

DOCUMENT #1**ASTHA's Community-Based Rehabilitation Programme in Lal Kuan****Adolescents Report and Documentation on
Disability Day Programme/Celebration in Lal Kuan on December 1, 2006****Prepared by:***6 Adolescents with Disabilities**Facilitated by Sonia Gulati, Volunteer/PhD Candidate***Wednesday December 13, 2006**

Background Information:**Why did adolescents with disabilities participate in the report writing and documentation for the Disability Day Programme/Celebration in Lal Kuan on December 1, 2006?**

- World Disability Day (“Viklang Devus”) is celebrated on December 3. ASTHA’s community-based rehabilitation programme in Lal Kuan held a Disability Day celebration on December 1, 2006.
- The day is celebrated in Lal Kuan in order to help raise awareness about disability and the potential/value of persons with disabilities.
- Staff and students from ASTHA’s multiple projects attended the celebration in Lal Kuan.
- Children, adolescents, and adults with and without disabilities participated in the programme.
- Approximately 200 community members attended the day’s festivities/events.
- ASTHA is responsible to document/write a report regarding any such events that take place through their community-based rehabilitation programme in Lal Kuan.
- To document the objective aspects of such events is a fairly easy process, however the question remains: “How did the participants or disabled people feel about the event?” Thus, persons with disabilities at the very least should be included in the subjective aspect of the documentation process.
- To date, young persons with disabilities have had no involvement in the documentation and report writing process for any such events.
- It is critical for the community-based rehabilitation programme to have a thorough understanding of the perspective of consumers in order to better assess their strengths and weaknesses when organizing such events.
- Since the bulk of this work is completed with and for disabled persons, their voice and perspective counts! Obtaining feedback from programme recipients is useful in determining how funds and resources for such events should be allocated.

Who was selected for the group discussion and the documentation for this event?

- A group consisting of 6 adolescents with disabilities was formed.
- Adolescents recruited for this discussion had either participated/performed in the programme (e.g., did a dance, sang a song, gave a speech, etc.) and/or attended the entire celebration to watch the programme.

How was the discussion process organized?

- The group was invited to the centre (Panchyat Ghar, Chungi No. 2, Lal Kuan) to discuss the Disability Day celebration that was held in Lal Kuan on December 1, 2006.
- The group understood that this year it was their responsibility to complete the documentation and report writing for this event.
- The group was encouraged to respond to a series of questions.
- The discussion was audio-taped and then transcribed by the facilitator in order to carefully examine the information provided by adolescents.

What types of questions/topics were used to guide the discussion?

1. Explain the rationale for the group discussion.
2. View the photographs and videos from the Disability Day celebration in Lal Kuan in order to re-orient adolescents to the programme.
3. What do you know about Disability Day (“Viklang Devus”)?
4. Why did we celebrate Disability Day in Lal Kuan?
5. How did you feel participating in the programme? How did you feel if you did not participate in the programme (i.e., you had only come to watch it)?
6. How did you feel attending/watching the programme?
7. What did you like about the Disability Day celebration?
8. What did you dislike about the Disability Day celebration?
9. How can we add to the program/make it better for next year?
10. Activity: On a piece of paper write down the different feelings you experienced during the Disability Day celebration (completed verbally).

Disability Day Programme/Celebration - Overview of Events:

- Celebration began with a band playing and people dancing. Many community members were dancing. Adolescents with disabilities were also observed dancing. ASTHA staff members were encouraging and assisting other children/adolescents with disabilities in dancing.
- A “rally” (e.g., consisting of a band, a large sign, and people dancing) took place in the community to encourage people to attend the celebration/programme.
- Introduction to the events by an adult with a disability and a community-based rehabilitation worker.
- A recent community-based rehabilitation worker (Kajol) gave a speech regarding her work with ASTHA.
- Group of non-disabled girls did a dance (name of song: “gol gol roti”).
- Group of children/adolescents with/without disabilities sang a song.
- A young disabled child (Tejpal) recited a poem.
- Group of non-disabled girls did a dance (name of song: “tokra uthyo”).
- Group of non-disabled girls did a dance (community-based rehabilitation worker’s daughter was in this performance).
- Speech from a parent about her work with ASTHA. Parent reported that she has two children with disabilities, and explained how ASTHA assisted her in providing support, getting her children to school, and so on. (Note: Coordinator of the community-based rehabilitation programme explained to team members that speeches given by parents do not need to solely praise ASTHA - they should be genuine and realistic).
- Speech by a disabled adolescent (Nauher) about himself and his involvement in ASTHA. Adolescent reported how ASTHA facilitated his school admission, and supported him in attending social events/outings to places like India Gate and Lucknow (to see how other NGOs work).
- Speech by another parent who has a child with disability. Parent discussed her involvement with ASTHA.
- Women’s group singing songs (e.g., used a “dholki”).
- Group of non-disabled girls did a dance (name of song: “lal dupta”).
- Band playing again while organizing additional events.
- Puppet show. Appeared to be the highlight of the day. Excellent turnout.
- Speech about persons with disabilities by a community-based rehabilitation worker.

The following is an overview of the subjective information provided by adolescents with disabilities (12 to 18 years of age) regarding the “Disability Day Programme/Celebration in Lal Kuan on December 1, 2006”. A sample of quotes used directly by participants highlights the perspective of young persons with disabilities.

1. Adolescents' Understanding of Disability Day

- There was general consensus among the group that Disability Day was initially developed because a group of disabled individuals must have gotten together and done ‘something’. The group stressed that people are only recently learning that this day is also celebrated.
- Adolescents believed that Disability Day is a day where disabled people, their activities, their knowledge, and lives are celebrated.

“Because if no one was disabled then there wouldn't be a “devus” (Disability Day)...because more than half the people are good (non-disabled), and less than half the people are actually disabled - so people are celebrated. There are some people who celebrate it happily and there are some people who celebrate it sadly. Those who are okay (non-disabled) they think ‘why should I go, I'm not disabled - if he is disabled he will go, if she is disabled she will go’. So in this way it feels very awkward. They think Disability Day is for us (the disabled). So if we (disabled) celebrate it then maybe the other people will come...if we are a part of their happiness, maybe they will be a part of our happiness. In this way it feels very good too...”
-Adolescent with disability-

2. Disability Day Celebration in Lal Kuan

- Group members reported that this day has been celebrated in Lal Kuan for the past five years.
- Participants agreed that the primary reason for celebrating Disability Day in Lal Kuan is to spread knowledge regarding disability and ASTHA's activities to community members.

