had not been asked about the upcoming activities, and ii) adolescents were not always aware of the magnitude of the activities (e.g., film shows; exposure visits; workshops; rallies) to make informed choices.  
- Adolescents were able to review the document and voice their opinions.  
- Understanding the perceived issues and desires of the target population is crucial for investing time, allocating resources, and promoting sustainability. |
| **Developers** | 6 adolescents with disabilities who had i) participated or performed in the Disability Day Celebration, and/or ii) attended the entire celebration to watch the program. | 4 adolescents with disabilities and 3 adolescents without disabilities. |
| **Title**   | *ASTHA’s Community-Based Rehabilitation Programme in Lal Kuan: The Voices of Adolescents with and without Disabilities*, Page designed for *ASTHA’s Annual Report 2008-2009* | |
| **Purpose** | - Adolescents were to design a page for ASTHA’s Annual Report that highlighted the messages they wanted to convey to community members.  
  - Adolescents decided what information to include (e.g., descriptions; quotes, photographs; drawings), and wrote and selected a few specific quotes to be published. | |
| **Developers** | 18 adolescents actively participated in developing this document. Work of all adolescent research participants contributed towards the development of this document. | |
Participatory Development Techniques

Participatory development techniques are used to gather information on community and disabled persons’ issues in a visual form (R. Chambers, 1997; Mosaic.net International, n.d.; Rifkin & Pridmore, 2001). Commonly associated with participatory research, participatory development techniques have been reported to provide great insight into the lives of community members, their difficulties and values (R. Chambers). Participatory development activities are being utilized more frequently in community research; however, the literature is descriptive in nature and provides limited statistical information on the reliability or validity of these techniques (R. Chambers; Rifkin & Pridmore). With greater emphasis being placed on child-centred practices, various strategies must be explored to elicit information from young people from diverse cultural backgrounds (Pridmore & Bendelow, 1995). I utilized several participatory development techniques in this study. Participants completed impact drawings, which reflected their individual understanding of disability. Adolescents developed a schedule of their typical day and a list of problems experienced by adolescents. Participants completed a force field analysis to highlight their present and future goals, the resources required to achieve their goals, and the obstacles that may prevent them from achieving their goals. I used fishes and boulders (adapted to cars and boulders) to learn about adolescents’ collective understanding of barriers and facilitators. Two examples of participatory development techniques used in this study are illustrated in Figure 3 and Figure 4. Written and visual strategies helped to support, reinforce and complement data in this study in a more enticing and complex way, and to promote further discussion.
Figure 3. Tree Diagram (Participatory Development Technique). Illustrates adolescents’ understanding and meaning of disability on ‘leaves’. The actual ‘tree’ developed was two metres high and contained several leaves (Developed by adolescents with and without disabilities during a focus group on the ‘Understanding of Disability’, April 22, 2005).

Figure 4. Cars and Boulders (Participatory Development Technique). More commonly known as the ‘fishes and boulders’ activity. Illustrates adolescents’ views regarding facilitators (cars) and barriers (boulders) in the lives of adolescents with disabilities. The actual ‘road’ was five metres in length and included several big circles (big problems), medium circles (medium problems), small circles (small problems), and cars (facilitators to deal with problems) (Developed by adolescents with and without disabilities during a focus group on the ‘Understanding of Disability’, April 22, 2005).
Writing Ethnographic Fieldnotes

Writing a ‘sound and true’ ethnography is highly contingent upon writing comprehensive fieldnotes from interactions and observations, and being able to adequately analyze and interpret those fieldnotes (Emerson, Fretz, & Shaw, 1995). In this study, I divided fieldnotes into three sections, including generic fieldnotes about the community and memos about my personal reflections; individual fieldnotes for each participant; and fieldnotes for group activities. When appropriate, I wrote basic fieldnotes at the fieldwork site, and then wrote detailed fieldnotes upon returning home. During the second trip to India, I dictated fieldnotes directly into my computer using © Dragon Naturally Speaking Preferred 8.1 software (ScanSoft, 2004).

Audio-Visual Data: Photography and Videography

Photos and videos served as supplementary sources of data in this study. Audio-visual data provide great potential to further study occupations and the multiple contexts across which occupations take place (Pierce, 2005). Audio-visual data allow for the continuous review of data, greater interpretation of non-verbal behaviour, and further analysis of the physical environment (Hammersley & Atkinson, 1983; J. J. Schensul, LeCompte, Nastasi, et al., 1999). Despite growing interest in audio-visual methods to collect data in health research, there is little information on criteria for quality, how to accurately manage and analyze the data (e.g., interpreting videos frame-by-frame; sequenced photography; comparison of software), and ethical issues (Close, 2007).

Although photos and videos were not systematically analyzed, they were helpful in the recollection of large amounts of data collected across a variety of situations over a span of two years. Audio-visual data stimulated interest during dissemination sessions
and member checking, and highlighted the extensive involvement and abilities of adolescents. Photos and videos provided support for many salient themes that emerged. I considered the influence of photography and videography on the setting. Participants were aware when being photographed or audio and video-recorded. I used a digital camera to take most photos and videos. Photos and videos became a supporting component of fieldnotes. I labeled photos and videos based on the activity they captured.

4.6.4 Saturation of Data

Data was collected as feasible and until saturation (repetition of data for general areas of concern and for some major categories that were emerging) appeared to occur; signifying that an adequate amount of data had been collected to reflect the salient themes and patterns (Streubert & Carpenter, 1995). Saturation of data appeared to occur after gathering data with 15 adolescents with disabilities; I recruited another six adolescents with disabilities to help ensure that little new information was emerging. I found similar issues and challenges emerging when discussing general areas of concern for adolescents, including family relations, friendships, daily life and occupation, community setting, school, work, and romantic relationships and marriage. I also wanted to ensure that some of the major categories that were emerging during the preliminary analysis were saturated during data collection in trip two. For example, the socio-cultural response to disability was emerging as an important category; thus, I ensured that little or no new properties that defined this idea were occurring.

4.6.5 Translation and Transcription

Data collected in Hindi was transcribed into English text. I made all efforts to maintain the integrity of the data (i.e., preserve the meaning, tone, order of words, and
repetition). I transcribed approximately 30% of the Hindi data into English text; the rest was completed by transcriptionists in India and Canada. Transcriptionists initially transcribed a sample tape (one shorter interview) so I could assess the quality of their work and determine whether they were suited to complete further transcription. I checked all the work completed by transcriptionists for accuracy.

4.7 Impression Management in Field

Building Rapport

Often explicit and implicit rules of doing research in the developed world do not easily translate to the developing world. I was aware that as an unmarried woman of South Asian descent traveling alone to engage in a study in the slums, I had to take care of my appearance and behaviour. Community members became aware of and accepted my role within the CBR Program. To avoid influencing adolescents’ responses or distancing them, I monitored my behaviour and stories to ensure that they were culturally compatible. I wore a traditional Indian suit, a salwar kamiz, at the fieldwork site. I shared many meals with participants. Adolescents were eager to learn about my personal and professional background. I addressed participants’ curiosity and maintained consistency in the information I discussed by sharing a personal photo album of my family, friends, university and residence in Canada after I collected demographic data. I focused on understanding local dialects and the ‘nuances’ associated with communication, including the term “affair” that referred to a romantic relationship between single, unmarried individuals, and “eve-teasing” that referred to the harassment of women.

Establishing positive working relationships with the community and adolescents evolved over time. My experience of building rapport with participants contradict
accounts that suggest foreigners may have difficulty in establishing trusting relationships with local participants (Swedish Organisation of Disabled Persons International Aid Association & World Health Organization, 2002). Sharing a similar ethnic background and being able to communicate in the local language was important in maintaining positive relationships with locals. Being a Canadian appeared to add an element of excitement and curiosity to the entire research process.

**Compensation and Exchange of Gifts**

There has been increased criticism of social researchers who fail to explain how such things like the exchange of gifts influence the researcher-participant relationship (Davis, 2000). Exchange of gifts to say thank you is customary in the Indian culture. I compensated adolescent participants and the CBR team for their time in a manner that was viewed appropriate by the organization, including providing snacks or lunch and small stationary items. At a formal dissemination session during my second trip to India, I provided adolescents with a gift pack that they understood was a way to recognize their hard work during the study; the package included stationary items, a scarf or shirt for males, hair or make-up accessories for females, and snacks. Upon completion of fieldwork, I gave adolescents a personal photo album that reflected their involvement over the course of the study. Given the timing when compensation gifts were distributed and the ongoing commitment of adolescents to the study, it appeared that adolescents had a genuine interest in the study; the gifts did not appear to entice participation.

Several adolescents had given me gifts during the study. I requested adolescents not to bring me gifts, but this had little effect on their actions. I discussed receiving gifts with the CBR team who recommended that I keep them, as they were ‘inexpensive,’
often hand-made art work, and a kind gesture by adolescents. A farewell event was arranged by ASTHA which indicated that the study had a positive effect on participants.

4.8 Ethical Considerations

This study was viewed as a part of ASTHA’s CBR Program’s daily activities and as a means to move their goals and mission forward, and not as a stand-alone project. Queen’s University Research Ethics Board (REH-220-04) and ASTHA, a registered charitable trust, approved this study. Confidentiality statements were signed by transcribers and individuals who had access to the research material. See Appendix C for ethics documents and Appendix D for information, consent and confidentiality forms.

Developed world literature has addressed ethical issues concerning research with young people (Dashiff, 2001; Jenkins & Parron, 1995; Petersen & Leffert, 1995). The articles provide information on the contextual factors that should be considered when doing research with young people, but provide little insight into the complexities of ethical situations in the developing world. Given power imbalances, adults must ensure that participating in a study does not bring harm upon young participants (Davis, 1998).

Ethical considerations concerning illiteracy and lack of familiarity with concepts such as privacy and confidentiality were addressed in a culturally appropriate manner. Once a potential adolescent participant was identified, a CBR team member and I would explain the purpose of the study and ask the adolescent if they were interested in participating. If the adolescent consented, the CBR team member or I would explain the study to the adolescent’s primary caregiver. Verbal consent from caregivers and adolescents in the presence of another individual sufficed. I regularly explained ethical issues to adolescents and obtained verbal consent prior to initiating any activities (e.g.,
two adolescents refusing to participate in one activity and one potential participant declining to participate suggested to me that adolescents understood the consent process. While adolescents shared personal information willingly, I confirmed with participants and also used my own judgment to determine which information was culturally appropriate and safe to include in the study.

The ethics process for this study was distinct from more conventional methods because of the ‘open’ environment in the slums. Community members were beginning to identify adolescents as taking part in some large activity, especially after dissemination sessions. However, this should not be mistaken for community members finding out about sensitive information shared by specific participants. Adolescents’ becoming known for their role as a research participant was viewed positively.

4.9 Quality Control: Trustworthiness and Rigour

The credibility of qualitative data depends significantly on the openness of informants to disclose sensitive information, and the rapport established between a researcher and participants (Lawlor & Mattingly, 2001). Trustworthiness is the term used to describe the soundness or accuracy of a study, and the truth-value or believability of the findings (Lincoln & Guba, 1985). Rigor is the ability to refer to alternative or competing explanations, and account for irregularities in data (Morse & Field, 1995).

Addressing several areas can help to establish trustworthiness in qualitative research (Krefting, 1991b). Credibility deals with submersing oneself within the research in order to better identify and verify recurrent patterns. Transferability involves providing a dense description of the research process and findings in order to allow others to determine the applicability of the research across various settings. Dependability
concerns the consistency of the findings. Confirmability deals with an external auditor being able to follow the research process or being able to reach comparable conclusions given the same data and context. Specific criteria or strategies have been established within these areas to allow researchers to enhance the credibility of their qualitative research projects (Creswell, 1998; Krefting, 1991b; Lincoln & Guba, 1985). The strategies described in Table 7 helped me to enhance the credibility of this study.

4.10 Dissemination: Knowledge Translation and Transfer

Dissemination of research findings on a continuous basis is critical to ensure the applicability of ethnographic research. Participants and key stakeholders should be involved in various stages of the decision-making process and program development (J. J. Schensul, LeCompte, Hess, et al., 1999). The process of disseminating information was integrated within the design of this study. ‘New’ knowledge was translated and transferred in a culturally sensitive, appealing and creative way at a local level to community members. Research findings were disseminated via a visual form, including photographs, videos, presentations on laptop computers, and sharing hard copies of documents. Establishing a welcoming environment and encouraging community members to ask questions and comment on information being shared was important to ensure that knowledge was being adequately understood. Formal dissemination sessions associated with this study are described in Table 8. I hope that knowledge transfer activities will encourage communities like Lal Kuan to embrace strategies for empowering young people with disabilities.
Table 7. Strategies to Enhance Trustworthiness and Rigour.

<table>
<thead>
<tr>
<th>Strategies</th>
<th>Application to Doctoral Study</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Audit Trail</strong></td>
<td>Retained all raw data, emails, schedule of activities, and feedback.</td>
</tr>
<tr>
<td>Ensuring that all research decisions are transparent for others to follow the process (Krefting, 1991b).</td>
<td></td>
</tr>
<tr>
<td><strong>Reflexivity</strong></td>
<td>Completed a subjectivity statement and a SWOT (strengths, weaknesses, opportunities, threats) Analysis to reflect on researcher role.</td>
</tr>
<tr>
<td>Reflecting on how the researcher’s background, views, and interests may influence the research (Krefting, 1991b).</td>
<td>Kept a field journal to record personal thoughts, feelings and biases.</td>
</tr>
<tr>
<td><strong>Prolonged Field Experience</strong></td>
<td>Spent increased time in field to ensure data, analysis and interpretations were based on long-term knowledge versus initial hunches.</td>
</tr>
<tr>
<td>Spending increased amount of time in field to rely on rich, long-term knowledge (Krefting, 1991b).</td>
<td></td>
</tr>
<tr>
<td><strong>Rich, Thick Description</strong></td>
<td>Provided significant methodological, contextual and demographic details.</td>
</tr>
<tr>
<td>Providing detailed information about the research setting, and participant demographics and accounts to allow others to determine credibility and the transferability of findings to alternative settings (Creswell, 1998).</td>
<td>Results supported by multiple quotes and activities from adolescent participants.</td>
</tr>
<tr>
<td><strong>Triangulation</strong></td>
<td>Used multiple methods ranging from conventional methods to less frequently used written and visual strategies to collect data.</td>
</tr>
<tr>
<td>Using multiple and different data collection methods, sources and theories to offer corroborating evidence (Creswell, 1998).</td>
<td></td>
</tr>
<tr>
<td><strong>Negative or Exceptional Case Contribution</strong></td>
<td>Some change had occurred in Lal Kuan since the CBR Program was established. Thus, located and analyzed an exceptional case (a female adolescent with a disability who was vocal and involved within the community) to avoid being selective with data collection and analysis, and to strengthen the findings that were applicable to the majority of adolescents.</td>
</tr>
<tr>
<td>Searching for aspects of data that do not support emerging patterns (Charmaz, 2006), which may offset the problem of selective data collection and analysis (Hegelund, 2005), and improve credibility of the analysis (Krefting, 1991b). Negatives cases can help to refine the analysis/emerging theory and explain for the majority of patterns.</td>
<td></td>
</tr>
<tr>
<td><strong>Member Checking</strong></td>
<td>Member checked data with participants during data collection to ensure information was being understood correctly.</td>
</tr>
<tr>
<td>Reviewing accuracy of emerging results and interpretations with participants (Creswell, 1998).</td>
<td>Given the 17 month gap between the two trips to India, preliminary findings were checked to ensure their applicability before embarking on the applied phase.</td>
</tr>
<tr>
<td><strong>Review of Translation and Transcription</strong></td>
<td>Checked data that was transcribed by others.</td>
</tr>
<tr>
<td>Re-visiting data and engaging in a code-recode procedure on the data especially during the analysis phase (Krefting, 1991b).</td>
<td></td>
</tr>
<tr>
<td><strong>Re-visiting Data</strong></td>
<td>Became increasingly familiar with data through transcribing data/checking transcripts.</td>
</tr>
<tr>
<td><strong>Peer Debriefing</strong></td>
<td>Discussed research decisions and findings with the advisory committee, graduate students, and the organization in India.</td>
</tr>
<tr>
<td>Providing an external check of the data through sharing ongoing research decisions and emerging findings with peers (Creswell, 1998).</td>
<td>Research issues and preliminary findings were presented at four conferences to learn from the reflections/feedback of colleagues.</td>
</tr>
</tbody>
</table>
Table 8. Local Formal Dissemination Sessions.

<table>
<thead>
<tr>
<th>Date and Presenter</th>
<th>Target Audience</th>
<th>Purpose</th>
<th>Culturally Sensitive Strategies Applied</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>November 24, 2006 By Sonia Gulati, PhD Researcher</td>
<td>10 Community-Based Rehabilitation Team Members</td>
<td>To disseminate preliminary findings from trip one to India, and reinforce the ongoing purpose of the study.</td>
</tr>
<tr>
<td>2</td>
<td>December 17, 2006 By Sonia Gulati, PhD Researcher</td>
<td>Approximately 45 community members, including adolescents with and without disabilities and their caregivers.</td>
<td>To disseminate preliminary findings from trip one to India, and reinforce the ongoing purpose of the study.</td>
</tr>
<tr>
<td>3</td>
<td>February 19, 2007 By Sonia Gulati, PhD Researcher</td>
<td>5 Community-Based Rehabilitation Team Members</td>
<td>Final formal presentation completed for CBR team members to discuss the three organizational documents developed by adolescent participants and strategies for continued involvement.</td>
</tr>
<tr>
<td>4</td>
<td>February 22, 2007 By Sonia Gulati, PhD Researcher</td>
<td>ASTHA’s director and assistant director.</td>
<td>Discussed the three organizational documents developed by adolescents, adolescents’ suggestions to improve organizational activities, and strategies to sustain study goals.</td>
</tr>
<tr>
<td>5</td>
<td>April 2007 By Anurodh, CBR Team Member</td>
<td>ASTHA staff members</td>
<td>To share the purpose and outcome of research with the entire ASTHA staff.</td>
</tr>
<tr>
<td>6</td>
<td>December 2007 By Radhika, Former ASTHA Director</td>
<td>Adolescents in the Lal Kuan community</td>
<td>To discuss strategies for the ongoing participation and involvement of adolescents in the community based on the goals of the study.</td>
</tr>
</tbody>
</table>
In this chapter I have explained the components of ethnography; described participant demographics and the social setting in which the study was conducted; explained the process for participant recruitment; provided an overview of the multiple strategies for data collection; discussed ethical considerations; and described the strategies used to enhance the credibility of this study. I continuously discussed methodological issues with the CBR team to ensure that the study activities could be effectively integrated within their organizational initiatives. The study purpose was embraced by the organization, as it fit well with their mission and goals.
Chapter 5

Ethnographic Data Analysis

To guide data analysis, I followed the process outlined in the *Ethnographer’s Toolkit* (Volumes 1 to 7) edited by LeCompte and J. J. Schensul (1999). The process for analyzing ethnographic data is both recursive and iterative; beginning as soon as the researcher enters the field until the entire project is completely written (LeCompte & J. J. Schensul, 1999a). Ethnographic analysis involves connecting, separating and interpreting the multiple data collected in order to make sense of the data as a whole. I selected LeCompte and J. J. Schensul’s (1999) approach to analysis because it provided a comprehensive approach to analyze data from initial entry into the field all the way through to higher and complex levels of analysis. Their approach to analysis is inclusive of ‘critical’ ethnography and theory, allowing the researcher to interpret data beyond higher levels of thematic analysis and model building to assessing program and policy relevance and emphasizing the concept of voice. The ongoing analytical process involved several steps and strategies, which I discuss in detail throughout this chapter.

5.1 Analyzing Core (Primary) versus Supplementary (Secondary) Data

Given the different types of data typically collected in an ethnographic study, it is important to distinguish between core or primary data and supplementary or secondary data in the analytical process (LeCompte & J. J. Schensul, 1999a). Although all data collected in this study played an important role in interpreting and supporting major overarching ideas, not all data was analyzed with the same intensity or held the same weight. The analytical process for core data is discussed in subsequent sections in this chapter; the role of supplementary data analysis is discussed in this section.
Review of Videos and Photos

Within the context of this study, I did not analyze videos frame-by-frame or photos using sequenced photography. Videos and photos facilitated my understanding of the group setting, provided support for adolescents’ view of the group setting being fun, and reinforced adolescents’ desire to interact with their peers, as was indicated by frequent chit-chatting, laughter and comfortable body language; elements that were often overshadowed when reviewing standard transcripts and fieldnotes.

Review of Documents

Organizational documents and client files provided information in four areas: the past, present and future activities of the CBR Program; main activities of the CBR Program; role of adolescents in the development and implementation of CBR activities; and whether CBR activities were consistent with adolescents’ preferences. A review of these documents indicated that a significant amount of time was devoted to providing mobility aids and equipment, facilitating educational opportunities including admission to school, and assisting with obtaining a disability certificate. Adolescents appeared to play no role in the planning of major activities; this issue was confirmed by adolescents. I found these documents to be helpful in generating options for activities that adolescents could work on during the applied phase of this study.

5.2 Overview of the Analytical Process

I compared data across adolescents with and without disabilities and analyzed data collected from the CBR Program because I expected that adolescents would initially use the CBR Program as a way to help themselves. I present how I adapted and applied the analytical process outlined by LeCompte and J. J. Schensul (1999a) in Figure 5.
Stage 1: In-Field Analysis

- Revising and solidifying the research question and problem.
- **Inscription** (making mental notes and jotting down words or phrases for later recall), **description** (elaborating on ideas to produce fieldnotes with thick descriptions), and **transcription** (transcribing audio-visual/written information, and photographing/videotaping).
- **Preliminary analysis** of data collected during trip one to India (initial reflections/interpretations; asking refined questions; data analyzed manually resulted in 10 initial overarching categories).
- Member checking and dissemination of initial overarching categories.
- **Negative (or exceptional) case** (adolescent with a more active role/voice in the community) sought to compare and validate data collected with the majority of adolescents with no voice.

Stage 2: Tidying Up & Organizing Data

- Organizing data based on ‘genre files’ (i.e., interviews; focus groups; observation sessions) for easy retrieval and comparison of the collective understanding rather than individual cases.
- Translating and transcribing interviews and written documents from Hindi into English.
- Converting data into electronic form.
- Managing data using a filing system and electronically with © QSR NVivo 7/© Microsoft Word.

Stage 3: Analysis from the Bottom-Up: The Item Level

- **Item level analysis** involved the process of naming/labeling items or elements in the data (e.g., transcripts; fieldnotes) by reviewing data line-by-line (for key informants) and event-by-event (for remaining adolescent informants) in order to identify broad meaningful units, to order and classify such items or units, and to establish initial codes.

Stage 4: Identifying Patterns and Structures

- **Pattern level of analysis** involved establishing connections and linkages among items that had been ordered and classified.
- **Structural level of analysis** involved organizing the relationships among patterns into structures.

Stage 5: Assembling Components, Structures and Constituents: Higher Level Interpretation and Model Building

- **Higher level interpretation** involved bridging together key structures and the ongoing theoretical memos to give greater meaning to structures in relation to existing information (e.g., the research concern; organizational initiatives; concept of empowerment; critical theory).

Stage 6: Creating Interpretations & Program/Policy Relevance

- **Design and implementation of applied component** (i.e., development of organizational documents by adolescents with and without disabilities highlighting their desires and preferences).
- **Advocating for the relevance of the findings** for program sustainability and intrinsic value.
- Knowledge translation and transfer at a local and organizational level to facilitate further data collection and analysis, and ongoing dissemination of results in a culturally sensitive manner.

Figure 5. Stages of the Analytical Process (adapted and applied to this study).
5.3 Mapping Social Contexts and Social Networks

The analysis of ethnographic data is a multifaceted process embedded in multiple social contexts and networks (LeCompte, J. J. Schensul, Weeks, & Singer, 1999; J. J. Schensul, LeCompte, Trotter II, Cromley, & Singer, 1999). I reviewed the accumulating data to discover the underlying social contexts and network of relationships, and to form further questions and interpretations of the impact of the socio-cultural environment. Reviewing fieldnotes from observations and informal interactions assisted in the mapping of social contexts and networks (e.g., conversations about school led me to observe a typical day at school and pursue discussions with the CBR team and parents about school). The common map of social contexts and social networks that evolved is presented in Figure 6 and Figure 7. The process of mapping social contexts and networks was essential given the purpose of this study since the empowerment of adolescents is both relational and relative. That is, empowerment occurs within the context of a specific network of relationships and interactions and during a specific period of time.

5.4 Item, Pattern and Structural Levels of Analysis, and Model Building

Item, pattern and structural levels of analysis are used to develop models and conceptual frameworks that illustrate information about the central research question or concern. To manage, code and conduct higher level analysis with core data, I entered 86 documents into © QSR NVivo 7 software (Qualitative Solutions Research International, 2006). Coding is a process for labeling aspects of data, separating specific elements, and sorting data into distinctive categories (LeCompte & J. J. Schensul, 1999a; Walsh, 2003). Analysis was an inductive process; no pre-defined categories or patterns were applied to the data.
Figure 6. Notion of Embedded Social Contexts (applied to this study).
Source: Idea adapted from LeCompte, J. J. Schensul, Weeks, and Singer (1999, p. 3)

Figure 7. Concept of Mapping Social Networks (applied to this study).
Source: Idea adapted from J. J. Schensul, LeCompte, Trotter II, Cromley, and Singer (1999, p. 35)
Item Level of Analysis

Item level analysis aims to identify naturally occurring items or units in the data, and attempts to order, classify and code such items (LeCompte & J. J. Schensul, 1999a). Documents in this study were coded line-by-line (for key informants) or event-by-event (for remaining participants) to establish free nodes or units, codes, and categories. Free nodes were developed using words and phrases directly from the documents. I named segments of data using “gerunds” in order to preserve the sense of action and process, as described in Charmaz (2006, p. 49). A total of 1589 initial free nodes were developed. This ‘free nodes list’ can be viewed as a comprehensive list of all the different labels or broad units that emerged from the data. To help distinguish between the free nodes that emerged from the different types of data, I used ‘square brackets’ to reflect free nodes from fieldnotes, the word ‘observation’ to indicate free nodes from observational data; all other free nodes were from interview or written data (this helped to enhance the credibility of the study because it illustrated when higher level concepts were supported by different types of data). I began to write memos that reflected my thoughts about the emerging data and higher level concepts. I continued to add to memos and developed new memos through the pattern and structural levels of analysis. I provide an example of how I conducted initial coding on a passage from an interview in Figure 8.

I examined the list of free nodes for items that supported the research questions and for broader themes, and to establish codes (shorter names or labels that represented a group of similar or specific items or ideas). I provide an example of some generic codes developed during data analysis in Figure 9. I reviewed, updated and applied codes as data analysis progressed. A codebook consisting of a list of codes was kept electronically.
Example

Passage from a semi-structured in-depth interview with a female adolescent with disability (translated from Hindi into English text):

Investigator: …Tell me [about any] problems, difficulties or tensions [faced by] disabled adolescents who are from 12 to 18 years of age.

Participant: …They (disabled adolescents) hesitate from going in front of new people. They think that their disability will appear awkward to others, all this will be wrong with [them]. They cannot comfortably mingle and talk with others. They remain hesitant and they remain stressed by all these things. They don’t want to appear in front of anyone, they don’t want to see anyone because inside [them] there are such problems that from seeing [them] they don’t want anybody to tease [them]. They remain scared that someone will tease them or that someone will say something to [them], so they don’t want to go out much or go in front of [others] or go in front of some new person mainly; they don’t like it…Their courage because of their disability, their strength decreases…

Line-by-Line Coding (naming/labelling segments of the data) & List of Free Nodes:

-(disabled adolescents) hesitating to go in front of new people
-(disabled adolescents) thinking that disability will appear awkward to others
-(disabled adolescents) cannot comfortably mingle with others
-(disabled adolescents) remaining hesitant and stressed
-(disabled adolescents) not wanting to appear in front of or see others
-(disabled adolescents) sensing problems within themselves
-(disabled adolescents) avoiding others to prevent being teased
-(disabled adolescents) remaining scared of being teased
-(disabled adolescents) not wanting to go in front of new people mainly
-(disabled adolescents) losing courage and (internal) strength due to disability

Memos (queries and conceptual reflections):

- Adolescents with disabilities feeling anxious about meeting new people or being around people in general; this appears to be a daily struggle. If this is the case, it must be a very challenging and overwhelming, as the slums are very crowded.
- Showing signs of low-self esteem or poor self-image.
- Being overly cautious about what others think about them or how others might react towards them.
- Assessing self-worth or judging value of self based on the reaction of others.

