... in Rural India - Tirunelveli ... ict of Tamil Nadu

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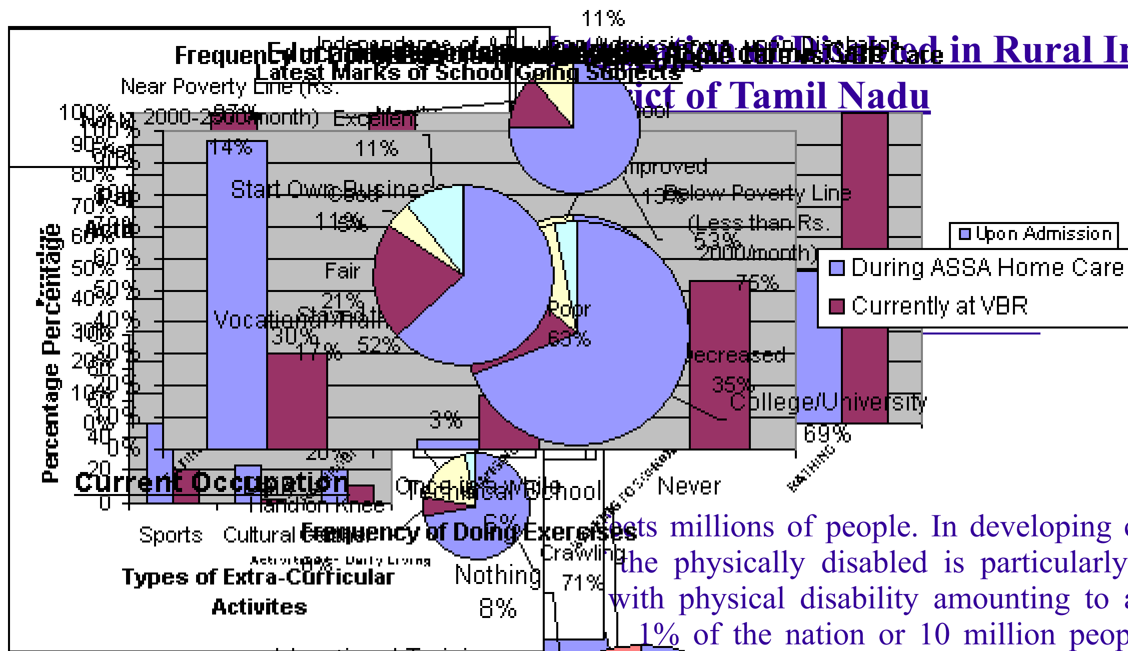


...cts millions of people. In developing countries where access to ... the physically disabled is particularly harrowing. In India, an ... with physical disability amounting to approximately 30 million ... 1% of the nation or 10 million people suffer from locomotor disabilities, out of which appro... an be attributed to polio.

Those who have the ... and rehabilitation care, education and vocational opportunities often come from the rur... Due to their lack of mobility, many families choose not to enroll their physically handica... Also, due to the lack of facilities in rural areas, children are not properly rehabilitated ... improve their physical functioning. Therefore, these uneducated and dependent people becom... their family and to society. In addition, there are social stigmas associated with the physically handi... in India, superstitions about disability such as "it is due to a curse" or "it is because the parents didn't do the correct prayers" are still present in rural areas. In some instances, families or rural communities embarrassed by the appearance of disabled children restrict their integration into society. In more extreme cases, the family and community abuse their disabled members emotionally and physically. Therefore, it is important to study the condition and social environment of the disabled living in rural India.

Some NGOs in India have taken up the task of rehabilitating, educating and training disabled people. Amar Seva Sangam is one such organization that serves the needs of the disabled in the rural region of Tirunelveli district of the state of Tamil Nadu. Amar Seva Sangam (ASSA) has a twofold approach to serving the disabled – in house rehabilitation and community outreach.

The in house rehabilitation facilities are situated in a small village called Ayikudy, where ASSA owns a 26-acre land area. The facilities include an integrated elementary and middle school, a vocational training institute for the disabled, a medical evaluation & rehabilitation center and an orthotics (caliper) making workshop, as well as a Spastics Center for educating the mentally challenged and living accommodations for disabled students, some staff members and volunteers.

As part of the community outreach, ASSA has community physical and mental rehabilitation workers who rehabilitate children and adults living in poverty in their own homes as well as social workers who promote awareness about disability issues amongst the public, organize disabled self-help groups and assist the disabled with social issues including education and vocational training.

One of the Sangam's major "in-house" activities called "Home Care" is to provide accommodations, rehabilitation and education for over 60 disabled children. Children with physical disabilities who are living in poverty in the rural areas of the district are admitted into the ASSA's "Home for the Handicapped," where they are provided with accessible daily living facilities, physical rehabilitation including referrals for free surgery, an integrated school education and sometimes vocational training (in computers, book-making, tailoring, or typing), many of which they might find difficult to get in their rural hometowns. Upon admission to home care, the

children are usually unable to function fully in their village. Their stay at ASSA should rehabilitate them to a level where they can function independently in their home, at which time they then "graduate" or are discharged back to their family where it is hoped they will continue their education or begin working.

Amar Seva Sangam continues the support of the children that are graduated to their homes through a program called Village Based Rehabilitation (VBR). Since the children returning home are usually returning to a poverty stricken household, the VBR-1 program assists students by providing them with their school fees, notebooks, textbooks and school uniforms. These students are also invited to ASSA's in-house facilities twice a year during their school holidays for a period of 10-15 days where they are given physical rehabilitation and exercises, along with adjustments to their appliances such as orthotic (caliper) devices and crutches. For those students who begin working or discontinue their schooling, they are put under the VBR-2 program where they are only provided with the biyearly rehabilitation visits to ASSA.

