

For background details about Hariksha and their current projects, please refer to the site visit report by Bhaskar Venkateswaran. ([http://www.ashanet.org/projects-new/documents/973/Site\\_visit.doc](http://www.ashanet.org/projects-new/documents/973/Site_visit.doc))

### **Introduction:**

Asha Irvine and Asha Seattle have funded this project since November 2008. The Hariksha learning center for children with cerebral palsy and mental retardation has been functional since December 4, 2008. The project partner, Mr. Ravi, has been very thorough in sending out monthly progress reports on time. However, as the project steward, I wanted to get a first-hand evaluation of the progress of this project. I arranged a site visit through the project partner, Mr. Ravi, for the 18<sup>th</sup> of August, 2009.

Bhaskar Venkateswaran, an Asha Chennai volunteer, did a site visit report for this project in April 2008. As part of his evaluation process, Bhaskar met eight children, who were affected by cerebral palsy and/or mental retardation. All of these eight children are currently attending the learning center. I requested Bhaskar Venkateswaran to join me in my site visit since I felt Bhaskar would be able to do a 'before' versus 'after' comparison of these children.

At about 7AM on 18<sup>th</sup> August, Bhaskar and I started driving to Avalurpet from Chennai. We picked up Ms. Elka Sinha, a short film maker, from Adayar. The project partner, Mr. Ravi, had requested Ms. Elka Sinha to create a short film about cerebral palsy and mental retardation in order to create awareness amongst the community. Elka's goal during this trip was to obtain ideas for the script of this short film by visiting and interacting with these special children.

Avalurpet is a village situated around 18 kilometers from Tiruvannamalai and 187 kilometers from Chennai. It takes about ~4 hours to drive from Chennai. We stopped for breakfast at around 9AM and continued driving to Avalurpet. We reached Avalurpet at around 11:30AM. The project partner, Mr. Ravi, met us on the main road and started directing us to the learning center.

As soon as we entered the learning center, a group of children welcomed us with a small bouquet. Many of the children tried to introduce themselves; some of them had difficulties in saying their names. I will start by describing the infrastructure of the learning center.

### **The Building:**

The learning center is a rented house that has an area of about 1400 square feet. There is a large open area in the center of the house that is partially covered with the help of few metal ropes. The house has a relatively large empty space on the backside that is about 900 square feet in size. In addition, I saw a small kitchen, an office room, a well and a couple of bathrooms in the back yard.

## **The Staff:**

We met the following staff during our site visit to Hariksha:

P. Ravi is the project partner. He has been working in the field of ortho equipments for about 11 years now. He is currently spending 100% of his time in the learning center. Throughout my interactions with Ravi, he has always been very motivated and dedicated towards sustaining this learning center. This was clearly visible during our site visit. Most children, if not all of them, had a very good relationship with Ravi. He and his wife, Sujatha, have been the primary driving force behind establishing and sustaining this learning center.

Sujatha, Ravi's wife, is the special educator for Hariksha. She has a degree in special education called "Multi-purpose Rehabilitation Technician for CP/MR children" from RDI (Rehabilitation of the Disabled in India), Pondicherry. She was part of a small team that did a survey in 2005 on behalf of SSA to visit and collect details about all CP/MR children in Melmalayanoor block. It is during this visit, that she realized the need for a learning center for children with cerebral palsy and mental retardation in this area.

Sujatha primarily deals with mentally retarded children. She seemed very meticulous in carefully documenting the progress of the children. For each child, she has dedicated a separate notebook, which contains all the information such as the goals and objectives for the child, the child's progress toward achieving these goals and his/her daily activities. Since she has the appropriate background in special education, she has been using varied assessment tools for gauging the progress of these children.

Kanchana is the physio-therapist. She has been with Hariksha only since the last three months. Initially, Ravi had difficulties finding a physiotherapist; he had hired someone but they discontinued due to the challenging nature of the work. Kanchana is currently commuting for more than three hours each way in order to coach these special children. She is considering moving to Avalurpet and living in a temporary housing in order to eliminate the long commuting.

Kanchana was very patient in answering all my questions regarding the various facets of cerebral palsy. She had detailed notes about the progress of the children. Kanchana primarily deals with children who have cerebral palsy and who are in need of therapy.