“Every time on Disability Day they (ASTHA) teach something.”
-Adolescent with disability-

“Because in Lal Kuan there is less knowledge. For the most part ASTHA [celebrates Disability Day] to give more knowledge, and show that disabled people aren't weak. So everyone's eyes are opened that there is a disability day. A lot of people don't even know what Disability Day is. Even I didn't know.”
-Adolescent with disability-

“Last year I had also given a speech...I said please...no parent wants that their child's life is ruined, but people make mistakes. [My parents] made that mistake - they didn't get the [polio] injection administered. If they had gotten it maybe this mistake wouldn't have happened...I wouldn't have gotten polio...My life too would have been okay...I really wanted to tell them

about this matter that 'please you people don't make this mistake'... The injection is administered for free - in the village, in the city, everywhere... [CBR Worker] said that it will be most beneficial if you speak about this, everyone will feel good. There was a lot of applause. Like there was a lot of clapping... [My] mother got so mad at me - she said 'you talk badly about me outside'... I said 'no I'm not talking badly about you, I'm just telling so that no one ever makes this mistake even accidentally because than you have to suffer'..."

-Adolescent with disability-

"We have to keep telling people. Like I am disabled, if I don't tell you...that my foot is not working well, my hand is not working well - like unless we tell each other people won't know that this person is disabled, he has polio..."

-Adolescent with disability-

"Ya the doctor (in the puppet show) was giving some information as well, about sicknesses and stuff."

-Adolescent with disability-

- The Disability Day celebration in Lal Kuan also provides opportunities for disabled and non-disabled children to work together on various arts and crafts projects, and prepare for performances such as dances and singing songs.

"...on Disability Day the disabled children together make stuff...whether it is a toy made from clay...on Disability Day this is important that the disabled get together and make something, and [show] that they too can do something. Whatever one desires - it's not that you have to do this thing, no, whatever one wishes to do...like [make] a toy or anything that you know...And some people even write something."

-Adolescent with disability-

3. Adolescents Feelings regarding the Disability Day Celebration in Lal Kuan

- Adolescents reported that they generally enjoyed this year's program the most.

"So many people came, people from outside were coming to give information about work. That's why we liked watching it very much. We also want that Disability Day is celebrated every year, and [that it] is celebrated well. Those people who do not have the knowledge, ASTHA comes...and gives information to those people. That's why we liked it."

-Adolescent with disability-

"[I] liked [the celebration] a lot because there was dances, dancing, and poems."

-Adolescent with disability-

"I liked [the programme] very much - that everyone was singing, laughing, talking, applauding."

-Adolescent with disability-

"I liked the puppet show!"
-Adolescent with disability-

- Adolescents with disability felt proud of their accomplishments and participation in the programme, and enjoyed being a part of and watching the programme very much.

"It felt really good [participating] in the programme because we helped in the singing of the song, and dancing. I know I helped the most in the singing of the song. All of us children got together and made a song that we all sang together on Disability Day...I liked doing it very much - it was the best - absolutely wonderful!"
-Adolescent with disability-

"I sang a song and everyone applauded. They realized that he (the disabled) to can do something."
-Adolescent with disability-

"[It felt] very good [to give a speech]...I gave information about myself. I told others about myself...They listened and applauded."
-Adolescent with disability-

"[W]e felt happy inside that all us children got together to celebrate Disability Day. Like someone sang a song, danced..."
-Adolescent with disability-

- With increasing involvement in programme initiatives, adolescents appeared to be empowered and realize that they would have to work hard towards making changes in their community and educating people regarding disability issues.

"It's not like God will come down to change something...You will have to change it."
-Adolescent with disability-

4. Adolescents Feedback for Improvements to the Programme/Celebration

- All participants voiced concern that they were not aware about the programme earlier. Participants reported that if they had more notice, they would have gotten involved in specific events and invited more community members to the programme.

"He is trying to say that he too wanted to [do] something, that he too could have sang."
-Adolescent with disability-

"I wanted to speak something from my heart...like I experience a lot of frustration in walking...I can't walk far distances so ASTHA helps us. Like if they go for an outing anywhere they take us too...they do something [like arrange for] a rickshaw, a car, a three-wheeler."
-Adolescent with disability-

"...[I]f I had known earlier I would have invited so many people because the people [in my block] don't know anything. The block in which I live, they don't even know what Disability Day is."

-Adolescent with disability-

- Although adolescents enjoyed the programme, the group emphasized changing the content of some programme events in order to highlight issues around disability more. For instance, adapting songs, dances, poems, and speeches so that the content reflects the lives and issues relevant to persons with disabilities.

"[We] liked everything...[but] a song you can sing anytime... this was a place to provide information. Here giving a speech would have been more appropriate, much better...There should have been more information given...It would have been better from every angle because so many people had come. Some people didn't even know why [the programme/celebration] was happening. There should have been more knowledge about that...Telling is the most important thing. Everyone can see that they are disabled, telling about [it] is very important...This time people paid more attention to dances and stuff, but the [last] time they paid more attention to speeches. I'm telling you truthfully - there was a lot of noise and shouting [but]...it's not like someone was getting married...Something is being celebrated so it should be celebrated in a manner that is appropriate - raising knowledge. It should not be just like any other function. Even last time, [the CBR worker] maintained it well. Speeches were done well. Everyone came..."

-Adolescent with disability-

"As well, the songs could have been such that [they gave a message] ... that 'yes we will do something and show you', than it would have been better...[T]he speeches could have been right in the songs." ; "[A song] in which we could have told something about ourselves."

-2 Adolescents with disabilities-

"There should have been a short "stage play" that would have been better. Then there wouldn't have been need for a speech even...Like how [their] whole life starts, how [disability] happens, what was the cause, why did it happen, whose fault was it - there are many things and in this way a play could have been developed."

-Adolescent with disability-

"[Y]oung, young children are unable to speak (about it), they won't be able to tell or understand...[The] (responsibility) should be given to such people who can shed light on to their life in front of people...Only by telling can our problems be solved... One person will listen - six people will find out. And from six people others can find out ahead."

-Adolescent with disability-

Additional Comments/Observations:

- The group reported never having had the opportunity to participate in the documentation/report writing process for any activities carried out through ASTHA's Community-Based Rehabilitation Programme in Lal Kuan. The group appreciated having the opportunity to participate in the documentation process regarding the "Disability Day Programme/Celebration in Lal Kuan on December 1, 2006".
- Participants were aware that this document would be shared with the community-based rehabilitation team in Lal Kuan and the director of ASTHA, Sudha Vohra.
- There was group consensus to take photographs and also provide the names of all individuals who participated in this group and in the development of this document. Although photographs are included, no names are listed in the document.
- The development of such documents highlights the value of young persons voices in the activities carried out in Lal Kuan.