ASSA's "Home Care" provides students with a protective environment where all the facilities for the handicapped are easily accessible such as disabled-friendly bathrooms, ramps for wheelchairs and everyone is provided with nutritious meals. It also provides a regimented environment where they are required to exercise and study daily and are provided with tutoring for class participants and opportunities for cultural and sports extracurricular activities. After rehabilitation, children are thrown from this nurturing environment into the real world where the conveniences of disabled friendly facilities may not exist, especially for those who are financially challenged. Some questions emerge from this migration. After graduating to VBR, do these children maintain their improved physical functioning? Do they continue their educational pursuits? Are they well integrated into their community and what are the attitudes of the rural community towards the disabled?

The purpose of the study is to examine (1) the impact of "Home Care" activities and (2) the functioning of children and youth enrolled in VBR 1 and VBR 2 by examining (a) their living and social environment, (b) whether they are maintaining the physical functions they have gained, (c) whether they are maintaining the educational accomplishments and extracurricular participation they had at ASSA's "home care", (d) their current educational and/or occupational endeavors and (e) how well the participants have integrated into daily rural life after staying at Amar Seva Sangam.

Methodology

The number of students who were in "home care" and who are currently in "village based rehabilitation 1 and 2" totals 60 people. Out of this, a random sample of 36 participants was taken and information about these participants was collected.

To measure the impact of ASSA's home care activities, the records of the participants who were previously under home care and are now under VBR 1 and 2 were obtained. To obtain information that wasn't available or that was missing in the records, "housemothers" - ladies who act as caregivers of the disabled children during "home care" were interviewed. By these two methods, information about the participant's home care was obtained including how the participant was referred to ASSA, the participant's mobility upon admission and mobility upon discharge to VBR and independence of Activities of Daily Living (ADL) upon admission and upon discharge to VBR.

All the information about the functioning of participants enrolled in VBR 1 and VBR 2 was ascertained by visiting the participants at their homes or in their schools and interviewing them and their families, if present. Through interview, the first thing that was ascertained was their living condition and this included asking them who lived in their house with them as well as what jobs family members held and what the average income for the entire household is. To assess the facilities available in their house in particularly hygiene and toileting facilities, participants were asked where they attended to their toileting needs –e.g. whether a bathroom was built at their home or whether they use an outdoor field or side street. Participants were also asked whether any modifications were done in the house to meet their needs as a disabled person.

Next, current physical functioning was assessed. This was done by first assessing their current mobility by asking them whether they can walk independently for long distances without another person's assistance either using or not using appliances such as calipers, crutches, etc. They were then asked whether their mobility has improved, stayed the same or worsened since time of discharge from ASSA's "home care". Next their compliance with usage of appliances provided to them (e.g. calipers, crutches, etc.) and with exercises was assessed by asking them how frequently they use their appliances and how often they do the exercises taught to them. Finally to measure physical functioning, they were questioned on their current ability to perform the activities of daily living (ADL) – eating, bathing, changing clothes, toileting and going to school or work independently.

Next, a comparison of educational performance between "home care" and VBR was assessed by obtaining their current school marks from social workers and obtaining their school marks in their last standard (grade) before graduation to VBR from the ASSA records or by asking the housemothers if this information was not available in the records. Extracurricular participation was also compared between "home care" and VBR by asking the housemothers what activities they participated in while in "home care" and by asking the participants what extracurricular activities they currently participate in.

Next, the participants ' current educational or occupational status was assessed by asking them what they are currently doing – i.e. going to school, studying at a college, studying at a technical institute, undergoing vocational training, working or currently not pursuing any education or work. In this part of the interview, any difficulties they faced were also addressed – i.e. the burden of college tuition fees, the reason for dropping out of school, etc.

Next, an assessment of the participants' integration in society was conducted. To measure the community response to the disabled the participant was asked: how do villagers and classmates treat them? The coping ability of the participant was measured by asking how he or she responds to negative comments by others. The number of friends and type of friends (disabled/non-disabled) a participant had was used to evaluate their interpersonal relationships. The participants were also asked how they transported themselves to school or work to see if they had the ability to utilized community transportation resources. The participants were asked if they had been approached by any person or group with false claims to help them - this was to measure if the disabled were being taken advantage of in society. The participants were asked what they would do if they saw another disabled person in need, to see if they had been inculcated with a service mentality when dealing with others in need.

Observations and Conclusions

Impact of Home Care

(1) Referrals

The impact of Amar Seva Sangam is profound; however, this impact would not exist if people did not know about the Sangam and its mission. Therefore, it is important to examine by what method children are being referred to the Sangam. The study found that the majority of participants admitted into ASSA heard about it through word of mouth (58%). This figure states that most of the villagers in the Tirunelveli district of Tamil Nadu are aware of the Sangam's activities. 31% of participants were referred to ASSA through a field social worker, meaning that the Sangam's staff is making a significant impact with regards to identifying and referring disabled children. The remaining 11% came to know about ASSA from through a friend who was staying there in "home care".

(2) Mobility

Upon admission to Amar Seva Sangam, participants were at various stages of mobility due to their disability. Crawling, the most hindering form of mobility was also found to be the most predominant. 71% of participants

were crawling before their admission into Amar Seva Sangam. 3% of participants were walking with one leg (or hopping) while 6% would walk using a hand on knee gait (using their hand to lift the leg). Only 20% could walk independently, and some of these participants could not walk for long distances. In this study, walking independently is defined as the ability to walk using only the two lower limbs without another person's assistance; this may be with appliances such as orthotics (calipers), crutches, specialized shoes, crutches, etc. or without any appliances or devices.

Upon examining the participants' mobility upon discharge to their own homes, it was found that the umber of participants who could walk completely independently had increased by more than 70%. All participants (100%) were able to walk independently when they were discharged to VBR.

