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## Reflection on the Methodological Aspects of a Critical Ethnographic Approach used to Inform Change for Adolescents with Disabilities

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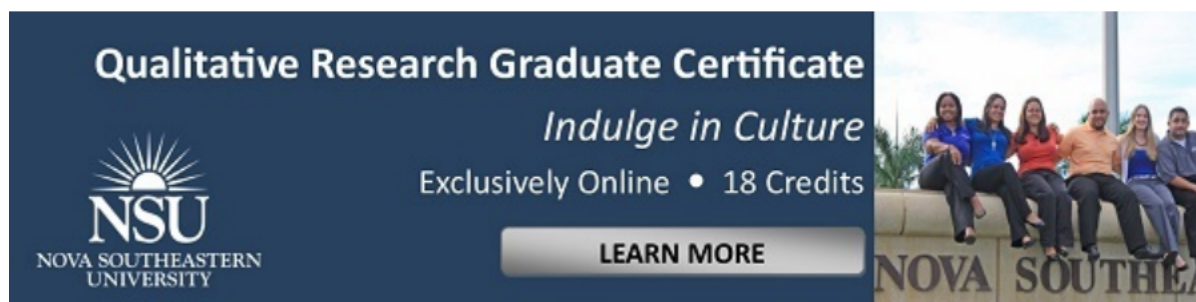
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### Abstract

Debate remains about how to effectively obtain information from adolescents with disabilities in marginalized areas and how to apply this knowledge to shape rehabilitation activities. This study explored how to empower adolescents in the urban slums of North India to assume greater control over their rehabilitation within the context of a local community-based rehabilitation program. Participants included 21 adolescents with and 11 adolescents without disability (aged 12 to 18 years), and 10 community-based rehabilitation workers. A critical ethnographic approach was adopted. Fieldwork was conducted from January to May 2005 and October 2006 to March 2007. This paper focuses on the methodological aspects of this study, and how critical ethnography was used to inform positive changes for adolescents with disabilities using their perspectives.

### Keywords

Critical Ethnography, Methodology, Adolescents, Disability, Community-Based Rehabilitation, Empowerment, Urban Slums, and India

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I sincerely thank ASTHA, the Community-Based Rehabilitation Program and all the adolescents and families who openly welcomed me into their lives. Your support was instrumental in carrying out a project of this magnitude. This study made me optimistic about our ability to work together in order

to inform change and empower young people with disabilities. I am grateful for the support I received for this study from the International Development Research Centre (IDRC), the Canadian Occupational Therapy Foundation (COTF), and Queen's University.

## **Reflecting on the Methodological Aspects of a Critical Ethnographic Approach used to Inform Change for Adolescents with Disabilities**

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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. The degree to which adolescents in the most disadvantaged regions in the world are able to communicate their views due to socio-cultural barriers, illiteracy, limited education and lack of assertiveness remains questionable. There continues to be debate about the most effective ways to obtain information from adolescents with disabilities living in highly marginalized or underserved areas, how to successfully apply this new knowledge to shape rehabilitation services, and how to maintain the participation of adolescents in rehabilitation activities.

This study explored how to empower adolescents in the urban slums of North India to assume greater control over their rehabilitation within the context of a local community-based rehabilitation (CBR) program.<sup>1</sup> A critical ethnographic approach was

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<sup>1</sup> Community-based rehabilitation (CBR) is defined as, "[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).

adopted. Culturally-sensitive strategies and a range of qualitative and participatory data collection methods were utilized to enable adolescents with and without disabilities to comfortably share their views. The *United Nations Convention on the Rights of the Child 1989* reinforces that children should have the right to express their views and have them considered (United Nations, 1989, Article 12), children should have the freedom to seek, receive and provide information in any medium they desire (United Nations, Article 13), and education should be cognizant of children's personality, culture, abilities and language (Davis, 1998; United Nations, Article 29 ).

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: (a) an adolescent subculture was apparent within the larger Indian culture in the slums, but it was inadequately understood; (b) there was limited understanding of the perceived rehabilitation challenges of adolescents with disabilities; (c) the rehabilitation problems of adolescents were believed to be influenced by the socio-cultural context, but the impact of the context was inadequately understood; (d) questions remained about how to inform rehabilitation activities using adolescents' perspectives; and (e) it was necessary to use a range of strategies to comfortably collect data from adolescents. An action/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).

In this research journey, the first author, Sonia, a doctoral candidate at the time and an Occupational Therapist, set out with a passion for understanding the role of occupational therapy in helping young people with disabilities to become more involved in their rehabilitation within an underserved community setting. The second and third author, Margo and Jennifer, were the PhD supervisors and acted as research collaborators to help make methodological decisions to focus the study. The fourth author, Rebecca, joined the team as a member of the advisory committee.

From the onset of this study, there was little argument against the notion that adolescents with disabilities who live in marginalized and underserved neighborhoods 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. The first author raised concern about the efficacy of community-based rehabilitation services when they fail to include the perspectives of adolescents.

The aim of this study was to provide adolescents with disabilities an opportunity to express their perspectives while simultaneously assisting a community-based rehabilitation program to carry out more meaningful activities within a specific socio-cultural and geographical location. This paper focuses on the methodological aspects of this critical ethnographic study, and how this approach was used to understand how to empower and inform positive changes for adolescents with disabilities using their

perspectives. The nature of critical ethnography, the use of multiple data collection strategies, and the analysis of multiple types of data are discussed.

### **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). Critical theory is concerned with how social issues, including power, culture, ethnicity class, gender, ability and sexual orientation form a socio-political system (Kincheloe & McLaren, 2003), and directly or indirectly dominate people's expressions (LeCompte & Schensul, 1999b). 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 & Schensul, 1999b).

Ethnography is the art and science of investigating and describing a social group, culture, subculture or cultural scene, which 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 & Schensul, 1999b; Morse & Field, 1995; Spradley, 1980). The interpretation of culture deals with three fundamental characteristics of human experience: (a) actions of people (cultural behaviour), (b) knowledge of people (cultural knowledge), and (c) 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 (Chambers, 2000).

Transforming 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 people's daily challenges at a grass-roots 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).