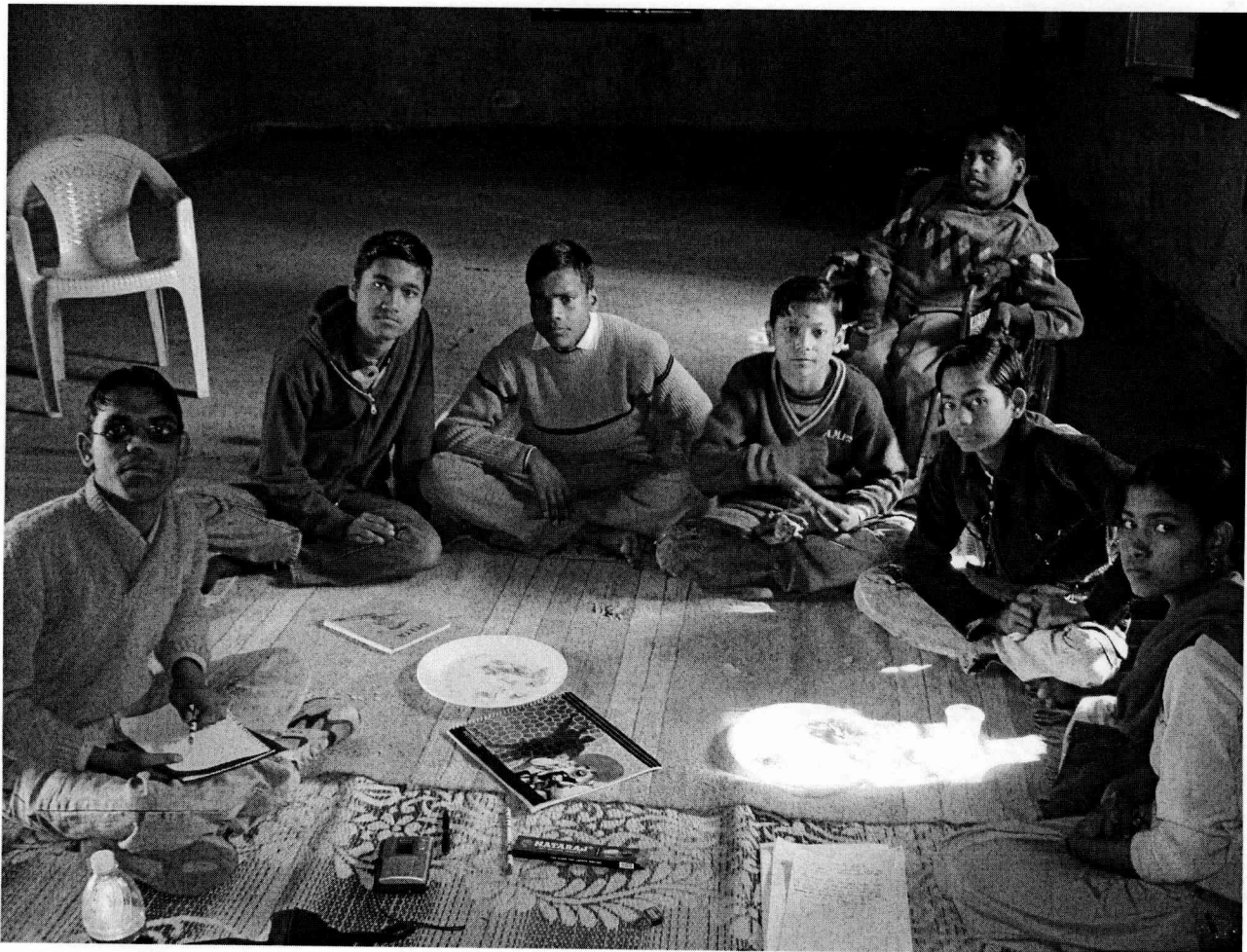
Thanks...

A special thanks to the community-based rehabilitation team in Lal Kuan for their ongoing support in trying new and different ways to engage young persons with and without disabilities in their organizational initiatives.

DOCUMENT #2

ASTHA's Community-Based Rehabilitation Programme in Lal Kuan

Adolescents Comments/Feedback on “ASTHA Plans and Budget 2007 Next Steps Project” Report



Prepared by:

4 Adolescents with Disabilities

3 Adolescents without Disabilities

Facilitated by Sonia Gulati, Volunteer/PhD Candidate

Friday January 12, 2007

Background Information:**Why did adolescents with and without disabilities participate in providing comments & feedback on “ASTHA Plans and Budget 2007 Next Steps Project” report?**

- ASTHA has prepared a document that highlights the organization's core beliefs and activities, and provides an overview of the activities that are to take place within their Community-Based Rehabilitation Programme in Lal Kuan in 2007. The document is 15 pages in length and is titled “ASTHA Plans and Budget 2007 Next Steps Project”.
- To date, all such documents have been prepared *primarily* by staff members with some input from adult community members. Young persons voices are often overlooked in such reports due to the nature and complexity of the documents, time restraints, lack of support, and cultural views that question young persons ability to participate in such activities.
- Adolescents/youth/children with and without disabilities have had minimal involvement in the development of such reports. Thus, adolescents 12 to 18 years of age with and without disabilities had the opportunity this time to thoroughly review this document and voice their opinions/suggestions.
- Community-based rehabilitation requires a thorough understanding of the perceived issues and desires of the target population (in this case adolescents with/without disabilities) in order to invest time/allocate resources appropriately and promote sustainability.

Who was selected for the group discussion?

- A group consisting of 7 adolescents with and without disabilities was formed.
- Adolescents with *and* without disabilities were selected for this discussion in order to promote collaborative work and help create awareness and sensitize young persons to the capabilities and challenges of adolescents with disabilities.

How was the discussion process organized?

- “ASTHA Plans and Budget 2007 Next Steps Project” report was carefully scrutinized by the facilitator. The focus remained on how the plan relates to adolescents 12 to 18 years of age. Thus, notes and questions were made in the margins of the entire plan to promote discussion.
- The group was invited to the centre (Panchyat Ghar, Chungi No. 2, Lal Kuan) to discuss ASTHA's 2007 plan and make suggestions/additions.
- Prior to discussing the 2007 plan, it was critical to determine the group's knowledge base regarding ASTHA's beliefs, missions, and activities. Thus, initially the group was asked basic questions regarding ASTHA and its Community-Based Rehabilitation Programme in Lal Kuan. Once the group provided its responses, the facilitator shared the information outlined in ASTHA's 2007 plan so individuals could see where there were similarities and inconsistencies in their knowledge about ASTHA's work in Lal Kuan.
- The discussion was audio-taped and then transcribed by the facilitator in order to carefully examine the information provided by adolescents.

What types of questions/topics were used to guide the discussion?