(3) Activities of Daily Living

Activities of daily living (ADL) involve activities that constitute everyday life, such as eating, toileting, changing, bathing and going to school. To measure the impact of "home care" rehabilitation, it is of extreme importance to measure the level of independence that children reached in regards to their ADL, as these are necessary tools for proper integration into society. The participants' housemothers were questioned as to the participants’ level of ADL independence upon their admission to "home care" and then upon their discharge to VBR. The percentage of participants who performed each ADL independently upon admission to "home care" and upon discharge to VBR was calculated. It was found that across every category, there was an increase in the number of students who were independent in their daily living activities after their rehabilitation in "home care". All of the categories, except one, showed that every participant in "home care" became completely independent upon their discharge. This means that all the students who were previously unable to bath, change, eat or use the bathroom independently learned how to do so during their stay at Amar Seva Sangam.

The one exception, going to school, although not showing a full recovery, still managed to show a large improvement. Before coming to ASSA, only 40% of students could walk to school independently. However, upon discharge, 94% of students could walk to school on their own, while the other 6% who could not walk, still traveled independently by tri-cycle or wheelchair.

Functioning of Children and Youth Enrolled in VBR 1

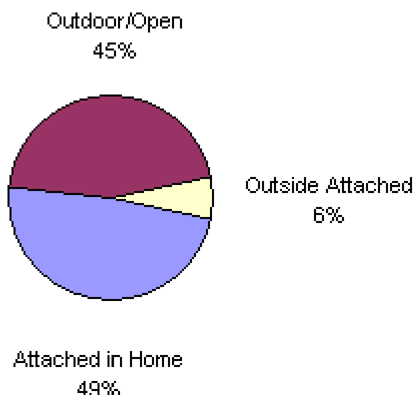
(1) Living and Social Environment

(a) Household Income

Once discharged from home care to VBR, the disabled participants are faced with the task of adjusting to their new homes in the rural areas, which are often financially deprived. By interviewing the VBR participants the household income and the types of jobs held by family members of study participants was determined. The average income for the entire household of VBR participants was determined to be 1908.21 Indian rupees ($42.41 US). The average number of family members living in a participant's house was 5 people**.** Family income ranged broadly from 400 Indian rupees ($8.89 US) a month to 8000 Indian rupees ($177.78 US) a month. The national poverty line in India has been established at 2000 rupees ($44.44 US) or less per month. 75 percent of the study population was below the poverty line, 14 % earned between 2001 ($44.46 US) to 2500 ($55.55 US) rupees and 11% earned above 5000 rupees ($111.11 US). Some of the different types of jobs held by family members are day labourers or coolies (who find available labour work on a daily basis), beedi rollers (beedies are a popular type of cigarette in India), farmers, shop owners, cloth making, sawmill work and automotive work. The households that earned the most money had a father who worked in the railway industry earning 5000 rupees per month ($111.11 US), a teacher earning 8000 rupees per month ($177.78 US), and a political representative, also earning 8000 rupees per month. (Though it is quite evident that most of the families are poor, it is important to note that people in these households in general had enough to eat and were not malnourished.)

(b) Household Facilities

The houses that the VBR participants lived in were mostly 2 room concrete structures with an attached kitchen area. Within ASSA, the bathrooms were readily accessible to disabled students, but outside "home care," it was found that some might have had difficultly going to the bathroom. Forty-nine percent of the participants used an attached bathroom in their house, forty-five percent of the participants used an outdoor, open area (which means they would go outside in the field or side streets), and six percent used an outside-attached toilet (an indoor toilet within another building).



Out of the study group, six girls out of ten had an indoor bathroom while the other four girls attended to their toileting needs outside in the open air. In the interview, when asked what difficulties if any they faced, three girls out of the four reported that attending to their toileting needs outside is a difficulty, while none of the males cited using the bathroom as a difficulty. Seven out of 36 families had bathrooms built specifically for their disabled child. It is worth mentioning that all seven families were either below the poverty line or just above it, one family only made 500 rupees a month. This shows that regardless of their status, the families aim to help the functioning of their disabled child.

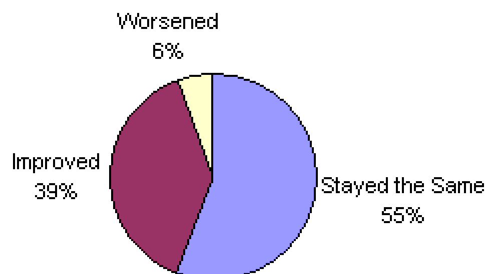
(c) Conclusions

It is quite evident that the living conditions for the disabled participants are quite different from "home care" at ASSA compared to their own homes. One of the challenges they face involves lack of facilities such as toilets. ASSA can use Self Help Groups (SHG) as a medium by which facilities such as bathrooms and ramps could be built within a disabled person's house. ASSA could also set up a program where they would sponsor a certain percentage (such as half) of the cost of building toilet facilities within a disabled person’s house who has been determined to be in high need of such facilities. ASSA could also attempt to get government grants for building toilets in disabled people's houses.

(2) Physical Functioning

(a) Mobility

Within "Home Care," the children's lives are structured and they must use their calipers and perform physiotherapeutic exercises. However, outside the Sangam, it becomes the participants' own responsibility to maintain or increase their physical mobility. 35 of the 36 participants interviewed have maintained their ability to walk independently, while only 1 person out of the 36 reported that she needed to hold on to someone for support while walking. When asked if their ability to walk and move around had improved, stayed the same or worsened; 39% of those interviewed said that their mobility had improved, while 55% said it had stayed the same and only 6% said their mobility had worsened.



Of those people whose mobility had worsened, one subject was using his calipers and crutches regularly while the other person was not. One was a female who wasn't wearing her calipers because she was embarrassed about being seen in public with calipers and because of the weight of the calipers. She was also the one individual who reported along with her family that she could not walk independently and could only walk a very short distance without falling. The second student whose mobility worsened was a male. His mobility decreased because the roads near his home are in a poor condition and he has a difficult time walking on them, but he still manages.