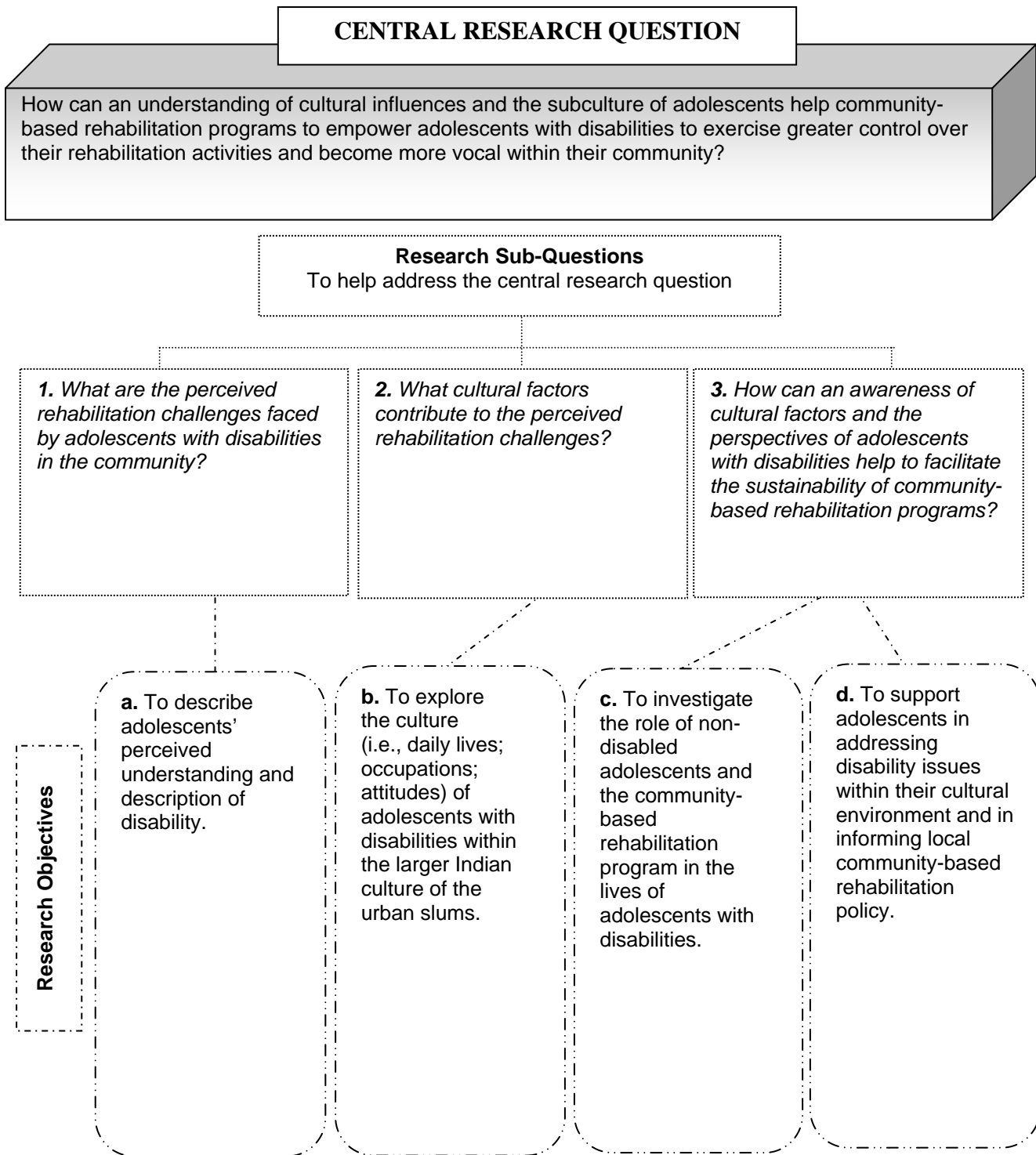
Giving young consumers a more powerful voice in society and health care is receiving greater attention (Barlow & Harrison, 1996). This study provided a forum for adolescents with disabilities to openly share and reflect on their knowledge and concerns about disability in their community, and to raise awareness about the social, political and cultural issues that diminish their quality of life. This study assisted adolescents in gaining awareness 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.

Critical ethnographies reveal how marginalized persons are situated in social and material relations, and how their disempowerment is manifested in cultural arrangements (Quantz, 1992). Critically-oriented research aims to make public those forces that pose as obstacles for individuals to participate in making decisions about their lives (Kincheloe & McLaren, 2003). Critical researchers act as advocates and determine through research, discourse and action, ways to promote changes in power, resources and policy (LeCompte & Schensul, 1999b).

### **Methodology**

To guide this study, the critical ethnographic approach as described in the *Ethnographer's Toolkit Volumes 1 to 7* (LeCompte & Schensul, 1999) was adopted. Critical ethnography as described in the toolkit was appealing for its modern-day view. 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 the positive aspects associated with adolescents with disabilities, including the concepts of resilience and coping. The first author's goal was to determine personally meaningful strategies that would make it more likely to empower adolescents with disabilities to (a) take the initiative to express their concerns and desires, (b) assume greater control over their rehabilitation activities, and (c) become more involved within their community. The research problem in applied ethnographies is concerned with promoting understanding of socio-cultural and political problems and using the increased awareness to create positive change in groups, communities or organizations (Schensul, Schensul, & LeCompte, 1999). The research questions and objectives that guided this study are presented in Figure 1. 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. An overview of the research design and five phases of this study are provided in Table 1. The study purpose and activities were integrated directly within ASTHA's Community-Based Rehabilitation Program initiatives because they were seen to have pragmatic value for the continuation of their activities with adolescents; thus, the study was not viewed as a stand-alone project.

Figure 1. Central Research Question, Sub-questions and Objectives



## **Fieldwork Site**

Preferred settings for critical ethnographic studies are those that impede community development and prevent public expression (LeCompte & Schensul, 1999b). The first author sought the support of ASTHA's Community-Based Rehabilitation Program in the urban slums of New Delhi, India for this study. The Community-Based Rehabilitation Program was initiated in 2001 by ASTHA, a local registered charitable trust that offers services for children and young people with disabilities, including information and resources, educational and vocational activities and workshops (ASTHA, 2008a, 2008b; ASTHA & Action Aid India, 2005). 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). The Community-Based Rehabilitation Program was situated on the outskirts of New Delhi. The area was a hilly area with deep quarries and narrow lanes spread over six square kilometers, and divided into 11 blocks with a population of about 35,000 people. The majority of people were of the Hindu faith and Hindi speaking. There were an estimated 500 young persons with disabilities in the area (ASTHA, 2001).

## **Participants**

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

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, 1998; LeCompte & 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. The inclusion/exclusion criteria for this study are described in Table 2.



Table 1. Five-Phases of Qualitative Critical Ethnographic Study<sup>2</sup>

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 Phases II, III & IV <i>Adolescent Driven/ Researcher Facilitated</i>	
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?					
Objective(s) of each Phase	To determine: a) utility of interview and observation protocols with young persons with disabilities.	To explore: a) understanding of disability, and b) perceived rehabilitation challenges of adolescents with disabilities, and c) the influence of the broader culture.	To investigate: a) subculture and occupations of adolescents without disabilities, and b) attitudes of young persons towards adolescents with disabilities.	To describe: a) CBR program, b) role of the CBR team members in the lives of adolescents with disabilities, and c) how an understanding of cultural factors and adolescents' perspectives can facilitate sustainability of the CBR program.	1. To member check and do follow-up interviews. 2. To disseminate preliminary findings to adolescents, caregivers, and CBR team. 3. To help adolescents work together on 3 agreed upon organizational documents: a) inform CBR documentation; b) provide feedback on annual plan; and c) design page for annual report. 4. To disseminate the three organizational documents developed by adolescents. 5. To explore the process of adolescents engaging in activities together.	
Sample Size	2	21	11	5	30 Adolescents	8 CBR Workers
Gender	2 male	14 male; 7 female	5 male; 6 female	2 male; 3 female	17 male; 13 female	3 male; 5 female
Age Range	12-16 years	12-18 years; x̄: 14.8	12-17 years; x̄: 13.7	35-39 years	13-20 years	27-42 years
Sampling Method	Convenience	Criterion, Purposive & Opportunistic	Criterion, Purposive & Opportunistic	Criterion	Criterion	
Fieldwork	Jun-Aug 2004 Canada	Jan 2005-May 2005 - Trip #1 to India			Oct 2006-Mar 2007 - Trip #2 to India	
Location	Community, Toronto	Community-Based Rehabilitation (CBR) Program in the urban slums of New Delhi, India				
Examples of Disabilities	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.					
Strategies to Collect Data	PRIMARY: 42 demographic profiles; 57 semi-structured interviews; 25 follow-up interviews; 8 participant observation sessions; 7 focus groups; participatory development techniques (31 drawings; 27 schedules; 27 list of problems; 27 force-field analyses; 1 group tree diagram; 1 group fishes and boulders; 1 group list of problems); 2 journal entries; 100+ casual interactions; daily observations and unobtrusive measures/outcroppings. SECONDARY: document review (16 client files; 8 organizational documents); 682 photos; 35 videos.					

<sup>2</sup> Each phase helped to inform subsequent phases (e.g., preliminary data collection indicated that adolescents enjoyed the group setting; thus, subsequent research phases involved more group-oriented activities and data collection methods). Details regarding pilot testing are not included in this paper.

*Table 2. Inclusion/Exclusion Criteria Based on Ten Areas*

<b>Domain</b>	<b>Criteria</b>
<b>Age</b>	Adolescents had to be between 12 to 18 years of age at the time of recruitment.
<b>Disability</b>	Adolescents with disabilities had to identify themselves as having a disability or with the concept of disability, but not necessarily as being disabled.
<b>Gender</b>	Both male and female adolescents were included to remain consistent with the organization's goal of promoting gender awareness.
<b>Comprehension</b>	Adolescents had to be able to demonstrate an understanding of the study.
<b>Communication</b>	Adolescents had to be able to verbally communicate.
<b>Family Members</b>	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.
<b>Severe Disabilities</b>	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.
<b>Marital Status</b>	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 or challenges that were beyond the scope of this study.
<b>Consent</b>	Primary caregiver(s) had to consent for the adolescent to participate on their own with little or no parental supervision. Adolescents had to willingly (without coercion from parents or the CBR team) consent to participate. Verbal consent in the presence of another individual other than the investigator was sufficient.
<b>Community-Based Rehabilitation (CBR) Team Members</b>	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.