1. Explain the rationale for the group discussion. Emphasize that the focus is on how ASTHA's plan for its Community-Based Rehabilitation Programme in Lal Kuan relates to adolescents ages 12 to 18 years. Introduce the idea of providing critical feedback in order to improve organizational initiatives. Emphasize that this specific discussion is for adolescents to educate us *and* for us to also educate young people about ASTHA's activities. Encourage adolescents to stop the facilitator at anytime to make comments or ask questions.
2. A) How do you understand ASTHA's goals/missions/beliefs? What are some of ASTHA's strengths/weaknesses? B) *Share basic information on some of ASTHA's activities.*
3. An important goal of ASTHA's Community-Based Rehabilitation Programme in Lal Kuan is to pass on information to persons with disabilities. What comments do you have about the passing of information to adolescents with disabilities?
4. A) How do you understand what ASTHA has done to date in Lal Kuan? How do you feel the culture has influenced their activities? B) *Share how ASTHA's Community-Based Rehabilitation Programme is going. Share more information from ASTHA's plan.*
5. A) *Explain ASTHA's planning process to develop the 2007 plan for its Community-Based Rehabilitation Programme in Lal Kuan.* B) How were the voices of adolescents reflected in the process?
6. A) What do you feel ASTHA should work on this year (in 2007)? B) *Share areas community members identified as focus areas. Share more information from ASTHA's plan. Share how the activities that adolescents have been doing relate to ASTHA's agenda.*
7. A) What do you think about ASTHA's plan for 2007 in Lal Kuan? B) *Share more information about ASTHA's plan for 2007.*
8. After having heard all this information, what else would you like to see ASTHA do this year, ideally? *Activity:* Individually write down at least two other things you would like to see ASTHA do in 2007. How will the culture inhibit or facilitate what you would like ASTHA to do (e.g., consider community members, the community-based rehabilitation team, family members)?
9. Do you have any other questions or comments?
10. Now that you have a more thorough understanding of ASTHA's Community-Based Rehabilitation Programme, I encourage you all to take the initiative to get involved wherever you feel interested.

The following is an overview of the information provided by adolescents with and without disabilities (12 to 18 years of age) regarding “ASTHA Plans and Budget 2007 Next Steps Project” report. Quotes used directly by participants highlight the perspective of young persons with and without disabilities.

1. Adolescents Understanding of ASTHA's Activities in Lal Kuan

- When questioned about ASTHA's beliefs, adolescents felt that the most significant goal that guides ASTHA's work is to decrease people's tension in the future. Participants believed that ASTHA does whatever is required for adolescents with disabilities to have a brighter future.

“They (ASTHA) hope that they (disabled) don't experience any tensions ahead (in their life).”
-Adolescent with a disability-

“Those who are educated, they get ahead and don't experience any tensions.”
-Adolescent without a disability-

“If [the disabled] get educated and become something, they don't experience any tensions...[if] education goes well...they get educated, [they] can do a job on their own.”
-Adolescent with a disability-

- Adolescents had a fairly good understanding of ASTHA's activities. The group reported ASTHA as a resource to gain information, obtain aids and equipment, make hospital visits, get vocational training and advice, and address issues regarding education/schooling.

“ASTHA works for disabled children. For instance, if there are some disabled children and they have a lot of problems... ASTHA looks after them, what they need. And if someone is completely handicapped, [ASTHA] gives them a wheelchair or something and [the disabled] feel support from that.”
-Adolescent without a disability-

“...if there are mothers and fathers who don't want to get treatment for their children...ASTHA calls people for them, calls teams of doctors for them...[to] do their treatment, and those who require very intensive treatment are admitted into the hospital.”
-Adolescent without a disability-

“...ASTHA works with disabled children - they do some work, take them for outings...”
-Adolescent with a disability-

“[ASTHA] help the disabled...If someone pity's them or calls them names they respond to that.”
-Adolescent without a disability-

“ASTHA staff do dramas with children, games and all.”
-Adolescent with a disability-

Facilitated by Sonia

- The group appeared to understand the concept of research, but had limited/no knowledge about ASTHA's research initiatives in Lal Kuan.

2. Adolescents' Feelings Regarding ASTHA's Involvement in Lal Kuan

- The group had mostly positive things to say about ASTHA's activities and involvement in the community due to ASTHA's ongoing support and assistance in getting disabled people involved in activities.

"I've started liking the organization ASTHA very much."

-Adolescent with a disability-

"ASTHA should continue to do a lot of work with disabled children."

-Adolescent without a disability-

"When we did that play, we worked really hard. All the children worked really hard. And when I went there and did the play and everyone applauded...even I realized that yes I can do something."

-Adolescent with a disability-

"We also want that in 2007 ASTHA doesn't leave, they should do more work with disabled children."

-Adolescent with a disability-

- Participants believed that ASTHA makes a genuine effort to encourage peer interaction of young people with and without disabilities through school and community visits.

"...[ASTHA] tells [non-disabled] children [to] make disabled children your friend, invite them to sit at your home, eat with them, talk to them nicely, if [they are] asking you to do some work - do that work, and make [them] your friend."

-Adolescent without a disability-

3. Adolescents Views on Community Attitudes Towards Disability

- The group reported that generally community members do not really seem to care about disability issues. Disability is not a priority for most of the community given the multiple things they are struggling with (e.g., lack of work; financial difficulties; limited supply of basic needs such as food, water, and adequate housing). Adolescents reported that the general attitude of community members towards the disabled is - "who cares about them, what can the disabled do for us anyways". Adolescents also criticized the community for not listening attentively when persons with disabilities are even performing plays.

"The majority [of people] here [are] those who don't support ASTHA...Because...everyone is only worried about themselves here...that [they] [get] ahead, they can't see others get ahead. 'Why should we help the disabled, what do they do for us, will they give us money, do this, do that' - these sorts of thoughts come into their mind, so they don't want to help."

-Adolescent without a disability-

"[I]n some people's mind there may be something, some may get irritated or jealous and say 'what is this - help the disabled!'. Even if [ASTHA] helps some [people] don't consider it a good thing that disabled children get help..."

-Adolescent without a disability-

"Like there is some disabled person going [and] children [are] playing...the disabled person says let me play - they refuse - 'no you are disabled, you won't be able to play with us' - [the disabled child] gets sad, cries and turns away. No one helps the disabled."

-Adolescent without a disability-

4. Adolescents Feedback Regarding ASTHA's 2007 Plan for their Community-Based Rehabilitation Programme in Lal Kuan

- There was group consensus that none of the participants had been asked anything about the upcoming activities that ASTHA is to carry out in Lal Kuan in 2007.
- Adolescents appeared to understand the development and implementation of ASTHA's 2007 plan in Lal Kuan. They appeared to understand the concept of funding and how such community-based programs are developed, implemented and maintained. The group would like to see ASTHA remain in Lal Kuan and look for alternative avenues for funding. The group was encouraged to think more broadly and be critical in order to improve program initiatives.