(b) Usage of Appliances

During their rehabilitation in home care, participants are assessed by physiatrists (physical and rehabilitation specialist doctors) and physiotherapists and are referred for free surgery and given free appliances such as calipers (orthotics), specialized shoes, wheelchairs, etc. While in VBR, students are given the opportunity to get their appliances fixed or get new appliances free of charge. The proper usage of appliances such as calipers are very important, as it prevents further deformities such as scoliosis and improves walking ability and physical functioning. For those provided with appliances, it is expected they use it on a daily basis in order to maintain their physical functioning. Seventy percent of those interviewed used their appliances on a daily basis. Twenty-two percent were irregularly using their appliances. The other eight percent did not need any appliances to assist them with walking. Reasons that were cited for not using appliances were that they caused pain, bruises, that calipers were heavy, that their appearance was embarrassing, that they could not climb stairs with calipers on and that they need to repair their appliances, but they hadn't come to ASSA to get it fixed yet.

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(c) Exercises

Another important variable in preserving physical functioning for the disabled is performing prescribed exercises. The health care workers at ASSA have taught all the participants exercises they need to do for strengthening of useable limbs and muscles, prevention of deformities and for other purposes. During, "home care", due to the presence of physiotherapists and housemothers ensuring daily exercise, 35 out of 36 or 97% of

children did exercises daily, while only 1 out of 36 did it once in a while. When asked how often they do exercises now that they are in their own homes, 53% said they never do exercises, while 30% said they do it daily and 17% said they do it once in a while.

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(d) Activities of Daily Living

One of the most important measures of physical functioning is whether one can perform the activities of daily living. After administering the questionnaire it was determined that currently at their own homes, 100% of the participants were bathing independently, 100% were eating independently, 100% were changing their clothes independently and 94% or 34 out of 36 were attending to their toileting needs independently. Of the 2 who said they needed assistance for going to the bathroom, one was male and he stated that he needed to use an outdoor field for his needs. However, he could not defecate with his calipers on, but he needed his calipers to walk to the field. Therefore, he was carried to the field. (It should also be noted that although 100% of the participants could bathe independently, many of the participants said that because of their disability and because they don't have running water in their houses, they need water brought to them.)

(e) Conclusion

The fact that almost all the participants are still walking independently, that mobility has improved or stayed the same in the majority of people and that almost all of the participants are able to perform their ADLs independently shows that the disabled rehabilitated by ASSA are maintaining their level of physical functioning after being sent to their home.

The fact that the majority of participants (70%) are still using their appliances regularly is a positive indicator. To encourage the other 22% to use their appliances appropriately, new technology calipers that are light weight and cosmetic to improve appearance can be suggested. Also, VBR participants and their family should be constantly educated on the importance of regular appliance use during social worker visits and during their biannual visit to ASSA.

The fact that 53% of the VBR participants never do exercises is a potentially harmful indicator. Physiotherapists should ensure that both participants and their families are properly taught the exercises that the disabled subject need to perform and encouraged to do it daily. Also, participants can be taught and encouraged to do exercises independently while at "home care" without the physiotherapists or housemothers' assistance, so that they can transfer this practice when they are in their own homes. Also, ASSA's advent of self-help groups (SHG's) which some VBR participants are part of, can act as a central meeting place for them to get together and do exercises as a group. For the cases where doing exercises are very imperative, ASSA could have physiotherapists, along with social workers, doing house visits.

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(3) Home Care vs. VBR - Comparison of Educational Performance and Extracurricular Involvement

(a) Educational Performance

Grades are a very important part of any student's life. For many, it is necessary to maintain a good grade average for acceptance into college, and thereafter a good job. Therefore, it is important to see if moving from home care to VBR will have an impact on how a subject performs in school. Fifty-two percent of the students' grades

remained the same from ASSA and VBR, thirty-five percent of students' grades decreased and thirteen percent had increased.
A few students cited the lack of opportunities to get tuition (tutoring) as the reason for their decrease in marks. Other possible factors could be the increase of workload in higher standards, lack of structures study times and difficulties with a new school without handicapped facilities (for example, one student said that they have to go upstairs for classes and therefore arrives late for classes).

(b) Extracurricular Activities

Participants at ASSA are encouraged to participate in extra-curricular activities including sports such as cricket, kabadi (a game similar to tag), tricycle racing; Indian cultural activities such as Thirukural (recitation of Tamil literature), folk songs and other activities such as debates, dramas, etc.
During home care, 88% of participants participated in extra-curricular activities. It was found that upon leaving "home care," the number of participants participating in extra-curricular activities dropped to 53%. Participants doing sports dropped from 73% to 21%, people doing Indian cultural activities dropped from 23% to 3% and those doing other extracurricular activities dropped from 21% to 11%. Possible factors for the drop are: the opportunities to participate in the same activities they did in ASSA are not available, the increase of standards may be too challenging for some participants to do both extra-curricular activities and study, and the encouragement to participate in such activities may not be present.

(c) Conclusion

There is a decrease in both the educational achievements and extracurricular participation of participants from home care to VBR. With the formation of self-help groups (SHG's) by ASSA, it can be encouraged for the VBR participants to participate in productive extracurricular activities such as disability awareness programs, assisting with the running of SHG's (a few VBR participants are already participating in such SHG activities and find it very positive experience). SHG's can act as a focus for other extracurricular activities such as sports, games, art classes, yoga, etc. They can also act as a focus for arranging private tuition (tutoring), so that students can be assisted with their weak subjects and marks could be improved.