Figure 8. Example of Line-by-Line Coding and Conceptual Memos (based on a passage from a semi-structured in-depth interview).
Example

1.0 AFFAIRS (Definition: Pre-marital male and female romantic relationships)
   1.1 Exist & Desired among Adolescents
   1.2 Adolescents’ Reaction
   1.3 Community’s Negative Response – – – –
   1.4 Impact on Family
   1.5 Meaning of Love
   1.6 Boundaries set by Adolescents
   1.7 Modes of Communication
   1.8 Disabled Adolescents’ Affairs

   Sample of some specific items under code ‘1.3 Community’s Negative Response’:
   • Affairs being condemned by the general community
     o free node: not letting anyone come to know about the affairs
     o free node: hiding affairs from the community
     o free node: affairs not being suitable for poor people
     o free node: poor people’s way of thinking being different
     o free node: community members not accepting affairs

   Sample of some specific items under code ‘4.3 Nature of Harassment’:
   • Disabled adolescents experiencing extensive name-calling
     o children & adolescents using derogatory names -
       free nodes: calling disabled adolescent monkey because of facial disfigurement & parrot because of disfigurement of hands
     o free node: calling disabled adolescents crippled
     o free node: calling disabled adolescents deaf and dumb
     o free node: calling disabled adolescents a lame
     o free node: calling disabled adolescents handicapped
     o free node: girls and boys calling disabled adolescents names
     o free node: being called names at school
     o free node: being called names in the community

4.0 BULLYING (Definition: Act of intentionally harassing, intimidating or harming a weaker individual through verbal, emotional or physical abuse)
   4.1 Boys Harassing Girls
   4.2 Non-Disabled Harassing Disabled
   4.3 Nature of Harassment – – – – – –
   4.4 Community’s Role & Responsibility
   4.5 Stopping Bullying

Figure 9. Example of Generic Codes (developed during data analysis). Codes are names use to represent a group of similar ideas. Codes were given shorter names that represented more concrete items to which they were applied.
Pattern Level of Analysis

Pattern level of analysis aims to establish connections among items that have been classified or grouped together (LeCompte & J. J. Schensul, 1999a). I examined each group of codes to see how they related to one another and organized them into higher-order patterns or cultural domains. Patterns consisted of groups of items that conveyed a particular idea, occurred frequently, or represented a consistent set of actions. Patterns or categories were given higher order conceptual labels.

I analyzed data simultaneously for explicit and implicit cultural factors that influenced information shared by participants. A cultural domain is a set of items, beliefs, behaviours or events that are defined by participants as belonging to the same cultural group or category, and shape how people conceptually understand and organize their world (S. Schensul, J. J. Schensul, et al., 1999). Cultural domains concern people’s perspectives on culture and not their preferences (J. J. Schensul, LeCompte, Nastasi, et al., 1999). I focused on depicting only selected cultural domains that I believed to be related to the perspectives and challenges of adolescents with disabilities. Codes and categories were organized hierarchically as branching tree diagrams with sub-categories and sub-sub-categories (see Figure 10 for an example). I continued to move important or significant categories forward in the analytical process.

Structural Level of Analysis

Structural level of analysis aims to link and find consistent relationships among patterns (LeCompte & J. J. Schensul, 1999a). As the analysis progressed, I assembled more data of patterned pieces to form structures until the most complete understanding of the data emerged. I illustrate item, pattern and structural levels of analysis in Figure 11.
Figure 10. Example of a Tree Diagram (providing a glimpse into the conceptual taxonomy for the cultural domain or pattern ‘socio-cultural response to disability’; a taxonomy is a visual representation of the hierarchical ordering of items and the relationships among items; this cultural domain reflects participants perspectives regarding the socio-cultural environment, and describes how the world is organized in the eyes of participants).
Figure 11. Example of Item, Pattern and Structural Levels of Analysis (illustrates items, sub-patterns and patterns being ordered hierarchically; once items have been identified and assembled into patterns and larger structures, they can be further manipulated to explore interrelationships and to create models).
Model Building

To further interpret relationships among patterns and structures, I regularly revisited the research question to identify relevant patterns and structures, and to group together ideas, codes and patterns relating to the concept of empowerment for further analysis (see Figure 12 for an example). Interpretation requires an understanding of patterns and structures in relation to previous or new theoretical foundations and paradigms (LeCompte & J. J. Schensul, 1999a). A framework evolved from constant questioning and theoretical memos to identify cultural, community and program operations, and how they supported or hindered adolescent empowerment.

5.5 Data Management

I managed data using a filing system and electronically using © QSR NVivo 7 software (Qualitative Solutions Research International, 2006). The software was helpful in managing transcripts and fieldnotes; for establishing free nodes, codes and tree diagrams; for writing ongoing reflective and theoretical memos; and for higher-level thematic analysis. I initially analyzed a small amount of data manually, and then entered it into the software for higher-level analysis. I also analyzed smaller amounts of data directly within © Microsoft Word (Microsoft, 2003).
Example of Higher Level Analysis (illustrating one process for further manipulating items, patterns and structures to address the central research question, which led to the development of one personally meaningful process for empowering adolescents with disabilities and their peers).

**Examples of:**

**Pattern:** CBR Program encouraging adolescent involvement

**Sub-Pattern:** CBR team promoting social interactions among adolescents

**Sub-Pattern:** CBR team praising adolescents with disabilities for performance

**Memo:** Important for adolescents to receive help to move their personal agendas forward

**Sub-Pattern:** CBR team increasing gender awareness

**Video Footage and Photos:** CBR team coordinating high-profile event regarding disability awareness in the community

**Structure:**

**Need for Supporting Factors**

3 Supporting Factors:

- i) Facilitating (adolescent participation)
- ii) Highlighting (adolescent strengths and abilities)
- iii) Encouraging (ongoing participation)

* Includes data (items; patterns; structures) concerning the perspectives, preferences and desires of adolescents.

Regarding the Research Question/Concern

Personally Meaningful Ways for **Empowering** Adolescents

Figure 12. Example of Higher Level Analysis (illustrating one process for further manipulating items, patterns and structures to address the central research question, which led to the development of one personally meaningful process for empowering adolescents with disabilities and their peers).
Chapter 6

Critical Ethnographic Findings: The Adolescent Group Empowerment Pyramid

6.1 Introduction to ‘Adolescent Group Empowerment’

The central focus of this research was to elicit ways to empower adolescents with disabilities and their peers within the urban slums of Lal Kuan. From ongoing fieldwork and data analysis, I gradually illuminated those factors that strengthened adolescents’ desire to take a more active role in their lives and rehabilitation. I developed a conceptual framework called the ‘Adolescent Group Empowerment Pyramid’ that presents one meaningful process for empowering adolescents with disabilities and their peers without disability within a community setting. Adolescent group empowerment refers to adolescents with disabilities working towards assuming greater control over their lives, rehabilitation activities and community involvement while collaborating with their peers. Group empowerment is achieved through enabling group-centered occupations. Group occupations are determined by and are meaningful to adolescents, and have a greater sense of purpose and direction. The ‘group’ concept provided the foundation for the framework because adolescents consistently viewed the group setting as the most fun, desirable and effective way of getting involved. The Adolescent Group Empowerment Pyramid was informed by adolescents’ stories and actions, the documents adolescents developed, the discussions I had with adolescents about their participation in CBR, and my observations of adolescents and their environment. Numerous socio-cultural factors influenced the adolescents’ perspectives. In this chapter, I illustrate what these young people want in an environment that they describe as overly conservative and as exerting significant control over their choices, actions and occupations.
6.2 The Adolescent Group Empowerment Pyramid

A visual representation of the Adolescent Group Empowerment Pyramid is presented in Figure 13. Four central themes were identified. The ‘pyramid’ or the core of the framework illustrates three personally meaningful areas for empowering adolescents: group participation, group demonstration, and group recognition; the outermost border of the framework shows the entire pyramid being superimposed on the notion of the socio-cultural environment and its interaction with disability. Adolescents consistently expressed the significant impact and control of the socio-cultural environment on persons with disabilities, the difficulty the community had in accepting and respecting persons with disabilities, and how challenging it was for people to look beyond a person’s disability. Three external support factors important for maintaining ongoing adolescent group empowerment and ten areas for nurturing the group empowerment process are presented and discussed later in the chapter.

Group participation describes disabled adolescents’ desire to engage in group occupations with their peers. Adolescents highlighted the importance of attending to control, quality and demographic factors in order to enable active group participation. The desire for group participation resulted mainly from contextual barriers that provided few opportunities for adolescents with disabilities to interact with their peers, including pressure to conform to traditional gender roles, little decision-making power, inability to attend school or work, and lack of meaningful occupations and social support. Group participation was linked to the notion of group demonstration. Group demonstration describes disabled adolescents’ desire to present their abilities while collaborating with their peers. Adolescents highlighted the importance of attending to the purpose, process
and audience in order to engage in successful group demonstrations. The desire for
group demonstration resulted mainly from the lack of opportunity that adolescents with
disabilities had to challenge discriminatory socio-cultural attitudes that questioned their
capabilities and right to live a fulfilling life. Group demonstration was seen as a
liberating way for educating community members. Group demonstration was linked to
receiving group recognition at the individual, peer group and community level. Group
recognition describes disabled adolescents’ desire to be recognized for their abilities
rather than their disability; adolescents wanted to be recognized for their contribution to
the group effort. Adolescents with disabilities believed that greater recognition would
help them to address the rejection they faced by their non-disabled peers, benefit from
similar opportunities as their peers, and access important resources and interventions.

The Adolescent Group Empowerment Pyramid highlights what the participants
believed was important for adolescents to integrate fully into the community, challenge
discriminatory attitudes and the philanthropic view of persons with disability, inform
local change of the substandard treatment of disabled adolescents, and improve one’s
overall self-worth. The framework provides one means for developing and strengthening
the qualities that typically define empowerment, including being able to express oneself;
greater perception of control, making decisions, greater self-esteem, and greater access to
opportunities. The framework broadens the understanding of empowerment by including
the concepts of participation, demonstration and recognition as a means to liberating
young people. Findings discussed throughout this chapter are based on the ‘slum’ culture
of one community in a specific locality, and a group of adolescents who willingly chose
to participate in the study. Contemporary Indian names have been used for pseudonyms.
Figure 13. Adolescent Group Empowerment Pyramid. Highlights one process for empowering adolescents with and without disabilities within a community-setting at a grass-roots level. Group empowerment is achieved through enabling meaningful and purposeful group-centered occupations.
Throughout this chapter, I will describe the four components that form the Adolescent Group Empowerment Pyramid: 1) group participation, 2) group demonstration, 3) group recognition, and 4) the socio-cultural environment’s interaction with disability. I also discuss the two additional overarching concepts important for sustaining adolescent group empowerment: i) the three supporting factors, and ii) the ten nurturing factors. I explain how these components emerged. I share the stories and quotes of many participants to reflect the contribution they made to my understanding of the collective voice, and to demonstrate the congruence between the components and data.

6.2.1 Significance of Group Participation in Empowering Adolescents

Participants continuously reflected on community members’ general lack of concern for disability. Disability was seldom seen as a priority given the multiple issues people continued to struggle with, including inadequate employment and housing, financial hardships, and the inability to meet basic needs. Sheila, a woman without a disability, described the community’s apathy towards people with disabilities:

> Everyone is only worried about themselves here. … ‘Why should we help the disabled? What do they do for us?’ … These sorts of thoughts come into their mind.

*(Sheila, 17 year-old Female without Disability, Follow-up Interview)*

My observations of the community and discussions I had with participants revealed that the setting, Lal Kuan, was characterized by the following details:

- Low socio-economic status and blue-collar or labour class employment.
- High illiteracy rate and low education rate.
- Patriarchal or male dominated, and traditional or stereotypical male and female roles.
- Close-knit and interdependent family structures, and increased respect for elders and parents.
- Adults exercising increased control over children and youth, especially females.
- Increased incidence of domestic abuse, violence, bullying, sexual assaults, substance use and petty crimes.
- Community gossip, and decisions and activities highly influenced by community views.
- Condemn premarital sexual or romantic relationships and opposite gender friendships.
- Support for arranged marriage and having children at a young age (under 18 years).
- Increased problems with access to water and electricity, and poor sanitation and hygiene.
Adolescents with and without disabilities found it very appealing to participate in a group with their peers in order to inform changes within their community. Participating in a group setting involved more than simply bringing adolescents together; adolescents described it as negotiating relevant occupations to work on and as determining group characteristics that would promote lively participation. I present these elements as the bottom layer of the Adolescent Group Empowerment Pyramid in Figure 14.

![Figure 14. Bottom Layer of the Adolescent Group Empowerment Pyramid. Highlights the importance of group participation (i.e., participating together in a group) desired by adolescents and the three important factors (control, quality and demographics) associated with meaningful group participation. Group participation forms the foundation on which the other central components (group demonstration and group recognition) of the group empowerment process are developed.](image)

Why is the notion of group participation desired by adolescents with disabilities, and why are the elements control, quality and demographic factors important for meaningful group participation? Adolescence is a time when individuals may have a particularly amplified need for being involved with their peers. Participants in this study expressed a strong desire to engage in social and work-related activities with other youth and make friends. To truly appreciate their desire to be with their peers, I had to develop a better understanding of adolescent perspectives on disability and the issues that influenced adolescents’ preference to participate in a group.

6.2.1.1 Emergence of Group Participation

One of the most significant issues influencing adolescents’ desire to meet with
their peers concerned the pressure they faced to conform to traditional gender roles, which prevented or limited them from interacting with friends and other youth in the community. The value of Indian adolescents and young adults was highly contingent upon their ability to contribute to the fabric of the family and household. For females this entailed taking care of the home, and bearing and raising children. For males it required being able to provide financially. Traditional gender roles were prevalent in the area with the exception that many young girls were attending school and were now responsible for both homework and housework. Young women carried out the bulk of housekeeping tasks, including cooking, laundry, cleaning and caring for siblings. Many young women disliked engaging in housekeeping tasks, but felt the need to support their mothers and sisters. Young women spent a considerable portion of their day at home; leisure time was even characterized by home-based activities such as watching television or movies, listening to music, working on sewing tasks, and talking to friends. Family members often escorted young women to the market. Adolescent women longed for greater freedom, social interaction and engagement in occupations outside their home, and expressed their frustration about not being able to negotiate for greater liberty with their family. Unlike women, adolescent men were responsible for running household errands and dedicating their time to studying. Young men were more likely to be involved in employment activities such as working at commercial shops. Able-bodied males spent more time playing, hanging out with their friends and engaging in hobbies. However, young men with disabilities reported feeling isolated within their home and spending most of their time sitting idle watching television. Ricky, a young man without a disability, acknowledged the boredom experienced by many adolescents with disabilities:
Disabled children have to sit at one place all the time getting bored. And the children who are fit, they keep jumping and playing.
(Ricky, 13 year-old Male without Disability, Follow-up Interview)

Adolescent men with disabilities especially reinforced their desire to interact and socialize with other youth, and engage in meaningful, age-appropriate occupations.

In addition to the home environment and immediate community, participants also acknowledged the lack of opportunities disabled adolescents had for peer interaction because they were unable to attend school. Although increasingly more adolescents with disabilities were attending government schools, many (particularly females) were unable to gain admission into schools; those who were admitted, were more likely to drop out due to difficulty traveling to school, an inaccessible school environment, and lack of resources to meet their special needs. Angela, a young woman with disabled siblings, voiced her frustration against those parents who isolated their disabled children and prevented them from benefiting from similar opportunities as their non-disabled peers:

People don’t educate disabled children here. They keep them at home and control them fully…. They should give them the knowledge, they are also human!
(Angela, 17 year-old Female without Disability, Individual Interview)

Adolescents with disabilities who were attending school were enrolled in mainstream educational settings where other classmates were typically much younger. I observed adolescents with disabilities standing alone during social periods at school and generally interacting less with their classmates. Non-disabled adolescents added that disabled children would often “just sit and watch students play at school” (Nitin, 15 year-old Male without Disability, Individual Interview). Another young man with a disability reported that, “only the teacher talks to disabled children” at school, while “other children continue to tease disabled children” (Omar, 15 year-old Male with Spinal Muscular Atrophy, Individual Interview). Adolescents demonstrated little understanding of the
purpose underlying mainstream education. Adolescents with disabilities had mixed
feelings about being in mainstream educational settings (i.e., wanting to study with
‘good’ (non-disabled) students, but disliking the harassment they experienced by their
peers). The following queries emerged about mainstream education after I consolidated
the information shared by adolescents: To what extent are we promoting the notion that
disabled children ought to be with and interact with non-disabled peers? To what extent
are we eliminating the choice and freedom of youth with disabilities? And to what extent
are we able to effectively mainstream young people with disabilities into resource-limited
educational systems in developing countries? Participants reported that greater exposure
to disabled peers at school may alleviate the stereotypes and discomfort associated with
interacting with adolescents with disabilities.

Given the harassment adolescents with disabilities experienced, they appeared to
be forced into distancing themselves from others, as Sabrina described:

Disabled adolescents hesitate from going in front of new people. They think that their
disability will appear awkward to others. … They cannot comfortably mingle and talk
with others. They remain hesitant and they remain stressed by all these things. … They
remain scared that someone will tease them or that someone will say something to them.
(Sabrina, 17 year-old Female with Speech Impairment, Individual Interview)

Participants suggested that friendly, non-threatening opportunities for social interaction
might lessen disabled adolescents’ hesitation to initiate interactions with others.

Adolescents discussed the long-standing history of disabled youth having small or no
social support networks. Kumar, a peer without a disability, shared his concern about
adolescents with disabilities leading a lifestyle characterized by loneliness and isolation:

If disabled adolescents don’t have any friends, don’t have any support, they feel that they
are alone. They think that they have no one in this world.
(Kumar, 14 year-old Male without Disability, Individual Interview)

Melanie, a young woman with a visual impairment added:
There are some things that disabled adolescents cannot talk about with their parents. We think that there should be somebody who can understand us.

(*Melanie, 15 year-old Female with Visual Impairment, Journal Entry*)

Participants reported that adolescents with disabilities could seldom “find anyone with whom they could talk openly and tell about their problems, sadness and pain”

(*Angela, 17 year-old Female without Disability, Individual Interview*). Adolescents’ accounts suggested that the impact of family and environmental factors, including an inaccessible physical environment and unaccommodating social attitudes was more influential on disabled adolescents’ social participation than the nature of their disability.

Davinder, a young man with a hearing impairment, reflected on the isolation disabled adolescents experienced in his impact drawing in Figure 15. Omar highlighted physical barriers and the dangers of the physical environment in his drawing in Figure 16.

![Impact Drawing: Isolation](image)

*Davinder, 12 year-old Male with Hearing Impairment, March 22, 2005.*

Figure 15. Impact Drawing: Isolation. Illustrates a male adolescent with a disability sitting on a chair inside his home (centre). The disabled boy remains isolated in his home and can only look outside through the window. (*Davinder, 12 year-old Male with Hearing Impairment, March 22, 2005*).
Participants discussed three dominant features that distinguished disabled adolescents sub-culture from that of non-disabled adolescents: i) spending increased time isolated in their home, ii) having to overcome multiple hurdles daily, and iii) engaging in activities at a slower rate. Participants believed that these characteristics reinforced disabled adolescents’ eagerness to participate in group-centered occupations with their peers.

6.2.1.2 Desire for Control: Active Group Participation

The family was viewed paradoxically as one of the greatest supports and obstacles for adolescents to achieve their goals. Adolescents described their parents and siblings as being helpful in work and school related endeavours, escorting them for social outings, providing them money, spending leisure time with them, lessening the impact of mobility restrictions, and assisting them with their activities of daily living. However, adolescents also described their families as preventing them from engaging in social activities with friends, pressuring them to marry, providing them little funds to advance their hobbies,
and occasionally preventing them from working or attending school. Angela, a key informant in the study, communicated adolescents’ frustration over having little freedom and playing a minimal role in day-to-day decision-making:

> Children cannot do much here; they don’t have much say. We children have no freedom. … It’s the worst feeling of all. … We children want to improve the community here, but no one allows us to do it. We can’t do anything.

*(Angela, 17 year-old Female without Disability, Individual Interview)*

This frustration was especially pronounced for adolescents with disabilities who had even less or no power in decision making. Leena, a woman without a disability, added how parents contributed to the lack of freedom experienced by disabled adolescents:

> Some parents do not allow disabled children to go outside. [Parents say], ‘No, you are disabled, what if someone makes you fall, you won’t be able to defend yourself.’

*(Leena, 16 year-old Female without Disability, Individual Interview)*

Adolescent women with and without disabilities appeared to experience many similar struggles as disabled adolescents. They reported significant frustration over being controlled, silenced and forced to respect their submissive role. Thus, the idea of actively participating with peers (e.g., being able to express one’s opinions) became increasingly appealing to adolescents. Rita, a woman with polio who was another key informant in the study, shared her view of taking charge to improve one’s life:

> It’s not like God will come down to change something – you will have to change it!

*(Rita, 16 year-old Female with Polio, Focus Group)*

Given the high degree of control exercised over adolescents, all adolescents desired more opportunities to engage in activities with their peers. However, non-disabled adolescents did not always report with the same intensity the desire to demonstrate or be recognized.

### 6.2.1.3 Desire for Quality: Meaningful Group Occupations in Group Participation

Participants provided constructive feedback to the CBR Program about making rehabilitation activities more relevant and appealing for adolescents. Adolescents
appreciated having choice in the activities they collaborated on with their peers, as was
described by Rita, who participated in the Disability Day Celebration that was organized
by the CBR Program to promote disability awareness in the community:

   On Disability Day this is important that the disabled get together and make something. …
   It’s not that you have to do this thing, no, whatever one wishes to do.
   (Rita, 16 year-old Female with Polio, Focus Group)

Despite adolescents’ desire to participate in several personally meaningful
occupations that promoted greater interactions among disabled/non-disabled and
male/female peers, participants raised legitimate concerns about the discrepancy between
what they found personally meaningful and what was considered culturally appropriate or
acceptable. Adolescents found it challenging to advance in a community that was
portrayed as overly traditional. This created a significant dilemma for adolescents
because they did not want to disrespect or bring shame upon their families. However,
Kumar argued that only through collaborating on meaningful activities can people with
and without disabilities help to improve the quality of life of young people:

   If non-disabled and disabled adolescents get together and do things, then maybe this
   world would be better.
   (Kumar, 14 year-old Male without Disability, Focus Group)

6.2.1.4 Consideration of Demographic Factors in Group Participation

As I explored the developmental stages of Indian adolescents, results indicated
that adolescents with and without disabilities expressed many similar desires and
challenges (e.g., learning about the opposite gender and spending time with friends). I
illustrate the perceived developmental milestones of Indian adolescents in Table 9.
Adolescents’ accounts provided support for bringing together adolescents with and
without disabilities to simultaneously address the many issues relevant to all participants.
Table 9. Perceived Developmental Milestones in Adolescents.

<table>
<thead>
<tr>
<th>Perceived Developmental Milestones in Adolescents</th>
<th>Descriptions from Adolescent Participants…</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Adolescence Brings Changes in Terms of…</strong></td>
<td>Sharing characteristics with children/adults.</td>
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<tr>
<td></td>
<td>Don’t belong to youngsters group or elders.</td>
</tr>
<tr>
<td></td>
<td>Becoming more mature and understanding.</td>
</tr>
<tr>
<td><strong>Transitioning from Childhood to Adulthood</strong></td>
<td>Thinking Changes:</td>
</tr>
<tr>
<td></td>
<td>• Adolescents share similar type of thinking.</td>
</tr>
<tr>
<td></td>
<td>• Thinking more about sex, particularly boys.</td>
</tr>
<tr>
<td><strong>Experiencing Psycho-Emotional Changes</strong></td>
<td>Fluctuating Mood:</td>
</tr>
<tr>
<td></td>
<td>• Get angry quicker/more easily.</td>
</tr>
<tr>
<td><strong>Experiencing Physical and Sexual Changes</strong></td>
<td>Changes outside and inside the body.</td>
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<tr>
<td></td>
<td>Changes in sexual organs.</td>
</tr>
<tr>
<td></td>
<td>Females beginning to menstruate.</td>
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<tr>
<td><strong>Changing Social Relations at Home</strong></td>
<td>Don’t like the home environment.</td>
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<td></td>
<td>Secret matters can’t be shared with parents.</td>
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<td></td>
<td>Unable to comprehend whether old or young</td>
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<td></td>
<td>due to parents’ contradictions.</td>
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<tr>
<td><strong>Lacking Freedom</strong></td>
<td>Can’t make own decisions.</td>
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<td></td>
<td>Dislike when told not old enough.</td>
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<tr>
<td></td>
<td>Increasingly difficult to go anywhere.</td>
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<tr>
<td><strong>Increasing Levels of Stress</strong></td>
<td>Have a lot of tensions about school/work.</td>
</tr>
<tr>
<td></td>
<td>Greater pressure to succeed academically.</td>
</tr>
<tr>
<td></td>
<td>Difficulty sleeping.</td>
</tr>
<tr>
<td><strong>Developing Concern for the Future</strong></td>
<td>Think more about what will happen ahead.</td>
</tr>
<tr>
<td></td>
<td>Have an aim for what they want to do in life.</td>
</tr>
<tr>
<td></td>
<td>Want to become something in life.</td>
</tr>
<tr>
<td><strong>Greater Interest in Socializing and Appearance</strong></td>
<td>Enjoy spending more time with friends.</td>
</tr>
<tr>
<td></td>
<td>Focus more on fun activities/entertainment.</td>
</tr>
<tr>
<td></td>
<td>Greater concern over wearing nice clothes.</td>
</tr>
<tr>
<td><strong>Experimenting with Substances</strong></td>
<td>Some drink alcohol, smoke beedies, and chew tobacco.</td>
</tr>
</tbody>
</table>

*Note.* Describes participants’ accounts of the developmental milestones that characterize the Indian adolescent development period. Adolescents’ descriptions were not ‘fit’ into pre-conceived categories or areas. These areas emerged from the adolescents’ descriptions.

Participants also suggested that bringing males and females together required added attention when participating in a group. Participants portrayed adolescent males as having greater freedom, possessing greater knowledge about the opposite sex, and harassing girls or “eve-teasing” (the local term used to describe the harassment of women). Adolescent women were described as living under significant control, being excluded from decision-making, receiving less education, and being blamed for interacting with males. Given the high degree of focus that community-based
organizations were placing on gender awareness in the community, several young males and females were known or seen to interact. However, community attitudes continued to oppose adolescent male-female interactions due to fear of premarital romantic or sexual activity, children’s safety, and growing concern regarding marital prospects. Girls were especially annoyed at the narrow-mindedness that would prevent young men and women from developing genuine friendships, as was described by Rita:

If some boy and girl are talking here, the thoughts that run in the mind of these people is that they are having an affair (romantic relationship). It’s not that they just might be friends! They can be friends! … For the most part ladies here are housewives, they are narrow minded and suspicious thoughts run in their mind.

(Rita, 16 year-old Female with Polio, Follow-up Interview)

Leena elaborated on the challenge of maintaining opposite gender friendships:

Ladies mostly think that a boy and a girl can never be friends. Girls can’t talk to boys. … The first thing they do is – they go to fill the ears of others’ mothers if they see someone’s daughter talking to a boy. Gossip happens a lot here.

(Leena, 16 year-old Female without Disability, Individual Interview)

Clearly, adolescent men and women desired to have positive relationships with one another. Adolescents spent a considerable amount of time discussing their view that boys and girls were capable of being just friends and described community members as being “narrow-minded and suspicious” (Angela, 17 year-old Female without Disability, Individual Interview). Adolescents reported that if more males and females had healthy relationships there would be fewer instances of boys behaving inappropriately with girls. Rita suggested that opposite gender friendships would promote greater understanding across adolescents:

There are many boys that have bad habits, but their [bad] habits can be changed if you make him understand like a friend; then he will never get spoiled. … So in this way the surroundings can improve.

(Rita, 16 year-old Female with Polio, Individual Interview)

Adolescents suggested that more work on gender sensitization was needed to promote
greater fairness for young women, as Geeta, a young woman with polio described:

[ASTHA should provide] increase gender education to families and parents regarding issues related specifically to females being involved in the community.  
(Geeta, 15 year-old Female with Polio, Focus Group)

Although participants desired to learn about the opposite gender in a group, they also acknowledged that some personal or gender-specific issues, especially puberty, should be dealt with separately to ensure comfort. Meaningful group participation was considered a prerequisite for adolescents to embark on their goal of successful group demonstration.

6.2.2 Significance of Group Demonstration in Empowering Adolescents

The most enthusiastic accounts that adolescents shared with me concerned their desire to demonstrate their potential to community members via meaningful group-centered occupations, including performing dramas, developing and singing songs and giving speeches. Participants emphasized that it was necessary to be clear about the purpose and process for demonstrating activities. I present the desire for group demonstration and the important factors linked to successful group demonstration as the middle layer of the Adolescent Group Empowerment Pyramid in Figure 17.

![Figure 17. Middle Layer of the Adolescent Group Empowerment Pyramid. Highlights the desire for group demonstration (i.e., demonstrating together in a group) desired by adolescent participants and the three important factors associated with successful group demonstration. Group demonstration brings adolescents another step closer to their goal of group recognition.](image-url)
Why is the notion of group demonstration desired by adolescents, and why is it important to consider the purpose, process and audience for successful group demonstration? Participants reported that the community was seldom exposed to the abilities and strengths of disabled individuals, which reinforced the negative image of persons with disabilities as incapable and having an invalid voice. Sheila described people’s indifferent attitude towards disabled persons:

Many people have such thinking that they can’t give due respect to the disabled. They say, ‘Brother you can’t do anything, this is our work. We are fit in hands, legs, we can do it.’ (Sheila, 17 year-old Female without Disability, Follow-up Interview)

Observations and accounts of adolescents and the CBR team highlighted community members’ preference to ‘watch’ messages rather than be given information in a lecture-type setting. Thus, occasionally adolescents participated in dramas and dance or singing groups to communicate information and draw people into watching and listening to them.