Increase Awareness for Community Members

- Participants generally believed that community members still lack awareness regarding the magnitude of ASTHA's activities. The group stressed that ASTHA should present more plays that highlight the organizations' activities and not only issues surrounding specific problems related to disability. Plays should clearly highlight what the organization does ("get your activities to reach people").

"They (ASTHA) don't do [their work] in front of people - they do it behind them, and therefore what is being done isn't being recognized...Like show a play to [the public]. By this [ASTHA's] profile will increase...A lot of people here don't even know about ASTHA. Like if there is some disabled person, [people] just say 'go and see ASTHA'."

-Adolescent without a disability-

"ASTHA should spread its information in the community...Everything that ASTHA does they should make sure it reaches the community so that the community can support them in this"

matter... ASTHA should do plays so that people can become aware of what ASTHA's activities are."

-Adolescent without a disability-

"[ASTHA] should give more information about [itself] so that the community can come forward to help them."

-Adolescent without a disability-

"ASTHA should take funds from the government to help with disability issues, and we all should be aware of ASTHA's services in the community."

-Adolescent with a disability-

"[ASTHA] has to do some program to encourage children who are physically challenged and normal; ASTHA has to tell people about their activities so that people can help them."

-Adolescent without a disability-

Provide Greater Knowledge to Adolescents Regarding ASTHA's Activities

- There was general consensus among the group that they were not fully aware of all the work and social related activities carried out by ASTHA (e.g., film shows, exposure visits, workshops, rallies). Thus, adolescents felt they were unable to make informed choices about where to get involved.

Promote Greater Involvement of Adolescents

- The group generally felt that ASTHA's involvement with adolescents from 12 to 18 years of age appears to be more periodic rather than ongoing (e.g., participants felt that ASTHA tends to keep more ongoing connections with parents rather than adolescents themselves).
- The group voiced interest in getting involved in "greater" exposure visits that require travel out of the city, and performance of further plays in the community that highlight important issues regarding disability.

"[ASTHA] should have exposure visits in different places for more children, and should continue to organize skits/plays regarding disability."

-Adolescent with a disability-

"We liked [doing plays] very much. It has been almost a year since this. We liked it very much. We want that ASTHA does more plays with the children - [and that people] learn something from the plays..."

-Adolescent with a disability-

- The group expressed interest in collaborative work among adolescents with and without disabilities. Participants suggested forming a large youth group consisting of 30 to 35 adolescents in order to work on specific issues with disabled children in an effort to move ASTHA's "curriculum" ahead. Adolescents also suggested developing a group consisting of adolescents with and without disabilities (males and females) to perform a large play on some agreed upon important issue.

"Like ASTHA works for disabled children - like this we want that 30, 35 of us children make a group and also do something for disabled children...and move our "curriculum" ahead."

-Adolescent with disability-

"[W]e want that disabled children and those who are okay (non-disabled), some boys, some girls...make a group and...do some play." - "So people's eyes can open (can become aware). We have only seen one or two of ASTHA's plays." - "To date we haven't done such a play with a big group."

-2 Adolescents without disabilities and 1 adolescent with disability-

Information Sharing

- The group acknowledged that sharing information is a significant aspect of ASTHA's work. Adolescents with disabilities raised some concern regarding receiving incomplete information or just simply not understanding the information provided to them (e.g., independently navigating the process for school admission). Adolescents requested more effective methods to directly pass on information to youth with and without disabilities.

"[ASTHA] doesn't tell us anything. They say nearby there is a tent school, go there and put your name on the list. Mummy told them that they don't write my name there, can you provide us some help, and [ASTHA] doesn't tell us anything."

-Adolescent with a disability-

Education and Vocation

- Adolescents acknowledged and appreciated ASTHA's involvement in promoting education and addressing issues around vocational training, and stressed that ASTHA should continue to spend ample time working on such issues in 2007 (e.g., increase facilities like Umang Centre). Some participants were aware that ASTHA had established the Umang Learning Centre in I-Block, but had some queries around how older children/adolescents could get involved in the centre.

"ASTHA should initiate more educational programs for children."

-Adolescent with a disability-

"ASTHA should open a school [and] start some tuition centres for the disabled so that children can think about future planning regarding employment."

-Adolescent without a disability-

"ASTHA should start some vocational training programs and time to time also organize some plays."

-Adolescent with a disability-

"ASTHA gives training to disabled children...disabled children tell what work they want to do and ...ASTHA thinks that 'yes this child will do this work' [and]...gives training to disabled children."

-Adolescent with a disability-

"We want that ASTHA should do more work for the disabled whose work has been left incomplete - ASTHA should complete that work. Like ASTHA says that we will give disabled children such training so that he can do a job and at least stand on his own two feet... We want that in 2007 ASTHA helps us more with that training, they doing some talking on our behalf."
-Adolescent with a disability-

Aids and Appliances

- Adolescents with disabilities raised concern regarding the ongoing adaptation and maintenance of aids and appliances. The group believed that services should be available/known that would help disabled individuals to maintain and adapt the equipment initially given to them.

"ASTHA should have more scope for providing and maintaining equipment (e.g., shoes)."
-Adolescent with a disability-

Gender Sensitization

- All participants stressed the importance of more work on gender sensitization especially regarding issues specific to girls and women; topics should go beyond education/schooling of girls to providing training and education to parents and community members.

"[ASTHA should provide] more detailed information regarding girls going to school, and increase gender education to families and parents regarding issues related specifically to females being involved in the community."
-Adolescent with a disability-

"ASTHA should place more attention on girls. Because over here girls aren't educated that much... The freedom boys get, girls don't get it... they should educate people."
-Adolescent without a disability-

Coping Mechanisms and Interventions for Youth

- Adolescents reported that this age group experiences increased tension and emotional issues, and requires further support. The group was pleased to hear that ASTHA plans to do further work on coping mechanisms for youth in the community.
- The group emphasized more frequent treatment for young persons with disabilities in order to maximize the benefits. Adolescents believed that parents/adults require further education regarding earlier treatment and services for their children with disabilities, with the goal of prevention and health promotion in mind.

"ASTHA should do treatments for disabled every week so that they can have some benefit."
-Adolescent without a disability-

"...and there should be a meeting with mothers and fathers...[about] how does the[ir] child feel, what does he think inside..."
-Adolescent without a disability-

Security and Safety of Young Persons with Disabilities

- Although ASTHA does not appear to have any goals/activities planned regarding the security and safety of young disabled persons, the group felt that some initiative should be in place to protect disabled children.

“ASTHA should protect disabled children.”

-Adolescent without a disability-

5. Sustainability and Taking Ownership/Responsibility for Getting Involved

- Adolescents had limited understanding of the concept of sustainability and taking ownership/responsibility to participate in ASTHA's activities. Adolescents tended to focus on what ASTHA should do for them rather than what they could do for themselves with minimal assistance from ASTHA or what they could do collaboratively with ASTHA (e.g., adolescents appeared to have little understanding of taking more control over activities such as obtaining disability certificates or admission in schools; activities that ASTHA has been working on for many years now.). The facilitator encouraged young persons to take ownership and responsibility within ASTHA's community initiatives, but also acknowledged that ASTHA must support and educate young persons in this endeavour.