(4) Occupational and Educational Pursuits

To consider rehabilitation fruitful, it is imperative for disabled people to be functional members of society and have the potential to be financially independent. Continuing education and/or having a job are two statuses that indicate the potential for financial independence. 31 out of the 36 (86%) participants were pursuing some sort of educational endeavour with 21 (57%) in school, 6 (17%) in college, 2 (6%) studying in a technical institute and 2 (6%) undergoing vocational training. 2 people (6%) were employed and 3 people were currently not involved in any education or job. (*It should be noted that this is a random sample of 36 out of the 60 people who are in VBR 1 or 2; it may or may not accurately reflect the percentages of all the VBR participants. Also 7, of the participants who studied in home care are now undergoing vocational training at ASSA and are now classified as DYT's or Disabled Youth Trainees and are not included in this study.*

(a) Attending School

For those who are currently in school, their most recent end of year final marks were recorded and classified according to the scale: Excellent for marks greater than 90%, Good for 80% to 90%, Fair for 60% to 80% and Poor for below 60%. According to this scale, the majority of students are doing poorly or fair (63% of students are doing poorly, 21% are doing fair), while only 5% are doing well and 11% are doing excellent. With this distribution of marks and the high cost of post secondary education (see below), it is unlikely that many of these participants will be able to pursue college or even technical education.

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(b) Attending College or Technical School

Of the 6 participants going to college, 2 are males taking a Bachelor in Commerce (B.Com) in their 2nd year of a 3-year course. After completion of this course, one wants to do chartered accounting and the other wants to do computer training. College tuition for them is approximately Rs.10000/year each ($222 US). 3 of the 6 participants are females who are studying at Parashakti College in Courtallam. They are taking a B.Sc. in Math, BA in Tamil and BA in Physics. College fees are approximately Rs.8000/year ($177 US) each. All three want to pursue teacher training. The final subject is going to begin his studies in pharmacy for which annual fees will be approximately Rs.15000 ($333 US).

Out of the two male participants undergoing technical education, one is studying electronics and the other, factory parts fitting. For both of them, annual education fees are approximately Rs.25000 ($555 US). For all these 8 participants, the annual income in their household is below the poverty line (below Rs.24000/year). ASSA sponsors approximately Rs.1800 ($40 US) per year of the education costs for each of these students. For some of the college going students, ASSA sponsors more. Extra funding is done on a case-by-case examination basis. As it can easily be seen, post secondary education expenses are a huge burden to the families and many are attempting to get scholarships and borrow or ask for money from relatives and friends to meet the expenses.

(c) Undergoing Vocational Training

The 2 participants in the study who are currently undergoing vocational training both studied only up to the 10th Standard or Grade 10 (please note that in India, formal education is completed at the 10th Standard, with the 11th and 12th of high school being optional for students interested in university). One failed out of high school and the other got excellent marks but dropped out of school because of difficulty he faced in taking the bus while carrying his books to school. The latter is learning tailoring at a store owned by his uncle. He hopes to buy his own equipment and start his own store. The other subject has taken driving lessons to become a professional driver; however he does not have money to pay for his licensing exam.

(d) Employed

Both of the participants who are currently working only studied up to 8th Standard and received failing marks in school. One person received vocational training in cot, chair and basket making and he now does contract work and earns Rs.500 per month. He wants to start his own business selling cots and chairs and applied for a bank loan for this purpose; he was however rejected. The other subject failed the 9th Standard twice and currently works at an automobile financing office, earning Rs.500/month. He uses the money to support his family, which is in a financial crisis. He hopes to study financing at the office. Since it is a private company, the manager does not require him to have an education, as long as he is literate.

(e) Doing Nothing

Out of the three participants that are currently not working or attending school, two are females and one is male. Out of the females, one has completed 12th Standard but failed Math and was therefore unable to graduate. She is currently getting private tutoring in math and hopes to rewrite the exam and pass it. She is not sure about her

future plans, but is considering going to college and/or taking a computer training course. The other female discontinued school after the 8th Standard with fair marks. The reason the family cites for the "dropout" is that to attend 9th Standard, she has to go to a new school further away from her house and it is too difficult for her to be transported there. From the interview with her and the family, it is evident that there is a lack of interest on the family's part to take the effort to send her to school. Though she may be interested in going to school, she seems to lack confidence and self-esteem. The male student that is not attending school completed the 10th Standard. Though he is constantly encouraged by the social workers from ASSA and his older brother to rejoin school, he lacks the interest and motivation.

(f) Future Plans

When asked what future plans they wish to pursue, 25 out of 36 or 69% of the study group cited professions, such as teachers, doctors, lawyers or accountants; all professions that require college education. 4 out of 36 said they wanted to start their own business; 6 out of 36 wanted to pursue a profession that required vocational training such as computers, and tailoring and 1 person who had dropped out of school simply said her future plan was to return to school.

(g) Conclusions

It is encouraging that the majority of the study group is engaged in productive work, whether school, training or job. However, with the cost of post secondary education being high and the chances that these participants will get scholarships at government colleges being low; because of poor marks most participants might not be able to attend college. Though an education has given them literacy, it does not greatly advance these disabled youths likelihood of gaining employment. With more and more VBR 1 and 2 students finishing their schooling, the need to train them in a trade in order to gain employment becomes important. Encouraging and setting up the infrastructure for VBR students to get training in ASSA's existing vocational facilities (tailoring, toy making, book making & binding, computer training, typing training) could be done. Also, investment of money into setting up new vocational training facilities in vocations that can yield jobs for the disabled can be another direction for ASSA. Another option is to help fund their vocational training at outside centers, or provide loans for such purposes. Also, though it is encouraging that the VBR participants have high goals and want to pursue college education, it is important for social workers and others at ASSA to counsel them properly about realistic occupational pursuits. It may be wise to encourage students that are failing or doing poorly, into the vocational line at an even earlier stage.