Participants in this study included 21 adolescents with disabilities, 11 adolescents without disabilities, and ten adult community-based rehabilitation staff members. The average age of adolescents was 14.3 years (ranged from 12 to 18 years of age at the time of recruitment). There were 19 male and 13 female adolescent participants. Adolescents were predominantly of the Hindu faith and Hindi speaking, and were living at home with their immediate family, were unmarried and had no children. Participants reported that this was the first time they comprehensively discussed their lives, experiences and culture, and were included in a research study. Both adolescent men and women appeared enthusiastic about participating in a research study. Of the 32 adolescents who participated, 14 acted as key informants.

Adolescents with disabilities had to identify themselves as having a disability or with the concept of disability. Nineteen participants with disabilities had visible or noticeable disabilities or multiple 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. All adolescents were known to the Community-Based Rehabilitation Program.

Adult community-based rehabilitation staff members were 27 to 42 years of age. All reported good health and no disability. Staff members were mainly of the Hindu faith and Hindi speaking (half of the staff members could also communicate in English). All, except one, could read and write in Hindi; roughly half could communicate in English as well. Five staff members had post-secondary education, four had high-school, one had no formal education, and seven had additional training in disability and rehabilitation. Three staff members lived within the slum area and seven lived outside. The role of staff in the Community-Based Rehabilitation Program included: two coordinators, three community workers, three teachers, one social worker, and one rehabilitation therapist.

## **Procedure**

The Community-Based Rehabilitation Program situated in the urban slums of New Delhi facilitated entry into the field and recruitment. The first author made two trips to India to collect data; the first trip was from January 2005 to May 2005, and the second trip was from October 2006 to March 2007. The first author spent eight to nine months in the area/urban slums over a period of two years, working four to five days per week for five to six hours per day in order to immerse in the community, develop rapport, and gain long-term knowledge of participants and their environment.

The study was described to potential participants while moving through the community. Adolescents and their primary caregiver(s) had to provide verbal consent in the presence of two individuals. Upon entering the field, the first author 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 conducting the first few interviews with adolescents, the first author was better able to adapt the study to local concerns. The role of an advocate and a facilitator was assumed predominantly during the second trip to India when the first author 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 problems and desires.

Adolescents' commitment to the study over two years reflected that the study purpose was important to their aspirations. The first author tried to present the researcher's role as the "student or learner" and adolescents' role as the "teacher" in order to break down power differences; however, many adolescents continued to view the first author as an authority figure using statements including, "I'm talking too much sister, you should talk now." Cultural practices appeared to sometimes hinder adolescents from speaking their mind or speaking too much in the presence of an authority figure.

## **Data Collection**

The first author was fluent in Hindi and collected all data with participants mainly in Hindi in the community (i.e., in the Community-Based Rehabilitation Program's local office, community centre or participants' homes). Considering the socio-cultural context, age, disability, educational qualifications and lack of opportunity, the first author utilized multiple qualitative and participatory methods to collect data to ensure that adolescents

could comfortably express their views. Data were collected and collated from the strategies outlined in Table 3.

Table 3. Data Collected and Collated

<b>Data Collection Methods</b>	<b>Description/Comments</b>
<b>42 Demographic Profiles</b>	Collected from adolescents and CBR team members.
<b>57 Individual Interviews</b>	Conducted with adolescents. Each ranged from 45 to 120 minutes.
<b>25 Follow-up Interviews</b>	Conducted with adolescents. Each ranged from 30 to 90 minutes.
<b>7 Focus groups</b>	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. 2 focus groups with the CBR team approximately 120 minutes each. Regarding the team's understanding of and work with adolescents.
<b>8 Participant Observation Sessions</b>	Observations of adolescents carried out during a school day, typical day, Teacher's Workshop, Arts & Crafts Workshop, Special Olympics practice, and Disability Day Celebration.
<b>7 Participatory Development Techniques</b>	
<i>31 Impact Drawings</i>	Drawn by adolescents. Regarding personal understanding of disability.
<i>27 Typical Day Schedules</i>	Completed by adolescents. Regarding individual daily routine.
<i>27 List of Problems</i>	Completed by adolescents. Regarding problems faced by adolescents.
<i>27 Force Field Analyses</i>	Completed by adolescents. Regarding future goals and resources needed.
<i>1 Group Tree Diagram</i>	Completed by a group of adolescents. Regarding their collective understanding of disability.
<i>1 Group Fishes (adapted to Cars) and Boulders</i>	Completed by a group of adolescents. Regarding their collective understanding of facilitators and barriers.
<i>Group List of Problems</i>	Completed by a group of adolescents. Regarding their collective understanding of problems experienced by young women and men, and adolescents with and without disabilities.
<b>2 Journal Entries</b>	Submitted independently by two adolescents.
<b>16 Client Files</b>	Reports on adolescents with disabilities obtained from CBR Program.
<b>8 Organization Documents</b>	Regarding ASTHA's CBR Program.
<b>100+ Informal Interactions</b>	With adolescents and CBR team members.
<b>Daily Observations</b>	Initiated immediately upon entering field.
<b>682 Photographs and 35 Videos</b>	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 & Schensul, 1999). In the following sections, the application of

some of the data collection methods utilized in this study are discussed.

*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. Participants were aware that they were being observed during activities or generally. The first author's role as an observer ranged from being moderately (i.e., observing a typical day at school or at home) to being actively (i.e., attending a Disability Day Celebration in the slums) involved.

*In-depth semi-structured interviews* are 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; Schensul, 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. The first author conducted interviews with participants in their first language. A semi-structured interview guide was used to facilitate the conversation, broad open-ended questions were used to generate discussion (e.g., tell me about your friends), and more direct questions were used 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). The first author encouraged adolescents to share stories that provided greater insight into their views. To ensure that data were not lost to mechanical malfunction, two cassette recorders were used to audio-record interviews.

*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; 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 the first author as the primary investigator; the first author 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 group facilitation. Several conditions were set for conducting focus groups in this study. First, the purpose of the focus group determined the number of adolescents to invite. There were from six to 11 participants in the focus groups. The two larger focus groups involved an introductory session and discussions,

and activities in smaller groups where the first author 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, the first author 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, the first author 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). Data were analyzed at the group level for sequence of events, activities, behaviours and interactions, collective responses, and response to the group setting.

*Participatory development techniques* were used to gather information on community and disabled persons' issues in a visual form (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 (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 (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). The first author 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. The fishes and boulders technique (adapted to cars and boulders) was used to learn about adolescents' collective understanding of barriers and facilitators. Examples of participatory development techniques used in this study are illustrated in Figures 2, 3, 4 and 5. 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. See Appendix A for a sample of interview questions and description of specific activities conducted with adolescents.

*Fieldnotes* in which interactions and observations are comprehensively recorded (and being able to adequately analyze and interpret those fieldnotes) are essential to writing a "sound and true" ethnography (Emerson, Fretz, & Shaw, 1995). In this study, the first author divided fieldnotes into three sections: (a) generic fieldnotes about the community and memos about my personal reflections; (b) individual fieldnotes for each participant; and (c) fieldnotes for group activities. When appropriate, basic fieldnotes were written at the fieldwork site, and then elaborated on in detail upon returning home. During the second trip to India, fieldnotes were dictated directly into a computer using © Dragon Naturally Speaking Preferred 8.1 software (ScanSoft, 2004). See Appendix B for an excerpt from the researcher's fieldnotes written on the first day of data collection.