“Like [ASTHA] refused that we won't get it (disability certificate) made, you get it made because it is your work... We said that you help disabled children so much - you take them for outings, you educate them, give them advice - you do all this, so why not just get them a disability certificate, it will be good for the disabled, to make a pass for a stranger. When ASTHA doesn't make it, these people (in the community) think that ASTHA is so useless.”

-Adolescent with a disability-

Additional Comments/Observations:

- The group appreciated having the opportunity to provide feedback regarding ASTHA's upcoming activities in Lal Kuan in the year 2007.
- Participants were aware that this document would be shared with the community-based rehabilitation team in Lal Kuan and the director of ASTHA, Sudha Vohra.
- There was group consensus to take photographs and also provide the names of all individuals who participated in this group and in the development of this document. Although photographs are included, no names are listed in the document.
- The facilitator encouraged young persons to take ownership and responsibility within ASTHA's community initiatives, but also acknowledges that ASTHA must support and educate young persons in this endeavour.
- The development of such documents highlights the value of young persons voices in the activities carried out in Lal Kuan.

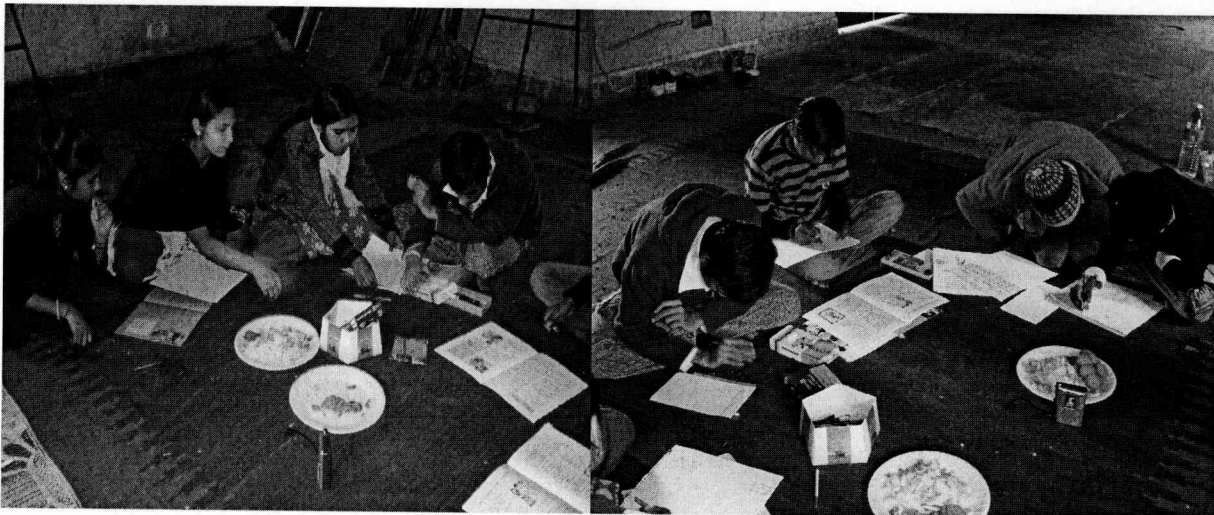
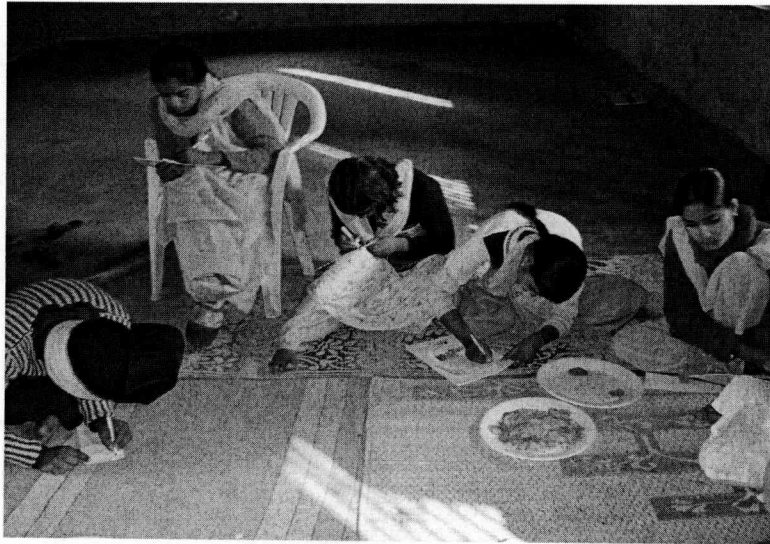
Thanks...

A special thanks to the community-based rehabilitation team in Lal Kuan for their ongoing support in trying new and different ways to engage young persons with and without disabilities in their organizational initiatives.

DOCUMENT #3

ASTHA's Community-Based Rehabilitation Programme in Lal Kuan

Adolescents Designed a Page for ASTHA's Annual Report



Contributors:

*21 Adolescents with Disabilities & 11 Adolescents without Disabilities
Facilitated by Sonia Gulati, Volunteer/PhD Candidate*

Wednesday January 24, 2007

Sunday February 11, 2007

Background Information:**Why did adolescents with and without disabilities participate in designing a page for ASTHA's Annual Report?**

- To date, adolescents with and without disabilities have not had the opportunity to design a page that would be published in ASTHA's Annual Report.

Who was selected for the group discussion?

- Two groups consisting of adolescents with and without disabilities were formed so that as many adolescents as possible could have the opportunity to work on this document.
- The first group consisted of 11 adolescents with and without disabilities and the second group consisted of 7 adolescents with and without disabilities.
- Adolescents with *and* without disabilities were selected for this discussion in order to promote collaborative work and help create awareness and sensitize young persons to the capabilities and challenges of adolescents with disabilities.

How was the discussion process organized?

- Two groups consisting of adolescents with and without disabilities were separately invited to the centre (Panchyat Ghar, Chungi No. 2, Lal Kuan) to work on designing a page for ASTHA's Annual Report.
- The first group worked together as one large group on the layout of the page (i.e., large chart paper posted on a wall was used). All participants independently had the opportunity to write down any issues/topics that they felt should be covered on the page.
- The second group worked in small groups to suggest ideas for how to design the page. Participants suggested specific quotes that should be used. One participant made a drawing that may be included on the page. All participants independently had the opportunity to write down any issues/topics that they felt should be covered on the page.