6.2.2.1 Emergence of Group Demonstration

Adolescents with disabilities frequently made statements such as: “why do people think the disabled can’t do anything; they can do everything” (Rita, 16 year-old Female with Polio, Individual Interview), and “I know now I can also do something [and] I want to show others I can become something” (Omar, 15 year-old Male with Spinal Muscular Atrophy, Individual Interview). Adolescents recommended that discriminatory attitudes be challenged by bringing to the forefront the stories and abilities of adolescents with disabilities. Nisha, a young woman without a disability, described the community’s disbelief in the capability and capacity of adolescents with disabilities:

Suppose a disabled adolescent is in a wheelchair and he wants to show that he can do something; everyone keeps saying that, ‘No he won’t be able to do it,’ even if the disabled child is completely confident that he can. … That’s why his hope gets broken. (Nisha, 16 year-old Female Adolescent without Disability, Individual Interview)
Angela discussed how adolescents with disabilities seldom received the opportunity to express their views:

No one asks disabled adolescents anything, they are not given any importance. … If someone wants to ask them anything, their parents silence them. If they speak a little and their parents support them, there is no one there to hear them. Their voice gets buried.

*(Angela, 17 year-old Female without Disability, Individual Interview)*

Adolescents consistently expressed interest in forming a group of adolescents to convey meaningful messages to the community. Adolescents with disabilities believed that by demonstrating that they were capable of giving a speech or performing in a drama they could change the negative image of young persons with disabilities; this was the strongest message that adolescents conveyed. In one focus group, adolescents simultaneously suggested organizing and performing a play of a large magnitude:

We want ASTHA to do more plays, so people learn something. … We want 30, 35 of us children to make a group, do something for disabled children, and move our curriculum ahead. … We want some disabled and non-disabled children, some boys and girls, to make a group and do some play, so people’s eyes open.

*(Multiple Adolescents with and without Disabilities, Focus Group)*

Group demonstration was illustrated as an effective means to spread information and knowledge throughout the community, as Rita described:

Only by telling can our problems be solved. … One person will listen, six people will find out, and from six people others will find out ahead.

*(Rita, 16 year-old Female with Polio, Focus Group)*

Adolescents who did perform in front of community members showed a great deal of excitement and enthusiasm, rather than anxiety that may be commonly associated with performing and speaking in front of large groups of people.

*6.2.2.2 Consideration of the Purpose, Process and Audience in Group Demonstration*

I observed adolescents demonstrate their skills and talents at various events. Although adolescents enjoyed performing in events organized by the CBR Program, they
claimed to play a minimal role in developing the content for such activities. Adolescents stressed that activities should reflect their intended purpose (e.g., activities to promote disability awareness should be demonstrated differently than performances at weddings). Participants wanted the content of performances to better reflect disability issues, as Rita explained regarding the Disability Day Celebration that was held in the community:

> A song you can sing anytime. … Here giving a speech would have been more appropriate. … There should have been more information given because so many people had come. Some people didn’t even know why the celebration was happening. … This time people paid more attention to dances and stuff. … There was a lot of noise and shouting, but it’s not like someone was getting married. … Disability Day should be celebrated in a manner that is appropriate – raising knowledge.
> (Rita, 16 year-old Female with Polio, Focus Group)

Adolescents suggested adapting songs, dances, poems and speeches to reflect the lives, challenges and desires of young persons with disabilities:

> The songs could have been such that they gave a message that, ‘Yes we will do something and show you!’ … The speeches could have been right in the songs. … A song in which we could have told something about ourselves.
> (2 Adolescents with disabilities, Focus Group)

Kumar suggested that the community required greater knowledge about system level issues and the role of disability-related organizations such as the CBR Program:

> Everything that ASTHA does, they should make sure that it reaches the community so that the community can support them in this matter. … ASTHA should do plays so that people can become aware of what ASTHA’s activities are.
> (Kumar, 14 year-old Male without Disability, Focus Group)

For group demonstrations to be effective, Rita emphasized that events should be organized in a timely manner to allow for the news to be spread across the community:

> If I had known earlier I would have invited so many people because the people in my block don’t know anything about Disability Day.
> (Rita, 16 year-old Female with Polio, Focus Group)

Furthermore, the purpose of events and performances should be communicated clearly in an age and culturally sensitive manner to selected audiences (e.g., parents versus children
versus the general community). Group demonstration provides adolescents with disabilities a mechanism to achieving their goal of group recognition.

6.2.3 Significance of Group Recognition in Empowering Adolescents

Adolescents with disabilities wished to be recognized by community members in order to benefit from similar opportunities as their non-disabled peers and to assume greater control over their circumstances, occupations and future. While participation was about ‘engaging’ and demonstration was about ‘doing or performing,’ the notion of recognition concerned ‘acknowledging’ the capability and capacity of young persons with disabilities. Together the concepts of participation, demonstration and recognition formed fundamental aspects of meaningful group empowerment for adolescents. I illustrate the ultimate goal of group recognition and the factors linked to desirable group recognition as the peak of the Adolescent Group Empowerment Pyramid in Figure 18.

![Figure 18. Top Layer of the Adolescent Group Empowerment Pyramid. Highlights adolescents’ desire for group recognition (i.e., adolescents’ desire to be recognized for their contribution to the occupations embarked on with their peer group) and the three domains (individual, peer group and societal levels) in which adolescents’ strive to be recognized. Group participation and group demonstration provide the foundation for adolescents to achieve their goal of personally desirable group recognition.](image-url)
Why is the notion of group recognition desired by adolescents, and why is it important for adolescents to be recognized at the level of the individual, group and society? Participants believed that self-acceptance, and being accepted at the level of the peer group and broader community was necessary for leading meaningful and productive lives. Adolescents with disabilities preferred to present their abilities in collaboration with their peers because they wanted to be recognized for their achievements and contribution to the group (rather than simply being romanticized for their individual performances as a disabled person). Adolescents with disabilities reported that the most rewarding aspect of performing in a play, giving a speech or singing a song was when they were recognized for their role and contribution through hearing people applaud or make positive comments. Adolescents wanted to engage in occupations that increased their profile and visibility in the community; this furthered adolescents’ desire to participate and share their views’ regarding important issues. The group setting was fundamental for the type of recognition adolescents with disabilities wanted to achieve.

6.2.3.1 Emergence of Group Recognition

Adolescents questioned the extent to which people genuinely believed in their potential, including those individuals and organizations that were dedicated to supporting them. Adolescents described that it was fundamental for young persons with disabilities to be recognized positively by the community in order to improve their opportunities to fully engage in their lives including having a job, getting married, and receiving an education. There was legitimate concern on many levels -- the individual, family, program and community -- about the future lives of disabled adolescents. Sheila reflected on how disabled people were consumed with thinking about their future:
Although all adolescents think about their future, disabled adolescents think about it more. They think about what will happen with them, whether they will be able to complete the work they started, what they will be able to do, who will help them.  
*(Sheila, 17 year-old Female without Disability, Individual Interview)*

Adolescents valued the role of education and vocation in hope of leading a more promising future. Given the harsh reality of living with a disability in the slums, it appeared that disabled adolescents’ dreams were often destroyed even before they could work towards their goals. Adolescents with disabilities worked hard to establish realistic and achievable future goals (e.g., taking a computer or beautician course; learning to paint or sew). Adolescents with disabilities expressed desire to work, but found it difficult to locate employers who would readily employ disabled youth; potential employers simply did not believe in the capabilities of disabled youth. Discrimination in the world of work was yet another reason supporting adolescents’ views that disabled youth needed to be recognized for their skills. Sabrina, a young woman who developed an undiagnosed speech impairment that resulted in a very low voice, reflected on being treated unjustly when interviewing for a job:

> I can’t get any [good] job. … When I had passed the tenth grade, I went for a job interview; they didn’t hire me. … They told me that I was too young, but it seemed to me it was because of my [disability]. … My cousin sister is only two and half months older than me, how much difference is that? She got the job.  
*(Sabrina, 17 year-old Female with Speech Impairment, Follow-up Interview)*

Given the obstacles adolescents with disabilities faced to get a job, often the work they did secure was not to their liking or in line with their skills, as was expressed by Sabrina regarding the low-status job she was finally hired for:

> I do a company job. Pens are made and I pack them in plastic bags. … I do not like the job, but if I did not have a [disability], I could have gotten a very good job. … At my place it is considered bad (inferior) to do a company job.  
*(Sabrina, 17 year-old Female with Speech Impairment, Follow-up Interview)*

I also observed young women and their families engaging in temporary or contract work
that involved stitching beads onto fabrics. According to CBR team members, it was common for retailers to recruit families in the area to engage in such work tasks. The adolescent women appreciated having respectable and convenient work to do, but some reported feeling underpaid for the long hours they invested. Some women demonstrated a fair understanding of issues around rights and vocational exploitation, but stated that the work was still important because it allowed them to earn money. Neil, an 18 year-old man with polio who already spent his nights and days working as a personal assistant for a businessman, shared the pressure he felt from his mother to be employed in a good job because it would also impact his marital prospects:

> The disabled adolescents here they just keep roaming around on the streets, no one gives them work. … My mother gets angry and says, ‘Why don't you work like a good boy? Work hard, stand on your own two feet. If you work, you'll gain strength inside and someone will even get married to you.’

*(Neil, 18 year-old Male with Polio, Individual Interview)*

This intensified adolescents’ desire to demonstrate and market their skills in order to be noticed by potential employers. Securing a good job, showing potential and being recognized by others were important factors for helping disabled youth to also improve their marriage prospects. Marriage was a fundamental goal in the lives of adolescents in the slums that appeared to often surpass goals concerning education and vocation.

Families were in search of finding the most appropriate and suitable match for their children. Participants expressed a great deal of frustration over the pressure they faced to marry at a young age. Often families were overly worried about the future of their young disabled daughters “because it was difficult to arrange their marriages; nobody wanted to pick such girls” *(Sabrina, 17 year-old Female with Speech Impairment, Individual Interview)*. Girls with disabilities were more likely to be arranged in marriage at a young age. Angela, who had a teenage sister with polio, discussed marriage as the
biggest problem for women with disabilities:

Their biggest problem is that people force disabled girls to get married at a very early age. … Disabled boys and girls are considered a burden on the family. … These girls, they are not fully ready and prepared for sex.

(Angela, 17 year-old Female without Disability, Individual Interview)

Given that disability was seen as a major deterrent in arranging marriages, people with disabilities were more likely to have arranged marriages with another disabled individual even when other characteristics such as age, class, education, family background and habits did not match. Sheila explained that it was only natural for everyone to desire a ‘nice’ marital partner:

Every boy or girl has a desire that their life partner should be nice. … No one wants to have a bad life partner. His complexion, looks should also be good. If the complexion is not good, at least his habits should be good. He should be fit with body. Disabled people think that if they are disabled, at least their partner should not be disabled.

(Sheila, 17 year-old Female without Disability, Individual Interview)

Adolescents were gradually developing greater awareness of their rights and the laws surrounding the marriage of young persons (those under 18 years of age). Adolescents were especially excited to discuss the development of romantic relationships during adolescence. However, given the long-standing tradition of arranged marriage in the area, pre-marital romantic relationships of any form were condemned by the general community. Fear of humiliation from society forced adolescents to either not pursue romantic relationships or to ensure that they remained hidden from the public. Romantic relationships normally began in middle to late adolescence, and adolescents often met on their way to and from school and communicated via letters. Dev, a young man with polio discussed the desire for, but obstacles associated with romantic relationships:

Adolescents like affairs (romantic relationship) a lot, but there are no people here who accept them. Suppose it is me and I love someone, and my mother and father find out, they would bear it, but the girl’s parents are humiliated when it is exposed.

(Dev, 17 year-old Male with Polio, Individual Interview)
Women appeared cautious about establishing boundaries for physical or sexual intimacy.

Rita described girls’ concern about disappointing or bringing shame upon their parents:

If I say yes [to having a relationship with him], my parents will feel bad when they will hear about it. … Why should I sacrifice so much happiness of my parents in order for a little happiness with him? … My mother and father love me so much.

(Rita, 16 year-old Female with Polio, Follow-up Interview)

Rita added that disabled adolescents often hesitated to share their romantic feelings due to the fear of being rejected because of their disability:

I see this with my friends – They do not want to tell the person [they like] because she is handicapped and the boy [she likes] is okay. … She is afraid the boy might say no.

(Rita, 16 year-old Female with Polio, Follow-up Interview)

Given the obstacles that one might face to pursue a pre-marital romantic relationship, adolescents described the increased likelihood of developing an intense emotional bond with a potential romantic partner. Thus, fear of break-up or a broken heart often prevented young persons from pursuing relationships.

6.2.3.2 Recognition at the Level of the Individual: Sense of Achievement Empowering Adolescents

Adolescents with disabilities displayed a range of negative feelings and a sense of low self-worth. Sabrina shared her depressed feelings with me:

I have had to bear so much because of my [disability]. … Now when I am thinking about it I feel overwhelmed, feel like crying. … I know that this is my truth. … All of my desires have died. … I don’t know what has happened to me, really.

(Sabrina, 17 year-old Female with Speech Impairment, Follow-up Interview)

Uncertainty about one’s future prospects or the idea of leading a grim future only appeared to magnify disabled adolescents’ depressed mood, as Omar described:

I feel that I shouldn’t have been born. … Till when will my mom and dad feed me? … One day they will go away. … I cannot eat with my hands and cook food. … In my heart I feel like dying. … I do not feel good. … I want to see my mum and dad happy.

(Omar, 15 year-old Male with Spinal Muscular Atrophy, Individual Interview)

Disabled adolescents questioned “what their future would be like ahead [and] whether
they would be able to do anything in their life” (Melanie, 15 year-old Female with Visual Impairment, Follow-up Interview). CBR team members also acknowledged the “inferiority complex that consumed adolescents with disabilities” (Sanjay, Male Community-Based Rehabilitation Team Member, Focus Group).

The empowerment process I described appears to have a positive impact on disabled adolescents’ confidence and sense of self-worth. Rita described how good she felt about playing the lead role in a community drama that demonstrated the challenges faced by young individuals with disabilities:

I played a role in this drama about wanting to go to school. … All of us adolescents had acted in it together. A video has even been made. … [CBR team member] said that I talked so great! … It took place at the largest stage. … I played the lead role both times! (Rita, 16 year-old Female with Polio, Follow-up Interview)

Adolescents felt proud of their achievements in group occupations and were seen to gradually internalize such feelings as they discussed their experiences with their peers.

One important change to the CBR Program’s regular practice was adolescents’ assuming responsibility over the development of three organizational documents that were normally dominated by adult staff members. Through developing these documents, adolescents saw their words expressed on paper and appreciated being given credit for their work. Participants were pleased with the final documents and what they had accomplished together as a group. Adolescents were especially excited to receive ASTHA’s Annual Report to view the page they had designed. They expressed feeling joy in knowing that their peers had selected their quotation or drawing to appear in the report. Adolescents collectively agreed that Ricky’s drawing shown in Figure 19 should appear on the page they designed for the report.
6.2.3.3 Recognition at the Level of the Peer Group: 
Acceptance by Peers Empowering Adolescents

One of the most significant accounts supporting disabled adolescents’ desire to be accepted by their peers concerned the magnitude of rejection and bullying they faced from their non-disabled peers. Adolescents with disabilities were rejected by their peers across multiple educational and social situations; however, the most frequently reported scenario was being excluded from social activities and play, as games commonly played in the area [e.g., cricket, pakdam-pakdai (similar to tag), hide and seek, seedi (running up and down stairs), pali (hop-scotch), and skipping] required greater physical capacity. Deepak, a young man with polio, felt that adolescents questioned the extent to which physically disabled adolescents could engage in play:
[Non-disabled children] don’t like disabled kids to play because they need fit kids. They think, ‘He is disabled, what will he do with us, he can’t talk, he can’t walk, he can’t play.’

*(Deepak, 14 year-old Male with Polio and Visual Impairment, Individual Interview)*

Amit, an adolescent with an upper extremity disability, highlighted the notion of disabled adolescents being excluded from play in his impact drawing in Figure 20. Nisha, an adolescent without a disability also reinforced this point in her drawing in Figure 21.

*Figure 20. Impact Drawing: Excluding Disabled Adolescents from Play. Illustrates a disabled adolescent with an amputated foot using a single-point cane (right) and a non-disabled adolescent (left). The non-disabled adolescent is pointing to and telling the disabled adolescent that, ‘You can’t play this game with us because you’ll get hurt. We’re not going to let you play.’ (Amit, 14 year-old Male Adolescent with an Upper Extremity Physical Disability, March 24, 2005).*

*Figure 21. Impact Drawing: Excluded from Play. Illustrates an adolescent in a wheelchair (left) and a non-disabled adolescent with a ball (right). The non-disabled adolescent is telling the disabled adolescent that, ‘You can’t play ball with me because you’re in a wheelchair.’ (Nisha, 16 year-old Female Adolescent without Disability, March 31, 2005).*
Adolescents with disabilities were often observed playing with much younger children or they were seen watching others play. Many participants advocated for social play and games to be adapted and modified.

In addition to facing rejection by peers, bullying had an especially emotional impact on adolescents with disabilities and appeared to be related to the breaking down of their internal will and self-confidence. Sandeep, a young man with polio, described instances of children in the community picking on and harassing children with disabilities:

Children tease disabled adolescents while walking. When he doesn’t move out of the way, they say, ‘You are disabled, what are you doing here!’ Then they will call him names and say, ‘You are like this, like that.’ So for this reason disabled people face difficulty.  
(Sandeep, 15 year-old Male with Polio, Individual Interview)

Disabled adolescents were often referred to as crippled, lame or limper. Particularly degrading was the name-calling that compared disabled adolescents to animals, including calling a child a “monkey” because of a facial disfigurement (Krishna, 13 year-old Male with a Cleft Lip/Palate, Individual Interview) or referring to a child as a “parrot” because of an abnormality of the upper limb and hand (Mohan, 17 year-old Male with an Upper Extremity Physical Disability, Individual Interview). Participants believed that children “harassed disabled adolescents for their fun” (Amit, 14 year-old Male with an Upper Extremity Physical Disability, Individual Interview). Deepak, a young man with multiple disabilities, stressed how helpless he felt when he was bullied or beaten by other young people in the community:

Like [children] abuse me and run away. … They just run away after beating me up. I, what can a disabled child do? A disabled child can’t do anything. Those who are non-disabled can beat up a disabled.  
(Deepak, 14 year-old Male with Polio and Visual Impairment, Individual Interview)

Krishna illustrated the problem of bullying in his impact drawing in Figure 22.
Adolescents had difficulty presenting strategies for the prevention of bullying (with the exception of suggesting that the bully’s parents should be notified, which adolescents themselves questioned as an effective strategy). However, participants suggested that drawing attention to the abilities of adolescents with disabilities may promote greater acceptance and social inclusion of young people with disabilities amongst their peers.

The adolescent period was characterized by greater focus being placed on one’s appearance. Adolescents with disabilities were tired of being criticized for wanting to be in line with the latest fashion. Rita, who was well-known for advocating for people with disabilities, expressed her frustration over peers criticizing disabled adolescents for wanting to be fashionable:

One girl said to me, ‘You should wear small earrings.’ I asked her why and she replied that, ‘You just keep sitting friend, the big earrings don’t look good [on you].’ … She meant to say that I should only wear simple stuff. … What is her problem! What she meant to say was that I am disabled so I should wear small, small earrings.

(Rita, 16 year-old Female with Polio, Follow-up Interview)

Adolescents with disabilities wanted their peers to accept their right to take interest in their appearance.
Over the course of data collection, I observed that non-disabled adolescents appeared to become more accepting of the potential and abilities of disabled youth and children in the community. Sheila shared stories of adolescents with disabilities being capable of engaging in many more activities than community members may expect:

One disabled person by seeing another disabled can do something good. Many examples have been set. Many disabled have done work that even normal people can’t do. … Like someone is disabled by the eyes, but they are able to work on the computer. Someone is disabled by their hands, but they can write with their feet. … They too can do everything. (Sheila, 17 year-old Female without Disability, Follow-up Interview)

6.2.3.4 Recognition at the Level of the Society: Appreciation by Community Members Empowering Adolescents

Adolescents described living in an interdependent society that imposed fairly rigid expectations of acceptable norms for adolescents. Community views had significant influence on the course of events in adolescents’ lives. It became especially important for adolescents with disabilities to be viewed in a positive light by the broader community. Participants wanted “community members to feel that disabled adolescents are not less than anyone” (Omar, 15 year-old Male with Spinal Muscular Atrophy, Individual Interview). Sheila described how disabled adolescents were often seen as incapable and thus excluded from important community meetings:

There are many people who don’t like to include any disabled in any meeting. … They say that, ‘They are of no use there, don’t bring them there, they can’t do anything.’ (Sheila, 17 year-old Female without Disability, Individual Interview)

Adolescents longed for community members to realize their capabilities. Omar, a young man with spinal muscular atrophy who was wheelchair bound, became well known in the community for making significant progress in his life, including attending school regularly, giving speeches at community events, and participating in ASTHA’s activities. Although Omar continued to face many struggles in the community including attending
an inaccessible school and being bullied by other children, he described how good it felt to be appreciated by community members after performing in a play with his peers:

> When we did that play together, we worked really hard, everyone applauded and realized that yes we can do something!
> *(Omar, 15 year-old Male with Spinal Muscular Atrophy, Focus Group)*

The young man reflected on his heightened sense of satisfaction as a result of community members watching him speak and positively receiving his speech at community programs such as the Disability Day Celebration aimed at promoting disability awareness:

> It felt very good to give a speech. … I gave information about myself. … [Community members] listened and applauded.
> *(Omar, 15 year-old Male with Spinal Muscular Atrophy, Individual Interview)*

Although adolescents disliked the term disabled, they acknowledged the importance of the term for accessing necessary interventions and resources. Adolescents with disabilities mentioned that it was important to use the word ‘nicely’ or respectfully. Societal appreciation was about true social inclusion -- accepting, respecting, embracing individual differences, abilities and achievements, and enabling more tolerant and open-minded communities; and not about constantly focusing on ‘changing’ persons with disabilities or ‘hiding’ disabilities.

The process of addressing research sub-question number three and objective d, where I explored the concept of sustainability and implemented an applied component to enable adolescents to inform local CBR activities, solidified the ‘group’ concept and the core elements of the Adolescent Group Empowerment Pyramid, and encouraged the CBR Program to re-evaluate the role of adolescents within their program. Research sub-question number one and objective a, where I investigated the perceived rehabilitation challenges and understanding of disability, provided supporting data for the core elements (i.e., desire for participation, demonstration and recognition) that ultimately
formed the Adolescent Group Empowerment Pyramid. Research sub-question number two and objective b, where I explored the impact of the cultural context on the rehabilitation challenges faced by adolescents with disabilities, helped to enhance my understanding of the extreme influence that the socio-cultural context had on persons with disabilities, and provided the backdrop on which the core elements of the Adolescent Group Empowerment Pyramid were superimposed.

### 6.2.4 Influence of the Socio-Cultural Environment in Empowering Adolescents

Given adolescents’ accounts, the notion of empowering adolescents in the community cannot be adequately understood without considering the significant impact of the local socio-cultural environment on the quality of life and progress of adolescents with disabilities. Thus, I present the core of the Adolescent Group Empowerment Pyramid as superimposed on the notion of the socio-cultural environment and its interaction with disability in Figure 23.
Why is it critical to understand the role of the socio-cultural environment when determining personally meaningful ways to empower adolescents? The socio-cultural context of the slums was described as hindering progress and change (e.g., excluding persons with disabilities, gender discrimination, and preventing interaction between adolescents). Participants attributed many of the tensions they experienced to the generational gap (i.e., way of thinking and behaving) between adolescents and adult community members. Adolescents stressed the important role of others (i.e., family, relatives, peers and community members) in disabling young persons with disabilities, and consistently informed me of the importance of understanding the Lal Kuan area in order to promote disability awareness and to inform changes for and within young people.

6.2.4.1 A Conservative Community: A Challenge for Changing Ideals

I explored adolescents understanding of the term culture. The local meaning of culture was similar to the common western understanding of culture, such as defining culture in terms of local customs-and-practices:

Culture comprises the customs-practices of that place. Like various kinds of festivals, dresses, foods, all these constitute sanskriti or culture.
(Nisha, 16 year-old Female without Disability, Follow-up Interview)

Adolescents described the culture in terms of good or bad. The culture appeared to play a fundamental role in dictating what young people were allowed to do. Sheila who openly discussed having male friends and desired to go to college, issues not generally supported by the community, emphasized the control the culture had on people’s actions:

India is such a country where at every step the culture changes. … All different types of way of living, life exists here. Culture means nothing special – it tells you what to do and what not to do.
(Sheila, 17 year-old Female without Disability, Follow-up Interview)

CBR team members acknowledged adolescents’ accounts that “in the Indian culture,
whatever one wants to do, you have to take permission and advice from the parents”  
(Sanjay, Community-Based Rehabilitation Team Member, Focus Group).

I developed both a cynical and hopeful impression of the community. Through observing adolescents with and without disabilities going to school and engaging in employment initiatives (e.g., working in shops and learning to tailor), I felt optimistic that some degree of advancement was taking place in a community that had been described as “backwards,” “overly-traditional,” and “closed-minded.” However, the urban slums of Lal Kuan continued to be described as impeding community development.

Adolescents criticized the occurrence of senseless violence in the area. Tara, a
young woman without a disability, described it in the following way:

Most of the people here start fighting immediately on a small matter. … The people here are uneducated so they fuel the fight. … The people of the older generation mostly.  
(Tara, 13 year-old Female without Disability, Individual Interview)

In addition to petty crimes and violence in the area, the abuse of substances (e.g., common street drugs and alcohol) was prevalent across young and older adults, and men and women, but with little knowledge about the use of substances among young women. It was common to see males drinking alcohol and smoking drugs while simply walking through the community. Ruby, a young woman with polio, who described her father as a heavy drinker and gambler, blamed the problem on the lack of meaning in people’s lives:

The whole area here seems worthless to me. … People just stay aloof here, just loitering around, some work, some don't work, they are just looking here and there, everyone is just sitting like that. … They just spread filth here.  
(Ruby, 16 year-old Female with Polio, Individual Interview)

Adolescents were eager to share their views on the traditional mentality and narrow-mindedness of many elders in the community. Nisha criticized the conservative thinking of community members as impeding community development:
The thinking of people is totally different here. … They don’t think at a high, high stage. … They live here as backwards. Like the same old thinking, backward thinking.  
(Nisha, 16 year-old Female without Disability, Individual Interview)

Adolescent women reflected on their frustration of being treated unfairly from boys. A number of adolescent men acknowledged the unfair treatment of girls in the community. Young women continued to be kept under strict supervision and were often prevented from spending time outside the home, especially for leisure and social pursuits.  

Rita expressed her frustration over women being controlled while boys enjoyed freedom:  

Boys, they are masters of their choice. … Girls always live under control. No matter what she is like, whether she is fair or dark, at this age, she can’t be the master of her choice.  
(Rita, 16 year-old Female with Polio, Individual Interview)

Leena was especially annoyed at the gossip that took away the freedom of young women:  

Going out for even a walk in this society is a hurdle. Ladies come and fill parents’ ears with wrong things and ask them why their daughter is roaming around – it is not healthy. … People of my mother’s age who are of a traditional mentality, it is mostly those who will do such things, mostly women. … By gossiping about it.  
(Leena, 16 year-old Female without Disability, Follow-up Interview)

However, many participants were torn because they agreed that girls required greater protection, as women were at greater risk of being harassed by men in the community. Given the rumours circulating throughout the area, families genuinely feared for their young daughters’ safety. For young women, merely leaving the home to go to school was even viewed as a significant problem. As Tara, a highly protected, but school-going Muslim female without disability stated:  

They do not want girls to study further because they will have to go school and there will be boys there, and then they will get involved in inappropriate affairs, and due to this everyone (family/relatives) gets humiliated.  
(Tara, 13 year-old Female without Disability, Follow-up Interview)

Nisha who had two sisters (all three young women were going to school) added that educating young women was seen as a worthless task as they were unlikely to apply their education after marriage:
They say that, ‘You are a girl, what will you do after your studies. After studying this much you will just sit at home anyways!’… So they don’t educate us girls a lot because some people think that she just has to do the sweeping and mopping anyways.

(Nisha, 16 year old Female without Disability, Individual Interview)

Women blamed the limited opportunity for education as one of the greatest barriers to advancing themselves, which was only magnified for females with disabilities. With the increased opportunities provided by government and non-governmental organizations, adolescents were hopeful that certain aspects of the culture and community were amenable to change.

6.2.4.2 Socio-Cultural Response to Disability

Long-established negative views of disability were still prevalent in Lal Kuan, including pitying persons with disability and viewing persons with disability as inferior. According to the CBR team, there had been a gradual change in people’s thinking from viewing disability as a punishment from God to accepting disability as a limitation resulting from some medical or health problem or accident. However, conversations with community members and adolescents reinforced the notion that God, fate and karma played a fundamental role in making someone disabled. Many adolescents with disabilities struggled with the idea of why God had made them disabled, as Ruby shared:

When I see others who are even more disabled I think that why has God made them like this, why is his life like this? My heart weeps at this very much that why has God created humans like this. … I believe in God so much. So why has he made me like this?