Chithra is the care giver and Kumari is the cook. I did not get an opportunity to talk to them in detail.

Kamatchi and Shanthi are the care takers. Both of them seemed very dedicated. They were constantly working when we were there. One of the children had an involuntary bowel movement, as he was not potty-trained. The caretakers took him out and washed him.

## **Transportation:**

I realized the importance of transportation only after seeing the Avalurpet area. Even though this area has decent route bus facilities, it would be highly impractical for the parents to drop their children off on a daily basis. Hariksha currently uses a rental van that covers a total of almost 140 kilometers per day. This includes about 10kms within the town and the remaining distance outside the town. The make and the model of the van that Hariksha uses is TATA Magic with a 7 + 1 seating capacity.

The van makes two trips; one for covering the areas within the Avalurpet town and the other for areas outside the town. This van leaves at 6:45AM and picks up the first student at 7:15AM and reaches the learning center at 9:45AM after picking up various children along the route. As a result, the first student to be picked up almost spends two and a half hours each way traveling in the van. In the evening, the van leaves the learning center at about 3:30PM.

Various villages that are covered in the van's route include: Thazanur, Melmalayanur, Chekkadikuppam, Maniyandhapattu, Nochalur, Sindhipattu, Kaplambadi, Thazangunam, Melvailamur, Edhapattu, Parayampattu, Kundhalampattu, and vadugupoondi. Even though this current configuration works efficiently for picking up children within the Avalurpet area, it is extremely inefficient for children coming from outside the town.

Currently, Hariksha does not require any fees from the parents in order for their children to use the van. However, they encourage parents to donate towards this cause, either in the form of money or fuel, when affordable. Typical donations received include Rs. 250 to Rs.300.

## **The children:**

Hariksha currently has about 30 enrolled children. However, the average attendance during the month hovers between 20 and 25. This is primarily because some children become ill either due to common causes such as cold and fever, or due to medical problems that are more long-term in nature.

We met two groups of children during our site visit. These groups included children who are in need of physical therapy and children who need special education. These two groups are accommodated in different areas of the house. There were about equal number of children in both these groups.

Admittedly, children who are in need of physical therapy are in a more desperate situation. A good number of these children are in a bed-ridden state. Other children in this group were either seated in chairs or in a corner seat. These children were generally not in a position to talk to us. However, they were generally very responsive. They seemed to understand and follow the instructions provided by the physiotherapist.

On the other hand, children who are in need of special education were able to interact with us, better than the other group of children. Generally, most children in this group either did not need physical therapy or they had already been through the physical therapy group. Normal progression for a CP/MR child entering the Hariksha learning center includes going through the physical therapy group first, followed by going through the special education group.

Current statistics include the following:

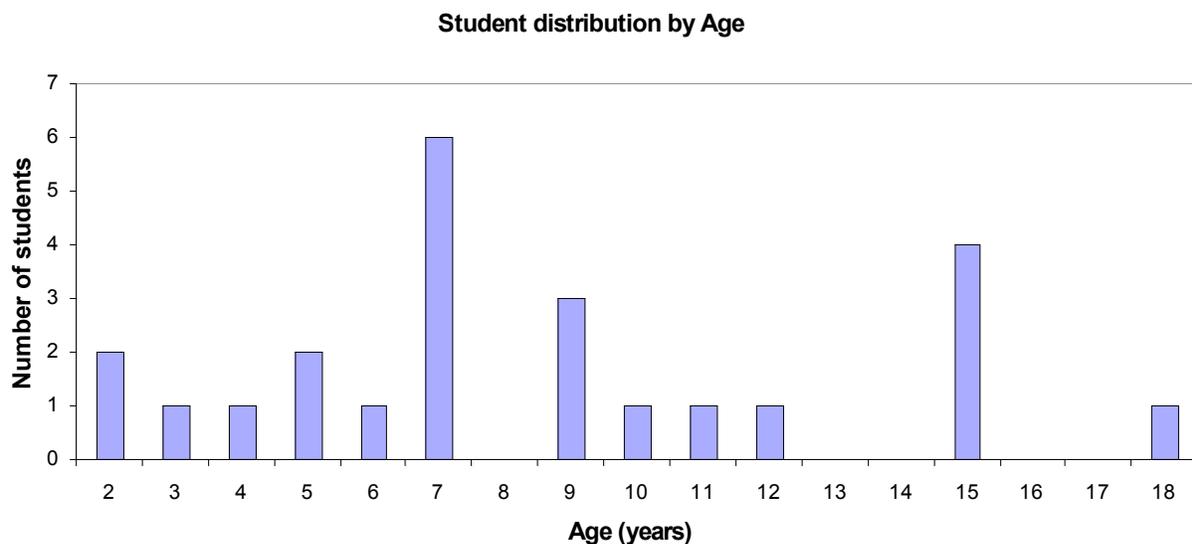
Total students enrolled: 30

Male: 17

Female: 13

Children who need therapy: 15

Children who need special education: 15



The student distribution by age shows a fairly consistent spread among ages.

### **The Assessment process:**

Each child who is admitted to the Hariksha learning center goes through a formal assessment process. This assessment is based on an elaborate standard developed by the Madras Developmental Programming System (MDPS), to assess the level of disability of the children. Parents are typically present during the assessment process. Various children activities that are used in the assessment process include:

- Gross Motor Activities
- Fine Motor Activities
- Meal Time Activities
- Dressing
- Grooming
- Toileting
- Receptive Language
- Expressive Language
- Social Interaction
- Reading
- Writing
- Number
- Time
- Money
- Domestic Activities
- Community Orientation
- Recreation Leisure Time
- Vocational Activities

In addition, the child is also assessed based on his/her need for physical therapy. At the end of the assessment process, the short term and the long-term goals are determined. Current goals for the thirty children can be found at the following link:

[http://www.ashanet.org/projects-new/documents/973/Hariksha\\_Children\\_Goals.xls](http://www.ashanet.org/projects-new/documents/973/Hariksha_Children_Goals.xls)

### **Our day at Hariksha:**

I have to admit that my interaction with CP/MR children has been very minimal, prior to this site visit. So, I was initially a little overwhelmed; however, Bhaskar readily started interacting with the children. He started engaging the children in a few games.

My goal was to understand, visualize and verify the progress of the children. I started with the group of children who needed physical therapy. Kanchana, the physiotherapist, briefly explained the medical reasons for the occurrence of cerebral palsy. I started asking her about the progress of the various children. In response, she gave me a copy of her notes, which included the assessment records and the current progress of various children.

We met each child while simultaneously going through her notes of each child, as she explained the progress of the child from before till present. She also shared with me, the feedback from the child's parents and how their parents currently treat the children. This helped me in visualizing the complete picture and I began to appreciate the progress made by these children.

Various tools and equipments used for physical therapy training include: stimulator, physio-ball, physio-mat, corner chair and the standing frame. About 5-6 children in this

group were in a bed-ridden state. Due to the continued laying on their heads, these children had certain spots in their heads, which lacked hair growth. Physiotherapy training enables some of these children to change their laying posture. We were able to notice that fresh hair had started growing in these selected spots as a result of the physiotherapy training.

I noticed some children sitting in a corner seat, which is typically used once the child gains some mobility in the bed-ridden state. The corner seat is expected to improve the sitting posture of these children. I saw a few children using the standing frame, which is used as the next step after the child completes the corner seat training. I saw a few other children sitting in chairs. One of the children, Poovarasam, suddenly fell down from the chair, but fortunately was not injured.

Some of these children suffer from their inability to control salivating. Simple treatments for such issues include providing sweets to these children, which results in these children attempting to pull in the sweet taste and thereby reducing involuntary salivation.

Examples of other forms of treatment in the physical therapy group include simple passive stretching with the help of the physiotherapist, guided passive movement of limbs, and stimulation of muscles.

It took me over two hours to go through the records of about 15 children in this group, while simultaneously meeting them and understanding their background. It was clear that these children have made significant progress and Ravi later told me that 60% (on an average) of the short-term goals for this group of children has been achieved at the end of first quarter evaluation.