For those who are undergoing vocational training and even for those who are currently working, the major obstacle of finding sustainable employment still exists. ASSA could play a leading role in encouraging self-employment by giving small business loans to vocationally trained disabled students. ASSA could also set up a job placement or co-op program for the disabled where they could work with companies and encourage them to hire trained disabled candidates. Another possibility is setting up a factory within ASSA's premises that produces various goods such as soaps, candles, incense etc. where the disabled are hired to work and profits from such ventures could fund ASSA's charitable programs.

For the VBR participants in college, fees are a serious burden. Such a burden may prevent exceptional students from pursuing higher education. Currently, ASSA helps college-going participants by funding a small portion of their education and helping them apply for government and other scholarships. However, many of these families are still left to raise a lot of funds to put their children through college. With a few exceptional VBR participants (11%) currently in school, it may be worthwhile for ASSA to set up a "scholarship fund" or a student loan program and specifically raise money to fund students who have shown dedication, hard work and ambition and who are not able to fund their education through other scholarships and means. (ASSA is already informally doing this by giving more money to deserving participants in college on a case-by-case basis. If a formal college-funding program is made, funds may be more easily mobilized.)

For those who have discontinued school and who are not working or getting vocationally trained, ASSA's social workers should work closely with the subject and their families and find out where these participants' interests and strengths lie and try to determine a path that can lead them to success. It is particularly important to educate parents about the importance of allowing their children to pursue their educational and vocational goals, because sometimes it may be the parents that are disinterested in their disabled child's education.

(5) Integration into Society

(a) Community Response to Disabled Persons

It is one thing to rehabilitate the disabled, but unless their community accepts their differences, the individual's confidence can never be up to par. Therefore, the participants were questioned on how their community responds to their disability. They were asked whether they were teased or put down because of their disability or assisted in their schools and villages. The results showed that overall most community members (85%) accepted and positively responded to the disabled. These participants stated that people in their school and village were for the most part very helpful to them. Only 3% of participants in the study have been treated negatively by others because of their disability. 9% said their community was ambiguous to them, neither treating them negatively nor positively, while the remaining 3% have experienced both sides.

(b) Coping with Social Challenges

It is also important for the participants to respond confidently if faced with a negative attitude by the community. When asked how they would respond if someone expressed a negative view about their disability, significant coping differences were found between males and females. Of males dealing with negativity, it was discovered that most (50%) would do nothing, while 33% would stand up for themselves and 17% would inform an authority figure. The majority of females (49%) would respond by crying, while 38% would do nothing and only a small percentage (13%) would stand up for themselves.

There is a difference in the way males and females respond to negative comments; while the majority of males would do nothing the majority of females would cry. Crying by itself is not necessarily a bad reaction but in some cases it is accompanied with thoughts of depression like not wanting to leave the house.

This could be an indicator that girls need, more than boys, to participate in activities that will increase their self worth and confidence. In fact many students reported that their confidence has increased upon graduation from ASSA. One student said, "Before coming to ASSA, if people made fun of my disability, I would cry. Now, because of my calipers, I am able to stand up and see people face to face."

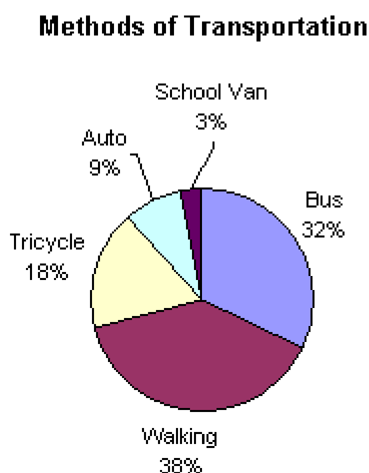
(c) Interpersonal Relationships

A good measure of the disabled youth's integration into society is his/her interpersonal relationships. As the participants in the study were mostly of school-going age, the amount of friends and type of friends the subject has is a strong measure of interpersonal relationships. As males and females tend to differ in social relationships, the data was separated according to gender.

In the majority of cases, both males (79%) and females (67%) were found to have friends. These friends were mostly non-disabled which not only shows that the disabled students have integrated well, but also that their non-disabled peers accept them. However, in females, a surprisingly high number, 33% were found not to have any friends. Also, the interviews revealed that 50% of the disabled females in the study never left the house other than going to school due to embarrassment about their disability or restriction by their parents. Such embarrassment or restriction was not seen in the male population studied. In one case, an 18-year-old female said she takes an awkward side path to school instead of the main road, because she doesn't want to be seen if she accidentally falls. In two cases, the disabled female didn't go out with her family even when the rest of the family went out. In one case, a girl did not attend her elder sisters wedding which was in a nearby town to where the family lived. Reasons the families cited for this sort of restriction included concern about the child falling and difficulty with mobility. However, since such reasons did not prevent male children from going out, one reason could be there is a greater social stigma against disabled females or parents being overly protective of their disabled female children. It was also evident that some of the disabled females were very quiet and introverted. Whether this is a natural personality trait or was caused by their disability is unknown. Furthermore the social stigmas surrounding women and social interaction are quite high in India. Whether the reason that the girls tend to be shy and less friendly is due to disability or because they are female cannot be determined.

(d) Transportation

Another important measure of integration into society for the disabled is whether they are able to use the facilities available to society at large. Since the vast majority of people don't have their own vehicles, an important measure of integration is how disabled are able to transport themselves. The study group was asked how they transported themselves to school or work. 56% use the most inexpensive form of travel – either walking or using their tricycle. 32% use public transportation, a relatively inexpensive form of travel. 12% use more expensive forms of travel such as an auto rickshaw or school van, which ranges from Rs.500 ($10 US) to Rs.600 ($12 US) per month.



(e) Fraud:

There are many stories of disabled people being taken advantage of in small communities by "conmen" who promise to get them special disability cards, government pensions, etc. in exchange for collecting a fee. Once the fee is paid, these thieves disappear without providing them with any of the things they promised. The study participants and their families were asked if anyone had approached them with such a claim. Only one out of

thirty six participants' family was approached and they refused, saying that ASSA is already helping them. This may suggest that ASSA's presence protects the disabled from such "conmen" in this region of the country.