(Ruby, 16 year-old Female with Polio, Individual Interview)

Neil wished that God made no one else suffer from having a disability:

Why has God given me so much suffering? … I pray to God that there should be no disability in this world. It would be very good if there were no disabled persons.

(Neil, 18 year-old Male with Polio, Individual Interview)

Neil illustrated the life of hardship faced by disabled persons in his impact drawing in Figure 24. Ruby saw no difference between poverty and disability, and reflected this
view in her impact drawing in Figure 25.

Figure 24. Impact Drawing: Wandering Spirit of a Disabled Person. Illustrates a house in which a person with a disability used to live. The image of the face in the house represents the ghost/spirit of the disabled individual after death. The participant stated that a disabled person’s soul can never rest in peace due to all the hardships experienced during life, and because “disability is not a worthwhile life.” (Neil, 18 year-old Male with Polio, March 2, 2005).

Figure 25. Impact Drawing: Poverty and Disability. Illustrates a person with disability surrounded by dirt and garbage. The participant reported that there is no difference between being disabled and being poor. (Ruby, 16 year-old Female with Polio, February 21, 2005).
Another commonly held belief in the area was that disability was contagious.

Geeta who had polio shared how community members, both children and adults, promoted segregation due to fear of being infected by the disability:

> Some people speak nicely and some don’t talk to you at all. They say, ‘They are disabled, if we talk to them, then this illness can happen to us as well.’ This is how some people think. They say, ‘We can also get infected with some illness.’
>
> (Geeta, 15 year-old Female with Polio, Follow-up Interview)

Omar, a young man with spinal muscular atrophy who was visibly disabled, also described community members’ belief that they could catch the disability:

> They find me to be a lame and don’t even come near me because they think that they will also become like me. … And if they come, they come against their will, they make faces. … They tell others, ‘Don’t sit near him or you will also become like this.’
>
> (Omar, 15-year-old Male with Spinal Muscular Atrophy, Individual Interview)

Melanie, a young woman with a visual impairment whose disability was obvious to the community, highlighted the differential treatment between the disabled and non-disabled:

> Sometimes I feel very, very sad that in the world’s eyes I wish I was okay. So far in my life I like my friend the most because she does not treat me and other children differently. … The world might think that they treat us the same as they treat other people, but we [disabled] think that the world treats us as we are disabled.
>
> (Melanie, 15 year-old Female with Visual Impairment, Individual Interview)

Melanie illustrated an individual simply staring at disabled adolescents in her impact drawing in Figure 26. Sheila, a non-disabled woman, highlighted the differential treatment between disabled and non-disabled siblings in her impact drawing in Figure 27.

Disabled adolescents who managed to attend school, described instances of being segregated at school, which was often supported by both teachers and students but it was predominantly by students. Non-disabled adolescents corroborated the stories regarding the poor treatment of disabled adolescents at school. Particularly illustrative was a story by Omar who was isolated from other classmates because of an inaccessible classroom:
At school they make me sit in the sun, while the other children sit inside. My wheelchair does not go inside the classroom – it is a small house. They say that my wheelchair blocks the doorway for coming and going. So they have a board outside and they give me work on it. I feel hurt that they make me sit in the sun. I might get ill.

(Omar, 15 year-old Male with Spinal Muscular Atrophy, Individual Interview)

Figure 26. Impact Drawing: Staring at Adolescents with Disabilities. Illustrates a young disabled boy using crutches (far left), a young disabled girl with a visual impairment (centre), and a non-disabled young girl simply staring at the two disabled adolescents from her window. (Melanie, 15 year-old Female with Visual Impairment, March 10, 2005).

Figure 27. Impact Drawing: Differential Treatment between Disabled and Non-Disabled Siblings. Illustrates a mother (centre), a disabled daughter with tears (left), and a non-disabled daughter (right). Shows the disabled daughter sitting at her sewing machine wishing that she could also graduate from school like her non-disabled sister (who just received her diploma and made their mother very proud). The participant stressed that education was especially important for persons with disabilities in order to compensate for their other deficits. (Sheila, 17 year-old Female without Disability, March 9, 2005).
Participants emphasized that “community members continued to think that there are differences between boys and girls and between disabled and normal people, [and] that disabled people cannot do what normal people can do, and girls cannot do what boys can do” (Sheila, 17 year-old Female without Disability, Individual Interview). Ruby added that the community further disabled persons with disabilities by constantly ‘throwing it in their face’ that they were disabled:

A lot of people here make them disabled by constantly saying it to them, like, ‘How does he walk, how does he live, how does he do that.’ A lot of people by constantly saying it, make us even more disabled, they make us even more ashamed. (Ruby, 16 year-old Female with Polio, Follow-up Interview)

Considering the socio-cultural context, adolescents reflected on how challenging it was for the community to see beyond an individual’s disability. For a person with a disability, it was as though their disability was ‘stamped’ or superimposed all over them; they were their disability. Common terms that adolescents used to describe or distinguish between adolescents with and without disabilities are presented in Table 10.

Table 10. Terms used to Describe Adolescents with and without Disabilities.

<table>
<thead>
<tr>
<th>Terms used by Participants to Describe Adolescents in the Urban Slums</th>
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</thead>
<tbody>
<tr>
<td>Adolescents WITH Disabilities</td>
</tr>
<tr>
<td>“Handicap”</td>
</tr>
<tr>
<td>“Disabled”</td>
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<tr>
<td>Lame or Limper</td>
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<tr>
<td>Crippled</td>
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<tr>
<td>Blind</td>
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<tr>
<td>Deaf</td>
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<tr>
<td>Deaf and Dumb or Mute</td>
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<tr>
<td>Slow</td>
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<tr>
<td>Weak</td>
</tr>
<tr>
<td>“Oppressed”</td>
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<tr>
<td>Poor Boy or Girl (Pity)</td>
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</tbody>
</table>

Note. Words in quotation marks represent English words used directly by participants. The other words were translated from Hindi into English.

Participants’ perceived understanding of disability is described in Table 11.
<table>
<thead>
<tr>
<th>Adolescents’ Perceived Understanding of Disability</th>
<th>Descriptions from Adolescent Participants…</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Describing Disability in Terms of…</strong></td>
<td></td>
</tr>
<tr>
<td>Acquired versus Congenital</td>
<td>• Happens from childhood or an accident.</td>
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<tr>
<td></td>
<td>• Resulted from not getting medicine for polio.</td>
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<tr>
<td></td>
<td>• Limitation from medical/health problem.</td>
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<tr>
<td>Visibility</td>
<td>• I can see it.</td>
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<td></td>
<td>• People look at you.</td>
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<td></td>
<td>• Walk with crutches.</td>
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<tr>
<td>Imperfection</td>
<td>• God does not make everyone equal - makes some okay and some imperfect.</td>
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<tr>
<td></td>
<td>• Disabled can’t live as we live.</td>
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<tr>
<td>Problems with Body Structure or Function</td>
<td>• Specific part of body is unable to function.</td>
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<td></td>
<td>• Problem with body parts.</td>
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<tr>
<td></td>
<td>• Limb Deformities</td>
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<td></td>
<td>• Hands and legs are crooked</td>
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<td></td>
<td>• Doesn’t have feet so they can’t play.</td>
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<tr>
<td></td>
<td>• Sensory Limitations</td>
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<tr>
<td></td>
<td>• Can’t hear; can’t see.</td>
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<tr>
<td></td>
<td>• Cognitive Limitations</td>
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<td></td>
<td>• Mind is not perfect or complete.</td>
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<tr>
<td></td>
<td>• Have a weak mind (not intelligent).</td>
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<tr>
<td></td>
<td>• Mental Health Deficits</td>
</tr>
<tr>
<td></td>
<td>• Has a mental problem.</td>
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<tr>
<td></td>
<td>• Some don't have a mind at all, mad people.</td>
</tr>
<tr>
<td>Restricted Mobility</td>
<td>• Can’t walk; limp while walking.</td>
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<tr>
<td></td>
<td>• Can’t stand or climb stairs.</td>
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<tr>
<td></td>
<td>• Can’t go from one place to another.</td>
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<tr>
<td>Activity Limitations and Participation Restrictions</td>
<td>• Can’t carry out activities.</td>
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<tr>
<td></td>
<td>• Handicapped, can’t do anything.</td>
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<td></td>
<td>• Can’t eat or go to the toilet.</td>
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<tr>
<td></td>
<td>• Can’t play or work.</td>
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<td></td>
<td>• Can’t talk to others.</td>
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<tr>
<td>Weakness</td>
<td>• Very weak.</td>
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<td></td>
<td>• Little endurance inside.</td>
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<tr>
<td>Dependency</td>
<td>• Helpless because they can’t do anything.</td>
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<td></td>
<td>• Have to ask others for help</td>
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*Note.* Describes adolescents’ accounts of their perceived understanding of disability. Adolescents’ descriptions were not ‘fit’ into pre-conceived categories or areas. These areas emerged from the adolescents’ descriptions.

Drawings made by adolescents focused heavily on the appearance of persons with disabilities. Rohit, a man with Down Syndrome, illustrated the ‘different’ appearance of persons with disabilities in his impact drawing in Figure 28. Vikram, a male with polio, highlighted the visible or noticeable aspects of disability in his drawing in Figure 29.
Figure 28. Impact Drawing: Appearance of Adolescents with Disabilities. Illustrates a disabled male (left) and non-disabled male (right). The participant emphasized the awkward appearance (i.e., the large face) of the disabled boy and indicated that the disabled boy in the drawing resembled his appearance. (Rohit, 18 year-old Male with Mild Down Syndrome, February 16, 2005).

Figure 29. Impact Drawing: Visible or Noticeable Disability. Illustrates a well-built/strong non-disabled male (right) and a disabled adolescent using crutches (left). Reinforced the visible or noticeable aspects of being disabled. (Vikram, 12 year-old Male with Polio, February 21, 2005).
Adolescents with and without disabilities offered a fairly negative picture of the socio-cultural environment and its response to disability. However, accounts and observations of participants also highlighted several positive aspects and strengths of the Indian culture and Lal Kuan community. Participants portrayed an interdependent family unit with immediate family members and siblings supporting young people with disabilities. Participants demonstrated a great deal of respect for elders in their community, especially their parents. Parents and children expressed a strong sense of obligation towards one another. Informal interactions with parents suggested a life-long dedication towards their children with disabilities. Adolescents with disabilities who had at least one good friend reported and were observed to have supportive and caring relationships with their friend.

Participants raised concern about adolescents with disabilities being at risk of developing a secondary mental health disability as a result of the harsh treatment they experienced by community members. Adolescents with disabilities described greater levels of and prolonged periods of stress, worry and sadness, which they attributed primarily to the daily struggles of being harassed, being isolated and receiving few social opportunities, and being anxious about their future; non-disabled peers supported the accounts of adolescents with disabilities. Sabrina, the young woman with a speech impairment, highlighted the sadness adolescents with disabilities experienced as a result of not being able to express their thoughts and feelings in her impact drawing in Figure 30. Geeta, a young woman with polio, stressed the importance of humour and happiness to enhance the quality of life of adolescents with disabilities in her drawing in Figure 31.
Figure 30. Impact Drawing: Frustration and Sadness. Illustrates a female adolescent with tears rolling down her cheek. The participant reported that the disabled girl was experiencing a great deal of sadness because she was unable to express her concerns as a result of her disability. (Sabrina, 17 year-old Female with Speech Impairment, March 15, 2005).

Figure 31. Impact Drawing: Joker to make you Laugh. Illustrates that adolescents with disabilities need a joker to make them laugh because they experience a great deal of sadness. (Geeta, 15-year-old Female with Polio, May 12, 2005).
Adolescents advocated that extensive measures should be taken to promote coping mechanisms that are targeted at the level of the disabled adolescent and their peer group. Adolescents appreciated the CBR team’s hard work in attempting to change people’s negative attitudes. However, adolescents believed that changing the conditions in slum communities may take a long time. Angela, who aspired to be a social worker, voiced her frustration over the community’s unwillingness to improve the surroundings:

> The community needs to have some knowledge and understanding, but they have to be ready to learn. That is the biggest problem. Even if we just ask one question, ‘Can we talk to you?’ They will give you ten reasons why not. Very few people care for these things. No one cares about disability. Everyone says that they don’t have time.

*(Angela, 17 year-old Female without Disability, Individual Interview)*

Since ASTHA’s move into the community, the CBR team has helped to increase educational opportunities, facilitate vocational training, provide subsidies to start-up small businesses (e.g., women’s candle making project), develop parent and women’s groups, and help individuals access health, medical and social services. The slums of Lal Kuan continue to be described as slow to progress and in need for individuals to take greater control to improve their opportunities and circumstances. Despite the negativity expressed by adolescents surrounding their socio-cultural environment, some change for young people with and without disabilities was evident, as was articulated by Sheila:

> There has been a lot of improvement here since ASTHA, this organization, has opened. … People have begun to pay a lot more attention to disabled children. Earlier if there was a disabled child, they would just give him food and he just sat there, but now people have begun to understand that they have to at least send their children to school and get their disabled child to reach their potential.

*(Sheila, 17 year-old Female without Disability, Individual Interview)*

A story shared by Sheila showed great promise for young people to take the initiative to think outside the box:
This disabled girl’s mother told me she had a lot of frustrations because her daughter does nothing at all. They have a gas stove at their home, but it is kept at a high level and the girl can’t stand at it and cook food. Then I said to the mother, ‘If you want your daughter to prepare food, keep the gas stove low.’… Next day when I went to their home, the daughter was making roti (Indian bread) on the gas stove. She said her mother placed the gas stove at a low level and now she can do work at home.

(Sheila, 17 year-old Adolescent without Disability, Individual Interview)

Given what I was learning about the community and culture, I was vigilant about the most culturally effective ways of bringing adolescents together. Thus, based on the desires of adolescents and remaining consistent with the CBR Program’s mission to promote disability and gender awareness, I frequently disseminated all research activities and processes that adolescents engaged in to community members, especially to parents, in order to alleviate any hesitation or anxiety they experienced about teenage boys and girls, non-disabled and disabled adolescents, working together. Research sub-question number three and objective c, where I explored the concept of program sustainability and investigated the role of peers and the CBR Program in the lives of disabled adolescents, provided more in-depth explanations regarding why adolescents preferred certain group-centered occupations given their socio-cultural context.

6.2.5 Three Supporting Factors for Adolescent Group Empowerment

As the study progressed, adolescents expressed the need to work with the CBR Program in order to bring their voices to the forefront and to engage in meaningful group occupations. Kumar emphasized the need for external support to inspire adolescents with disabilities to participate in the community.

Disabled adolescents are in no way incapable. They are such people who are able to do everything, but a backup support is needed for them, like friends, or they get the support from their parents or someone consoles them or someone helps them in every work. So with this they get the inspiration ahead and then they move ahead.

(Kumar, 14 year-old Male without Disability, Follow-up Interview)

The CBR Program was considered the most appropriate choice to empower adolescents,
educate protective parents, connect to the broader community, create space, and facilitate “face-to-face interactions among disabled/non-disabled and male/female adolescents” (Monica, Female Community-Based Rehabilitation Team Member, Focus Group).

Adolescents wished for the CBR Program to remain in their community, and I encouraged them to share their views with the program. Young persons with disabilities expressed enjoying events and outings organized by the CBR Program (e.g., attending the World Social Forum and World Disability Day Celebration at India Gate), and appreciated being introduced to numerous community resources (e.g., government schools, learning centers, financial amenities, local doctors, health care facilities, disability certificates, and access to mobility aids). Adolescents occasionally sought advice and assistance from CBR staff to mediate when conflicts would arise in their families. Omar was particularly appreciative of the role the program played in his life:

Earlier I used to think that I would just sit at home and that I would not be able to do anything. But when I found ASTHA, then I realized that I will be able to do something. (Omar, 15 year-old Male with Spinal Muscular Atrophy, Focus Group)

Adolescents recommended that the CBR team initiate more social activities with youth, continue to promote disability awareness, provide greater instruction for maintaining health, and avoid sporadic interactions that suggest desire to interact with adolescents only when specific organizational goals have to be met. Participants believed that ongoing external support and facilitation was fundamental to empower young people in the community because they may go through periods of feeling empowered and disempowered. Three external support factors important for maintaining ongoing adolescent group empowerment are presented in Table 12. I discuss the three external support factors in this section.
Table 12. Three Supporting Factors for Adolescent Group Empowerment.

<table>
<thead>
<tr>
<th>3 Supporting Factors for Adolescent Group Empowerment</th>
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<tbody>
<tr>
<td>I Facilitating group participation and the group demonstration process.</td>
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<tr>
<td>II Highlighting or drawing attention to adolescents’ strengths, abilities and contribution.</td>
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<tr>
<td>III Encouraging ongoing participation.</td>
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</table>

Note. Describes three supporting factors believed to be necessary for maintaining the adolescent group empowerment process. Participants suggested that adolescents with disabilities would experience periods of feeling empowered and disempowered. Thus, external support would be necessary for promoting rehabilitation activities. Adolescents viewed the Community-Based Rehabilitation (CBR) Program as the most appropriate choice for supporting young people with and without disabilities in the Lal Kuan community. An empower-er/empower-ee relationship was evident.

I. Facilitating group participation and demonstration

Despite adolescents’ desire to interact with their peers, occasionally adolescents were observed to be shy and slow to get started when working on group activities, especially during larger group sessions consisting of 20 or more children such as the monthly Arts and Crafts Workshop. The connection between “lack of social exposure and awkward social skills, [and] lack of self-confidence” was noted frequently (Tarik, Male Community-Based Rehabilitation Team Members, Focus Group). The CBR team discussed the negative impact of limited social exposure for disabled adolescents’ social and emotional developmental.

Adolescents appreciated having some guidance when carrying out tasks alongside their peers. The CBR team was viewed as especially helpful for gathering community members so adolescents could demonstrate specific activities. Adolescents reported their preference for control over group-centered occupations, while CBR team members described their role as providing choices:

Whatever work we are doing, we are only providing options. Ultimately, it is they who decide. We don’t say that this is one way and you have to do this. We suggest different options to disabled adolescents and then they try to build themselves up and they themselves choose among the options. Indirectly, the goal is empowerment. 

(Tarik, Male Community-Based Rehabilitation Team Member, Focus Group)
Tarik, a CBR team member, believed that it was essential to avoid treating persons with disabilities as children in order to consider them as equal partners in decision-making:

People with disability we treat them as kids for a long time. Sometimes I also tend to behave like that. We don’t respect them as an adult. When we are not even willing to accept disabled persons as adults, then how will we think of giving them choices.  
(Tarik, Male Community-Based Rehabilitation Team Member, Focus Group)

According to adolescents, the extent to which CBR team members were consistently offering adolescents’ options remained questionable. Adolescents reported that the CBR Program was an important resource because they had greater knowledge about the availability of diverse opportunities in which adolescents could participate, including film shows, exposure visits and workshops. The CBR team was investing greater time on promoting disability awareness and social inclusion, as Monica described:

We are bringing together all the children, non-disabled as well as disabled. One thought which is growing in them is that they can sit and talk together. We can’t say that inclusion exists. … How can we achieve this in our work – we will have to think over it.  
(Monica, Female Community-Based Rehabilitation Team Member, Focus Group)

Sanjay further reflected on the CBR Program’s goal of achieving social inclusion:

We are trying to increase sensitization. … We visit the school and talk with the teachers and with the children. Now we have started a creative arts workshop – its main focus is social inclusion of the children who are disabled and non-disabled. If social interaction and inclusion takes place, then such [discriminatory] thinking does not exist and violence doesn’t occur. The effort is being made so that these things can be tackled slowly.  
(Sanjay, Male Community-Based Rehabilitation Team Member, Focus Group)

Adolescents criticized the program for failing to inform them of the magnitude of opportunities available in order to make informed decisions. The idea of the CBR team ‘facilitating’ rather than ‘doing’ things received great attention.

II. Highlighting adolescents’ strengths, abilities, and contribution

Adolescents were particularly appreciative of the ongoing praise they received by CBR team members, which drew attention to disabled children’s strengths and abilities.
Sanjay, a male CBR team member, was observed “spreading the news” and “praising an 18 year-old male with mild Down Syndrome for winning a medal at the Special Olympics” (Sanjay, Male Community-Based Rehabilitation Team Member, Focus Group).

The CBR team worked hard to break down traditional myths and stereotypes about disability by educating community members through one-to-one discussions, speeches, pamphlets and booklets, workshops, social events, and dramas. Suman, a CBR team member, described the purpose of promoting disability awareness:

Disability awareness means giving information to a maximum number of people, and creating awareness inside them that disabled children are not different from them. They are the same as [normal] people are. It is true that they have a little difficulty in walking or in seeing or in speaking, but they are part of our community; they are like us. They should not be separated from us.

(Suman, Female Community-Based Rehabilitation Team Member, Focus Group)

Suman highlighted the positive changes that were apparent in the community as a result of the CBR team’s work on promoting disability awareness:

Earlier schools and teachers themselves were not in favour of disabled children [attending school] and questioned how a disabled child would do amongst all the other children. Now the same teachers ask you to bring the children. So there is change…

(Suman, Female Community-Based Rehabilitation Team Member, Focus Group)

Adolescents hoped that greater awareness would encourage people to see disabled people through a different lens and challenge views of the disabled as worthless or incapable.

**III. Encouraging ongoing participation**

Adolescents and the CBR team stressed the importance of encouraging disabled adolescents to participate in activities, especially during times when they feel hopeless:

We should encourage disabled adolescents so that they can show the world that they can become something. God has also given them strength too.

(Unidentified Adolescent Participants, Small Group Activity)

The CBR team stressed that adolescents with disabilities must “try to mix-up with the community; only then will the community accept them” (Suman, Female Community-
Based Rehabilitation Team Member, Focus Group). Adolescents were grateful for the encouragement they received from the CBR team, which motivated them to continue to engage in meaningful group occupations such as the monthly Arts and Crafts Group.

6.2.6 Ten Areas for Nurturing Adolescent Group Empowerment

From talking to and observing adolescents in numerous group occupations, I found 10 areas that appeared to nurture ongoing healthy and meaningful participation amongst adolescents with/without disabilities and males/females. The ten areas for nurturing the group empowerment process are presented in Table 13. I describe these 10 areas in this section.

Table 13. Ten Areas for Nurturing Adolescent Group Empowerment.

<table>
<thead>
<tr>
<th>10 Areas for Nurturing Adolescent Group Empowerment</th>
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<tbody>
<tr>
<td>1 Working together on meaningful tasks.</td>
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<tr>
<td>2 Observing one another.</td>
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<tr>
<td>3 Helping one another.</td>
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<tr>
<td>4 Educating and learning from one another.</td>
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<tr>
<td>5 Sharing with one another.</td>
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<tr>
<td>6 Receiving positive affirmation.</td>
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<tr>
<td>7 Providing positive affirmation.</td>
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<tr>
<td>8 Developing and refining skills and abilities.</td>
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<tr>
<td>9 Forming relationships and friendships.</td>
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<tr>
<td>10 Having fun.</td>
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Note. Describes ten areas seen to nurture the adolescent group empowerment process. These ten areas were seen to be embraced by adolescents, and may facilitate adolescents with and without disabilities to empower themselves or feel empowered.

1. Working together on meaningful tasks

A group approach appealed to adolescents in order to decide which activities would help to improve the lives of adolescents in the community. Adolescents were especially enthusiastic about suggesting that boys and girls, disabled and non-disabled adolescents “should not be separated,” should have opportunities to “work together,” and “get together to do something” (Angela, 17 year-old Female without Disability, 17 years old).
During focus group and observation sessions, adolescents were observed to make decisions together including deciding which quotes and photos to include in the page designed for the organization’s upcoming Annual Report.

2. Observing one another

Participants were surprised at disabled adolescents’ achievements after observing some of their performances and successes. Naveen, a young man with polio, expressed his desire to “also want to give a speech” about his life after watching his disabled peers give speeches during the Disability Day Celebration that was held in the community (Naveen, 15 year-old Male with Polio, Focus Group). Over the course of the study, adolescents reported feeling more responsible to “think about disability” and to view people with disabilities in a more positive manner (Leena, 16 year-old Female without Disability, Individual Interview).

3. Helping one another

Adolescents with disabilities stressed the importance of having someone to understand their thoughts and needs, to help them with the occupations they wished to and needed to carry out, and to help them access necessary resources and services. While working on small group activities over the course of the study, participants were seen to assist those adolescents who were unable to read or write to share material. Adolescents with disabilities reported appreciating the assistance they received from their peers. Angela described the importance of helping adolescents with disabilities in order to enable them to move forward in their life:

We should help them get ahead so that they can become something and show us. (Angela, 17 year-old Female without Disability, Individual Interview)

The notion of receiving and giving help appeared to be one-sided, with disabled
adolescents being the primary recipients of help. Participants began to recognize and appreciate the idea of mutual support. Participants wanted to help their peers with disabilities, but were unsure of how to provide the help.

4. Educating and learning from one another

Adolescents reported that activities to raise knowledge were essential for improving the overall condition of the community. Participants with disabilities were adamant that disabled adolescents “should be taught the truth,” but also be “taught not to lose their hope” (Sabrina, 17 year-old Female with Speech Impairment, Follow-up Interview). Rita added that only when a “man has confidence within, will everything happen” (Rita, 16 year-old Female with Polio, Individual Interview). Rita shared with her peers her belief that “when they will try hard, only then they will get success” (Rita, 16 year-old Female with Polio, Individual Interview). When educating people about disability, Sabrina, a woman with disability, suggested that one should avoid emphasizing the concept of disability, which may promote further or unintentional segregation:

Don’t focus so much on the [concept of] disabled. … I want that the attitude of people should change a little. I don’t know if their language will ever change. … But explain to people that the disabled too are natural. We shouldn’t show them so much as being a limper, we shouldn’t separate them. … Like if I have to say something, people say let her speak first. … Disabled are shown separately, shown that they are disabled. … Why? (Sabrina, 17 year-old Female with Speech Impairment, Follow-up Interview)

During discussions with non-disabled adolescents, they told me that they would like to ask their disabled peers the following: why disabled adolescents stay so depressed; what are some of the difficulties they experience; how they accept or cope with their weaknesses; what kinds of feelings they experience when they see their non-disabled peers; how they pass their day; what their experience is like at school; and what their ambition is? Adolescents with disabilities also wanted to educate their peers by telling
them that disability is a harsh move from nature; disabled adolescents dislike being called
disabled; disabled adolescents have hope; disabled adolescents have a few friends, but
spend most of their time at home; and to not harass adolescents with disabilities.

Adolescents found it both fun and necessary to work alongside their peers in order
to learn how to achieve necessary changes in their community. Adolescents expressed
gaining knowledge and thinking more about disability when interacting with their peers.
The CBR team believed that through awareness raising activities (e.g., discussions,
meetings and performances), adolescents were learning about their basic human rights:

Disabled children themselves are also gaining awareness that they have rights, that they
do not consider themselves inferior to anyone. … If someone speaks to them [unfairly],
then they question them at the same time by asking, ‘Why are you saying this to me?’ So
somewhere the impact of the work is happening. So this is a big change.
(Sanjay, Male Community-Based Rehabilitation Team Member, Focus Group)

Furthermore, participants were very passionate to learn about the opposite gender via
mixed gender group work rather than formal educational sessions and single gender
workshops. CBR team members supported the idea of young men and women learning
about the opposite gender:

If someone is male he should also have knowledge about females, if she is female, she
should know about males. … Within the company of one another, boys and girls develop
the capacity to understand one another.
(Sanjay, Male Community-Based Rehabilitation Team Member, Focus Group)

Participants suggested providing greater opportunities for group-centered occupations,
including camps and social gatherings in order to learn from their peers and gain greater
knowledge about issues relevant to young people in the community.

5. Sharing with one another

During focus group discussions and my observations of adolescents at community
events, adolescents were seen to share their experiences of living with a disability, how
they became disabled, their anger/frustrations/regrets, and their thoughts on romantic relationships. Adolescents with disabilities reported feeling comforted by “sharing their views with someone” (Melanie, 15 year-old Female with Visual Impairment, Follow-up Interview). Female participants with and without disabilities were thrilled about “sharing with their friends” about the work they were doing (Rita, 16 year-old Female with Polio, Follow-up Interview; Melanie, 15 year-old Female with Visual Impairment, Follow-up Interview; Angela, 17 year-old Female without Disability, Follow-up Interview; Leena, 16 year-old Female without Disability, Follow-up Interview). Participants’ friends occasionally showed up at focus groups and dissemination sessions to observe, join in the activities, and expressed interest in ongoing involvement.

6. Receiving positive affirmation

Adolescents emphasized that it was necessary for disabled adolescents to be acknowledged for their contribution, their skills, and the information they shared because they often displayed a negative self-image. Angela, the young woman with disabled siblings, stressed the importance of lifting the spirits of adolescents with disabilities:

Community members and families should think that we should not discourage a disabled to such a level that they totally get frustrated. … So he should be motivated in such a way that he builds an aim, a goal, which he can achieve.

(Angela, 17 year-old Female without Disability, Focus Group)

7. Providing positive affirmation

In addition to receiving positive feedback and acknowledgement, adolescents also valued the opportunity to offer advice and words of encouragement in order to motivate others to “build their confidence” (Rita, 16 year-old Female with Polio, Individual Interview). Adolescents with disabilities were also able to reassure and guide others when they shared heartfelt stories about issues such as being teased or having difficulty
with romantic relationships. Adolescents placed significant focus on exploring and helping adolescents to excel at their “individual interests” (Sheila, 17 year-old Female without Disability, Individual Interview).