Reading the last site visit report by Bhaskar Venkateswaran in April 2008, I was particularly interested in monitoring the progress of brothers, Gowtham and Lokeswaran, as they were in a pitiable state before. In his site visit report, Bhaskar described their condition, as *“Gowtham was lying outside on the porch, completely naked, on a dirty sari with flies buzzing around him. Lokeswaran was lying inside in a similar state. We weren't quite sure if Gowtham had been fed or not. Lokeswaran is in a worse state; he cannot speak or respond. His limbs are loose and his eyes unfocused. The mother who was working close by, came over shortly, and hurriedly dressed the children. She told us she had taken the children to doctors at 1½ and they were diagnosed of Cerebral Palsy. The doctors had not given any medication however, and taught the parents a few exercises to administer. The parents did the exercises for sometime, but gave up later on. She demonstrated a few when Ravi asked her to. The children are in a pitiable state, lying stark naked in the heat, in very unhygienic conditions.”*

However, once the learning center started functioning, the brothers, Gowtham and Lokeswaran, have made significant progress. Physiotherapy has enabled them to gain more mobility and they have started using the corner seat in an effort to improve their sitting posture. They have improved neck and hip control, and improved upper limb actions in reaching overhead, grasping and releasing activities. Pleased with the progress

made by Gowtham and Lokeswaran, their parents have started showing more interest in their children. This is just one of the examples of improvements made by the children in this group.

In the meantime, the children started having lunch. While children in the special education group can typically eat without help, children in the physiotherapy group needed to be fed by the caretakers. Since there were only two caretakers, some of these children had to wait for their turn to have lunch. The two caretakers were busy, constantly helping out the kids and it was clear that Hariksha could benefit from having a third caretaker.

Having understood the progress made by children in the physiotherapy group, I wanted to understand the progress made by children in the special education group. I started talking to Sujatha, the special educator. I wanted to go through the records for each child, while simultaneously meeting them and understanding their progress.

Sujatha has been very meticulous; she has been documenting the assessment report for each child and the progress made by the children on a daily basis. She told me that she and the other staff spend at least a few hours daily to document the activities of these children. This was obvious looking at the number and the size of the records. It seemed impractical to go through the records of all children in detail since we only had limited time. She walked me through the record of one child, in detail. Ravi told me that 75% (on an average) of the short-term goals for this group of children has been achieved at the end of first quarter evaluation.

Ravi also gave me a document that contained the feedback from the parents. There were hand-written notes from parents on how their children have improved since the learning center started functioning. When we finished discussing the progress of the children in the special education group, it was already 3:30 in the evening. While Bhaskar, Elka and I started having lunch, Ravi and Sujatha discussed all the financial documents with us. As expected, receipts for all transactions that happened using Asha funds have been retained and documented. We also went over the audited financial report for the year 2008 – 2009. Hariksha has also maintained a donation book, where they document all the donations. Their local donations typically include sponsoring of lunch, or providing a few hundred rupees or the fuel equivalent to cover the rental van running costs.

After lunch, Ravi gifted us with artwork that was prepared by Kalaiselvi, Shahul Hameed and other children in the special education group. Following this, Elka discussed her ideas on the script for the short awareness film with Ravi. In the meantime, the children started leaving in the rental van. The caretakers also accompany the children during the entire trip.

### **Interest from the local community:**

There seems to be a positive perception of Hariksha in the local village community of Avalurpet and the surrounding villages. This is apparent from the large number of

requests to admit new students to the learning center. Currently, there are about 16 children waiting to be admitted into the Hariksha learning center.