(f) Helpfulness to Other Disabled People

To examine whether the VBR participants had inculcated any of the service mentality of ASSA, they were asked what they would do if they saw another disabled person, in particular a disabled child or student. The majority of participants simply responded that they would help. When asked how they would help, they were for the most part unable to give specific helpful things they would do; while some said they would help carry books or push wheelchairs. They did not, for example, say they would tell the disabled person about government pensions or scholarships that are available for the disabled. Also, on some visits to schools, it was discovered that the VBR participants aren't taking an active role in educating other disabled students about such opportunities or about rehabilitation opportunities at ASSA. In one house visit that was made for this study it was discovered that when a particular subject's young nephew had a disability, he didn't even bother to tell his uncle and aunt about ASSA and that they could help.

(g) Conclusion

The disabled participants' integration into society has been for the most part quite successful. The rural community has responded to them positively and is somewhat helpful. However, there is a clear disparity between the status of disabled males and females with regards to social integration into society. Amar Seva Sangam conducts awareness campaigns about disability through cultural dramas and programs in the various rural communities. A main focus of such education should be the empowerment of females. The rural community and particularly parents of disabled should be educated that it should not be an embarrassment for disabled females to be seen in public. Also, it is important to involve females in activities that instil self-confidence in them during both "home care" and VBR.

Also during the interview process, it was noticed that some participants lacked communication skills and lacked self-confidence when speaking to whom they viewed as authority figures (i.e. the researchers) and/or social workers. Through observation of "home care" activities it was also seen that the current group of disabled children in "home care" may lack interaction with non-disabled, particularly non disabled adults. Their interaction with non-disabled adults usually consists of interaction with teachers and housemothers. Such interaction though done with care and concern is often simply command based – i.e. "Go eat your dinner now", "Time to do your exercise", etc. Promoting friendly interaction (i.e. simply talking and listening to the concerns of the disabled children) can instil greater self-confidence in the disabled when they are in the real world. It will also allow them to improve their communication skills, may allow them to be more "worldly" in their knowledge and may teach them how to cope with social challenges. Housemothers and teachers can be taught to interact with the children this way or even other ASSA staff can be encouraged to do this.

This data also shows that the people who are acting negatively are not properly being reprimanded, as majority of the victims of negative attitudes will simply ignore and keep the problems to themselves. Perhaps, field workers should educate VBR participants on effective coping methods, and promote self-confidence within the disabled so that more people can stand up for themselves and/or inform the proper authority figures.

The fact that the majority of the disabled people who are economically poor are able to use commonly used and inexpensive forms of transportation is a very positive indicator for integration. Only a few are forced to rely on more expensive forms of transport. However, during the interview when asked what difficulties they face in society, some participants responded that they had difficulty walking on the roads (because they weren't properly paved), using the bus and using their tricycles on some roads. Two people even dropped out of school citing difficulty in taking the bus as their main reason. Therefore, one still sees the need for organizations like ASSA to work with governments and other groups to improve the facilities available for the disabled such as disabled-friendly buses, paved roads, etc.

The lack of initiative shown by some participants with regards to helping other disabled may indicate that ASSA needs to take a greater role in educating students about the need to help other disabled so that they act as "social workers" to seek out and assist other disabled people. Simply telling VBR students to tell other disabled students at their school about scholarship and rehabilitation opportunities for the disabled could go a long way.

Conclusions and Recommendations

By examining each of the components of the study, it can be concluded that Amar Seva Sangam's efforts to rehabilitate and integrate the physically disabled are generally effective. Across the board, it was discovered that independence of activities of daily living, mobility and maintenance of physical conditioning generally improved from the time of admission into ASSA. The Sangam's "Home Care" program is effective in physically rehabilitating the disabled for their re-integration into society; however social factors could be adjusted. As seen, maintenance of academic and extra-curricular performance dropped during VBR and interpersonal relationships do not seem to be high for females. As well, administrative issues found during the preliminary report can be improved upon in order to keep the information and tracking of records easier to obtain. From the findings of the study, a set of recommendations has been set forth below. The recommendations have been placed into different categories and within each category are prioritised starting form the most important and/or urgent to less important and/or urgent. This priority scale simply reflects the opinion of the researchers based on the study – the ASSA administration should feel free to set up their own priority scale.

Administrative Recommendations:

1) **Organize and computerize all information in student's file.** On Microsoft Access or other database program, a folder could be opened up for every student. In the folder, there could be various sections that contain different important information – general information, marks, physical assessments, social worker visit, etc. After a set of new marks is obtained or a new physical assessment is done or a social worker visits, a new entry could be made into the database into the appropriate section.

2) **Create a form, which has to be filled out each time a social worker visits a student.** The form could include, current education status (e.g. attending 11th Standard), changes in physical condition and mobility if any, a section for other concerns that arise among other things and what the social work did at the visit (i.e. helped fill out scholarship form, paid school fees, etc.) A supervisor can then sign off a completed form. A form could also be created for each time a physiotherapist does a physical assessment when the disabled participant visits ASSA. This will ensure proper and consistent record keeping.

3) **Ensure the number of times a social worker should visit a student is followed by tracking each social worker visit with proper paper work (see above).** Have a supervisor or manager look over the paperwork (information taken by the social workers during the field visits) and if it is acceptable, sign it. It could then be typed into the computer by administrative staff. Also, ensure that visits occur at certain critical times such as the beginning of the school year. For example, if the social worker visits a family at the beginning of a school year and finds out that the student is not attending school, he could work with the family to find out the reasons and possibly create a solution.

4) **Communicate to the social workers the importance of documentation**, especially of the various concerns and problems that arise. This will allow supervisors to detect patterns and create wide-ranging solutions. Emphasize that social workers will not get into trouble for situations out of their control.