8. Developing and refining skills and abilities

It was difficult for adolescents with disabilities to take advantage of social, educational and vocational occupations available to their peers; as a result, adolescents with disabilities were unable to develop or practice certain life skills. Many adolescents experienced discomfort when talking to others. The group setting promoted reciprocal interactions. Adolescents with disabilities were no longer passive recipients during occupations, but developed skills and recognized that they were able to contribute to the group effort. Omar reflected on the skills he developed by reporting, “Now I know I can do something” (Omar, 15 year-old Male with Spinal Muscular Atrophy, Focus Group).

9. Forming relationships and friendships

Participants with disabilities wished “to have friends who were of a similar age” (Omar, 15 year-old Male with Spinal Muscular Atrophy, Individual Interview). The nature of disabled and non-disabled adolescents’ friendships appeared to be different on many levels. Adolescents without disabilities appeared to have more friends of a similar age and engaged in numerous activities with their friends. Adolescents with disabilities tended to have friends who were much younger or were relatives, had difficulty maintaining friendships, and appeared to depend much more on their friends to console and help them. Angela, who was non-disabled, discussed how people seldom want to become friends with adolescents with disabilities:
Those who are general (non-disabled), everyone talks to them, everyone wants to become friends with them, but no one wants to become friends with disabled.

*(Angela, 17 year-old Female without Disability, Individual Interview)*

Rita, who was an adolescent with a disability, described her fear of making friendships:

> If there is a person or a girl with whom I want to make a friendship, I cannot say anything to her because I am disabled, that is I am oppressed, I am handicapped. … If I say something to her, she may say or think something wrong about me. … Due to this fear I cannot say anything to her.

*(Rita, 16 year-old Female with Polio, Individual Interview)*

The reciprocal nature of disabled adolescents’ friendships was not apparent.

Adolescents reported that friends were especially important at this age because you could share your feelings, provide support to one another, and problem solve together. There was group consensus that adolescence was a critical time for wanting, needing and maintaining friendships, and that making friends should be central to any community-based program’s activities.

Disabled adolescents too want to do something, they want to become something, they too want to make friends, want to make a circle of friends, want to talk to all of them, but there are so many hurdles which prevent them from doing anything.

*(Leena, 16 year-old Female without Disability, Individual Interview)*

The CBR team suggested that opportunity for interaction was essential for adolescents with disabilities to build a circle of friends:

One thing that comes to my mind is whether the disabled who are in the age group of 12 to 18 years are getting the opportunity to meet people of their age group. For them they are at the age when meeting children of their age group is necessary. … Particularly in our society they can’t talk to their parents.

*(Tarik, Male Community-Based Rehabilitation Team Member, Focus Group)*

Comfort in group situations was apparent as adolescents talked, shared stories, smiled and laughed, and sat in close proximity to one another. This comfort evolved over time, demonstrated respect for each other and helped adolescents to work together on group occupations. I observed adolescents engaging in friendly conversations prior to embarking on research or work tasks. The CBR team reported that these casual
interactions happened seldom earlier because of the lack of opportunity or an inadequate setting. The development of relationships was also supported through follow-up interviews where participants would ask whether another adolescent would be attending a group session, request to meet another participant or report that another participant was now a friend. Leena illustrated the potential for adolescents with and without disabilities to become friends in her impact drawing in Figure 32.

![Figure 32. Impact Drawing: Friendships between Adolescents with and without Disabilities. Illustrates the potential for a non-disabled girl (left) and a disabled girl with a crooked leg (right) to hold hands and be friends. (Leena, 16-year-old Female without Disability, March 21, 2005).](image)

10. Having fun

Adolescents enjoyed programs such as the Disability Day Celebration and social outings simply because they had the opportunity to have fun, laugh, smile, and meet other adolescents. Social or group events and occupations were seen as good means to alleviate the tension adolescents experienced on a daily basis, and to embark on new opportunities away from their normal daily routine and protective home environment.
6.3 An Exceptional Case

Changes had occurred in Lal Kuan since the CBR Program had been established in 2001. The CBR team members identified one adolescent with disability, who as a result of ongoing interventions, was able to bring a different perspective to the research. I believed that such an ‘exceptional case’ would help me to better understand the factors that empowered this adolescent to take greater control of their life and rehabilitation situation, and how they were able to overcome many obstacles.

I was introduced to Serena, a 15 year-old woman with polio, who was well known to the CBR team and the community for her extensive involvement in the CBR Program. I was not expecting that the one individual who would overcome many barriers would be such a young woman. Serena had traveled extensively across India to learn about work on disability being done by other non-governmental organizations, she participated in a documentary on aids and appliances, and gave many speeches at community events.

I met Serena during my first trip to India. I was warmly welcomed into her family’s home. Serena was not wearing her calipers or using her crutches for mobility at the time; instead, she was using her hands to slide along the floor in her home. I squatted down next to Serena so that I could speak to her comfortably. My immediate impression of Serena was that she was a very mature, friendly, well-groomed, enthusiastic, assertive and well-spoken young woman. I decided to interview Serena on the same day that I met her. Over the course of my trips to India, Serena shared many stories with me about her friends and relatives’ negative attitude towards persons with disabilities and females, and her strength to challenge community members.

Serena was living in a multi-storey home with both her parents and three younger
sisters. Her father was employed in the metal industry, and her mother was a homemaker. All of her sisters attended school and were non-disabled. Serena’s primary occupations included going to school and helping to take care of her siblings and home. Serena was in the sixth grade in a mainstream educational setting when I first met her. However, at 17 years of age after completing the ninth grade, she dropped out of school due to difficulty traveling to school. Serena believed that she might have made a mistake dropping out of school, and was now considering doing “open schooling” (home schooling). She also expressed interest in receiving vocational training for sewing, but wanted to eventually advance to a more personally meaningful job.

Despite all the factors working against young disabled women to succeed in the community, Serena recognized the importance of taking initiative and working hard in order to make positive changes in her life:

I want to do a job after finishing school. Such a job which requires education – like a professional job. I feel that I can do it, but it will not happen unless I do it. When I will try hard, only then I will get success.

She was critical of individuals who would solely put “blame” on others for their lack of achievement and difficult living circumstances. Over the years Serena had accepted that it was okay to “ask for help” in order to advance herself and carry out her daily tasks:

Obstacles have always come, however, difficulties can be overcome. … Most of my obstacles have been overcome since I started getting help from ASTHA. I always get help. If it doesn’t happen from home, I get help from outside. … At present, I get most of my help from the centre. … The tutor they provided did so much for me so that I could go to school. Now I am realizing my wish.

Serena was especially defensive towards community attitudes that forced women into submissive or passive roles where they were prevented from expressing their views:
Everyone at my home says that I speak too much and that girls should speak less. I say, ‘Why girls!’ My parents, my relatives, everyone says it. I get angry. I say, ‘If I have to talk, I will talk. If someone comes to you and you don’t talk to him, how will he feel?’ They should think about this. No problem arises from just talking to someone.

Serena was frustrated by the charitable view of disability held by many community members, and challenged the community to think otherwise:

If someone calls me a poor girl (pity), I feel very hurt. ‘I am not a poor girl!’ I have replied many times. I said, ‘I am not a poor girl, I have a mother and father also, I have a whole family, for what reason am I a poor girl! Can’t I do what you can do!’ Then people become quiet because they get a stern reply. If someone uses this word I feel so mad. I can walk. I have friends. I cook food. I go to school, whatever work they do, I do more. … My neighbours used to say it before, but now they don’t say it, I replied to them! I said, ‘I’m not a poor girl…I know all the things.’

She became even more infuriated when others would suggest that it was inappropriate for disabled persons to be ‘stylish or fashionable’:

People will say that, ‘She is disabled, she is a very strange girl, she talks to everyone, she stays very fashionable, she wears big-big earrings.’

Serena refused to let others dictate how she should present herself. She criticized her disabled peers for creating a disabled sub-culture by accepting others’ stereotypes.

Especially promising was the nature of support this woman received from her parents and siblings. She was often encouraged by her parents to stand up for her beliefs:

I hide nothing from my mother. I told my mother that today someone called me a poor girl (pity). My mother asked me if I replied back. I told my mother that I said nothing back, I just listened to it and came home. My mother said, ‘You’re stupid! If anyone says it again, tell him that you are not a poor girl, you too can do what other children can do.’ … I get the most support from my mom.

Over time, Serena developed a strong will, hope and confidence that allowed her to cope with the community’s harsh response towards persons with disabilities:

There are some people who may think that I am weak. But if I don’t feel myself to be weak, then no one will get chance to say it. … Keep yourself fine from within and then no one can say it. And if anyone says it, ignore them. He will say it once, he will say it twice, but the third time he himself shuts up. This has always been my thinking. Earlier when someone would say it to me, I used to cry so much. I used to think about why they said it. The younger I was, the more people used to say it. My mother would tell me to let it go, let them say it, then they will not say it again.

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I recognized that Serena had numerous opportunities over the years to interact with other individuals in the community, to travel independently with the CBR Program, and to give speeches at community events and gatherings:

Disabled children only want to meet with other disabled children because they don’t get the opportunity to meet other non-disabled children. … All the friends of [Serena] are non-disabled because she has gotten that chance.

(Tarik, Male Community-Based Rehabilitation Team Member’s, Accounts on Adolescent)

In addition, Serena was one of the few disabled women that I observed CBR team members joke around with about romantic relationships. Her photo and stories were also published in numerous organizational and local publications.

In summary, the following were the most significant areas that helped this young woman to overcome socio-cultural barriers in her community: taking action to be recognized, seeking help, questioning females’ submissive role, challenging stereotypes ‘on the spot,’ having supportive parents, becoming resilient, and embracing opportunities for social interaction. Serena was a very inquisitive woman and did not hesitate to ask questions. A combination of personal and environmental factors appeared to emancipate this young woman with a disability to take greater advantage of available opportunities and to have her voice heard at social events and community gatherings. Her sense of confidence and self-esteem appeared to be associated with her longstanding involvement with the CBR Program, and this led to additional opportunities to participate in numerous occupations.

6.4 Significance of Adolescent Group Empowerment

Throughout this chapter, I highlighted the numerous challenges and barriers to empowerment that adolescents experienced. The community and culture of Lal Kuan was portrayed as highly interdependent. Adolescents’ accounts suggested that they
wanted to use the interdependent aspect of their community to work on their personal and collective agendas for change and justice. Adolescents were seeking social and occupational justice in a manner that would not upset or disrespect their families and community members. Thus, using the ‘group’ concept to empower themselves appeared to be very appropriate and feasible given their cultural context and local circumstances.

I discovered that adolescents with disabilities were capable of engaging in many more meaningful group-centered occupations than was commonly perceived by the general community. Being involved in rehabilitation initiatives was fun and exciting for adolescents, and the participants anticipated that such a process would continue to be fun and important for adolescents with disabilities and their peers. Both the process and potential outcomes resulting from the group empowerment process are considered to be empowering for adolescents with disabilities and their peers. The process highlighted in the Adolescent Group Empowerment Pyramid can assist CBR programs to empower adolescents to assume greater ownership over their rehabilitation and sustain adolescent participation both in the community and CBR programs.

The concept of empowerment incorporated genuine happiness, greater interaction with peers, moving forward in life, being encouraged and supported, having greater freedom, being less isolated, and a desire to be involved, recognized and appreciated. Adolescent group empowerment may be achieved through enabling group-centered occupations. Group-centered occupations are activities that are determined and undertaken collaboratively by adolescents, have significant meaning and relevance to adolescents, and have a greater sense of purpose and direction.

Although all three areas -- group participation, group demonstration and group
recognition -- may be empowering individually and have been shown to be used independently by the CBR team, the findings from this study suggested that the greatest benefit would occur from combining these areas to promote empowerment among young people. Positive group recognition may help to raise further awareness about disability and achieve justice within a community setting, which is essential for health and well-being. The Adolescent Group Empowerment Pyramid illustrates the ongoing nature of promoting empowerment in community-based settings. It provides a means to develop the qualities that define empowerment and give young persons with and without disabilities a voice in the issues they deem important. Adolescents in this study understood that the goal of sharing information was not to solve their problems, but rather to have the opportunity to express their views and seek additional opportunities to engage in meaningful occupations. With greater involvement, adolescents recognized that this might lead to addressing their specific problems.

The Adolescent Group Empowerment Pyramid is a conceptual framework that can assist in guiding and facilitating group empowerment among youth with and without disabilities. The best contribution that we can make as a society is to help emphasize the skills, abilities and opportunities that would increase the chances for these young individuals to succeed and excel in communities where they are too often forgotten or isolated. I present a photograph of all the participants in Figure 33. The photograph became representative of this critical ethnographic study because it illustrates that by working together adolescents can collectively enhance their lives.
Figure 33. Collection of Adolescent Photographs. This collection of adolescent photographs became representative of this critical ethnographic research study. The photograph suggests a unity among adolescents in the community without drawing attention exclusively to disability. (Presented at Dissemination Sessions on Friday November 24, 2006, Community Classroom, and Sunday December 17, 2006, Community Centre, Lal Kuan, New Delhi, India).

“It’s not like God will come down to change something - you will have to change it…”

-Adolescent with Disability-
Chapter 7

Discussion

The research literature on the perspectives of adolescents with disabilities in the developing world and the role that these adolescents play in shaping their rehabilitation is limited or not readily accessible. There continues to be debate about the most effective ways to obtain information from adolescents, how to successfully apply this new knowledge to shape rehabilitation services, and how to maintain the participation of adolescents with disabilities who live in some of the most marginalized areas in the world. Little has been reported about personally meaningful and culturally sensitive ways of empowering young people with disabilities who live in highly disadvantaged or under-resourced areas. Any research that has been conducted appears to be poorly disseminated to communities who may be able to use the information to develop local programs.

I used a critical ethnographic approach to gain insight into the perspectives of adolescents with disabilities and their non-disabled peers in the urban slums. I have described the factors that would make it more likely to empower adolescents with disabilities to assume greater ownership over their rehabilitation, and the socio-cultural factors that influenced their desires.

Empowerment continues to be a fundamental goal of many community-based organizations, but the concept remains ambiguous. No single model for empowerment is applicable across all situations, environments and cultures (World Bank, 2002; Zimmerman, 1995). Speculation remains about the most effective ways to empower someone, whether an empowerer-empoweree relationship exists, and the best way to determine whether someone is empowered (Khwaja, 2005). I will focus on three major
areas throughout this discussion. First, I offer a more liberal approach to empowerment and change. Second, I discuss the use of working with small groups of individuals as a means to empower young people. Third, I discuss the Adolescent Group Empowerment Pyramid in relation to existing occupational therapy theory and critical theory, particularly the concept of occupational justice. Last, I present the contributions and limitations of this research, and propose some recommendations for change.

7.1 A More Liberal Approach to Empowerment and Change

The concept of empowerment has been traditionally dominated by masculine values such as individualism, power, control, competition, and mastery (Riger, 1993; World Bank, 2002). Given the dominant view of empowerment, Riger raised concern about the conceptualization of empowerment in community psychology and research, and the disconnect between the individual and community. The dominant view of empowerment may also be counterproductive within the field of community development or rehabilitation, especially in underprivileged communities where people may be competing over multiple issues and where concepts such as individualism and independence may be inconsistent with cultural values. The concept of power is at the root of empowerment. Theoretically power has been described in three separate ways (Hollander & Offermann, 1990; Riger). ‘Power over’ describes power that exerts explicit or implicit control over others. ‘Power to’ means sharing power more freely with others in certain circumstances. ‘Power from’ implies that a person resists the control of others. Research has focused on self-empowerment rather than true changes in power over resources, decision-making and policies. This may make a political platform personal and support the status quo rather than ensure empowerment (Riger).
Pure liberalism supports the dominance of individual rather than corporate rights (Riger, 1993). Therefore, examining empowerment of the individual may be viewed as being consistent with western dominant political ideology (Riger). The issue of power and empowerment are not easily challenged in a world that has valued western economic and social ideals of individualism, success and capitalist society (Riger). Globally, there is a disparity between the rich and poor and the dominance of able-bodied persons. A significant percentage of the world’s population, including young people with disabilities lives in oppressing social conditions. Young people with disabilities have the right to be offered the opportunities, choices, resources, support and safety that enable them to exercise true power over the issues that impact their quality of life.

A newer vision of empowerment would integrate the individual, empowerment and community, and be inclusive of less frequently mentioned concepts including cooperation and relatedness (Riger, 1993). From the data I collected, I would support a goal to embrace both the concept of empowerment and collaboration at the level of the peer group and broader community. Findings from this study support strengthening the sense of community through enabling and demonstrating meaningful group occupations locally in order to challenge negative attitudes and power differences. The perspectives of adolescents in this study promoted a more liberal means to empowering young people. A more liberal approach to empowerment would embrace concepts such as peace and collaboration rather than conflict and competition; interdependence rather than independence; shared benefits rather than individual gain; and the interaction of community groups. A more liberal approach to empowerment and change in a developing community would promote a harmonious balance between empowerment and
community. This would strengthen both the individuals and community and lessen the aggressive approach to gaining power over or from others who may already be in a marginalized position. Greater research that integrates empowerment and community connectedness is needed to understand the relationship between them and the effect they have on community functioning (Riger).

Focusing solely on cognitive or individual aspects in empowerment research minimizes the important influence of situational circumstances. This can lead to examining only individual solutions to broader human problems, and depoliticizes the issues and the concept of empowerment (Riger, 1993). Issues surrounding empowerment must address both personal and political dimensions of human and social problems (Cox, 1991). Decisions concerning young people in South Asia are often made by experts, parents or caregivers. Excessively controlling parents have been associated with young people internalizing problems, including social anxiety (Gladstone, Parker, & Malhi, 2006). Zimmerman (1990) distinguishes between individual empowerment which focuses heavily on individual traits and attributes, versus psychological empowerment which also takes into consideration the importance of contextual factors and promotes the notion of the person-environment interaction. Individual or intrapsychic factors in empowerment theory such as cognition, personality, emotions and motivation are also important (Zimmerman, 1990). I have provided evidence to support group empowerment positively influencing individual attributes such as emotions and motivation. I have demonstrated the intertwined nature of individual characteristics, experiences and perspectives, and the significant impact of contextual factors, suggesting that understanding both are fundamental for informing change, control and well-being.
This research was consistent with the works of Freire (1970) who advocated that the liberation of marginalized, disadvantaged and oppressed groups could only be achieved when groups collectively reflect on their history, issues and systemic barriers, and work together to change their daily reality (Fransen, 2005; Lang, 1999). To achieve social change at the grassroots level, liberation or empowerment can only be realized through the collective group process, and the role of the facilitator is just that, a facilitator -- a mutual teacher-student relationship where both are involved in educating and learning from one another (Freire; Freire & Shor, 1987). Empowerment is seen to have both intrinsic and instrumental value (World Bank, 2002), and the data from this study supports these values.

7.2 The ‘Small Group’ as a Means to Empowering Young People

The philosophy underlying empowerment is concerned with individuals or groups that are seen as separate from the dominant society due to demographic factors or other physical, social or emotional characteristics (Riger, 1993). Results from this study indicated that the ‘small group’ process may provide great potential for empowering young people particularly in more conservative or traditional communities. G. A. Fine (2003) has promoted the study and observation of group dynamics within the context of small groups that already exist in a community (e.g., young people’s sports teams). Small groups may be naturally occurring or may be intentionally developed and facilitated within the natural context as I chose to organize and observe them in this study. The small group provided an outlet for young people to confront their loneliness, see the similarities they shared with others, share their ideas, challenge one another, see their role in the problems they experienced, and work together to change their current
circumstances. Through group collaboration, individuals can define meaningful goals, learn from one another, provide mutual aid, instill hope, and work towards possible change (Asch, 1986).

Adolescents with disabilities in this study viewed active and meaningful participation as the fundamental component on which other elements of the group empowerment process were developed. Increased participation has been linked positively to empowerment (Zimmerman & Rappaport, 1988). However, a common concern raised in the literature is that increasing participation may be equated with empowerment, suggesting that changing procedures or participating may automatically inform changes in the context or resources (Riger, 1993). Simply putting children together, as was evident in the early model for mainstreaming, is not enough to ensure positive social participation (Harry, Park, & Day, 1993). Results from this study suggested that participation must be more purposeful and directed if it is to inform change in the community. The role of participation is more than supporting the act of participation. Participation is linked to the act of demonstrating and the ultimate goal of recognition. The assumption is that if adolescents are achieving their goal of recognition then both implicit and explicit changes leading to the overall well-being of young people should be present. For example, a greater number of young people with disabilities may be employed in more meaningful occupations, engage in organizational activities, and pursue romantic relationships. The concept of recognition has been linked to well-being (P. Fisher, 2008). Positive feelings about oneself have been shown to translate to greater energy and optimism (Gordon, 2004).

India is seen as a collectivistic and interdependent culture in which individuals
tend to organize themselves and validate the ‘self’ in relation to others and the social system (Kuebli, Reddy, & Gibbons, 1998). The individual is seen as internalizing recognition by others, which solidifies a shared social understanding and externally validates the individual’s status (P. Fisher, 2008). Recent discussions have suggested that human reliance on recognition in society revolves around three elements of life. These three elements are love (the notion of intimate relationships), legal order (the idea of being equal), and achievement (the idea that individuals experience greater self-esteem as a result of their abilities being valued) (P. Fisher).

Some individuals may argue that judging one’s value or self-worth based on the recognition of others may place already oppressed young people at greater risk for developing a poor self-image and be counterproductive to promoting well-being. This idea provides greater support for the adult and peer support factors that are highlighted in this study, which may encourage a healthy self-image in young people with disabilities regardless of the degree of recognition that they are able to achieve. The human desire for recognition that emerged from this research grew out of adolescents’ struggle to challenge ‘misrecognition.’ P. Fisher (2008) argued that parents’ quest to construct a more positive image of their lives with their children with disabilities was hindered by ‘misrecognition’ that perceived them as inferior. The dominant neo-liberal understanding of empowerment and well-being are based on dual understandings of concepts such as normal/abnormal or independent/dependent (P. Fisher). Such understandings promote a view of individualism and a bio-medical view of disability (P. Fisher). There is a greater need for societal recognition that values diversity. Recognition must be achieved in both the private and public spheres (P. Fisher).
Inadequate social inclusion has been associated with adverse health and impaired social and emotional development (Stevens et al., 1996). Peer victimization or bullying appears to be a global phenomenon crossing numerous cultural and social contexts, and disability is a risk factor for being bullied (Gladstone et al., 2006). Clearly, adolescents with disabilities in this study experienced a significant amount of rejection by their peers in the community. The experience of being bullied in childhood has been associated with higher levels of anxiety, depression, social phobia and agoraphobia in adulthood (Gladstone et al.). S. K. Egan and Perry (1998) found that being bullied was associated with diminished self-worth and self-esteem, which may play a significant role in perpetuating a vicious cycle that solidifies a child’s status as a victim of peer abuse. Participants in this study expressed concern regarding disabled adolescents developing secondary mental health disabilities as a result of the harsh treatment they experienced by community members. Adolescents with disabilities longed to fit in and be accepted by their peers. Peer acceptance has been associated with lower rates of depressive and anxiety symptoms and greater self-esteem in disabled children (Bakheit & Shanmugalingam, 1997). Interventions to enhance quality of life for adolescents with a mobility disability might address reducing stress and developing resilience by personal and social resources (Alriksson-Schmidt, Wallander, & Biasini, 2007). Reducing environmental and social obstacles in order to enable social inclusion of adolescents with disabilities in various aspects of their lives may help enhance their quality of life (Edwards, Patrick, & Topolski, 2003). Generic and specific education on disability and the opportunity for disabled teens to engage in structured activities that demonstrate ability versus disability is necessary to improve the attitudes and behaviours of non-
disabled peers (Doubt & McColl, 2003). Getting to know a person with a disability through integration is one of the most effective strategies for challenging negative attitudes (Law et al., 1999).

Adolescents’ desire to work together required collaboration rather than individual occupations aimed solely at individual recognition. Galheigo (2005) noted that group empowerment or collective action can be encouraged by community organizations engaging in culturally exciting activities such as popular celebrations, bazaars and festivals; group activities are seen as fundamental for development and belonging. Drama, a key group occupation desired by adolescents in this study, has been viewed as a powerful means to encourage community members to see prejudices (Swedish Organisation of Disabled Persons International Aid Association & World Health Organization, 2002). There is evidence that CBR programs are able to increase the likelihood of social inclusion when they are able to ‘show’ community members that persons with disabilities have skills and are able to contribute to the fabric of the community (Swedish Organisation of Disabled Persons International Aid Association & World Health Organization, 2002). Empowerment involves the development of a positive sense of self, and the recognition of the worth of oneself and others (Rodwell, 1996).

Self-determination is especially important for adolescents with disabilities (Field, Hoffman, & Posch, 1997). Adolescents with disabilities rarely see themselves as capable of giving assistance and informing positive changes in the community (Brill, 1994). This study reinforced the notion of group-determination that nurtured individuals’ spirit to grow, advance and contribute to the group effort to help inform change. A self-
determined individual has greater awareness of his or her strengths, limitations and potential; is better able to set goals and engage in decision-making; is appropriately assertive; is able to interact with others in a socially appropriate manner; and has a better understanding of how to become a productive member of society (Serna & Lau-Smith, 1995). Successful participation has been related to the following factors: having fun, feeling successful, engaging in activities, being with others, and doing things independently and collaboratively (Heah, Case, McGuire, & Law, 2007). Confidence and self-determination resulting from active and successful participation in a single self-help endeavour can increase the likelihood for an individual to take greater initiative and control over other aspects of daily life (Twible & Henley, 1993).

Adolescents in a focus group reported by Hutchinson et al. (2002) described the meaning of social participation as being with friends, making friends, having family support, dialogue/talking, and having fun. The ‘active’ group process is seen as an avenue for training and developing skills that are needed for increasing competence in all aspects of life, personal change, social action, and empowerment (Cox, 1991). Zimmerman (1990) reports that empowerment which stresses the cohesiveness of the person-environment fit, includes notions of collective action, skill development, cultural awareness, individual interests, personal motivation, personality, locus of control, and self-efficacy. In this study, 10 important areas were identified for nurturing group empowerment processes among young people. Participants found the ‘small group’ setting as the most fun and effective way of getting involved. Having fun was an important factor that solidified the group empowerment process. However, the concept of ‘fun’ and its relationship to empowerment has received little attention in the literature
and requires further investigation. The process of engaging in occupations with similar aged peers appeared to be a very liberating experience for young people with and without disabilities in this study.

VanderPlaat (1995) has suggested that empowerment should be investigated through discourse and participant-participant interaction rather than focusing exclusively on methodology or technique. Participants have expressed the importance of discovering the collective voice (VanderPlaat). Although recent work on empowerment attempts to strengthen the notion of collective action, many studies continue to discuss empowerment in terms of the ‘self’ (e.g., sense of personal control or strength, choice, action, independent decision-making, self-reflection, self-determination, confidence). Thus, little continues to be known about the collective process, its impact and outcomes. The important role of group participation and offering mutual support is often overlooked (VanderPlaat).

Traditional approaches that promote group work have often focused on single concerns such as education or socialization (Cox, 1991). The group process has been noted to have great potential for encouraging sharing among people when they are attempting to confront both their individual and common problems (Cox; Lang, 1999). Participation within groups is seen as fundamental in the ‘raising awareness’ process (Cox). The group process allows individuals to supplement and share their strengths and achievements over the course of undertaking empowerment-related activities (Cox). Furthermore, the group is seen as a medium for demonstrating to members that they may be able to accomplish activities with limited external support (Cox). Given the findings from this study, the group process served multifunctional purposes, from adolescents
developing organizational documents that informed local CBR policies and activities, to
the 10 areas that were seen to nurture the ongoing group empowerment process.

7.3 Adolescent Group Empowerment and Occupational Therapy Theory:
From a Critical Perspective

How does the concept of adolescent group empowerment relate to occupational
therapy theory from a critical perspective? The concept of empowerment is integral to
occupational therapy (OT) practice. Empowerment and participation experiences are
complex and vary significantly in content and quality. The Adolescent Group
Empowerment Pyramid emphasizes enabling group-centered occupations to empower
young people. The goal is to promote recognition for ability rather than disability, which
will hopefully lead to young people being more fully and meaningfully occupied. Recent
definitions of OT highlight enabling philosophy and language, as described in the
following definition:

[OT] is the art and science of enabling engagement in everyday living, through
occupation; of enabling people to perform the occupations that foster health and
well-being; and of enabling a just and inclusive society so that all people may
participate to their potential in the daily occupations of life (Polatajko et al., 2007,
p. 27)

When an adolescent in this study was not engaged in meaningful occupations (e.g., not
working, not going to school, not able to get married, and not interacting adequately with
others) their status in the community was questionable. Enablement philosophy in OT is
inclusive of the existence of power, power relations and people being active agents in the
process of individual and social change (Townsend, Beagan, et al., 2007). Townsend,
Beagan, et al. suggest that it may be helpful for occupational therapists to discuss, “How
does change work in groups when [people] are engaged in shared occupations” (p. 104).

There is a need to explore the role of group-centered occupations in informing social change.