**Immediate challenges:**

1. Originally, when Hariksha had submitted the request for funding to Asha, there was a salary allocated for a coordinator. However, given the difficulties finding a qualified coordinator, Ravi was forced to fill the position himself. Unfortunately, this meant that he couldn't use the salary allocated for the coordinator to pay himself, as he is one of the board members of the Hariksha trust, which is ultimately benefiting from the Asha funds. Indian government's tax laws preclude the use of Asha funds for the benefit of the board members, as this is a conflict of interest. A good portion of Ravi's salary last year came from a personal donor in India, thereby excluding the use of Asha funds for this purpose and the need to route funds through the FCRA permit. This is an outstanding problem and this problem needs to be resolved during the next year's funding cycle. I am afraid that if we don't resolve this issue soon, his motivation and dedication levels may be reduced in the long run, as he also has a family with two children to support. Some of the possible solutions include starting a new Asha project in order to pay his salary. This does not create a conflict of interest as Hariksha trust will not be the beneficiary of this potential project and Ravi, as an individual, will be the beneficiary.
2. Hariksha currently has a one-time FCRA, which enabled them to receive the funds that they requested for the first year, from Asha. Recently, they applied for a permanent FCRA permission, but got rejected by the Government of India, for reasons that are not clear to us. Ravi told me during our site visit that he would be applying for another one-time FCRA permission in order for Hariksha to receive funds during their second year of operation. He would also be applying for a permanent FCRA permission again. This would enable them to receive unlimited funds from foreign sources such as Asha. Obtaining one-time FCRA permission takes a minimum of 90 days and requires a commitment letter from the sponsoring Asha chapter (Irvine, in this case).
3. Hariksha has been constantly faced with prolonged absences of some of the children. In spite of advice and financial help from Hariksha, some parents don't provide appropriate care to their children and take them to alternative medicinal practitioners. In extreme cases, such lack of awareness amongst parents has resulted in the death of two children, Priya and Arun Kumar. Especially, when Arun Kumar fell ill because of a fever in the middle of the night, his parents took him to a local priest, whereas Ravi had specifically asked them to take the child to a pediatric physician. Also, Priya's death was unfortunate and happened due to lack of appropriate care and awareness. Moreover, this happened before the learning center even started functioning in December 2008.

4. Hariksha's ability to admit new children depends primarily on the fact that whether these new children would be picked up by the rental van without significantly deviating from the current route. Moreover, it does not make sense to go with the rental option on a long-term basis. Rather, it will be more economical to purchase a van after a few years, than to rent. However, since this project is new, it may be difficult for Hariksha to obtain the necessary funding approval for buying a van.

### **Long-term challenges:**

1. Hariksha currently uses a rental building as the location for the learning center. Hariksha is paying a rent of Rs. 2000 per month for this building. The owner of this house lives nearby and we had a chance to talk to her towards the end of the day. Bhaskar thanked her for letting Hariksha use this building as the learning center. However, she sounded a little negative in her responses and it seemed like she was not ready to rent this place to Hariksha on a long-term basis. Ravi has been talking to me about constructing a new building for the learning center and the possibility of Asha funding this. I explained to him that it may be difficult to obtain funding for such capital expenses especially when the project is less than three years old.
2. Since the children in the learning center have varying degrees of disabilities and IQ levels, they may need different training times at the learning center before they can successfully 'graduate' from the learning center. Especially, children affected with severe cerebral palsy and mental retardation typically require life-long care and supervision and are often confined to institutions. At this point in time, it is unclear as to how Hariksha is planning to deal with such children.

### **Risk mitigation:**

Recognizing some of these challenges, Hariksha has already taken a few steps in order to mitigate some of the risks associated with this project. Meetings with parents are conducted on a regular basis. Ravi and Sujatha have been instrumental in driving the formation of a parents self help group, KALKI, where parents donate a certain amount of money every month towards the improvement of their children. Ravi has also been working with Elka, the short filmmaker, in order to raise awareness about cerebral palsy and mental retardation amongst the local community.

### **Summary:**

Overall, I was pleased with what I saw and Bhaskar shared similar feelings as well. It seems that the project partner, Ravi, has delivered on most of his commitments with minimal use of resources. The staff, ranging from Ravi all the way to the cook, shows great dedication as they work for substandard salaries in rural conditions, while serving the most disadvantaged children in this society. Infact, it is Ravi and Sujatha's vision and leadership that needs to be appreciated in this regard.



**Figure 1: Front view of the Hariksha learning center for children with cerebral palsy and mental retardation**



**Figure 2: Central open area of the learning center. Two groups of children are accommodated in two different areas of the house separated in the middle by this open area.**



**Figure 3: Back side of the learning center**



**Figure 4: Well in the backyard of the learning center**



**Figure 5: Bathrooms in the backyard**



**Figure 6: Area where children who need physiotherapy are seated**



**Figure 7: Picture showing some of the physiotherapy equipment**



**Figure 8: Picture of the standing frame**



**Figure 9: Picture showing some of the special education related materials**



**Figure 10: Picture showing the kitchen in the learning center**