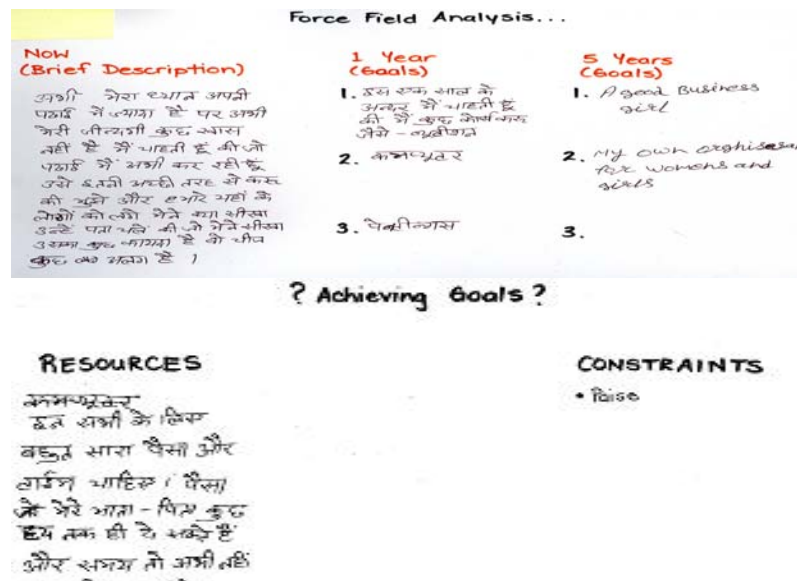




Figure 4. Impact Drawing: Bullying. A disabled boy with a broken arm and leg (left) and an able bodied adolescent (right) who is hitting the boy with a disability as he continues to yell, "Ouch!" (Drawn by a 13 year-old male with a cleft lip/palate)



Figure 5. Force-Field Analysis (Participatory Development Technique). Outlining an adolescent's present and future goals, and the resources and constraints associated with achieving those goals. (Developed by a 17-year-old female with a speech impairment)





*Audio-visual data -- photography and videography* -- served as supplementary sources of data in this study. Audio-visual data provide great potential to further research activities 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; 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 in this study, 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. The first author considered the influence of photography and videography on the setting. Participants were aware when being photographed or audio and video-recorded. A digital camera was used to take most photos and videos. Photos and videos became a supporting component of fieldnotes. Photos and videos were labeled based on the activity they captured.

Data were collected as feasible and until saturation (repetition of data for general areas of concern and for 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; another six adolescents with disabilities were recruited to help ensure that little or no new information was emerging. The first author found similar issues and challenges emerging when discussing general areas of concern for adolescents, including family relations, friendships, daily life and occupation, the community setting, school and/or work, and romantic relationships and marriage. The first author 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, the first author ensured that little or no new properties that defined this idea were occurring.

Data collected in Hindi were translated and transcribed into English text. Every effort was made to maintain the integrity of the data (i.e., preserve the meaning, tone, order of words, and repetition). The first author 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) in order for the first author to assess the quality of their work and determine whether they were suited to complete further transcription. The first author checked all the work completed by transcriptionists for accuracy.

### **Impression Management in Field**

Often explicit and implicit rules of doing research in the developed world do not easily translate to the developing world. The first author was especially cognizant of her

appearance and behaviour as an unmarried woman of South Asian descent traveling alone to engage in a study in the slums. Community members became aware of and accepted the first author's role within the Community-Based Rehabilitations Program. To avoid influencing adolescents' responses or distancing them, the first author monitored her behaviour and stories to ensure that they were culturally compatible. The first author wore a traditional Indian suit, a salwar kamiz, at the fieldwork site and shared many meals with participants. Adolescents were eager to learn about the first author's personal and professional background. The first author addressed participants' curiosity and maintained consistency in the information by sharing a personal photo album of her family, friends, university and residence in Canada after collecting demographic data. The first author focused on understanding local dialects and the "nuances" associated with communication, including the term "affair" that could refer 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. The first author's 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.

### **Ethical Considerations**

This study was viewed as a part of ASTHA's Community-Based Rehabilitation 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.

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 community-based rehabilitation staff member and the first author would explain the purpose of the study and ask the adolescent if they were interested in participating. If the adolescent consented, the community-based rehabilitation staff member or the first author would explain the study to the adolescent's primary caregiver. Verbal consent from caregivers and adolescents in the presence of another individual sufficed. The first author 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 that adolescents understood the consent process). While adolescents shared personal information willingly, the first author confirmed with participants and also used her 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.

### **Ethnographic Data Analysis**

To guide data analysis, the process outlined in the *Ethnographer's Toolkit Volumes 1 to 7* (LeCompte & Schensul, 1999) was used. 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 & Schensul, 1999a). Ethnographic analysis involves connecting, separating and interpreting the multiple data collected in order to make sense of the data as a whole. LeCompte and Schensul's (1999) approach to analysis was selected because it provided a comprehensive approach to analyze data from initial entry into the field all the way through to abstract 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 are discussed in detail throughout this section.

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 & Schensul, 1999a). Although all data collected in this study played an important role in interpreting and supporting major overarching ideas, not all data were analyzed with the same intensity or held the same weight. The first author compared data across adolescents with and without disabilities and analyzed data collected from the Community-Based Rehabilitation Program because it was expected that adolescents would initially use the program as a way to help themselves. The adaptation of the analytical process outlined by LeCompte and Schensul (1999a) is provided in Figure 6.

Figure 6. Stages of the Analytical Process (adapted and applied to this study)<sup>3</sup>

#### 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 and written information, and photographing and videotaping).
- **Preliminary analysis** of data collected during trip one to India (initial reflections and interpretations; asking refined questions; data analyzed manually resulted in ten initial overarching categories).
- **Member checking and dissemination** of initial overarching categories.
- **Negative (or exceptional) case** (adolescent with a more active role and voice in the community) sought to compare and validate data collected with the majority of adolescents with no voice.

#### Stage 2: Tidying Up and 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 in Hindi into English.
- **Converting data into electronic form.**
- **Managing data** using a filing system and electronically with © QSR NVivo 7 and © Microsoft Word.

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

- **Item level of 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 and 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.

<sup>3</sup> Idea adapted from LeCompte and Schensul (1999a).

Data were organized by genre, and managed 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. The first author initially analyzed a small amount of data manually, and then entered it into the software for higher-level analysis; a small amount of data were also analyzed directly within © Microsoft Word (Microsoft, 2003).