There appears to be a connection between group recognition and achieving occupational satisfaction and justice. Discussions in the literature appear to be dominated by ‘individual’ benefits of empowerment rather than reciprocal benefits. Little research has investigated how empowerment of one group may relate to other groups. G. S. Fisher and Hotchkiss (2008) highlight the problem of occupational deprivation and occupational imbalance, and introduce *A Model of Occupational Empowerment* for disenfranchised groups; their work provides significant support for the use of occupational engagement in disempowering environments in order to facilitate positive or healthy occupational change. This new way of illustrating the role of occupation in empowerment is important for future research on empowerment and participation.

This research was supported by a participatory approach that was grounded in adolescent-centered practices. Enabling or supporting factors were clearly important to adolescents and necessary given the socio-cultural context. Enabling involves a range of holistic and participatory practices that oppose paternalistic, reductionist and caregiving practices that solely ‘do’ things for people (Townsend & Whiteford, 2005). In this study, I did not mistake facilitating critical self/group-reflection, supporting ideas, and advocating with and for adolescents with strictly ‘doing’ things for participants. Visually, I chose not to illustrate the supporting factors surrounding the Adolescent Group Empowerment Pyramid because I did not want the supporting factors to ‘over power’ the core of the framework. The Adolescent Group Empowerment Pyramid illustrates that
collaboration is fundamental to the empowerment process, unlike many existing frameworks that appear to be developed around the individual.

The concept of disability was incorporated within the Adolescent Group Empowerment Pyramid, but I did not present it as the central focus. Although adolescents with disabilities identified with the concept of disability, they viewed themselves as having the potential to be very ‘able’ in many aspects of their life. I avoided highlighting the term ‘disability’ in the framework because it has traditionally been associated with negative attitudes, and appeared to be inconsistent with promoting empowerment approaches. This is consistent with other OT frameworks like the Canadian Model of Occupational Performance where the focus remains on enabling occupation and not highlighting disability (M. Egan & Townsend, 2005).

I do not want to promote a prescriptive approach to empowerment. However, I do believe it is important to make explicit those factors that may promote empowerment-oriented approaches and encourage social inclusion. This will allow occupational therapists to consider, adapt and modify approaches to meet the needs of their clients and communities. Given the community-orientation of this research, I have explicitly defined numerous concepts in the hope that this research will be accessible to a wider audience, including community-based groups, workers and researchers, and program developers.

Enabling participation is a fundamental aspect of OT practice. Although group participation or social participation has received significant attention in the OT literature, it has received little attention in the context of group demonstration and group recognition. Future research might explore the concept of occupational recognition and what this means for social change and the personal and collective growth of individuals,
especially in under-resourced communities that define themselves as highly interdependent. Literature indicates that occupational therapists continue to be more concerned about attending to impairments rather than achieving the well-being of people and communities (Hammell, 2008). There remains a tendency to address issues at the level of the individual; it is challenging to simultaneously understand and integrate the concerns of groups of people.

Recent literature suggests that OT is still not well known for its contribution to enabling social change on a global scale (Townsend, Cockburn, et al., 2007). Occupational rights and justice must be seen as part of larger political and social justice issues affecting the well-being of people in conditions of poverty or oppression (Hammell, 2008). Discussions regarding social justice, human rights, poverty and empowerment appear to be incomplete without a more explicit understanding of new and emerging concepts, including occupational justice, occupational empowerment, and occupational recognition. The concept of ‘occupational’ broadens previous understandings of rights and justice by highlighting the breadth/depth of occupation, by emphasizing the need for quality, meaning and value, and by highlighting that rights and justice are not ‘static’ concepts even in the current state of affairs. However, the connection between occupational rights, well-being and human rights requires further attention, and must be made more explicit (Hammell).

7.4 Contributions and Limitations of this Research, and Recommendations for Change

This research introduces a group empowerment framework that is applicable to adolescents with disabilities and their peers, and takes into consideration the adolescent development period and the grass-roots level context. I made explicit those factors that
strengthen the connection between empowerment theory and practice. The study describes how individuals might contribute to a group effort for collective action. This research demonstrates a bottom-up approach to empowerment that would be adolescent-directed and would demonstrate adolescents’ collective potential to build local capacity. An external support system that may include CBR workers, teachers, social workers and parents can promote a bottom-up approach to CBR that highlights equality, breaks down authoritative styles of communication, and promotes greater control over decision-making by recipients (Werner, 1990).

The rights of children and adolescents remain an issue that requires further attention. Those who have knowledge of rights must ensure that knowledge is shared and enforced. Often the idea of adolescents as active participants is rejected because adults doubt their capacity to act constructively and competently (Call et al., 2002). In this study I demonstrated that this idea is not necessarily appropriate. In a true community-based approach, individuals will have the freedom to consider, choose and adapt advice from the information made available to them, whereby increasing the likelihood that rehabilitation activities are meaningful (Werner, 1990).

The Adolescent Group Empowerment Pyramid that evolved from this study promoted flexibility in the degree of involvement preferred by adolescents, including simply participating to assuming leader roles. The pyramid outlines the factors that may help to both initiate and sustain youth involvement. Adult support is seen as fundamental to effective youth engagement or empowerment (Camino, 2000; Centre of Excellence for Youth Engagement, 2007; Messias, Fore, McLoughlin, & Parra-Medina, 2005). This research provides more specific recommendations about the role of adults in empowering
young people. It is unlikely that oppressed individuals will simply empower themselves or be emancipated in the absence of others or without support (Freire, 1970).

Adolescents’ increasing desire to share information over the course of this study appeared to indicate that change was occurring (assuming that theoretically, empowered individuals are more likely to provide ongoing information). My goal was not to romanticize young people in underprivileged areas, but instead to enable them to share their perspectives and the occupations that they found meaningful.

To truly do justice to this study, the recommendations for change that I made to ASTHA were the ones highlighted by adolescents based on the three documents they developed, and the underlying components that informed the Adolescent Group Empowerment Pyramid. I attempted to describe the ambiguous concepts of empowerment, participation and recognition, and the elements that make them personally meaningful for young people. Within the context of this study, the way in which CBR activities were carried out changed on four levels. First, adolescents assumed responsibility for developing/informing organizational documents that were normally dominated by adult CBR staff members. Second, the organization expressed greater interest and scheduled more time in obtaining, considering and incorporating the ideas of adolescents’ within organizational initiatives and organizational staff were meeting more regularly with the adolescents who participated in this study. Third, the CBR Program developed a community youth group that addressed adolescent-specific issues, concerns and agendas and the group is currently being led by Sanjay, a male CBR team member. When I left India, I was informed that several participants from this study were active members in the youth group. Fourth, adolescents were also willing to support the
organization and be involved in meaningful activities that were facilitated by the program.

I was able to use a critical approach to research that demonstrated a partnership between a developed world investigator and a developing world CBR Program. Perhaps one of the greatest strengths of this study was the local dissemination sessions that were integrated directly within the design of the study. The dissemination and use of rehabilitation information has the potential for self-empowerment for persons with disabilities and their families, and to influence the practices and attitudes of professionals, workers, planners and organizers (Miles, 1996).

Replication is rarely possible in ethnographic studies as subsequent investigations seldom take place during the same time, space or context (LeCompte & J. J. Schensul, 1999b). However, cultural theories developed in one ethnographic study are useful in constructing a narrative or theory of local cultures or subcultures that is predictive at the least in the short term for hypotheses, observed patterns, and interpretations that can be explored in similar settings (LeCompte & J. J. Schensul, 1999b). Accounts obtained from such studies should not be dismissed on the grounds of being applicable only to a certain group in a specific location; on the contrary, such accounts can be useful in their own right for interventionists, practitioners, theoreticians, researchers, and policy makers who need rich, detailed knowledge of people’s activities at particular places and times (Snow, Morrill, & Anderson, 2003).

The Adolescent Group Empowerment Pyramid is a dynamic process that may be understood within the local and current state of affairs. The discussions I had with adolescents explained how things exist, why they exist as they do, and what they ought to be like. This research focused on a local level amongst already poor individuals. People
generally don’t find poor people threatening. This research did not confront higher level organizations and policies to address disabled adolescents’ problems. The organizational, economic and political environments require further investigation. To position human rights for disabled persons on a more ‘solid’ platform, one must identify cultural, social and political forces that hinder disability advocacy and those that might facilitate critical discourse/action in order to respond more holistically to participation in daily life (Bickenbach, 2001). Research does suggest that ‘true’ change requires the interaction of local, state, national and international levels.

Sharma and Bhatia (1996) used the strengths, weaknesses, opportunities and threats (SWOT) analysis to review the literature on emerging trends of voluntary organizations in community health in India and used the information to predict future trends. Key areas for progress and strengthening voluntary organizations included strengthening the collective force, increasing use of participatory action strategies, and achieving empowerment at the level of the individual, organization and community through doing/acting rather than merely asking for rights. The concept of empowerment in underdeveloped areas is further complicated because community members often become accustomed to or dependent on community-based programs that do things for them (Ganguly & Brar, 1993). Programs may fail to help community members develop the ability to control their own lives, and community members may not utilize programs to gain control over their daily occupations (Ganguly & Brar). Inadvertently, CBR programs get caught in an unexpected cycle of ‘doing CBR’ (Ganguly & Brar). Despite CBR’s history spanning over 20 years, it continues to view persons with disabilities as recipients of services and to a lesser extent as active agents with a voice and choices
(Swedish Organisation of Disabled Persons International Aid Association & World Health Organization, 2002). Contemporary literature suggests that community-based programs be grounded within a human rights approach (International Labour Organization, United Nations Educational, Scientific and Cultural Organization, & World Health Organization, 2004). However, community members must actually be aware of their rights if such programs are to truly work and be empowering.

The current state of research is becoming increasingly concerned with the pragmatic value of multiple meanings and the social world (Holstein & Gubrium, 2005). The purpose of this study was not to criticize traditional communities like Lal Kuan, but to instead identify oppressing practices (e.g., exploitation or unjust treatment of vulnerable groups, including children, disabled persons or women; under-age marriages; dowry system) that are being challenged globally; and to nurture the strengths of such communities to build local capacity. Within the realms of international development, the most pragmatic strategy may be to facilitate a political environment that allows persons living in poverty to organize themselves, and visibly increases their power at district, state and national levels (Moore, 2001). It may be difficult for even empowered individuals to strengthen organizations that allow few opportunities for others to get involved in organizational activities (Zimmerman, 1990). Powerlessness over destiny has been identified as a risk factor for poor health and disease; empowerment is viewed as an important factor in health promotion (Wallerstein, 1992). Considering the contemporary view of empowerment theory, I am not suggesting that one approach (e.g., group versus individual) is better for empowerment. Instead, I think it is critical to broaden the scope of empowerment research in order to consider different options as it is highly unlikely
that any one approach will be applicable across all developing communities and situations. Adolescents’ accounts in this study also suggested a need for both disability-sensitive and gender-sensitive approaches to empowerment. It is critical to develop strategies that allow disempowered young people to organize themselves in order to create social change through removing barriers that contribute to their disempowerment, including providing young people with the necessary knowledge, providing access to necessary resources and services, and facilitating the role of young people in programs and policies.

I believe that true, sustainable change comes when we enable people to help themselves, people work together to challenge systemic barriers, and those with power also assume responsibility to help address those barriers. Empowerment cannot simply be imparted upon oppressed individuals (Northway, 2000; Oliver, 1992). Social inclusion of disenfranchised groups into all policies and programs is required in order to increase awareness of their unique issues, and for ongoing advocacy to ensure that their voices aren’t lost within mainstreaming (Huber, 2003). Adolescents’ accounts provide significant support for studying the person-environment paradigm and the role of contextual factors in empowering young people with and without disabilities. I do not see empowerment as an unrealistic ideal. Instead, I believe it is necessary to explore the concept of empowerment in order to enable people to develop the skills and motivation needed to navigate a complex set of intertwined systems.
Chapter 8

Conclusion

Investigating and empowering young persons with disabilities has emerged as an important field of study in contemporary society. Millions of young people, particularly across the developing world, continue to struggle with disability related issues as a result of living in poverty, dealing with illness or disease, and residing in conflict zones. Poverty continues to be the reality for millions of young people around the globe. Globally, many health and social development issues (e.g., poverty reduction; malnutrition; HIV/AIDS; primary education; labour) receive significantly more attention than disability, despite the fact that disability may be intertwined with these issues. Given that poverty and disability are often linked, this supports further investigation of disability and rehabilitation. I am a strong advocate for the health and welfare of young persons with disabilities being a global responsibility.

To address the issue of empowering young people with and without disabilities, I introduced a conceptual framework that I called the ‘Adolescent Group Empowerment Pyramid’. The framework highlights three meaningful areas for empowering adolescents: group participation, group demonstration, and group recognition; which may be achieved through purposeful group-centered occupations. The following elements were seen as important for meaningful group participation: control, quality, and demographic factors. The following elements were seen as important for successful group demonstration: clarity about the purpose, process and audience. The ultimate goal was for adolescents to achieve group recognition at the level of the individual, peer group, and society in order to be respected, acknowledged and in a better position to take advantage of the
opportunities available in the community. Two additional areas important for understanding adolescent group empowerment included: i) three supporting factors believed to be fundamental for maintaining the ongoing group empowerment process (i.e., facilitating the group process, highlighting adolescents’ strengths, and encouraging ongoing participation), and ii) ten areas for nurturing adolescent group empowerment (i.e., working together, observing others, helping one another, educating and learning from one another, sharing stories, receiving positive affirmation, providing positive affirmation, developing skills/abilities, forming relationships, and having fun). I illustrated the entire framework as superimposed on the concept of the socio-cultural environment because the social and cultural context had a significant impact on the lives of the young people in this study. I recommend the continued use and critique of the Adolescent Group Empowerment Pyramid in order to determine its applicability across different settings and youth groups with disabilities, and to improve such emergent frameworks.

As developed world researchers, we must remember that our role is to collaborate and facilitate, and not to control the ‘change’ process or impose upon others strictly western ideals. It is important to understand and respect interdependent structures of eastern communities, but simultaneously work to identify forces that limit occupational development (Townsend & Wilcock, 2004). Cultural and community differences can be a source of strength (Fransen, 2005). While it is important to note the strengths of various communities, we cannot discount the numerous barriers and negative attitudes that may produce occupational challenges in all communities and cultures across the globe, including western and eastern communities. Elements of democratic governance, progress, and culture must be well balanced in communities like Lal Kuan if the local
people are to embrace such research opportunities to inform sustainable change.

The perspectives of adolescents with disabilities are critical in developing meaningful and appropriate rehabilitation interventions, particularly in an era that is dealing with numerous economic and resource constraints. Without attempting to break the vicious cycle of isolation, submissive behaviours and systemic barriers in a culturally sensitive manner, adolescents with disabilities will merely remain passive recipients of services and have little role in helping to make programs personally meaningful and sustainable. To ensure the relevance and sustainability of community-based rehabilitation (CBR) initiatives, program developers and implementers must be aware of the personally meaningful factors and occupations that may empower and maintain the interest of the target population. Greater work is required to ensure that we are assisting young people with disabilities to bring to the forefront the issues that affect their lives and to find possible solutions and interventions to address their issues.
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Appendix A

ASTHA’s Community-Based Rehabilitation Program Lal Kuan

Information Pamphlet

Where your support will go:
- To be able to acquire land and build a disabled friendly facility which will serve as a base for our work.
- Funds to pay professionals who are associated with us.
- Funds to support our projects.
- Funds to conduct various workshops and training programs.
- Sponsor a child
- Volunteer your time
- Be a friend
- Enrich their experience by sharing your talent

Every individual, whatever their ability, has the right to live a life with dignity. It is our endeavor to ensure that we all respect this right.

Information Communication & Counseling Unit

Helpline

The helpline is a walk-in and telephone service to provide free counseling and information to persons with disabilities and anyone else who seeks information on disability. The service is the first of its kind in Delhi and has been operational for over five years, touching lives of persons with disabilities and their families in and around Delhi.
ASTHA is a registered charitable trust that has been set up as a non-profit organization providing services to children/persons with disabilities and their families.

Rights of individuals with disability have been at the core of ASTHA’s belief and work ethics.

Started in 1993, ASTHA is one of the few institutions that reach out to children/persons with disabilities irrespective of the type and severity of disability.

**Mission**
- To provide services to children/persons with disabilities and their families.
- To disseminate information and conduct research on issues that affect the lives of people with disabilities while working in close partnership within their families.

**Beliefs**
- Each and every person in society, however severely disabled they may be, is equal and has the right to equal opportunity in society.
- Working with persons/children with special needs is not an act of charity but a profession where people learn to care for each other.
- Each person, disabled or non-disabled, has his or her own unique contribution to make and this contribution must be recognized by society.
- Children/persons with disabling conditions should not be isolated from other children/persons and that both sets of children/persons benefit a great deal from interacting with each other.

**Our Projects**

**Centre For Children with Special Needs**

We provide quality services for children with multiple and severe disabilities.

- Located in Giri Nagar Kalkaji.
- Our Services include special education, physiotherapy, speech therapy, provision of aids and appliances, medical intervention, arts and crafts, music, theatre and other.
- Developing an inclusive curriculum for children with special needs.
- Working in partnership with families.

**Outreach Program**

We open our doors weekly to children/persons with disability and their families in and around the community who do not have access to regular services.

- To enable parents to manage their children/persons with disability effectively through necessary intervention and training.
- To provide information related to disability issues and need-based referrals.

**Govindpuri-Extension Program**

A program in the slum community of Govindpuri provides rehabilitation services to children with disability and support services to their families. This program aims to:

- Link disability issues with larger community issues.
- Empower the community to become partners and catalysts in the rehabilitation process of children and persons with different disabilities.

**Community Based Rehabilitation-Lal Kuan**

A CBR program is located in Lal Kuan area aimed at building up rehabilitation services for persons with disabilities, with particular focus on:

- Disability management and awareness raising.
- Disability and Gender Sensitisation.
- Provision of Functional Rehabilitation Services.
- Provide information about developmental issues with special emphasis on disability and education to families of persons with disabilities and knowledge of how to access services.

- Link Disability issues with larger community issues.
- Create education opportunities and mainstreaming.
Establishment of ASTHA’s Community-Based Rehabilitation Program (2001)

Urban Slums within the District of Lal Kuan, New Delhi, India (Adapted)
Provided By Program Manager ASTHA

Background of the Implementing Partner

ASTHA is a registered charitable trust that has been working in the field of disability since 1993. ASTHA was started with the twin aim of providing high quality of services to people with disabilities and their families. Finding strategies and solutions in the field of disability that stem from the Indian situation through the areas of research, documentation, communication and information. Over the years, ASTHA has consistently worked on these twin aims through its:

- Centre for children with special needs: catering to children with multiple disabilities with emphasis on children with severe disabilities.
- Slum program: catering to children and persons with disabilities and their families. This project caters to any person with any disability within the Govindpuri slum area.
- Extension services: which involve weekly services to children and persons with any disabilities and their families.
- Research projects: over the years ASTHA has consistently taken up research on issues that have come up during the course of its work (e.g., addressing medical information needs of families with children with cerebral palsy) and researching legal provisions for persons with disabilities.
- Regular workshops: every year ASTHA organizes workshops on issues that it sees as important in the area of disabilities such as setting up trusts for persons with disabilities, dealing with abuse of children with disabilities; ASTHA has also been involved in conducting legal literacy workshops for various organizations.
- Development of communication material.
- Help-line counselling and referral services: over the years ASTHA has collected a lot of information in the area of disability and aims to disseminate this information and link people to the right services and information through this unit.

Project Background

ASTHA’s Centre for Children With Special Needs has been based at Tughlakabad village since 1997. Over the years we found that a large number of families from the surrounding areas needed to access services for their family members/children with disabling conditions. There are very few organizations that had the capacity to deal with the whole range of disabling conditions. Keeping this need in mind ASTHA started its extension program in 1997. Through this program, families of persons/children with disabilities have continuous access to therapists, educators, speech therapists, counsellors and information and referral services at very nominal and often no cost. From April 1998, families from the Nardan Basti Lal Kuan area visited our extension services at Tughlakabad village with their children with special needs. Of these, five families have been coming on a regular basis. These parents have also referred other parents to our extension service. Over the years, parents have been asking whether ASTHA could start a school in the area. While ASTHA cannot start a school, preliminary talks have been held with parents of children with disabilities about starting services for their children within the basti.

A preliminary survey was conducted by CARENIDHI (an organization with expertise in the area of multiple disabilities and research) with ASTHA’s support in January-February 2000. ASTHA now intends to initiate a community-based rehabilitation program in the Lal Kuan area.
Project Area

The project area will be the Lal Kuan area which is just off the Mehrauli Badarpur road, near the Tughlakabad fort in South Delhi. Our visits to the Lal Kuan area and conversations with different people revealed that the area is divided into different blocks. The blocks range from A to K. The people who live in these communities refer to these blocks by the following names:

- A & B : Chungi No. 2
- C & D : Chungi No. 3 and Shiv Camp
- E, F & G : Panchmukhi Mandir
- H & I : Bhairon Mandir (also called Lal Kuan MB road)
- J : Prem Nagar (Surja Camp)
- K : Nardan Basti

The ASTHA team has now visited Nardan Basti and Surja Camp (Prem Nagar), Chungi No. 2 and the Panchmukhi Mandir area. In Chungi No. 2 we spoke with a group of men who were seen as the elders in the community. We also spoke at length with Shri Murli Lal also known as Master ji who seems to be the informal Pradhan [head] of the area. The elected Pradhan of the area has passed away and there is no other person who has been elected formally in this area. In the Panchmukhi Mandir area, Shri Shish Pal directed us to a Shri Dharampal who he said knew all about the area. Our conversation with these people revealed the following information:

All the communities that we have listed above are within Delhi. However, adjoining these communities are other urban villages (if we call them that) that fall within the Haryana boundary. All the communities have been there for the last 50 years. It seems that people came here because there was stone mining work here and have settled here. Most of the people we spoke to are second-generation people in the community.

Most of the people in the area are Hindus. There are very few Muslims and even fewer Christians. We were told that most of the Hindus were from the scheduled castes. Most of the people come from Rajasthan, Uttar Pradesh, Bihar and some from Himachal Pradesh.

All the communities are interconnected by road, a large part of which is motorable. However, our own impression was that the communities were not greatly interactive with each other.

According to all the people we spoke with, the voters list indicate the there are approximately 12,000 to 15,000 voters in this area. This would mean that actually there are about 30,000 to 35,000 people in the area. Some estimates were even higher than this. There is a Gram Vikas Samiti and most people have ration cards and voters identity cards.

Most of the population here belongs to the lower income groups, with most men and women being labourers. There is a smaller percentage of lower middle class people. A large number of people still seem to be working at stone crushing by hand, or on construction plots nearby (there is a more affluent Wishvakarma colony coming up nearby). Some even go to Tughlakabad goan and the Okla Industrial area. The level of education is very low and a large number of women are in Purdah [cover faces with a veil]. There is a lady in the Panchmukhi area who has been teaching stitching to women in the particularly community.

The people are now getting sensitized and are attempting to send their children to school. There are (some said two) MCD [government] schools in the area which go up to Class-V. After that children have to go to the school in Railway colony nearby. In one of the larger schools there are
about 1,500 children studying while in another there are about 700 children studying. All the children are not going to school.

There are approximately 10 anganwadis running in the whole area of children from 3 to 6 years. Children get bread and biscuits here and immunization is also carried out for children and pregnant women.

There was a unanimous feeling that health facilities are sorely lacking in the area. There seems to be a high incidence of TB in the area. All the people reported that a van comes once a week and gives medication. It was not clear whether they dealt only with TB or other health difficulties too.

There is a water problem in the area and some people have electricity with metres while most seem to tap electricity. According to Shri Shish Pal some areas are authorized and some are not. The people living in the community were not clear which areas were authorized and which were not.

There are no special services for people or children with disabilities in the area and we have been offered space to start work there. The initial response we have got is a very open and welcoming one. According to Shri Murli Lal, there are at least 500 children with disabilities in the area. However, no survey or actual counting has been done. There were conflicting responses about whether there were other NGOs working in the area. Nobody was able to give us any names. It was also clear to us that people did not know about the facilities available in the other blocks or community areas.

In our few visits to the area we have already encountered ten children with disabilities. Two of these have already accessed our services since then. What seemed to be positive about the communities is the fact that they seemed to be working as communities. People seemed to know each other and there are many families that have been living in the area for many years.
Appendix B

Data Collection Protocols and Guides

Overview

Protocol #1: Informal Observations of Community Setting

Protocol #2: General Fieldnotes and Memos

Protocol #3: Initial Meeting, Informal Observations & Recruitment with Adolescents

Protocol #4: Demographic Data for Adolescents

Protocol #5: Demographic Data for Community-Based Rehabilitation Team Members

Protocol #6: Audio-Visual Data (Audio-Recording, Photography, and Videography)

Protocol #7: Individual Semi-Structured In-Depth Interviews with Adolescents

Protocol #8: Participant Observation - Activity Specific - with Adolescents

Protocol #9: Focus Group #1 (of 5) with Adolescents
Regarding Collective Understanding of Disability

Protocol #10: Focus Group with Community-Based Rehabilitation Team
Regarding Understanding of and Involvement with Adolescents

Protocol #11: Document Review of Client Files and Organizational Documents

Protocol #12: Follow-Up Interviews with Adolescents

Protocol #13: Focus Group #2 (of 5) with Adolescents
Regarding the Disability Day Celebration/Program in the Community

Protocol #14: Focus Group #3 (of 5) with Adolescents
Regarding Community-Based Rehabilitation Program’s Plan for 2007

Protocol #15: Focus Group #4 & 5 (of 5) with Adolescents
Regarding Designing a Page for ASTHA’S Annual Report
Protocol #1: Informal Observations of the Community Setting

1. Refer to Spradley (1980, p. 78) checklist for making general observations of the community setting:
   1. Space: physical location(s)
   2. Actor: persons involved
   3. Activity: series of interconnected acts that people engage in
   4. Object: material items that are present
   5. Act: single acts that people engage in
   6. Event: series of connected activities that persons carry out
   7. Time: series that occur over time
   8. Goal: what people are attempting to accomplish

2. Unobtrusive measures/outcroppings.

3. Fieldnotes and memos.

<table>
<thead>
<tr>
<th>Fieldnotes</th>
<th>Memos</th>
</tr>
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<tbody>
<tr>
<td>Diagram of Physical Setting and Space:</td>
<td></td>
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**Protocol #2: General Fieldnotes and Memos**

<table>
<thead>
<tr>
<th>Fieldnotes</th>
<th>Memos</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Questions to consider:</strong></td>
<td><strong>Questions to consider:</strong></td>
</tr>
<tr>
<td>▪ What do you see? What do you hear?</td>
<td>▪ What thoughts are coming to your mind? Why?</td>
</tr>
<tr>
<td>▪ What are people doing? How are people behaving?</td>
<td>▪ What hunches are you having? Why?</td>
</tr>
<tr>
<td>▪ What are people saying? How are people saying it?</td>
<td>▪ What are you feeling? Why?</td>
</tr>
<tr>
<td>▪ What emotions are being expressed?</td>
<td>▪ Is there anything you would like to follow-up on? Why?</td>
</tr>
<tr>
<td>▪ Refer to observation checklist as necessary.</td>
<td></td>
</tr>
<tr>
<td>▪ Take photographs and videos as necessary.</td>
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</table>

Diagram of Physical Setting(s) and Space(s):
Protocol #3:  Initial Meeting, Informal Observations & Recruitment with Adolescents

<table>
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<th>Investigator:</th>
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<tr>
<td>Name of Participant: (with or without disability)</td>
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<tr>
<td>Describe Research Study Phase (I, II, III, IV, V):</td>
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<tr>
<td>Individuals Present:</td>
</tr>
<tr>
<td>Adult Facilitators &amp; Nature of Facilitation:</td>
</tr>
<tr>
<td>Community-Based Rehabilitation Worker(s) Involved in Consent Process:</td>
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<tr>
<td>Consent to Participate Provided By: (Name of Caregiver &amp; Adolescent)</td>
</tr>
<tr>
<td>Recruitment (Date, Time, Place):</td>
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<tr>
<td>Additional Comments:</td>
</tr>
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</table>

1. Consent Process:
   
   (Note: Details regarding consent described only if caregiver & adolescent agree to participate)
   - How was the research study described? Who described the study?
   - Was the investigator present during the initial consent?
   - If the investigator was not present during the initial consent, how did the community-based rehabilitation worker explain the study and issues regarding consent (i.e., What were the circumstances under which consent was obtained? What did the caregiver say? What did the adolescent say? Did both the caregiver and adolescent appear comfortable?).

2. Initial interaction between the investigator, participant, and caregiver:
   - How did the initial introduction between the investigator and participant occur? Who initiated the introduction (i.e., investigator, community-based rehabilitation worker, parent/caregiver, adolescent, or another family member/relative)?
   - Who was present during the initial interaction?
   - Describe the interaction between the investigator and the caregiver/other family members.
   - How did the investigator introduce herself and the study? How did the investigator reiterate the purpose of the study and issues regarding consent?
   - Describe the physical and social environment during the initial interaction.

3. Investigator’s initial impression of the adolescent participant:
   - What was the adolescent’s reaction to meeting the investigator (i.e., What was the nature of the conversation? What did the adolescent say? Describe the adolescent’s body language, facial expressions, gestures, and tone of voice.)?
   - What was the adolescent’s reaction to participating in the study?
   - Describe the adolescent’s communication style (i.e., use of language; ability to verbally communicate).