5) **Create a form for previously unidentified disabled persons.** Social workers should carry a form during each field visit that will allow them to document information about a previously unidentified disabled person they see. Encourage social workers to follow up on all previously unidentified disabled persons that the villagers report.

Vocational / Educational Recommendations:

(1) Setting up the mechanism and infrastructure for VBR students to get training in ASSA's vocational training facilities. Though an education has given them literacy, it does not greatly advance these disabled youths likelihood of gaining employment. **With more and more VBR 1 and 2 students finishing their schooling, the need to train them in a trade in order to gain employment becomes important.**

(a) **Infrastructure:** ASSA's vocational training facilities are underutilized (i.e. two wheeler repair, tailoring, etc.) and could easily take in more trainees. However, ASSA's hostel facilities are full. Therefore, expanding the living facilities for disabled youths would be beneficial.

(b) **Counselling:** It is important to ensure the proper funnelling of disabled students graduating from school into vocational training. SHG's and social workers can counsel and educate the students about the various vocational training available, help them finding their interest and channel them into the proper field.

(c) **Sponsorship:** For VBR 1 and 2 students under sponsorship, the sponsorship can be continued to allow them to get vocational training. For those in VBR 1 and 2 not under sponsorship, a program could be set up whereby they are allowed to get free training or heavily subsidized training.

(d) **Infrastructure:** Investment of money into setting up new vocational training facilities in vocations that can yield jobs for the disabled can be another direction for ASSA. Examples include carpentry, plumbing, electrician training, automotive mechanics, etc.

(e) **Outside Training:** Another option is to help fund their vocational training at outside centers, or provide loans for such purposes.

(2) Finding suitable employment for vocational trainees.

(a) **Small Business Loans:** ASSA could play a leading role in encouraging self-employment by giving small business loans to vocationally trained disabled students.

(b) **Job Placement Program:** ASSA could also set up a job placement or co-op program for the disabled where they could work with companies and encourage them to hire trained disabled candidates.

(c) **ASSA Factory:** Another suggestion can be setting up a factory within ASSA's premises that produces various goods such as soaps, candles, incense, etc. where the disabled, even those that are not educated, are hired to work and profits from such ventures could fund ASSA's charitable programs.

(3) Set up a "scholarship fund" and/or student loan program. Specifically raise money to fund college students who have shown dedication, hard work and ambition but are unable to fund their education through other means.

(4) Social workers should work closely with students and their families who have given up school. They should aim to find out where these students' interests and strengths lie and try to determine a path that can lead them to success. As well, it is particularly important to educate parents about the importance of allowing their children to pursue their educational and vocational goals, as it may be the parents' restricting their children from attending school.

Social Issues Recommendations:

(1) Encourage the empowerment of females. It was found that in matters of interpersonal relationships and their social environment; females had more difficulty with coping than males. The rural community and particularly parents of disabled should be educated that it should not be an embarrassment for disabled females to be seen in public. This can be done through direct conversation with parents and awareness programs in the community. Also, it is important to involve females in activities that instil self-confidence in them during both "home care" and VBR. One example is getting females involved in SHG and SHG awareness programs.

(2) Improve facilities for the disabled. Organizations like ASSA and other NGO's need to work with governments and other groups to improve the facilities available for the disabled such as disabled-friendly buses and paved roads. ASSA can also use SHG as a medium by which facilities such as bathrooms and ramps could be built within a disabled person's house. ASSA could also set up a program where they would sponsor a certain percentage (such as half) of the cost of building toilet facilities within a house of disabled person who has been

determined to be in high need of such facilities. ASSA could also attempt to get government grants for building toilets in disabled people's houses.

Physical / Rehabilitation Recommendations:

(1) Ensure that exercise routines are properly maintained.

a. Physiotherapists have to make sure that the disabled students understand the need to perform their exercises daily. Also, children should be taught to do exercises independently while at "home care" without the physiotherapists or housemothers' assistance, so that they can transfer this independent practice during VBR.

b. Encourage exercise practice in Self Help Groups. ASSA's advent of self-help groups (SHG's) which some VBR students are part of, can act as a central meeting place for participants to get together and do exercises as a group.

c. For cases where doing exercises are imperative, physiotherapists or social workers trained in exercises should make house visits to ensure the students are keeping up with their routine and be taught new methods upon progress of their disability.

(2) Encourage appropriate and regular appliance use. Since a percentage of participants were found to be irregularly using or not using their appliances, new technology calipers that are light weight and cosmetic to improve appearance can be suggested. Also, during social worker visits, VBR participants and their family should be constantly educated on the importance of regular appliance use.

Other Recommendations:

(1) Formation of more Self Help Groups for VBR students. SHG's can be used to encourage the VBR students to participate in productive extracurricular activities such as disability awareness programs and assisting with the running of SHG's themselves. They can also act as a focus for arranging private tuition (tutoring), so that students can be assisted with their weak subjects and marks could be improved. The students can also work together and help each other out by forming study groups within the SHG's.

(2) Take a greater role in educating students about the need to help other disabled people like themselves, so that they act as "social workers" to seek out and assist other disabled people.

(3) Within ASSA Home Care promote friendly interaction between disabled and non-disabled and between adults and disabled children (i.e. simply talking and listening to the concerns of the disabled children). Such interaction would instil greater self-confidence in the disabled when they are in the real world. It will also allow them to improve their communication skills, may allow them to be more "worldly" in their knowledge and may teach them how to cope with social challenges. Housemothers and teachers can be taught to interact with the children this way or even other ASSA staff and volunteers can be encouraged to do this.

Obviously, not all these suggestions can be implemented immediately, however these recommendations should be considered as a long-term vision for Amar Seva Sangam; whereby we can aim that the integration of the Village Based Rehabilitation participants after their "home care" stay at ASSA will produce fully confident and functioning members of society.