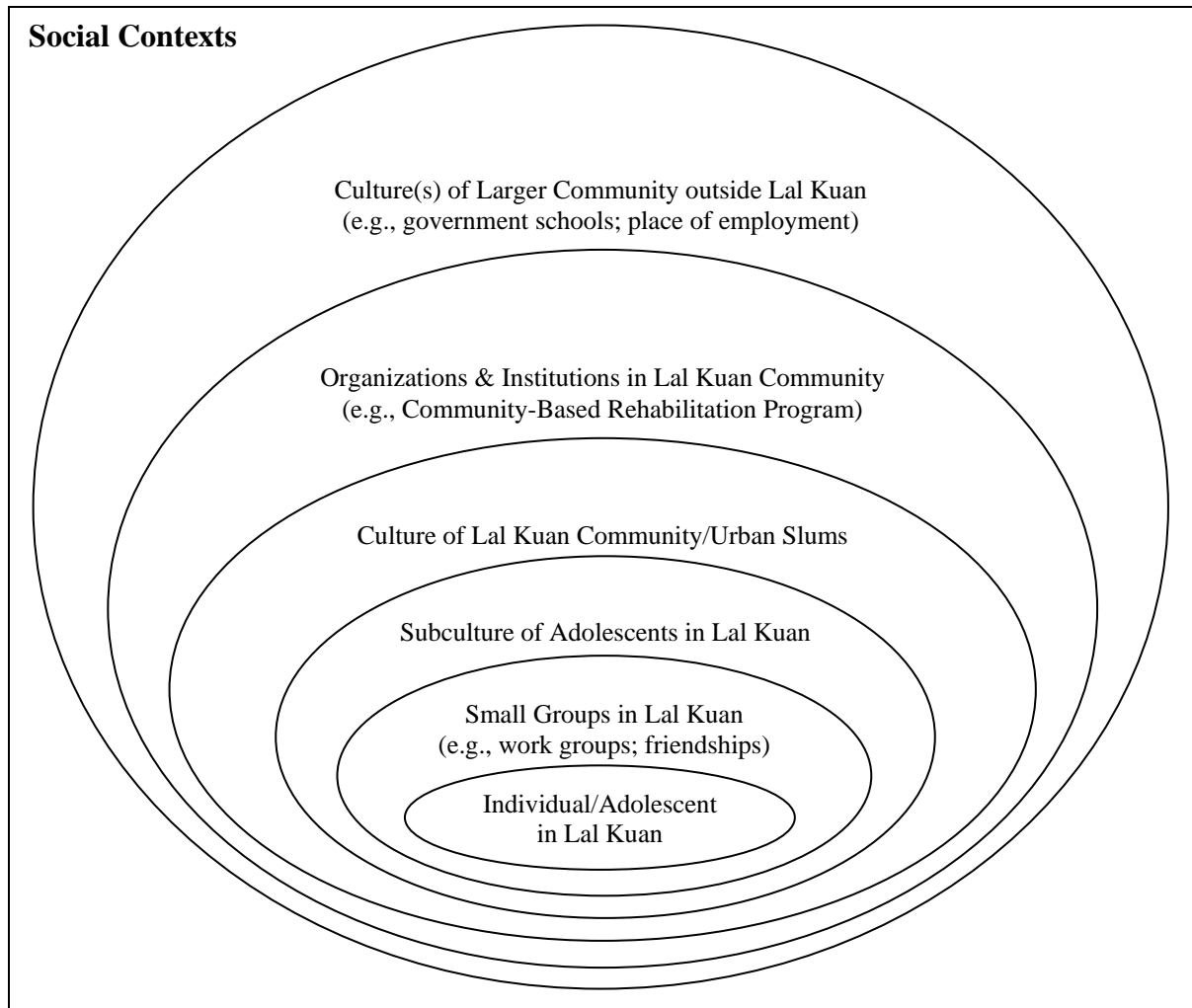
The analysis of ethnographic data is a multifaceted process embedded in multiple social contexts and networks (LeCompte, Schensul, Weeks, & Singer, 1999; Schensul, LeCompte, Trotter II, Cromley, & Singer, 1999). The first author reviewed the accumulating data to discover the underlying social contexts 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 to observing a typical day at school and pursuing discussions with the community-based rehabilitation team and parents about school). The common map of social contexts and social networks that evolved is presented in Figures 7 and 8. 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.

To manage and code primary data, 86 documents (e.g., interview transcripts; observational fieldnotes) were entered 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 & Schensul, 1999a; Walsh, 2003). Analysis was an inductive process; no pre-defined categories or patterns were applied to the data.

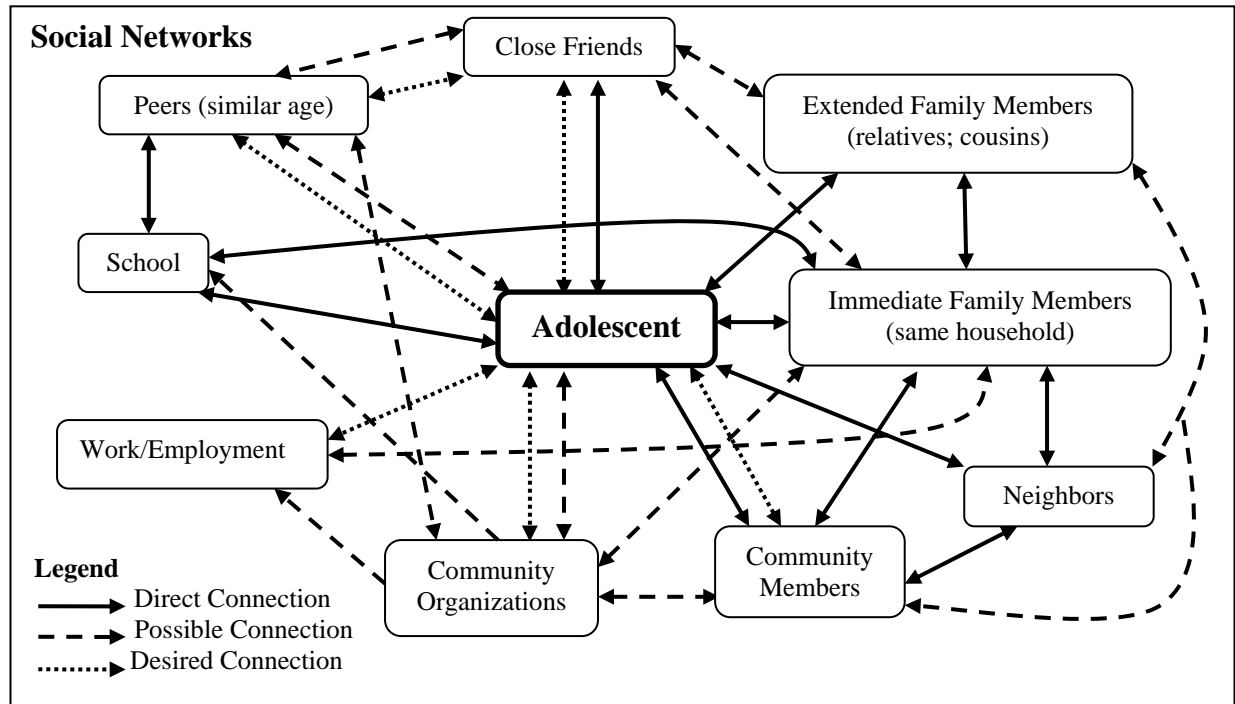
*Item level of analysis* aims to identify naturally occurring items or units in the data, and attempts to order, classify and code such items (LeCompte & Schensul, 1999a). Item level analysis involved reviewing data line-by-line (for key informants) or event-by-event (for remaining participants) to establish items or free nodes (a shorter meaningful description for a line(s) using the participant's words). Segments of data were named using "gerunds" in order to preserve the sense of action and process, as described in Charmaz (2006, p. 49). A total of 1589 different free nodes or items were developed. To help distinguish between the free nodes that emerged from the different types of data, 'square brackets' were used to reflect free nodes from fieldnotes, the word 'observation' was used 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). An example of how initial coding was conducted on a passage from an interview is provided in Figure 9. The list of free nodes or items was examined to establish codes (shorter labels for a group of similar items). Codes were reviewed, updated and applied as data analysis progressed. A codebook (list of all codes) was kept electronically. An example of some generic codes developed during data analysis is provided in Figure 10. The first author wrote theoretical memos regularly that reflected on the emerging data and higher

level concepts; memos were elaborated on and new memos were developed throughout the process.

Figure 7. Notion of Embedded Social Contexts (applied to this study)<sup>4</sup>



<sup>4</sup> Idea adapted from LeCompte, Schensul, Weeks, and Singer (1999, p. 3)

Figure 8. Concept of Mapping Social Networks (applied to this study)<sup>5</sup>

*Pattern level of analysis* aims to establish connections among items that have been classified or grouped together (LeCompte & Schensul, 1999a). Pattern level of analysis involved organizing codes into categories that conveyed a particular idea, occurred frequently, or represented a consistent set of actions. Categories were given higher level conceptual labels. Data were analyzed 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 (Schensul, Schensul, et al., 1999). Cultural domains concern people's perspectives on culture and not their preferences (Schensul, LeCompte, Nastasi, et al., 1999). The first author focused on depicting only selected cultural domains that were 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 11 for an example). Important categories were moved forward in the analytical process.

<sup>5</sup> Idea adapted from Schensul, LeCompte, Trotter II, Cromley, and Singer (1999, p. 35)

Figure 9. Example of Line-by-Line Coding and Conceptual Memos (based on a passage from a semi-structured in-depth interview).