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**Protocol #4: Demographic Data for Adolescents**

| Participant Name: |  |
| Date: |  |
| Age: |  |
| Date of Birth: |  |
| Gender: | Female ☐ Male ☐ |
| Religion/Caste: |  |
| Contact Information: | Address:  |
| | Telephone:  |
| Type of Accommodation/Housing Situation: |  |
| Family Description: |  |
| Health Status/Nature of Disability: |  |
| Education/Vocation: |  |
| Communication/Language: | Able to Verbally Communicate: yes ☐ no ☐ |
| | Hindi: speaking ☐ writing ☐ reading ☐ |
| | English: speaking ☐ writing ☐ reading ☐ |
| | _______: speaking ☐ writing ☐ reading ☐ |
| | Comments: |
| Additional Comments: |  |
## Protocol #5: Demographic Data for Community-Based Rehabilitation (CBR) Team Members

<table>
<thead>
<tr>
<th>Participant Name:</th>
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<tr>
<td>Date:</td>
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</tr>
<tr>
<td>Age:</td>
<td></td>
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<tr>
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<td>Religion/Caste:</td>
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<tr>
<td></td>
<td>Telephone:</td>
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<tr>
<td></td>
<td>Email:</td>
</tr>
<tr>
<td>Role/Responsibilities within Community-Based Rehabilitation Program:</td>
<td></td>
</tr>
<tr>
<td>Health Status/ Nature of Disability:</td>
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</tr>
<tr>
<td>Educational/Vocational Background:</td>
<td></td>
</tr>
<tr>
<td>Communication/Language:</td>
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</tr>
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<td>writing □ reading □</td>
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<tr>
<td>English: speaking</td>
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<tr>
<td>______: speaking</td>
<td>writing □ reading □</td>
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<tr>
<td>Comments:</td>
<td></td>
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</tbody>
</table>

Describe your experience (personal and professional) with regards to the research population of interest (i.e., adolescents with disabilities)?

____________________________________________________________________________________
____________________________________________________________________________________
____________________________________________________________________________________
____________________________________________________________________________________
Protocol #6: Collecting Audio-Visual Data
(Audio-Recording, Photography, and Videography)

1. **Respect and Confidentiality:** Continuously re-explain purpose of tape recording, photographing, and videotaping to adolescents, caregivers, and community-based rehabilitation workers. Re-address issues of confidentiality and identity being revealed.

2. **Comfort:** Ensure that participants are comfortable (i.e., inquire and use personal judgement).

3. **Audiocassettes:** To be heard and reviewed by investigator and transcriber(s) only.

4. **Photographs:** No names associated with photographs. To be used respectfully and for academic purposes primarily (e.g., during presentations, to disseminate information, with academic committees). To be shared with appropriate audiences in order to advocate for young persons voices and abilities.

5. **Video Footage:** Entire video-recordings only to be heard/reviewed by investigator (and transcriber(s) as necessary). Carefully selected video-footage may be used only for academic purposes (e.g., during presentations/conferences, to disseminate information, with academic committees). To be shared with appropriate audiences in order to advocate for young persons voices and abilities.
**Protocol #7: Individual Semi-Structured In-Depth Interviews with Adolescents with/without Disabilities (Includes written/visual activities)**

<table>
<thead>
<tr>
<th>Investigator/Interviewer:</th>
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<tbody>
<tr>
<td>Name of Participant/Interviewee: (with or without disability)</td>
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<tr>
<td>Describe Research Study Phase (I, II, III, IV, V):</td>
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<td>Consent to Interview Independently Provided By:</td>
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<tr>
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<td>Date:</td>
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<td>Time:</td>
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<tr>
<td>Place:</td>
</tr>
<tr>
<td>Transcriber(s) Involved:</td>
</tr>
<tr>
<td>Additional Comments:</td>
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</table>

**Background Information and Introduction:**

1. Review information booklet, consent forms, and research process in detail again.
   - Ensure participant understands the following:
     - Choice to participate. Right to withdraw at anytime.
     - Right to participate in selected questions and activities. Participant does not have to answer all questions or engage in all activities.
     - Confidentiality.
     - Research is regarding adolescents with and without disabilities who are between 12 to 18 years of age.

2. Establish comfort and rapport. Carefully address participant’s curiosity about the investigator. Show investigator’s personal photo album regarding family, friends, and occupations.

3. Complete demographic data form with participant.

4. Re-assure participant that there are no wrong responses; everything reported is correct. Remind participant that they are the “teacher” and that the investigator is there to learn from them.

**NOTE:** Interview to be completed over a period of 2 sessions.

**Initial Open-Ended Questions**

- **Area #1: Definition/Understanding of Disability**

**Questions:**
1. How would you define disability? What is the meaning of disability?
2. When you hear the word disability what thoughts come to your mind? How do you feel?

**Activity: Impact Drawing**

**Purpose:** To visually describe the term disability. To use the drawing to further probe about the participant’s understanding of disability.
Option #1: Draw anything you like regarding disability or disabled people (who are between 12 to 18 years of age).
Option #2: Draw an adolescent with and without a disability.

Questions:
3. Tell me about your drawing. What have you drawn and why?
4. (For Adolescents with Disabilities) If you could tell an adolescent without a disability anything about your disability/day/life, what would you tell them?
5. (For Adolescents without Disabilities) If you could ask an adolescent with a disability anything about his/her disability/day/life, what would you ask them? How do you think he/she would respond/reply?

Area #2: A Typical Day

Questions:
6. Describe your typical day from the time you get up in the morning till the time you go to bed (i.e., morning/afternoon/evening; weekdays/weekends).

Activity: Daily Schedule
Purpose: To learn about the participant’s daily routine thoroughly. To use the schedule to probe about additional activities in the participant’s day.
Activity: Complete/fill out in detail a schedule outlining what you do from Monday to Friday, and what you do on Saturday and Sunday.

Questions:
7. Of all the activities you do during your day, which of these activities do you enjoy and why? Which of these activities do you dislike and why?
8. Of all the activities you do during your day, are there any activities you have difficulty doing/problems with? If so, tell me about it.
9. Tell me about any activities that you would like to engage in? Why are you not engaging in these activities at this time?

Area #3: Roles and Responsibilities

Questions:
10. You mentioned activities you do during your day (list activities participant mentioned earlier), tell me about what you do in each (e.g., at home, at school, at work, and so on).
11. (If participant mentions family) Tell me about your relationship with your family members.
12. (If participant mentions friends) Tell me about your friends. (Explore further later)

Area #4: Community Involvement/Participation

Questions:
13. You mentioned activities you do during your day (reiterate/list some of the activities participant mentioned earlier), which of these activities do you do:
   a. In your home/outside your home?
   b. With your family/friends/others?
Intermediate Questions

- **Area #5: Gender Specific Issues in Adolescents' Social Participation/Interactions/Friendships**

  **Questions:**
  14. Tell me about your friends. Probes: Would you say you have a lot of friends? How and when do you meet? What do you do together? What do you like about your friends? Are your friends disabled or non-disabled or both?
  15. How would you describe the friendships of disabled adolescents versus non-disabled adolescents?
  16. What are your thoughts about male and female friendships at this age?
  17. What are your thoughts about “mixing” adolescent males and females for the purpose of:
     a. Education/schooling?
     b. Work/jobs?
     c. Learning about the opposite gender?
     d. This research study - working together?
     e. Leisure?

- **Area #6: Sexuality Issues in Adolescents**

  **Questions:**
  18. Would you describe yourself as a child or an adult or in-between? Why?
  19. Tell me about any changes you have noticed in yourself.
  20. Tell me about your thoughts regarding adolescents' romantic relationships (“affairs”). Probe: Tell me about the romantic relationships of non-disabled adolescents and disabled adolescents.
  21. Tell me about issues regarding marriage that arise during adolescence. How does being a disabled adolescent influence the concept of marriage?
  22. In your community, have you heard about any sexual mishaps or sexually inappropriate behaviour towards adolescents? Would you say such inappropriate behaviour is more likely with: i) females or males, or ii) adolescents with or without disabilities?

- **Area #7: Rehabilitation Problems/Difficulties of Adolescents with Disabilities**

  **Questions:**
  23. How would you describe the lives of adolescents with disabilities in your community?
  24. How are adolescents with and without disabilities different? Similar?
  25. What are the problems faced by adolescents with/without disabilities in your community?

  **Activity: Listing Problems**
  Activity: List up to 5 problems faced by:
  i. Adolescents without disabilities.
  ii. Adolescents with disabilities.

- **Area #8: Future Goals/Plans**

  **Questions:**
  26. Tell me about how you see your life right now. What will your life look like in one year? What will your life look like in 5 years?
27. How do you feel about your future?

Activity: Force Field Analysis
Activity: Complete/fill out in detail the following information on the following chart paper:
   a. Describe briefly what your life is like right now under the section that is labeled “Now”.
   b. Describe your three goals by the next one year under the section labeled “One Year Goals”.
   c. Describe your three goals by the next five years under the section labeled “Five Year Goals”.
   d. On the reverse side describe: i) the resources (people and things) you will require to achieve your goals, and ii) the obstacles (people and things) that will prevent you from achieving your goals.

For Adolescents with Disabilities:

☐ Area #9: Understanding of ASTHA’S Community-Based Rehabilitation (CBR) Program

Questions:
28. How did you learn about ASTHA’s CBR program?
29. How would you describe ASTHA’s CBR program?
30. Tell me about the services/help you receive or have received from ASTHA’s CBR program.
31. What aspects of ASTHA’s program are you satisfied with? Dissatisfied with?
32. What other activities would you like ASTHA to do with adolescents with and without Disabilities?

☐ Area #10: Current Intervention/Supports

Questions:
33. Tell me about other services that you receive or have received (e.g., from health care facilities, hospitals, schools, etc.).
   a. What aspects of such services do you like? Dislike?
   b. What other things would you like help with?
   c. What other services do you think would be helpful?

Ending Questions and Closing Remarks

34. What did you like talking about/doing today? What was the most important thing we talked about today?
35. What was the most difficult thing I asked you?
36. What other questions should I have asked?
37. Would you like to add any other points?
38. Would you like to ask me anything?
**Protocol #8: Participant Observation - Activity Specific - with Adolescents with/without Disabilities**

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<thead>
<tr>
<th>Investigator/Observer:</th>
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<tbody>
<tr>
<td>Name of Participant(s) Observed: (with or without disability)</td>
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<tr>
<td>Describe Research Study Phase (I, II, III, IV, V):</td>
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<td>Time:</td>
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<td>Place:</td>
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<td>Description of Activity Being Observed:</td>
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<td>Purpose and Rationale for Participant Observation:</td>
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<td>Individual(s) Present:</td>
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<td>Additional Comments:</td>
<td>Refer to photographs and videos for additional details.</td>
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**Areas to Consider:**

1. **Description of the activity being observed:**
   - Describe the activity the adolescent is involved in?
   - Why is the adolescent involved in the activity?
   - What is the purpose of the activity? What is trying to be accomplished?

2. **Adolescent role/involvement in the activity:**
   - What is the adolescent doing and why?
   - What is the adolescent’s reaction to the activity? Describe what the adolescent is saying. Describe the adolescent’s body language.
   - Who else is involved in the activity? Describe the other individuals involved in the activity. Describe the interactions between the other individuals and the adolescent (research participant).

3. **Description of the environment:**
   - Describe the physical atmosphere.
   - Describe the social environment.
   - What things are present in the environment?
   - Why is the activity or event taking place at this time?
   - Describe the adolescent’s presence and involvement in: i) the physical, and ii) the social environment.
Refer to: Checklist for Participant Observation (Spradley, 1980, p. 78)
1. Space: physical location(s)
2. Actor: persons involved
3. Activity: series of interconnected acts that people engage in
4. Object: material items that are present
5. Act: single acts that people engage in
6. Event: series of connected activities that persons carry out
7. Time: series that occur over time
8. Goal: what people are attempting to accomplish

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<thead>
<tr>
<th>Fieldnotes</th>
<th>Memos</th>
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<td>Diagram of Physical Setting and Space:</td>
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**Protocol #9:** Focus Group #1 (of 5) with Adolescents with/without Disabilities Regarding Collective Understanding of Disability (Includes written/visual activities)

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<th>Investigator/Interviewer:</th>
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<tr>
<td>Name of Participants/Intervieees:</td>
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<tr>
<td>(Adolescent with or without Disability)</td>
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<tr>
<td>Males:</td>
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<td>Describe Research Study Phase (I, II, III, IV, V):</td>
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<tr>
<td>Occasional Facilitation Provided By:</td>
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<td>Focus Group#:</td>
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<td>Date:</td>
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<td>Purpose and Rationale for Focus Group:</td>
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<td>Transcriber(s) Involved:</td>
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<td>Additional Comments: Refer to photographs and videos for additional details.</td>
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</tbody>
</table>

**Background Information and Introduction:**

1. Review information booklet, consent forms, and research process in detail again.
   - Ensure participants understand the following:
     * Choice to participate. Right to withdraw at anytime.
     * Participants may participate in selected activities. Participants do not have to answer all questions or engage in all activities.
     * Encourage participants to respect confidentiality and privacy of their peers/other participants.
     * Research is regarding adolescents with and without disabilities who are between 12 to 18 years of age.

2. Re-assure participants that there are no wrong responses; everything reported is correct. Remind participants that they are the “teachers” and that the investigator is there to learn from them.

3. Introduction: Tell us your name and what you would be doing if you were not here today?

4. Icebreaker: Ask the person to your right: a) what their favourite film is, and b) who their favourite actor/actress is. Tell the group your partner’s name and their response.

**Initial Questions and Activities**

- **Area #1: Understanding of Disability**

  **Discussion Questions:**
  1. Tell me what comes to your mind when you hear/see someone between 12 to 18 years of age who is disabled in your community.
2. How do people in the community treat adolescents with disabilities?

**Activity: Meaning of Disability Described on the Leaves of a Tree**

*Purpose:* To visually describe the term disability. To “show” adolescents understanding of disability.

*Activity:* On as many leaves as you like, write anything that comes to your mind about disability (e.g., what the term disability means, what the term disability reminds you of, and so on). Randomly ask individuals to read what is written on the leaves.

**Discussion Questions:**

3. What do you think about the information regarding disability presented on the leaves on the tree?

☐ **Area #2: Adolescents with and without Disabilities**

**Discussion Questions:**

4. Tell me about your thoughts regarding an adolescent with a disability versus an adolescent without a disability.

**Activity: Listing Problems**

*Activity:* Divide participants into two mixed groups (mix gender and mix disabled and non-disabled).

➤ Group 1 - To list on chart paper what the life/day of an adolescent without a disability is like.

➤ Group 2 - To list on chart paper what the life/day of an adolescent with a disability is like.

Consider the following areas: Self-care, productivity, leisure, and emotions.

**Discussion Questions:**

5. Share with the group what you have written regarding the life/day of adolescents without disability versus adolescents with disability (i.e., promote discussion about what participants have written in the activity above).

☐ **Area #3: Gender Specific Issues in Adolescents with Disabilities**

**Discussion Questions:**

6. What are the greatest challenges faced by: a) female adolescents with disabilities, and b) male adolescents with disabilities?

**Activity: Listing Problems**

*Activity:* Divide participants into two mixed groups (mix gender and mix disabled and non-disabled).

➤ Group 1 - To list on chart paper the challenges faced by female adolescents with disabilities.

➤ Group 2 - To list on chart paper the challenges faced by male adolescents with disabilities.
Discussion Questions:
7. Share with the group what you have written regarding the challenges faced by female versus male adolescents with disabilities (i.e., promote discussion about what participants have written in the activity above).

*LUNCH BREAK*

Intermediate Questions and Activities

- **Area #4: Rehabilitation Problems/Challenges of Adolescents with Disabilities**

  Activity: *Cars and Boulders (adapted from fishes and boulders)*
  
  Activity: Divide participants into pairs. Encourage participants to work together and help one another.
  Think about the problems faced by adolescents with disabilities; consider the following areas: self-care, productivity (education/work), leisure, friendships, community attitudes, emotions.
  - On the BIG rocks write down the problems that you think are big.
  - On the SMALL rocks write down the problems you think are small.
  - On the MEDIUM rocks write down the problems you think are in the middle.
  As you finish, place the rocks on the “long” road provided.

**Discussion Questions:**
8. Pick up a couple of rocks each and read what problems participants have described on the rocks regarding adolescents with disabilities (encourage participants to make comments and respond to what was written/being read).
9. Tell me what you think about the problems of adolescents with disabilities.

  Activity: *Cars and Boulders Continued (adapted from fishes and boulders)*
  
  Activity: Continuing to work in pairs, think about the resources, the people, and things that can help adolescents with disabilities to address their problems. List these resources on the cars, and place the cars on the “long” road provided.

**Discussion Questions:**
10. Pick up a couple of cars each and read what resources participants have described on the cars that are available to adolescents with disabilities (encourage participants to make comments and respond to what was written/being read).
11. Tell me what you think about the resources available to adolescents with disabilities in order to address their problems.

- **Area #5: Social Participation/Friendships**

**Discussion Questions:**
12. Tell me about the activities that adolescents in your community generally enjoy participating in for fun.
   a. Where do the activities take place?
   b. Who is involved in the activities?
   c. Why are the activities fun?
13. What is required for two adolescents to be friends in your community?
   a. What do you value in your friendships?
   b. Tell me about friendships with the opposite gender in your community.
   c. Tell me about the friendships of:
      i. Adolescents without disabilities.
      ii. Adolescents with disabilities.

☐ **Area #6: Acceptance, Integration, Inclusion**

14. Tell me about the things you have done with/for adolescents with disabilities.
15. How will we know when adolescents with disabilities are happy, accepted, integrated, and included in:
   a. Home?
   b. Community?
   c. School?
16. Tell me about your thoughts about adolescents with and without disabilities:
   a. Becoming friends?
   b. Going to school together?
   c. Working together?

**Ending Questions and Closing Remarks**

17. What was the most important thing we talked about today?
18. In order to learn from adolescents, what other things do you feel should be asked?
19. Would you like to add any other points?
20. Would you like to ask me anything?
## Protocol #10: Focus Group with Community-Based Rehabilitation Team
### Regarding Understanding of and Involvement with Adolescents
#### (Includes written/visual activities)

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<tr>
<th>Investigator/Interviewer:</th>
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<tr>
<td>Name of Participant/Interviewees:</td>
<td>Males:</td>
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<tr>
<td>(Community-Based Rehabilitation Team Member)</td>
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<td>Describe Research Study Phase (I, II, III, IV, V):</td>
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<td>Occasional Facilitation Provided By:</td>
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<td>Focus Group#:</td>
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<td>Transcriber(s) Involved:</td>
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<td>Additional Comments:</td>
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### Background Information and Introduction:

1. Review information booklet, consent forms, and research process in detail again.
   - Ensure participants understand the following:
     - * Choice to participate. Right to withdraw at anytime.
     - * Participants may participate in selected activities. Participants do not have to answer all questions or engage in all activities.
     - * Encourage participants to respect confidentiality and privacy of their peers/other participants.
     - * Research is regarding adolescents with and without disabilities who are between 12 to 18 years of age.

2. Re-assure participants that there are no wrong responses; everything reported is correct.
   Remind participants that they are the “teachers” and that the investigator is there to learn from them.

3. Participants to complete demographic data forms.

4. State your name and role within the Community-Based Rehabilitation Team in order to help distinguish between voices in the audiocassettes.

**NOTE:** Focus group to be completed over a period of 2 sessions.

### Initial Questions and Activities

- **Area #1: Understanding of Disability in Adolescence**

  **Discussion Questions:**
  1. When you hear that someone between the ages of 12 to 18 years is disabled or has a disability what thoughts come to your mind?
Area #2: Adolescent Development

Discussion Questions:
2. How is adolescence different from childhood? Similar?
3. How is adolescence different from adulthood? Similar?

Area #3: Adolescents with and without Disabilities

Discussion Questions:
4. Tell me about your thoughts on an adolescent with a disability versus an adolescent without a disability.

Intermediate Questions

Area #4: Adolescent Development in the Indian Culture

Discussion Questions:
5. Given your understanding of the Indian culture (particularly in Lal Kuan), how does it:
   i) Facilitate the development of adolescents with disabilities?
   ii) Hinder the development of adolescents with disabilities?
6. How do you talk about disability/disability issues in your community, taking into consideration the culture?

Area #5: Gender and Sexuality Issues in Adolescence

Discussion Questions:
7. Describe some of the greatest challenges faced by: i) female adolescents with a disability, and ii) male adolescents with a disability?

Area #6: Integration and Inclusion

Discussion Questions:
8. What do you mean by the terms integration and inclusion with regards to adolescents with disabilities?

Area #7: ASTHA’s Lal Kuan Community-Based Rehabilitation (CBR) Program

Discussion Questions:
9. Describe your role and the work that you have done with adolescents with and without disabilities in this community.

Activity: Listing and Describing Goals
Activity: As a group, on the chart paper list your goals for working with adolescents with and without disabilities.

Discussion Questions:
10. What are your most important goals with adolescents with disabilities?
    i) Which goals have you achieved?
    ii) Which goals are you currently working on? How can you achieve these goals?
11. Where do you see adolescents with disabilities in one year? In three years?
12. Describe where you see adolescents with disabilities once the Community-Based Rehabilitation Team in Lal Kuan gradually withdraws.

☐ **Area #8: Rehabilitation Problems/Challenges of Adolescents with Disabilities**

*Activity: Fishes and Boulders*

Activity: Working as a group, think problems faced by adolescents with disabilities.
- On the BIG rocks write down the problems that you think are big.
- On the SMALL rocks write down the problems you think are small.
- On the MEDIUM rocks write down the problems you think are in the middle.

As you finish, place the rocks on the “long” river provided.

*Discussion Questions:*

13. Pick up a couple of rocks each and read what problems have been described on the rocks regarding adolescents with disabilities (encourage participants to make comments and respond to what was written/being read).

14. Tell me what you think about the problems of adolescents with disabilities.

*Activity: Fishes and Boulders Continued*

Activity: Continuing to work as a group, think about the resources, the people, and things that can help adolescents with disabilities to address their problems. List these resources on the fishes, and place the fishes on the “long” river provided.

*Discussion Questions:*

15. Pick up a couple of fishes each and read what resources have been described on the fishes that are available to adolescents with disabilities (encourage participants to make comments and respond to what was written/being read).

16. Tell me what you think about the resources available to adolescents with disabilities in order to address their problems.

*Ending Questions and Closing Remarks*

17. What was the important thing we talked about today?

18. What additional things do you feel researchers should be asking or studying with regards to adolescents with disabilities within Community-Based Rehabilitation (CBR) Programs in India (i.e., broad research questions, focus group questions or individual interview questions)?

19. Would you like to add any other points?

20. Would you like to ask me anything?
**Protocol #11: Document Review of Client Files and Organizational Documents from Community-Based Rehabilitation Program**

**Client Files**

1. Locate and photocopy all client files kept on adolescents with disabilities who are participants in the research study.

2. Describe the general format of the client files. What areas/topics are addressed in the client files?

3. Carefully review each client file. Describe the activities specifically undertaken with adolescent clients.

**Organizational Documents**

1. Locate and photocopy documents written about the organization’s (ASTHA’s) Community-Based Rehabilitation Program in Lal Kuan (e.g., general documents regarding the organization’s activities; annual reports; upcoming plans; and so on).

2. Carefully examine each organizational document.

3. What strengths and weaknesses has the organization identified/written about?

4. Have adolescents been identified as a distinct group?

5. Outline activities undertaken that relate specifically to adolescents with and without disabilities.
Protocol #12: Follow-Up Interviews with Adolescents

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<tr>
<th>Investigator/Interviewer:</th>
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<tr>
<td>Name of Participant: (with or without disability)</td>
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<td>Transcriber(s) Involved:</td>
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Background Information and Introduction:
1. Remind participants of the consent and research process again.
2. Meet with participant and participant’s family again.

☐ Member Checking
- Explain the purpose of member checking. Show participant their file, work and photographs on the handheld computer to remind them of all the activities that they engaged in.
- Share the initial/preliminary findings with participant. Ask:
  - What are your thoughts about these overall initial findings from last year?
  - Is this how you felt last year (i.e., approximately 18 months ago)?
  - Would you like to change anything? Would you like to add anything?
  - Were there any changes in your life or thinking since we last met?
- Discuss activities that may happen next, this year (i.e., adolescents’ voluntary role in dissemination sessions, follow-up interviews, observation sessions and focus groups).
- Discuss adolescents’ role in possible organizational activities/development of organizational documents, and the investigator’s role as the facilitator to help bring adolescents’ voices and perspectives forward.

☐ After Thoughts About the Study
- How did you feel after I left?
- What thoughts did you have about the disability issues we talked about last time?

☐ The Concept of Culture
- Tell me about the general culture here, considering everyone, the whole area of Lal Kuan?
- Tell me about the adolescent culture?
- Would you say that the adolescent culture is different/similar to the larger culture?
- Tell me about the culture of adolescents’ with/without disabilities - are they similar or different? Can you please elaborate/explain?
- How does the culture contribute to the rehabilitation problems of disabled adolescents?

☐ Optional Activity: Journal Entry
I will be giving you a notebook. If you have any additional thoughts about this study, you can write them in this journal and give it to me before I leave (I can make you a copy of it).

Ending Questions and Closing Remarks:
- Is there anything else you would like to tell me about disability?
- Is there anything else you would like to ask me?
**Protocol #13: Focus Group #2 (of 5) with Adolescents with Disabilities**
Regarding the Disability Day Celebration in the Community
(Includes written/visual activities)

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<td>Additional Comments: Refer to large number of photographs and videos.</td>
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**Background Information:**
- Disability Day (‘Viklang Devus’) Celebration/Program was held in the Lal Kuan community on Friday December 1, 2006 (World Disability Day is celebrated on December 3).
- Disability Day was celebrated in the Lal Kuan community this year to help increase awareness about disability and the potential/value of persons with disabilities.
- Given that the program was organized by ASTHA’s community-based rehabilitation program, there was a significant focus on involving young persons with disabilities in the program.

**Rationale for Focus Group:**
- For every such event, the organization (the community-based rehabilitation program) is required to submit a report/complete documentation regarding the event (e.g., the schedule of activities, the program outcome, the success of the event, and so on).
- To document the objective aspects of such an event is a fairly easy task, but the question remains - ‘How did the participants or disabled people feel about the event?’
- Given that several children and adolescents (as well research participants) participated in and watched this program - why not involve young persons with disabilities in the documentation process for this event! Let’s get their feedback as well and include a subjective component in our report.
- It is critical for programs to have a better understanding of their strengths and weaknesses when organizing such events (i.e., are they achieving the purpose they think they are).
- We do work with these people - let’s hear what they have to say. Their opinion counts!
- Adolescents with disabilities who either participated in the Disability Day Celebration/Program or came to watch the entire program, were invited to participate in the focus group. Adolescents must be participants involved in this research study.
Areas/Questions to Consider:

1. Explain the rationale for the group discussion and why these specific participants were invited.

2. Do a slideshow of photographs/videos from the Disability Day Celebration/Program to re-orient adolescents to that day.

3. What do you know about Disability Day (‘Viklang Devus’)?

4. Why did we celebrate Disability Day in Lal Kuan?

5. How did you feel participating in the program? How did you feel if you did not participate in the program?

6. How did you feel attending/watching the program?

7. What did you like about the Disability Day Celebration/Program?

8. What did you dislike about the Disability Day Celebration/Program?

9. How can we add to the program/make it better for next year?

10. Activity: On pieces of paper write down the different feelings you experienced during the Disability Day Celebration/Program.

11. Explain that a report highlighting exactly what they said will be submitted to ASTHA and disseminated to various relevant groups (e.g., the community-based rehabilitation team, director of ASTHA, adolescent participants, and so on).

12. Would you like to add anything else? Would you like to ask me anything else?
Protocol #14: Focus Group #3 (of 5) with Adolescents with/without Disabilities Regarding ASTHA’S Community-Based Rehabilitation Program’s Plan for 2007 (Includes written/visual activities)

Investigator/Interviewer:

Name of Participants/Interviewees: (Adolescent with or without Disability)

| Males: | Females: |

* Absent & Reason

Describe Research Study Phase (I, II, III, IV, V):

Occasional Facilitation Provided By:

Focus Group#:

Date:

Time:

Place:

Description of Focus Group:

Purpose and Rationale for Focus Group:

Transcriber(s) Involved:

Additional Comments: Refer to photos and videos.

Background Information:

- ASTHA has established a report for what will happen within Lal Kuan’s Community-Based Rehabilitation (CBR) Program in 2007. The document is titled: “ASTHA - Plans and Budgets 2007 - Next Steps Project”.
- To date all such documents have been developed/prepared by adult staff members.

Rationale for Focus Group:

- This time adolescents with and without disabilities will have a chance to provide feedback, comments and add to this plan. A report by young persons will be added to this document that highlights the perspectives of adolescents - a new/different perspective.
- However, prior to providing feedback and additions to ASTHA’s 2007 plan - it is important to determine how much youth with and without disabilities already understand about the community-based rehabilitation program and the process of developing an annual plan for the program.
- Time constraints, lack of support or awareness, and cultural stereotypes about children’s abilities may prevent such programs from involving young persons in organizational level activities such as developing/organizing plans. However, despite such limitations, it is critical to get the perspectives of program recipients when developing such plans.
- If the goal is also to create awareness, sensitize people, provide opportunities for disabled and non-disabled persons to work together - than both disabled and non-disabled young persons must be involved in such activities.

