MBA Foundation's G.O.D.s

Summer Internship Project 2013

Understanding Lives of People with Disabilities

Sajal Nagwanshi
Interaction Design 2012-14
Roll No. 126330002
IDC-IIT Bombay

Declaration

I declare that this written submission represents my Ideas and experience in my own words. This is an authentic record of my own work as requirements of one month internship during the period of May 13 to June 13, 2013. I have adequately cited and referenced the original sources wherever external literature is used. I also declare that I have adhered to all principles of academic honesty and integrity and have not misrepresented or fabricated any data in my submission. I understand that any violation of the above will be cause for disciplinary action by the Institute.

Sajal Nagwanshi
Interaction Design
Roll No: 126330002

Acknowledgment

I had a very profound experience while working with MBA foundation for my internship. I don't think so I would have had an opportunity to meet so many inspiring and hardworking people had I not worked with them. Throughout my internship I met various people who have added tremendous amount of knowledge to me from the insights that they have gained through their experience.

The objective of the internship was to gain an understanding of the life of people with disabilities and also of those who take care of them, which I believe I have satisfactorily gained.

I would like to thank Dr.G.G.Ray for introducing me to this domain and motivating me to work for the benefit of people with disabilities. Dr.Ila D'souza who gave insights from her life long years of experience with physiotherapy.

I would like to thank Mrs. Jayshri Patil for giving me opportunity to intern with MBA foundation and also guiding me throughout the period of internship. Mrs. Meenakshi Balasubramanium, the founder and trustee of MBA foundation, who give me insights on how she leads an NGO and her past experiences of training children with disability. Mr. Cecil De Mello, the care taker at the Gorai centre for such a warm and hospitable experience at the centre. Mr. Rupesh, educator for children with special needs, who gave his invaluable insights on how to teach kids with special needs. I would like to thank Mr.Akhil Balasubramanium, Mr. Ravi Subramanium and Mr.Yogesh Raut, employees at MBA foundation, whom I accompanied on marketing and CSR meetings. Mr. Sanjay Pore, physiotherapist, who shared with me his knowledge about therapy for people with CP and the tools used for it. Mrs. Veena Advani, who is also one of the trustees of MBA foundation, shared her experience of raising a child with CP and the challenges she faces while running a day care centre at Chembur. All the students that I met in four centres who gave such a warm welcome and became friends in such short time.

Lastly I would like to thank IDC, IIT-Bombay to approve of interning at an NGO to gain valuable experience.

Table of Contents

Abstract

The objective of the internship was to gain insight about the life of people with disabilities, precisely of those with Cerebral Palsy (CP). It was an antecedent to my project which is to design an assistive tool for people with CP. MBA foundation is an NGO which works for people with various disabilities. It has four centres in Mumbai. Throughout my internship I visited all the four centres and gained insight by meeting care takers, special educators, social workers, physiotherapists and students themselves. Apart from the user study I also took part and volunteered for the various activities which were going on in the NGO.

Throughout the duration six people were observed at the four centres that had CP with varying levels. The process followed was to assist the students in their day-care activities in association with the special educators. While observing them doing activities like painting, applying glue on paper bags, counting and sealing aggarbatti etc. the challenges that they faced were evident. Some could do their work without assistance while others were heavily dependent on the care takers. The centre also had a physiotherapist who regularly gave therapy to the students. The insights gained by his experience about each of the student with CP were also worthwhile. It helped in understanding the history of each person and how treatment had helped in performing the activities. While no cure is known for any of the subtypes of CP, many of the capabilities of the patient can be improved using variety of methods.

The other activities which were part of the internship were marketing of the goods that were made by students of the NGO. 'Self esteem' foundation for the disabled, an umbrella company under MBA foundation, is a non profit Section 25 Company. It markets the products made by them, spreads awareness, provide them with job opportunities and explores other avenues to facilitate them to join the mainstream occupations. The activities included holding exhibitions of the products, meeting CSR managers of companies, making brochures and presentations and meeting marketing managers of organizations for hosting events.

About the organization

MBA Foundation was formed in 2001. It was started by a group of parents with a vision of providing education and Vocational Training and thereby providing job or Entrepreneurship Opportunity for people with disabilities. It has a mission of providing life with Self-Esteem & Dignity for the Disabled. Today the organization has four centres all over Mumbai with more than 1500 beneficiaries from their various programmes. Their centres are at Powai, Gorai, Thane and Chembur. They are now coming up with another centre which is at Airoli.

They provide Parental Counselling, Early Intervention Therapy, day care activities and Life-Care for people with disabilities. Their first centre was started in Powai. Eventually they progressed to a unique concept of care centres. They now have chain of small, community based satellite Units where they host group activities focused to keep people with disabilities mentally & physically occupied.