<p><b>Example</b></p> <p><i>Passage from a semi-structured in-depth interview with a female adolescent with disability (translated from Hindi into English text):</i></p> <p><b>Investigator:</b> ...Tell me [about any] problems, difficulties or tensions [faced by] disabled adolescents who are from 12 to 18 years of age.</p> <p><b>Participant:</b> ...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...</p>	
<p><b>Line-by-Line Coding</b> (naming/labeling segments of the data)  <b>&amp; List of Free Nodes:</b></p> <ul style="list-style-type: none"> <li>-(disabled adolescents) hesitating to go in front of new people</li> <li>-(disabled adolescents) thinking that disability will appear awkward to others</li> <li>-(disabled adolescents) cannot comfortably mingle with others</li> <li>-(disabled adolescents) remaining hesitant and stressed</li> <li>-(disabled adolescents) not wanting to appear in front of or see others</li> <li>-(disabled adolescents) sensing problems within themselves</li> <li>-(disabled adolescents) avoiding others to prevent being teased</li> <li>-(disabled adolescents) remaining scared of being teased</li> <li>-(disabled adolescents) not wanting to go in front of new people mainly</li> <li>-(disabled adolescents) losing courage and (internal) strength due to disability</li> </ul>	<p><b>Memos</b> (queries and conceptual reflections):</p> <ul style="list-style-type: none"> <li>▪ 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.</li> <li>▪ Showing signs of low-self esteem or poor self-image.</li> <li>▪ Being overly cautious about what others think about them or how others might react towards them.</li> <li>▪ Assessing self-worth or judging value of self based on the reaction of others.</li> </ul>



Figure 10. 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.

### Example

#### **1.0AFFAIRS** (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
  - free node: not letting anyone come to know about the affairs
  - free node: hiding affairs from the community
  - free node: affairs not being suitable for poor people
  - free node: poor people's way of thinking being different
  - free node: community members not accepting affairs

#### **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

Sample of some specific items under code '**4.3 Nature of Harassment**':

- Disabled adolescents experiencing extensive name-calling
  - children & adolescents using derogatory names - free nodes: calling disabled adolescent monkey because of facial disfigurement & parrot because of disfigurement of hands
  - free node: calling disabled adolescents crippled
  - free node: calling disabled adolescents deaf and dumb
  - free node: calling disabled adolescents a lame
  - free node: calling disabled adolescents handicapped
  - free node: girls and boys calling disabled adolescents names
  - free node: being called names at school
  - free node: being called names in the community

*Structural level of analysis* aims to link and find consistent relationships among patterns (LeCompte & Schensul, 1999a). Structural level of analysis involved assembling patterns into meaningful structures or important themes. Items, patterns and structures were reviewed regularly to understand how they addressed the research question and adolescents' empowerment (i.e., what would encourage adolescents with disabilities to take a more active role in their rehabilitation). As the analysis progressed, the first author assembled more data of patterned pieces to form structures until the most complete understanding of the data emerged. Three major themes or "structures" emerged (i.e., participating in a group, demonstrating in a group, and being recognized in a group situation) as important strategies for empowering adolescents. An example of the item, pattern and structural levels of analysis is presented in Figure 12.

*Model building* involved further interpretation of relationships among patterns and structures and identifying the most salient themes related to the concept of empowerment, which resulted in the development of a conceptual framework entitled the "Adolescent Group Empowerment Pyramid" (Gulati, Paterson, Medves, & Luce-Kapler, 2010). Interpretation requires an understanding of patterns and structures in relation to previous or new theoretical foundations and paradigms (LeCompte & 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.

Secondary data, including videos and photos facilitated the first author's 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 transcripts and fieldnotes. Review of organizational documents and client files provided information in four areas: (a) the past, present and future activities of the Community-Based Rehabilitation Program; (b) main activities of the program; (c) role of adolescents in the development and implementation of community-based rehabilitation activities; and (d) whether 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. The first author found document review helpful in generating options for activities that adolescents could work on during the applied phase of this study.

### **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).

*Figure 11.* 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).

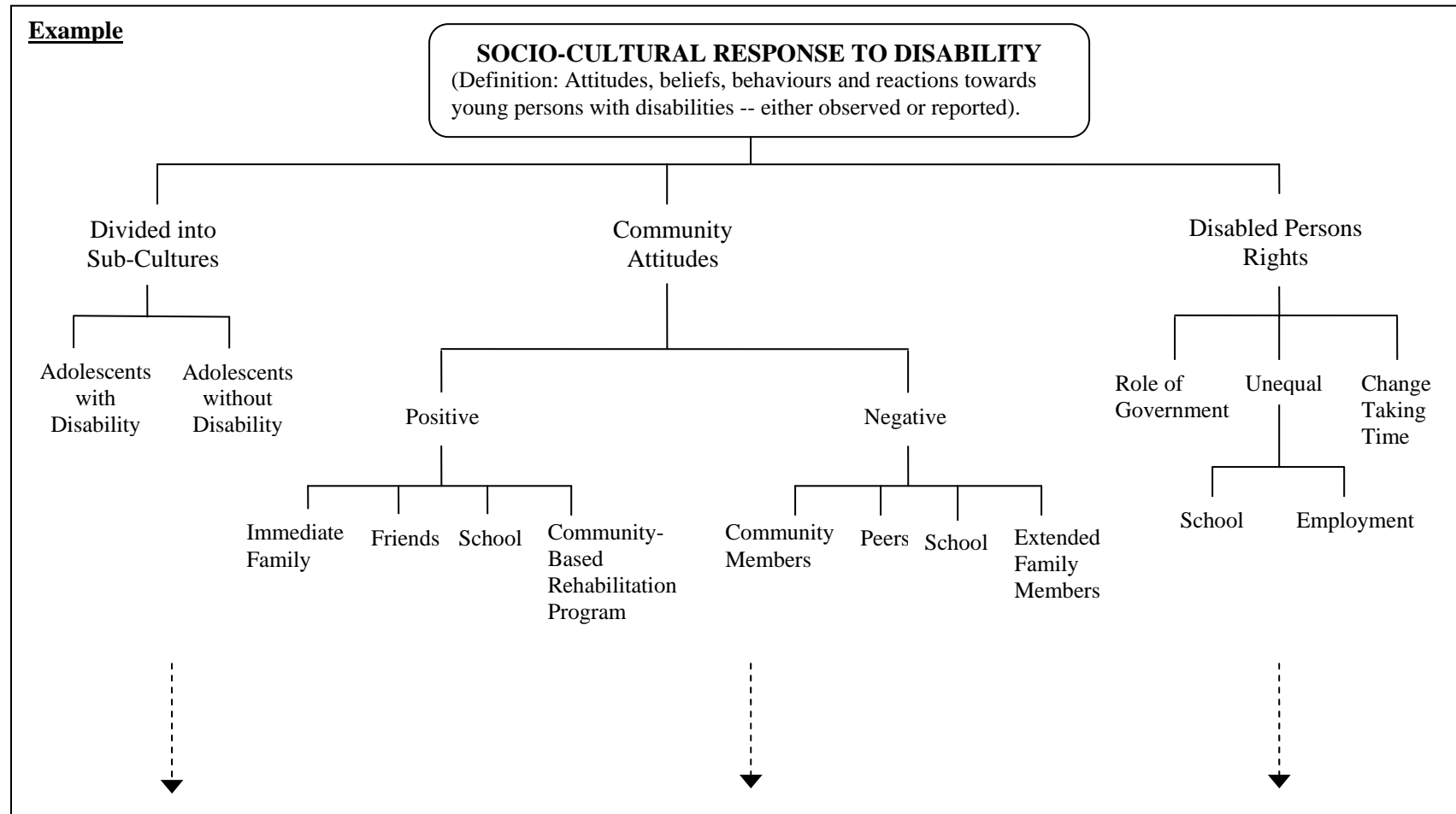
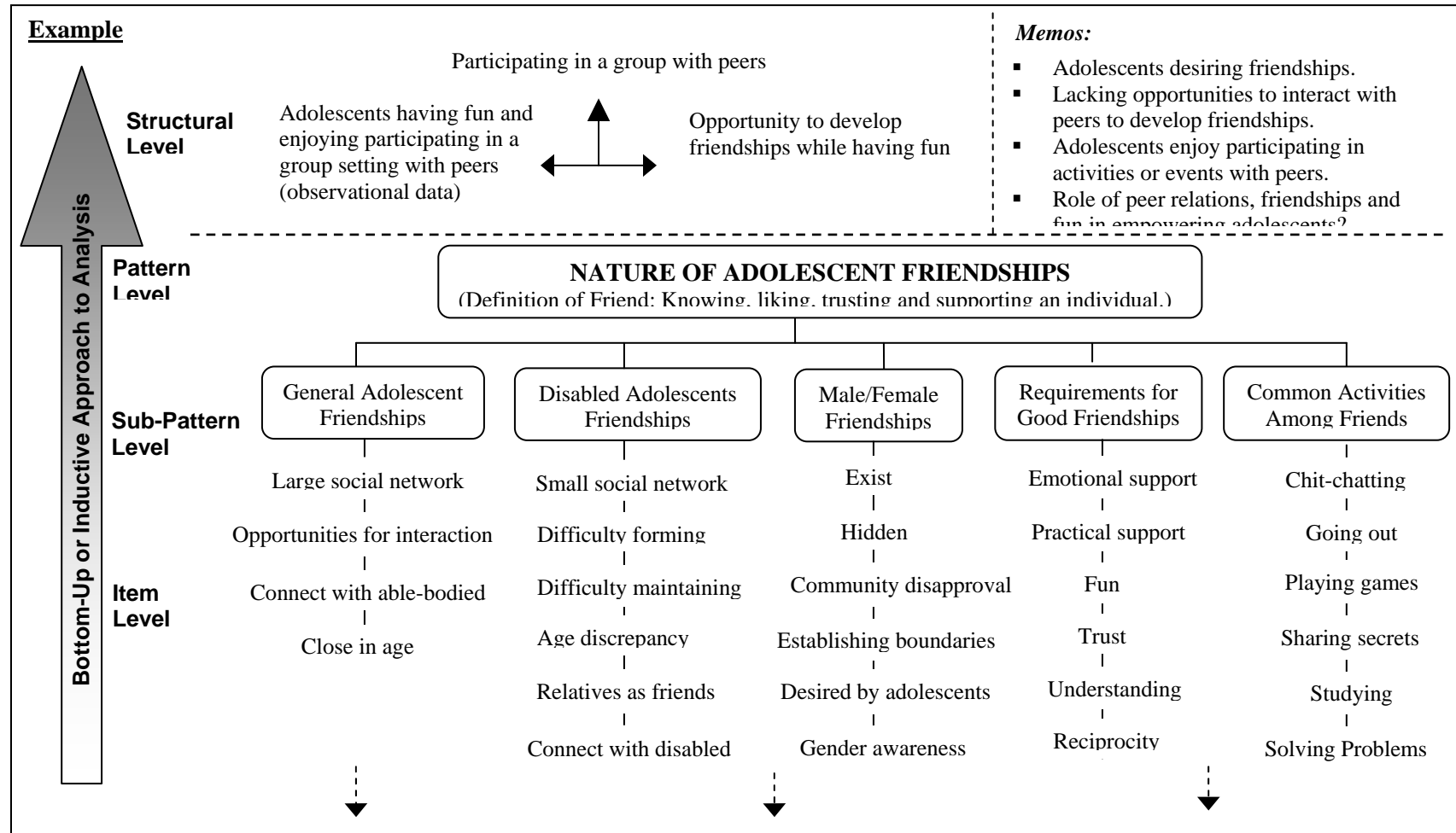