Adolescents suggested that the following items/topics should be included on the page:

- Photographs that show adolescents working together in groups (no individual photographs of participants).
- One drawing regarding disability completed by either an adolescent with or without disability.
- A few quotes made directly by adolescents.
- A few questions that encourage others to think about the unique issues of adolescents with disabilities and why their voices are often overlooked.
- Focus on people's attitudes (i.e., "thinking") towards persons with disabilities.
- Both groups agreed that the facilitator should write the introduction and purpose of the activities that the adolescents have been participating in.

Additional Comments/Observations:

- The group appreciated having the opportunity to design a page for ASTHA's Annual Report.
- Participants were aware that this document would be shared with the community-based rehabilitation team in Lal Kuan and the director of ASTHA, Sudha Vohra.
- There was group consensus to somehow acknowledge all the adolescents who participated in the activities/study (e.g., by the number of individuals who participated).
- The inclusion of young persons in the design of such documents highlights the importance of the perspective and voices of adolescents in Lal Kuan.

Thanks...

A special thanks to the community-based rehabilitation team in Lal Kuan for their ongoing support in trying new and different ways to engage young persons with and without disabilities in their organizational initiatives.

ASTHA's

Community-Based Rehabilitation Programme in Lal Kuan

The Voices of Adolescents with & without Disabilities...

Contributors:

21 Adolescents with Disabilities

11 Adolescents without Disabilities

Facilitated by Sonia Gulati, Volunteer/PhD Candidate

Purpose of activities:

- To emphasize the importance of giving a voice to adolescents (12 to 18 years of age) with disabilities in the activities and services directed towards them.
- To increase awareness of the perceived challenges of adolescents with disabilities and how such issues are embedded within/influenced by the socio-cultural environment (e.g., how the culture inhibits or provides few/no opportunities for disabled adolescents to voice their issues and participate adequately/thoroughly in organizational initiatives).
- To increase the involvement of young persons with/without disabilities at an organizational level within ASTHA's Community-Based Rehabilitation Programme in Lal Kuan.
- Young persons with disabilities may struggle in articulating their perceived rehabilitation problems as a result of their cultural background, age, disability and/or lack of opportunity. Thus, multiple activities should be used to help young persons with/without disabilities share their ideas comfortably.
- To present techniques that respect the culture, challenge negative attitudes, create awareness, but also influence change in the environment.
- Adolescents with *and* without disabilities participated in all activities in order to: 1) help raise awareness regarding disability among peers, 2) promote collaborative work, and 3) decrease the division present between the two groups.
- * Community-based rehabilitation requires a thorough understanding of the perceived challenges of the target population in order to invest time/allocate resources appropriately and promote sustainability.

All activities are linked with ASTHA's community-based rehabilitation activities. Activities took place from January 2005 to May 2005 and October 2006 to March 2007.

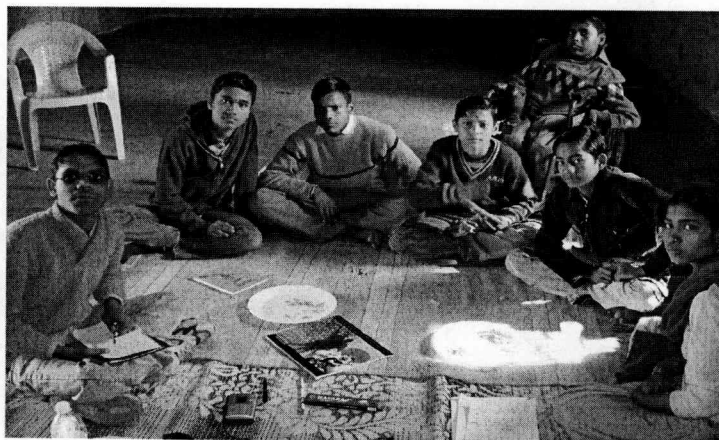
"It's not like God will come down to change something...you will have to change it."

-Adolescent with disability-



Overview of topics discussed/covered:

- Definition/understanding of disability
- Rehabilitation problems/challenges of adolescents with disabilities
- Concept of culture (i.e., general culture; adolescent culture) & how the culture contributes to the rehabilitation problems
- A typical day
- Roles and responsibilities
- Gender specific issues in adolescents
- Social participation/interactions/friendships
- Future goals/plans
- Community involvement/participation
- Current interventions/supports for adolescents with disabilities
- Understanding of ASTHA'S Community-Based Rehabilitation Programme



Overview of activities individuals participated in:

- Informal/casual interactions
- Individual and group discussions
- Observation sessions
- Visual and written activities (e.g., participatory development techniques such as impact drawings on disability; force field analysis regarding future plans; fishes and boulders (adapted) regarding small/medium/big problems and possible facilitators to overcome barriers/problems; overview of a typical day; list of problems of disabled/non-disabled adolescents)
- Journal entries
- Demographical information
- Review of files/documents

-Disability Drawing by an Adolescent without a Disability-



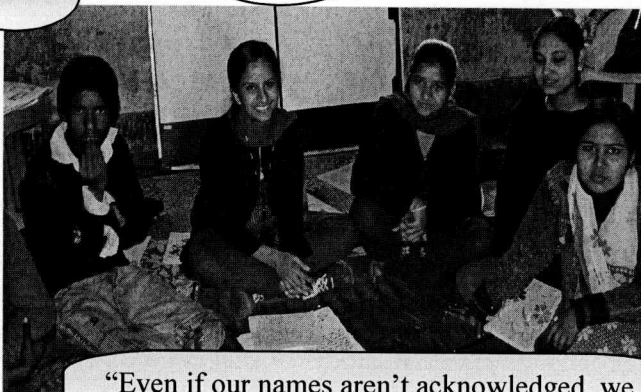
“...People shouldn’t differentiate between one who is disabled and one who is not because we all are one and our lives are the same, only our thinking is a little different. People [should] get all the happiness so they don’t realize that they are disabled.”

-Adolescent with disability-



“Disability is not a curse. Disabled people are not being given the kind of respect that a normal human being gets. In today’s time, people still call them disabled and frustrate them. Disabled people have all the rights only on paper, but in reality this is not the case.”

-Adolescent without disability-



“Even if our names aren’t acknowledged, we still know all the work we did!”

-Adolescent without disability-

Development of 3 Documents:

The volunteer facilitated the development of three documents that highlight the perspective, voices, and capabilities of adolescents with and without disabilities; all documents have been submitted to ASTHA’s main centre and Community-Based Rehabilitation Programme in Lal Kuan.