Areas/Questions to Consider:

* Use “ASTHA - Plans and Budgets 2007 - Next Steps Project” (regarding Lal Kuan’s Community-Based Rehabilitation Program) document/report to guide this protocol.
1. Explain rationale for group discussion and how/why participants were selected. Focus today is on how ASTHA’s Community-Based Rehabilitation Program plan relates to adolescents from 12 to 18 years of age. This group discussion is slightly different in that the investigator wants to learn from you, but also teach you and share some information with you regarding ASTHA’s Community-Based Rehabilitation in Lal Kuan.

2. A) How do you understand ASTHA’s goals/missions/beliefs? What are some of their strengths/weaknesses?  
   B) Share basic information on some of ASTHA’s activities.

3. A) A significant goal of ASTHA’s is to pass on information to persons with disabilities. What comments do you have about the passing of information to adolescents with disabilities?  
   B) Share more basic information from ASTHA’s plan.

4. A) How do you understand what ASTHA has done to date in Lal Kuan? How do you feel the culture has influenced their activities?  
   B) Share how ASTHA’s program is running and more basic information from ASTHA’s plan.

5. A) Explain ASTHA’s process to develop the program’s plan for 2007.  
   B) How were adolescents’ voices and perspectives reflected in the process and in the development of the plan?

6. A) What do you feel ASTHA should work on in this year, in 2007?  
   B) Share areas that community members identified as focus areas. Share how the activities the adolescents’ have been doing fit in here.

7. A) What is your feedback/comments regarding ASTHA’s plan for 2007.  
   B) Share more information about ASTHA’s plan for 2007.

8. After having heard all this information, what else would you like to see ASTHA do this year, ideally, for adolescents?

9. Activity: Everyone write down at least two other things that you would like to see ASTHA do in 2007. How will the culture inhibit or facilitate this?

10. Do you have any other questions or comments?

11. Explain that the a report highlighting their feedback and comments exactly will be submitted to ASTHA and disseminated to various relevant groups (e.g., the community-based rehabilitation team, director of ASTHA, adolescent participants, and so on).

12. I encourage you all to get involved wherever you feel interested - share your ideas!!
Protocol #15: Focus Group #4 & 5 (of 5) with Adolescents with/without Disabilities Regarding Designing a Page for ASTHA’S Annual Report (Includes written/visual activities)

<table>
<thead>
<tr>
<th>Investigator/Interviwer:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name of Participants/Interviewees: (Adolescent with or without Disability)</td>
</tr>
<tr>
<td>Males:</td>
</tr>
<tr>
<td>* Absent &amp; Reason</td>
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</tbody>
</table>

Describe Research Study Phase (I, II, III, IV, V):
Occasional Facilitation Provided By:
Focus Group#:
Date:
Time:
Place:
Description of Focus Group:
Purpose and Rationale for Focus Group:
Transcriber(s) Involved:
Additional Comments: Refer to photos and videos.

Background Information:
- ASTHA publishes an annual report highlighting all its programs and activities.

Rationale for Focus Group:
- Perspective of adolescents’ with/without disabilities is limited in ASTHA’s Annual Reports.
- To help adolescents design a page for ASTHA’s Annual Report for 2007-2008 based on all the work they have completed over the past two years. Adolescents will have to decide as a group what they would like to include and express.

Areas/Questions to Consider:

1. Explain the rationale for the group meeting. To design a page for ASTHA's upcoming Annual Report that reflects the voices of adolescents. Show examples of previous annual reports.

2. Provide overview of all the work completed to date. Do slideshow.

3. Promote discussion regarding disability and adolescents.

4. Work on designing what information should be included on their 1 to 2 pages in ASTHA’s upcoming annual report. Invite participants to draw and write things.

5. i) Participants that attended session 1: To work together as a large group using the whiteboard. List two ideas/quotes that you would like to include.
   ii) Participants that attended session 2: To work in smaller groups of 3-4 and brainstorming on chart paper. List two ideas/quotes that you would like to include.

Ask participants to share what they have written individually and what they have developed in groups/pairs.
Appendix C

Ethics Review

May 12, 2004

Ms. Sonia Gulati
School of Rehabilitation Therapy
Queen’s University

Re: “Your Voice Counts”… Exploring the Rehabilitation Needs of Adolescents with Disabilities Living in Urban Villages in North India: An Ethnographic Study” REH-220-04

Dear Ms. Gulati,

I am writing to acknowledge receipt of your recent ethics submission for the above-named study. I have reviewed the materials and do not feel that it is necessary for the study to undergo a full REB review. I have therefore given the study an expedited review and an approval sheet is appended for your records. This study will be reported to the Research Ethics Board.

Yours sincerely,

Albert Clark
Ph.D.
Chair
Research Ethics Board

AFC/kr

c.c.: Dr. Sandra Olney, School of Rehabilitation Therapy
       Dr. Margo Paterson, School of Rehabilitation Therapy
December 20, 2004

Ms. Sonia Gulati
121 Columbia Avenue
Ottawa, Ontario K1V 1Z3

Re: “Your Voice Counts … Exploring the Lives and Perceived Rehabilitation Needs of Adolescents with Disabilities in the Urban Slums of North India” REH-220-04

Dear Ms. Gulati,

I am writing to acknowledge receipt of your letter dated December 15, 2004 which outlined some additions to your study. I have reviewed these changes and hereby give my approval. These additions to your study will be reported to the Research Ethics Board.

Yours sincerely,

Albert Clark
Ph.D.
Chair
Research Ethics Board

AFC/kr

c.c.: Dr. Sandra Olney, School of Rehabilitation Therapy
      Dr. Margo Paterson, School of Rehabilitation Therapy
QUEEN'S UNIVERSITY HEALTH SCIENCES & AFFILIATED TEACHING HOSPITALS RESEARCH ETHICS BOARD

Queen's University, in accordance with the “Tri-Council Policy Statement, 1998” prepared by the Medical Research Council, Natural Sciences and Engineering Research Council of Canada and Social Sciences and Humanities Research Council of Canada requires that research projects involving human subjects be reviewed annually to determine their acceptability on ethical grounds.

A Research Ethics Board composed of:

<table>
<thead>
<tr>
<th>Name</th>
<th>Role</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dr. A.F. Clark</td>
<td>Emeritus Professor, Department of Biochemistry, Faculty of Health Sciences, Queen's University (Chair)</td>
</tr>
<tr>
<td>Dr. S. Burke</td>
<td>Professor, School of Nursing, Queen's University</td>
</tr>
<tr>
<td>Rev. T. Deline</td>
<td>Community Member</td>
</tr>
<tr>
<td>Dr. M. Green</td>
<td>Assistant Professor, Department of Family Medicine, Queen's University</td>
</tr>
<tr>
<td>Mr. C. Kenny</td>
<td>Community Member</td>
</tr>
<tr>
<td>Ms. T.C. Knott</td>
<td>Research &amp; Evaluation, Southeastern Regional Geriatric Program, Providence Continuing Care Centre – St. Mary's of the Lake Hospital Site</td>
</tr>
<tr>
<td>Dr. J. Low</td>
<td>Professor, Department of Obstetrics and Gynaecology, Queen's University and Kingston General Hospital</td>
</tr>
<tr>
<td>Dr. H. Murray</td>
<td>Assistant Professor, Department of Emergency Medicine, Queen's University</td>
</tr>
<tr>
<td>Dr. W. Racz</td>
<td>Professor, Department of Pharmacology &amp; Toxicology, Queen's University</td>
</tr>
<tr>
<td>Dr. B. Simchison</td>
<td>Assistant Professor, Department of Anesthesiology, Queen's University</td>
</tr>
<tr>
<td>Dr. A.N. Singh</td>
<td>WHO Professor in Psychosomatic Medicine and Psychopharmacology Professor of Psychiatry and Pharmacology Chair and Head, Division of Psychopharmacology, Queen's University</td>
</tr>
<tr>
<td>Dr. S. Taylor</td>
<td>Director, Office of Bioethics, Queen's University and Kingston General Hospital; Associate Professor, Department of Medicine, Queen's University</td>
</tr>
<tr>
<td>Dr. G. Torribble</td>
<td>Community Member</td>
</tr>
</tbody>
</table>

has examined the protocol and consent form for the project entitled “Your Voice Counts” ... Exploring the Rehabilitation Needs of Adolescents with Disabilities Living in Urban Villages in North India: An Ethnographic Study” as proposed by Ms. Sonia Gulati, Dr. S. Olney and Dr. M. Paterson of the School of Rehabilitation Therapy at Queen’s University and considers it to be ethically acceptable. This approval is valid for one year. If there are any amendments or changes to the protocol affecting the subjects in this study, it is the responsibility of the principal investigator to notify the Research Ethics Board. Any adverse events must be reported to the Chair within 48 hours.

Chair, Research Ethics Board

Date

REH-220-04

EX

245
February 22, 2007

Re: Sonia Gulati, BScOT, PhD (Candidate)
School of Rehabilitation Therapy
Queen’s University
Kingston, Ontario
K7L 3N6 CANADA
E-mail: 8sg3@qlink.queensu.ca

To Whom It May Concern:

Ms. Sonia Gulati has a Bachelor of Science in Occupational Therapy and is currently a PhD candidate in the School of Rehabilitation Therapy at Queen’s University, Kingston, Ontario, Canada. She was involved on a voluntary basis within ASTHA’s Community-Based Rehabilitation Programme in Lal Kuan, New Delhi, India from January 2005 to May 2005 and October 2006 to March 2007.

Ms. Gulati’s research interest was in giving a voice to adolescents with and without disabilities within our Lal Kuan Community-Based Rehabilitation Programme. Her aim was to help ASTHA’s community programme in this one area. She engaged in informal interactions, individual and group discussions, written/visual activities, and other tasks with adolescents. Ms. Gulati’s activities were not independent of ASTHA; thus, ASTHA was pleased to support her in all such activities. Ms. Gulati was not financially compensated by the organization or any community members.

The community-based rehabilitation team was aware of Ms. Gulati’s activities. The team assisted Ms. Gulati in establishing rapport with the community and in explaining the purpose of activities to caregivers/adolescents. Caregivers and adolescents agreed to participate in the activities. Ms. Gulati is of Indian descent and was able to effectively communicate in Hindi with community members.
Ms. Gulati held multiple sessions with the community-based rehabilitation team in order to orient them to the nature of the activities and to encourage the participation of adolescents with and without disabilities at an organizational level. Ms. Gulati assisted with the development of three documents that draw attention to the perspective and abilities of adolescents with and without disabilities; these documents have been submitted both to ASTHA’s main centre and ASTHA’s Community-Based Rehabilitation Programme in Lal Kuan.

We were honoured to have Ms. Gulati be a part of our team. We look forward to maintaining our relationship with Ms. Gulati and hope to work with her again in the near future.

Sincerely,

Sudha Vohra, Director of ASTHA

ASTHA’s Centre for Children with Special Needs
Basti Vikas Kendra, Bal Mukand
Giri Nagar, Kalkaji
New Delhi, 110019
INDIA
Tel.: 26449029
Alt. Tel.: 91-9910237904
E-mail: asthaiindia@rediffmail.com

Sanyam Maratha, Coordinator of Community-Based Rehabilitation Programme (Lal Kuan)

Community-Based Rehabilitation Programme (Lal Kuan)
Chungi No. 2, Lal Kuan
New Delhi, 110044
INDIA
Tel.: 26365239
Alt. Tel.
E-mail:
Dear Sonia,

We would be very happy to have you here working with us when you do get here. …

Radhika and I have both gone through your proposal and we agree with the way you want to do the whole interviews and the follow-up.

We look forward to seeing you in February.

Regards,
Ranjan

Ranjan Koul,
Coordinator of Community-Based Rehabilitation Programme Lal Kuan
ASTHA Tel.: 26449029
E-mail: ranjankoul@rediffmail.com

Radhika Alkazi,
Director of ASTHA
ASTHA Tel.: 26449029
E-mail: asthaindia@rediffmail.com
Appendix D

Information, Consent and Confidentiality Forms

School of Rehabilitation Therapy
Kingston, Ontario
K7L 3N6 CANADA

Information Form for Participation in a Doctoral Study

Project Title:
“Your Voice Counts”…
Adolescents with Disabilities in the Urban Slums of New Delhi, India:
A Critical Ethnographic Study in the Developing World

Investigator: Sonia Gulati, B.Sc.OT, Ph.D. (Candidate)
Local Phone: 9811370567
Phone: 613-
Email: 8sg3@qlink.queensu.ca

Academic Advisors: Dr. Margo Paterson
Associate Professor
Phone: 613-533-6094
Email: patersom@post.queensu.ca

Dr. Sandra Olney
Professor and Director, Associate Dean (Health Sciences)
Phone: 613-533-6102
Email: olneys@post.queensu.ca

ASTHA Advisors: For 2004 & 2005

Mr. Ranjan Koul
Coordinator
Phone: (011) 91-011-26449029 OR (011) 91-9871659922
Email: ranjankoul@rediffmail.com

Mrs. Radhika Alkazi
Director
Phone: (011) 91-011-26449029 OR (011) 91-9811167293
Email: asthaindia@rediffmail.com
Background Information
- You are being invited to participate in a study directed by Sonia Gulati and facilitated by ASTHA staff members.
- This study investigates the perceived rehabilitation challenges/problems of adolescents with disabilities living in the urban slums in Lal Kuan, New Delhi, India.
- This study is being supported by and shared with ASTHA, an organization that is currently providing community-based rehabilitation (CBR) services in Lal Kuan.
- The focal point of the study is to understand and describe the lives, problems, challenges, and desires of adolescents with disabilities.
- You are being invited to participate in one of three groups: 1) You are an adolescent with a disability; 2) You are an adolescent without a disability, or 3) You are a CBR team member.
- Sonia Gulati and/or an ASTHA staff member will review this information form with you, describe the details of this study, and answer any questions that you may have.

Details
- The purpose of this study is to investigate the perceived rehabilitation challenges (e.g., social, vocational, educational, leisure, emotional or and/or mental health) of adolescents with disabilities who live in Lal Kuan and are also involved with the CBR program run by ASTHA; and to explore personally meaningful strategies to help CBR programs empower adolescents with/without disabilities to be more vocal and involved in their community.
- For this study, adolescents refer to individuals between the ages of 12 to 18 years.
- The term disability refers to difficulties in carrying out activities or participating in life situations as result of physical, neurological, and/or mental health difficulties.

Central Research Question
How can an understanding of cultural influences and the subculture of adolescents help community-based rehabilitation programs to empower adolescents with disabilities to exercise greater control over their rehabilitation activities and become more vocal within their community?

Research Sub-Questions
1. What are the perceived rehabilitation challenges faced by adolescents with disabilities in the community?
2. What cultural factors contribute to the perceived rehabilitation challenges?
3. How can an awareness of cultural factors and the perspectives of adolescents with disabilities help to facilitate the sustainability of community-based rehabilitation programs?
Research Objectives
a. To describe adolescents perceived understanding/description of disability.
b. To explore the culture (i.e., daily lives; occupations; attitudes) of adolescents with disabilities within the larger Indian culture of the urban slums.
c. To investigate the role of non-disabled adolescents and the community-based rehabilitation program in the lives of adolescents with disabilities.
d. To support adolescents in addressing disability issues within their cultural environment and in the development of local community-based rehabilitation policy.

Need for this Study
• The need for this study has been supported by ASTHA. ASTHA has placed increased emphasis on child rights and is determined to give a voice to children and adolescents with disabilities.
• ASTHA would appreciate a more in-depth investigation of the perceived rehabilitation challenges/problems of adolescents with disabilities in order to truly embrace their voice, and for the sustainability of the CBR program, as ASTHA prepares to gradually reduce its services within the community over the next few years.
• The investigator, ASTHA staff, and potential community members will work collaboratively to determine the best way to utilize the findings from this study in order to improve services within the CBR Program.
• This project is a shared initiative among all those involved.

Importance and Benefits of this Study
• This study aims to give a voice to adolescents with disabilities. We want to ensure that individuals providing rehabilitation and health services to adolescents with disabilities consider their perceived problems/challenges, wants, desires, and goals.
• This study attempts to improve the quality of rehabilitation services provided by ASTHA and hence improve the quality of life of adolescents with disabilities.
• This study has the potential to directly benefit the lives of adolescents with/without disabilities living in the urban slums in Lal Kuan who are currently and in the future may be receiving services through ASTHA.
• This study may also benefit other adolescents with/without disabilities, given that organizations that provide them services can gain access to the results of this study.

Data Collection for this Study
• Sonia will be the principal investigator responsible for gathering information for this study.
• Information for this study will be collected using the following methods: in-depth interviews with adolescents; observing adolescents in their daily activities independently and/or with others; review of relevant documents and personal journals; focus group interviews; and various written/visual activities. Occupational therapy theory/the Canadian Model of Occupational Performance will be used as a guide for collecting data. Data will be collected from January 2005 to March 2007.

Participation in this Study
• The investigator and ASTHA staff will be responsible for selecting appropriate participants for this study who are likely to provide rich information.
• Adolescents with disabilities are the primary/key participants in this study. Adolescents without disabilities and CBR team member are also being asked to participate. Families, relatives, and friends may also be asked to participate/contribute in some manner as deemed appropriate.
• Adolescents with/without disabilities and their families (i.e., their parents or caregivers) must demonstrate an understanding of the study and consent to participate. No adolescent will be selected for the study without the consent of his/her primary caregiver(s) who also agrees to allow the adolescent to be interviewed on a one-one basis at some point in the study. Given the curiosity of community members, the investigator recognizes that it may be challenging to interview adolescents on a one-one basis even with consent.
• Adolescents selected for this study must demonstrate competency and be able to communicate (preferably verbally) with the principal investigator.
• Participants in the study may be asked to partake in the following activities: approximately two to three interview sessions; permit the investigator to observe the course of a typical day; participate in group interviews with other adolescents; and provide the investigator access to personal documents or journals. Sessions will be held at a convenient time and location. Interviews and observation sessions will help to address the research objectives and to gain an appreciation of the participant’s experience of living with a disability.
• Since much of the research conducted in developing countries includes photographs of the environment and participants, participants (that is, adolescents with/without disabilities, CBR team members/staff, caregivers, and other community members) will be asked for verbal consent prior to being photographed.

Voluntary Participation and Freedom to Withdraw from Study
• There are no risks to your participation in this study and participation is voluntary.
• Participants do not have to participate in all research activities.
• Participants may withdraw from the study at any time. Withdrawal from the study will in no way affect the rehabilitation services that an individual is currently receiving or may be receiving in the future through ASTHA’s CBR program.

Investigator and Translation/Transcription
• The investigator will be able to verbally communicate with participants in the following languages: Hindi, Punjabi, Urdu and English, and will thus be responsible for collecting most of the data independently.
• The investigator may occasionally request the assistance of ASTHA staff to help with translation of information or to assist in posing questions. The investigator will be present at all interview and observation sessions, and translators and ASTHA staff may be present occasionally.
• Assistance from ASTHA staff (specifically the staff who are working in the CBR program) may be required to translate Hindi documents that may be provided.
• Furthermore, a transcriptionist may be required to assist with transcribing audio-taped data that is in Hindi into English. All other notes will be written in English by the investigator.

Respect for Confidentiality and Privacy
• As the population being studied may not be familiar with concepts such as privacy and confidentiality, the investigator will continuously explain these concepts and be respectful of all participants’ wishes.
• All efforts will be made to ensure the privacy and confidentiality of the information provided by adolescents and their families, especially during one-on-one interviews.
• No information will be reported without approval of the participants.
• Due to the nature of the Lal Kuan environment, it is likely that community members will be aware of the individuals participating in the study. If this is identified as a problem, the
investigator will spend time with adolescents who are not key informants to decrease the likelihood of the identity of the true participants being revealed.

- There is some possibility that community members may be able to identify participants based on the life stories and details reported, however the chances of this occurrence are small. Given the high number of participants in this study it is unlikely that any information reported will be traced back to any one participant.

- No participant names (or identifying characteristics) will be associated with the data. Information collected will be identified and reported using a pseudo name or number.

- Photographs taken during the sessions will be used for professional, academic, educational, and/or dissemination purposes and for presenting results to a professional audience (e.g., faculty members and ASTHA staff). Photographs may be included in the final study. Participants’ names and details of their life situations will not be associated with the photographs. Participants will be asked to provide verbal consent to be photographed.

- Audiotaped information, fieldnotes and transcripts will be confidential.

- The investigator, translators/transcribers, caretaker of research material, and academic advisors may have access to the information obtained from interviews, observation, and documents. It is the investigator’s responsibility to ensure that all translators and transcribers are aware of and demonstrate respect for confidentiality.

- The information will be published in a manner that ensures confidentiality.

**Dissemination of Information**

- Information from the study may be disseminated locally, at a grass-roots level during formal (pre-organized)/informal dissemination sessions.

- Efforts will be made to make this study available to organizations throughout India.

- A copy of the study will be available through the School of Rehabilitation Therapy at Queen’s University.

- A videotape presenting the findings and a copy of the study will be provided to ASTHA.

- In collaboration with ASTHA staff, the investigator will develop guidelines to present the findings in a culturally sensitive manner to participants and community members in Lal Kuan.

**NOTE:** Information and consent forms for this study will be translated into Hindi as needed.
Consent Forms for Participation in a Doctoral Study

Consent from Primary Caregiver

I have had this research study explained to me clearly and in detail. I have read the information above or have had the information read/explained to me. Any questions about my participation and my child’s participation in this study have been addressed to my satisfaction. I have been given adequate time to think about this study and to obtain advice from others regarding my participation.

BY SIGNING THIS FORM I ACKNOWLEDGE THE FOLLOWING:

- I understand that my participation in this study is voluntary.
- As the primary caregiver, I understand that I am voluntarily permitting my child to participate in this study. I understand that my child may engage in interviews independently with the investigator, and that the investigator may be involved in observing my child in activities he/she engages in within the home and community.
- I understand that my child must also agree to voluntarily participate in this study.
- I understand that my child and I do not have to participate in all research activities. I understand that I do not have to answer all questions.
- I understand that the information I provide in interviews or information collected from observation sessions will be treated confidentially to the best of the investigator’s ability given the nature of the environment. I understand my name will not appear on any reports (only in raw data that the investigator has access to).
- I understand that photographs may be taken throughout this study. I agree to have my child and myself photographed. I understand our names will not appear on any photographs.
- I understand that issues regarding respect for confidentiality will be discussed on an ongoing basis with translators, transcribers, ASTHA staff, and academic advisors.
- I understand that the investigator and the research advisory committee (supervisors and professors) will have access to all the researched material.
- I understand that I and/or my child may withdraw from the study at any time. I also understand that my child must withdraw from the study upon my request.
- I understand that any changes or modifications to this study will be explained to me in a timely fashion.
- I understand that the results of this study will be provided and explained to me in a culturally sensitive manner in Hindi.
- A copy of the information and consent form has been provided to ASTHA for safekeeping. Upon request, you can access (or request a copy) of both the information and/or consent forms.
By signing this consent form, I am indicating that I understand the information above and agree to participate in this study.

Signature of Primary Caregiver  Signature of Witness  Signature of Researcher

Date

☐ Check here if Form Described and Verbal Consent Obtained

Individual(s) Present:

_________________________________________________________________________________________
Consent from Adolescent

I have had this research study explained to me clearly and in detail. I have read the information provided above or have had the information read to me. Any questions about my participation in this study have been addressed to my satisfaction. I have been given adequate time to think about this study and to obtain advice from others regarding my participation.

BY SIGNING THIS FORM I acknowledge the following:
- I understand that my participation in this study is voluntary.
- I understand that this study focuses on adolescents with disabilities.
- I understand that I may engage in interviews independently with the investigator, and that the investigator will be involved in observing my day-to-day activities within the home and community.
- I understand that I do not have to participate in all research activities. I understand that I do not have to answer all questions.
- I understand that the information I provide in interviews or information collected from observation sessions will be treated confidentially to the best of the investigator’s ability given the nature of the environment. I understand my name will not appear on any reports (only in raw data that the investigator has access to).
- I understand that photographs may be taken throughout this study. I agree to be photographed. I understand my name will not appear on any photographs.
- I understand that issues regarding respect for confidentiality will be discussed on an ongoing basis with translators, transcribers, ASTHA staff, and academic advisors.
- I understand that the principal investigator and the research advisory committee (supervisors and professors) will have access to all the researched material.
- I understand that I may withdraw from the study at any time. I also understand that I must withdraw from the study upon the request of my caregiver.
- I understand that any changes or modifications to this study will be explained to me in a timely fashion.
- I understand that the results of this study will be provided and explained to me in a culturally sensitive manner in Hindi.
- A copy of the information and consent form has been provided to ASTHA for safekeeping. Upon request, you can access (or request a copy) of both the information and/or consent forms.

By signing this consent form, I am indicating that I understand the information above and agree to participate in this study.

Signature of Participant   Signature of Primary Caregiver  Signature of Researcher

Date

☐ Check here if Form Described and Verbal Consent Obtained

Individual(s) Present:
Consent from Community-Based Rehabilitation Team Member/Personnel

I have had this research study explained to me clearly and in detail. I have read the information provided above or have had the information read to me. Any questions about my participation in this study have been addressed to my satisfaction. I have been given adequate time to think about this study and to obtain advice from others regarding my participation.

BY SIGNING THIS FORM I acknowledge the following:
- I understand that my participation in this study is voluntary.
- I understand that this study focuses on adolescents with disabilities.
- I understand that I may engage in focus groups, interviews independently with the researcher, and that the researcher may be involved in observing my day-to-day activities within the CBR program.
- I understand that I do not have to participate in all research activities. I understand that I do not have to answer all questions.
- I understand that the information I provide in interviews or information collected from observation sessions will be treated confidentially to the best of the investigator’s ability given the nature of the environment. I understand my name will not appear on any reports.
- I understand that photographs may be taken throughout this study. I agree to be photographed. I understand my name will not appear on any photographs.
- I understand that issues regarding respect for confidentiality will be discussed on an ongoing basis with translators, transcribers, ASTHA staff, and academic advisors.
- I understand that the principal investigator and the research advisory committee (supervisors and professors) will have access to all the researched material.
- I understand that I may withdraw from the study at any time.
- I understand that any changes or modifications to this study will be explained to me in a timely fashion.
- I understand that the results of this study will be provided and explained to me in a culturally sensitive manner in Hindi.
- I have been given a copy of this consent form.

By signing this consent form, I am indicating that I understand the information above and agree to participate in this study.

_________________________________________  ______________________________  __________________________
Signature of Participant   Signature of Primary Caregiver  Signature of Researcher

_________________________________________
Date

☐ Check here if Verbal/Written Consent Obtained
Individual(s) Present:
Confidentiality Statements for Participation in a Doctoral Study

Statement from Transcribers/Translators

The researcher has adequately explained the nature of my work to me (i.e., guidelines regarding transcription/translation of research material and necessary background information regarding study). By signing this statement, I agree to respect confidentiality and privacy of all research participants in this study, this includes all information that I personally seek, provide, read, hear, and/or observe. I will not discuss this information with anyone other than the researcher.

______________________________________________
Name of Transcriber/Translator

Contact Information

______________________________________________
Address

______________________________________________
Telephone

______________________________________________
E-mail

______________________________________________  ________________________  
Signature of Transcriber/Translator   Date

______________________________________________  ________________________  
Name & Signature of Witness/Researcher  Date

□ Check here if Verbal Consent Obtained
Individual(s) Present:

______________________________________________

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Statement from Individual Regarding the Care of Research Material

The researcher has adequately explained the nature of my work to me (i.e., guidelines regarding the care of research material that has been copied and given to me for the purpose of: a) to distribute to transcribers upon the researcher’s request, and b) as the study was completed internationally, to keep a “back-up” copy of the material locally in the event it is required for any further purposes). By signing this statement, I agree to respect confidentiality and privacy of all research material/participants in this study, this includes all information that I personally seek, provide, read, hear, and/or observe. I will not discuss this information with anyone other than the researcher. I understand that the material must be kept in a secure and safe place. I understand that I must immediately return the material to the researcher upon request.

______________________________________________  
Name of “Caretaker”

______________________________________________  
Contact Information

______________________________________________  
Address

______________________________________________  
Telephone

______________________________________________  
E-mail

Signature of “Caretaker”  Date

Name & Signature of Witness/Researcher  Date

☐ Check here if Verbal Consent Obtained
Individual(s) Present:

______________________________________________

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Statement from Researcher (Principal Investigator)

I have carefully explained this study to research participants in Hindi and/or English. To the best of my knowledge, participants understand the purpose of this study including the benefits and risks, and the extent and nature of their involvement in this study.

_____________________     ______________________
Signature of Researcher      Date

If at any time you have any questions, concerns or problems regarding this study you may contact any of the following individuals (costs for calls will be compensated):

Sonia Gulati, Principal Investigator at 613-526-9156 OR 9811370567
Dr. Margo Paterson, Supervisor, Queen’s University at 613-533-6094
Ranjan Koul, Program Coordinator, ASTHA at 91-9350802826
Sanyam Maratha, Program Coordinator, ASTHA at 91-9899816993

NOTE: Information and consent forms for this research study will be translated into Hindi as needed.