Figure 12. Example of Item, Pattern and Structural Levels of Analysis (illustrates items, sub-patterns and patterns being ordered hierarchically; once items have been identified and assembled into patterns and larger structures, they can be further manipulated to explore interrelationships and to create models)



Addressing several areas can help to establish trustworthiness in qualitative research (Krefting, 1991). 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; Lincoln & Guba, 1985). The strategies described in Table 4 helped to enhance the credibility of this study.

### **Dissemination of Information and Finding**

Dissemination of research findings on a continuous basis is instrumental to ensure the applicability of critical ethnographic research. Participants and key stakeholders should be involved in various stages of the decision-making process and program development (Schensul, LeCompte, Hess, Nastasi, Berg, Williamson, et al., 1999). 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). The process of disseminating information was incorporated within the design of this study, as each phase informed subsequent phases. “New” knowledge was translated and transferred in a culturally appropriate and creative way at a local level to community members. Six dissemination sessions were held locally for adolescents, caregivers and staff; four were held by the first author and two were led by the staff at the Community-Based Rehabilitation Program/organization. Research findings were disseminated via a visual form, including photographs, videos, presentations on a laptop computer, 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.

Table 4. Strategies to Enhance Trustworthiness and Rigour

Strategies	Application to Doctoral Study
<b>Audit Trail</b> Ensuring that all research decisions are transparent for others to follow the process (Krefting, 1991).	<ul style="list-style-type: none"> <li>Retained all raw data, emails, schedule of activities, and feedback.</li> </ul>
<b>Reflexivity</b> Reflecting on how the researcher's background, views, and interests may influence the research (Krefting, 1991).	<ul style="list-style-type: none"> <li>Completed a subjectivity statement and a SWOT (strengths, weaknesses, opportunities, threats) Analysis to reflect on researcher role.</li> <li>Kept a field journal to record personal thoughts, feelings and biases.</li> </ul>
<b>Prolonged Field Experience</b> Spending increased amount of time in field to rely on rich, long-term knowledge (Krefting, 1991).	<ul style="list-style-type: none"> <li>Spent increased time in field to ensure data, analysis and interpretations were based on long-term knowledge versus initial hunches.</li> </ul>
<b>Rich, Thick Description</b> 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).	<ul style="list-style-type: none"> <li>Provided significant methodological, contextual and demographic details.</li> <li>Results supported by multiple quotes and activities from adolescent participants.</li> <li>CBR team indicated that the sample of disabled/non-disabled adolescents reflected typical adolescents in the community.</li> </ul>
<b>Triangulation</b> Using multiple and different data collection methods, sources and theories to offer corroborating evidence (Creswell, 1998).	<ul style="list-style-type: none"> <li>Used multiple methods ranging from conventional methods to less frequently used written and visual strategies to collect data.</li> </ul>
<b>Negative or Exceptional Case Contribution</b> Searching for aspects of data that do not support emerging patterns (Charmaz, 2006), which may offset the problem of selective data collection and analysis (Heglund, 2005), and improve credibility of the analysis (Krefting, 1991). Negatives cases can help to refine the analysis/emerging theory and explain for the majority of patterns.	<ul style="list-style-type: none"> <li>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.</li> </ul>
<b>Member Checking</b> Reviewing accuracy of emerging results and interpretations with participants (Creswell, 1998).	<ul style="list-style-type: none"> <li>Member checked data with participants during data collection to ensure information was being understood correctly.</li> <li>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.</li> </ul>
<b>Review of Translation and Transcription</b>	<ul style="list-style-type: none"> <li>Checked data that were transcribed by others.</li> </ul>
<b>Re-visiting Data</b> Re-visiting data and engaging in a code-recode procedure on the data especially during the analysis phase (Krefting, 1991).	<ul style="list-style-type: none"> <li>Became increasingly familiar with data through transcribing data/checking transcripts.</li> <li>Conducted preliminary analysis manually to disseminate initial themes to adolescents.</li> <li>Re-visited data for further interpretation and to integrate different types of data (e.g., coding/re-coding segments of transcripts).</li> </ul>
<b>Peer Debriefing</b> Providing an external check of the data through sharing ongoing research decisions and emerging findings with peers (Creswell, 1998).	<ul style="list-style-type: none"> <li>Discussed research decisions and findings with the advisory committee, graduate students, and the organization in India.</li> <li>Research issues and preliminary findings were presented at four conferences to learn from the reflections/feedback of colleagues.</li> </ul>

## Discussion

In this paper, focus was placed on the methodology used in a critical ethnographic study, which led to the development of a conceptual framework called the *Adolescent Group Empowerment Pyramid*, which is discussed elsewhere (Gulati et al., 2010). The fundamental goal of any critical ethnographic study is to inform change in some aspect for the vulnerable group being studied. To truly do justice to this study, the recommendations for change that the first author made to the organization 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.e., the desire for group participation, group demonstration, and group recognition). Within the context of this study, the way in which community-based rehabilitation activities were carried out changed on four levels. First, adolescents assumed responsibility for developing and informing organizational documents that were normally dominated by adult community-based rehabilitation staff members (e.g., (a) adolescents' helped to write the subjective aspects of documentation about an event held in the community to increase disability awareness; (b) adolescents' provided feedback regarding the Community-Based Rehabilitation Program's upcoming annual plan; (c) adolescents' helped to design a page for the organization's Annual Report). 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 Community-Based Rehabilitation Program developed a community youth group that addressed adolescent-specific issues, concerns and agendas and the group is currently being led by a male community-based rehabilitation staff member. When the first author left India, she 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.