1. Report/Documentation on Disability Day (“Viklang Devus”) Programme/Celebration in Lal Kuan on December 1, 2006

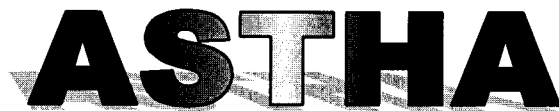
Prepared by: 6 Adolescents with Disabilities

2. Adolescents Comments/Feedback on “ASTHA Plans and Budget 2007 Next Steps Project” Report
Prepared by: 4 Adolescents with Disabilities & 3 Adolescents without Disabilities

3. The Voices of Adolescents with & without Disabilities...(Page Designed for ASTHA’s Annual Report)

Contributors: 21 Adolescents with Disabilities & 11 Adolescents without Disabilities

A special thanks to the Community-Based Rehabilitation team in Lal Kuan for their ongoing support in trying new and different ways to engage young persons with and without disabilities in their organizational initiatives.



(ALTERNATIVE STRATEGIES FOR THE HANDICAPPED)

COMMUNITY-BASED REHABILITATION (CBR) PROGRAMME IN LAL KUAN

Project On:

“THE VOICES OF ADOLESCENTS WITH AND WITHOUT DISABILITIES...”

Activities Facilitated By:

Sonia Gulati, BScOT, PhD Candidate - Volunteer -

Documents Attached

Note: The following documents include the voices of adolescents living in the urban slums in Lal Kuan, New Delhi, India. Adolescents selected for the project were either affiliated with ASTHA's Community-Based Rehabilitation Programme or they were simply recommended by ASTHA. As these were new activities for the adolescents, I helped to facilitate the process. Each document includes a summary at the beginning to explain why the adolescents participated in the development of the document.

1. Report/Documentation on Disability Day (“Viklang Devus”) Programme/Celebration in Lal Kuan on December 1, 2006

Prepared by:

6 Adolescents with Disabilities

Facilitated by Sonia, Volunteer/PhD Candidate

2. Adolescents Comments/Feedback on “ASTHA Plans and Budget 2007 Next Steps Project” Report

Prepared by:

4 Adolescents with Disabilities

3 Adolescents without Disabilities

Facilitated by Sonia, Volunteer/PhD Candidate

3. The Voices of Adolescents with and without Disabilities...
(Page Designed for ASTHA's Annual Report)

Contributors:

21 Adolescents with Disabilities

11 Adolescents without Disabilities

Facilitated by Sonia, Volunteer/PhD Candidate

List of Individuals Who Participated in Activities

[illegible]

Background Information

☐ A team approach where I helped as a facilitator...

- To emphasize the importance of giving a voice to adolescents (12 to 18 years of age) with disabilities, particularly in the activities and services that are targeted towards them.
- To raise awareness of the capabilities of adolescents with and without disabilities.
- To increase the involvement of young persons with and without disabilities at an organizational level within ASTHA's Community-Based Rehabilitation Programme in Lal Kuan (For example, adolescents should have opportunities and support to work on documentation/reports, provide feedback on plans developed, participate in annual reports, and other tasks).
- * All activities are linked with ASTHA's goals/mission; they are not independent of ASTHA's community-based rehabilitation programme. Activities took place from January 2005 to May 2005 and October 2006 to March 2007. My aim was to help ASTHA in this one area given the high volume of work that is required in a community setting.
- * Adolescents with *and* without disabilities participated in all activities in order to: 1) help raise awareness regarding disability among peers, 2) promote collaborative work, and 3) decrease the division present between the two groups.

☐ Literature on Indian culture and adolescence suggests the following:

- Since children grow up with a natural dependency on the family, independence during adolescence is met with hostility.
- Adolescents have little control over decision-making.
- Adolescents with disability are at a *double* disadvantage, as they have a limited peer support network to which they can voice their concerns.
- Studies on community-based rehabilitation have investigated and served adolescents with disabilities from the adult perspective (e.g., caregivers, community workers, and professionals).
- There is a lack of information on the unique/perceived rehabilitation challenges (e.g., self-care; productivity; leisure; social; sexual; mental health) of disabled adolescents.
- Considering the issues mentioned above, it is obvious that many young persons with disabilities would struggle in articulating their perceived rehabilitation problems as a result of their cultural background, age, disability and/or lack of opportunity.
- * Community-based rehabilitation requires a thorough understanding of the perceived challenges of the target population in order to invest time/allocate resources appropriately and promote sustainability.

☐ Overview of topics discussed/covered:

- Definition/understanding of disability

- Rehabilitation problems/challenges of adolescents with disabilities
- Concept of culture (i.e., general culture; adolescent culture) & how the culture contributes to the rehabilitation problems
- A typical day
- Roles and responsibilities
- Gender specific issues in adolescents
- Social participation/interactions/friendships
- Future goals/plans
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- Current interventions/supports for adolescents with disabilities
- Understanding of ASTHA'S Community-Based Rehabilitation Programme

☐ Overview of activities individuals participated in:

- Informal/casual interactions
- Individual discussions
- Group discussions
- Observation sessions
- Visual and written activities (Some examples of participatory development techniques include: impact drawings on disability; force field analysis regarding future plans; fishes and boulders (adapted) regarding small/medium/big problems and possible facilitators to overcome barriers/problems; overview of a typical day; list of problems of disabled/non-disabled adolescents)
- Journal entries
- Demographical information
- Review of files/documents

☐ Purpose of activities:

- To increase awareness of the perceived challenges of adolescents with disabilities, and how such issues are embedded within/influenced by the socio-cultural environment (e.g., how the culture inhibits or provides few/no opportunities for disabled adolescents (12 to 18 years of age) to voice their own issues and participate adequately/thoroughly in organizational initiatives).
- To share techniques that respect the culture, challenge negative attitudes, create awareness, but also influence change in the environment.

☐ Two major dissemination presentations were held:

- 1) With community-based rehabilitation team members in Lal Kuan (10 individuals attended), and 2) With adolescents with/without disabilities and their parent(s) (~ 40 individuals attended).
- Presentations highlighted the capabilities of young persons with disabilities (that is, they are able to share ideas adequately if given the right opportunity), the culture, and the use of multiple activities to help young persons with/without disabilities provide information and share their ideas comfortably.

Thank You

I would like to take this opportunity to thank you all for welcoming me into your organization. I was able to see firsthand the many wonderful activities ASTHA has been doing across its multiple projects. I sincerely hope that the information shared here and the activities I facilitated with your support will continue to influence change(s) in how young persons with and without disabilities participate in your organizational initiatives.

A special thanks to Radhika Alkazi, Ranjan Koul, Sudha Vohra, Krishna Das, Sanyam Maratha, and all the community-based rehabilitation team members and adolescents in Lal Kuan who participated in the activities and so warmly welcomed me into their lives...you will truly be missed. Wishing you all the best in your future endeavours.

Sincerely,
Sonia Gulati
E-mail: sonia_ot@hotmail.com

Acknowledgements

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International Development Research Centre, Ottawa, Canada.
Information on the Centre is available on the web at www.idrc.ca.*

Canadian Occupational Therapy Foundation (COTF)

Queen's University