## Conclusions

The first author was able to use a critical approach to research that demonstrated a partnership between a developed world investigator and a developing world Community-Based Rehabilitation Program. This paper provides greater insight into the use of a critical ethnographic approach with adolescents with disabilities in order to give them a more powerful voice in their rehabilitation activities. The use of critical ethnography as a research strategy with adolescents, the use of and analysis of multiple qualitative and participatory data collection methods, and important ethical, rigour and dissemination considerations are discussed in detail.

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 limited resources, living in poverty, dealing with illness or disease, residing in conflict zones, and dealing with negative societal attitudes. 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. The purpose of this study was to identify oppressing practices that are being challenged globally, and to assist people in building local capacity. Cultural and community differences can be a source of strength (Fransen, 2005). However, 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.

The perspectives of adolescents with disabilities are critical in developing meaningful rehabilitation interventions. 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 play a minimal role in helping to make programs personally meaningful and sustainable. To ensure the relevance and sustainability of community-based rehabilitation 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 raise the issues that affect their lives and to find possible solutions and interventions to address their challenges.

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## **Appendix A**

### **Sample of Data Collection Activities Conducted with Adolescents<sup>6</sup> (Adapted from Original Data Collection Protocols)**

#### **Interview Questions (Sample)**

1. What is the meaning of disability? When you hear the word disability what thoughts come to your mind?
2. What would you tell an adolescent without disability about your disability/life? What would you ask an adolescent with disability about their disability/day/life?
3. Describe your typical day from the time you get up in the morning till the time you go to bed.
4. Tell me about your relationship with your family members.
5. Tell me about your friends. Are your friends disabled or non-disabled or both? How would you describe the friendships of disabled versus non-disabled adolescents?
6. What do you think about adolescent boys and girls being friends? What are your thoughts about mixing adolescent boys and girls for: education, work, learning about the opposite gender, this study, and leisure/fun?
7. Would you describe yourself as a child or an adult or in-between and why? Tell me about any changes you have noticed in yourself.
8. Tell me about your thoughts regarding adolescents' romantic relationships ("affairs"). Tell me about issues regarding marriage that arise during adolescence. How does being a disabled adolescent impact marriage?
9. Have you heard about any inappropriate behaviour towards adolescents? Would you say such behaviour is more likely with: i) girls or boys or ii) adolescents with or without disabilities?
10. How would you describe the lives of adolescents with disabilities in your community? What are the problems faced by adolescents with and without disabilities in your community?
11. Tell me about how you see your life right now. How do you feel about your future?
12. How did you learn about ASTHA's CBR program? How would you describe the program? Tell me about the help you receive or have received from the program. What aspects of the program are you satisfied or dissatisfied with? What other activities would you like the CBR Program to do with adolescents?
13. Tell me about other services that you receive or have received (e.g., from health care facilities; hospitals; schools). What aspects of such services do you like or dislike? What other things would you like help with? What other services do you think would be helpful?

#### **Follow-up Interview Questions (Sample)**

1. What are your thoughts about these preliminary findings from last year? Were there any changes in your life or thinking since we last met? What thoughts did you have about the disability issues we talked about?

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<sup>6</sup> Many questions and activities were developed and modified as the study progressed.

2. Tell me about the general culture here and the adolescent culture? Would you say the adolescent culture is different/similar to the larger culture? Tell me about the culture of adolescents with and without disabilities?
3. Does the culture contribute to the rehabilitation problems of disabled adolescents? How?

### **Participatory Development Techniques -- Visual/Written Strategies (Sample)**

1. Impact Drawing. (a) Draw anything you like about disability or people with disabilities (from 12 to 18 years of age) or (b) draw an adolescent with and without a disability. Tell me about your drawing.
2. Daily Schedule. Complete a schedule outlining what you do from Monday to Friday and on Saturday and Sunday. Which activities do you enjoy or dislike and why? Are there any activities you have difficulty doing? Tell me about any activities that you would like to engage in? Why are you not engaging in these activities?
3. Listing Problems. List up to 5 problems faced by: (i) non-disabled adolescents and (ii) disabled adolescents.
4. Force Field Analysis. Fill in the following information: (a) describe what your life is like right now under “Now”, (b) describe three goals that you want to achieve within one year under “One Year Goals”, (c) describe three goals you want to achieve within five years under “Five Year Goals”, and (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.
5. Journal Entry. If you have any additional thoughts, you can write them in this journal.
6. Group Tree Diagram. Describe meaning of disability on “leaves”. What do you think about the information?
7. Group List of Problems. Group 1 list what the day/life of non-disabled adolescent is like. Group 2 list what the day/life of a disabled adolescent is like. Consider self-care, work/school, leisure, and emotions. Discuss. Group 1 list the challenges faced by adolescent girls with disabilities. Group 2 list the challenges faced by adolescent boys with disabilities. Discuss.
8. Cars and Boulders (adapted Fishes and Boulders). In pairs, think about the problems faced by adolescents with disabilities. On the “big” rocks write the problems that you think are big. On the “small” rocks write the problems you think are small. On the “medium” rocks write the problems you think are in the middle. Place the rocks on the “road”. Discuss. In pairs, think about the resources (people/things) that can help adolescents with disabilities to address problems. List these resources on the “cars” and place along the “road”. Discuss.

### **Focus Group Questions (Sample)**

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. How do people in the community treat adolescents with disabilities?

2. Tell me about an adolescent with a disability versus an adolescent without a disability. What are the greatest challenges faced by: (a) adolescent girls with disabilities, and (b) adolescent boys with disabilities?
3. Tell me about the activities that adolescents in your community enjoy.
4. What is required for two adolescents to be friends? What do you value in your friendships? Tell me about girl-boy friendships in your community. Tell me about disabled versus non-disabled adolescent friendships.
5. Tell me about the things you have done with or for adolescents with disabilities. How will we know when adolescents with disabilities are happy and accepted in the home, community or school?
6. Tell me about your thoughts on adolescents with and without disabilities becoming friends, going to school, and working together?

*Regarding the Disability Day Celebration Held in the Community*

1. What do you know about Disability Day (Viklang Devus)? Why did we celebrate it in the community?
2. How did you feel participating in the program? How did you feel if you did not participate in the program? How did you feel attending/watching the program?
3. What did you like or dislike about the Disability Day Celebration/program?
4. How can we make the program better for next year?
5. Activity. Write down the feelings you experienced during the Disability Day Celebration/program.

*Regarding ASTHA's Community-Based Rehabilitation Program, Plan for 2007*

1. How do you understand the organization's goals? What are some of their strengths and weaknesses?
2. A significant goal of the organization is to pass information to persons with disabilities. What comments do you have about the passing of information to adolescents with disabilities?
3. How do you understand what the organization has done in the community? How do you feel the culture has influenced their activities?
4. How were adolescents' perspectives reflected in the development of the organization's plan for 2007?
5. What do you feel the organization should work on this year, in 2007?
6. What is your feedback regarding the organization's plan for 2007?
7. What else would you like to see the organization do this year for adolescents?
8. Activity. Write down two things that you would like to see the organization do in 2007. How will the culture inhibit or facilitate this?

## **Appendix B**

### **Excerpt from Researcher's Fieldnotes & Memos, February 7, 2005**

#### **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 coordinator 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...



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### **Authors' Note**

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