In the centres, they provide day care services and Life Care Services. Day care service is provided to those who have guardians to take care of them. Life care services which are the permanent residency program, are provided to them who either are completely dependent on others or do not have guardians to take care. Facilities for Life Care include Accommodation, Food, Personal and Medical Care, in addition to the Facilities offered in Day Care.
The organization has a long term vision to start many more integrated care centres with all the modules to cater to all ages and levels of differently abled and to facilitate other parental groups to replicate their model care centres in many more areas either as part of MBA foundation or as independent groups.[8]

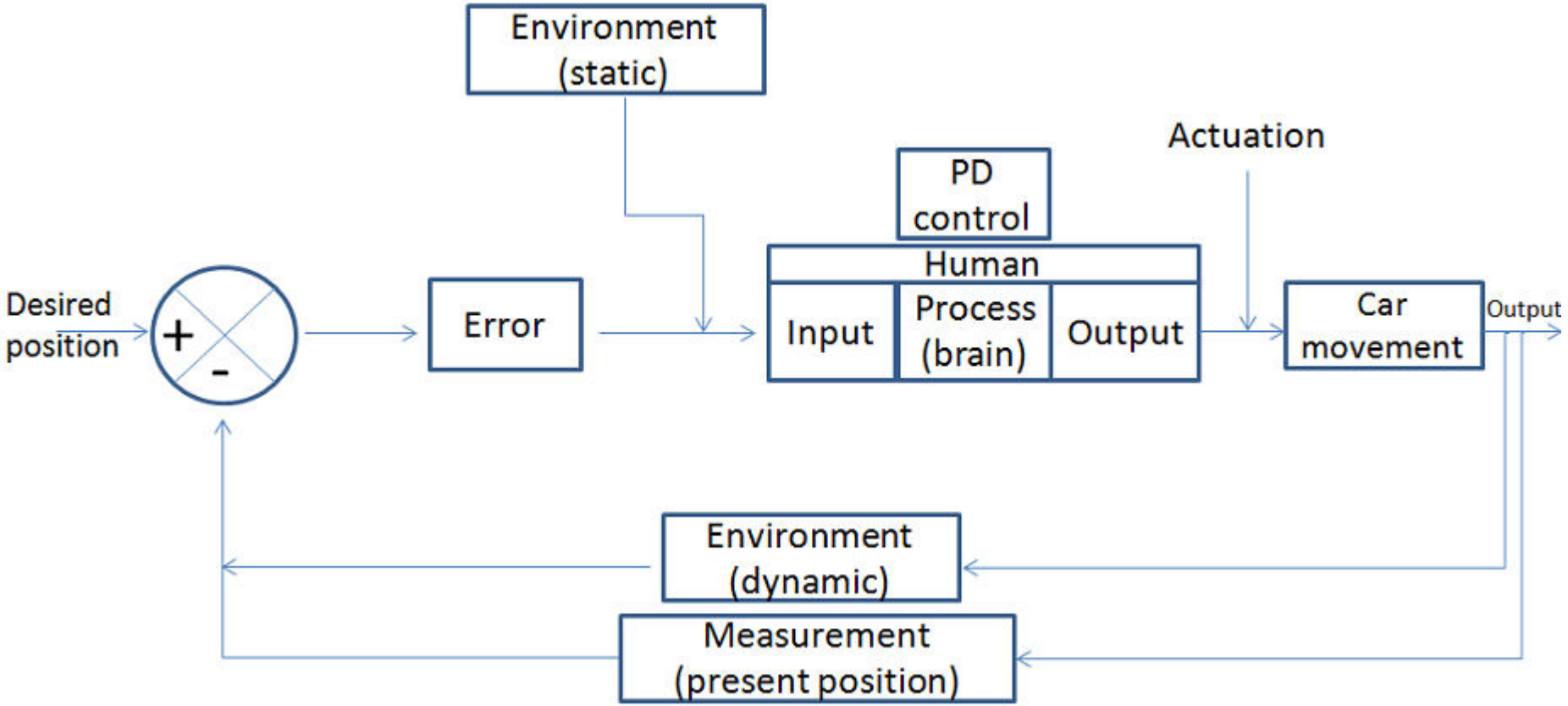
Introduction

Purpose

The purpose of this report is to draw out the experiences of the internship which was carried out at MBA foundation. The internship was of one month duration was carried out from 13th May to 13th June, 2013. MBA foundation has four centres across Mumbai with 135 beneficiaries all over. It was carried out mainly at two centres, namely GODs (group of disabled) Saagarika situated at gorai and GODs Heaven situated at powai. Two weeks were spent at each of the centre while one day was spent at the centres in Thane and chembur each. The main activities that were part of internship were to assist students in the day-care activities and also to look into marketing side of the NGO's products.
The report also highlights the present scenario of the NGO and suggests on some area for improvement as per observations.

Background

I was introduced to the topic of people with disability while studying the subject 'Human factors in interaction design'. The subject talked about modelling human's behaviour and actions. The systems were classified into closed loop feedback system. A system which would self corrects itself while constantly comparing to a desired value. A system is defined by inputs, processes and outputs. Any task which is taken by humans can be modelled by the system. But there are some cases when this does not work as expected. Like A case of CP, in which the inputs i.e. the sensory may not function or the brain may have some problems or there is problem with limbs. Cerebral palsy causes permanent damage and disabilities. The motor disorders may affect a child's ability to walk or perform manipulation tasks, and may make overall arm and leg movements slow or unsteady. In addition, the brain injury may cause other medical disorders, such as impaired intellectual development, seizures, and spinal deformities. It may also delay the growth and development of a child, affect vision, speech, hearing, or behaviour.



Picture 1: The process of driving a car represented as a closed loop system with feedback

About Cerebral Palsy

Cerebral palsy (CP) refers to a group of permanent and non progressive brain dysfunctions that affect a patient's ability to move. CP is one of the most common causes of childhood physical disabilities, though the effects differ from person to person depending on severity. A child with severe CP may not be able to walk at all, causing them to seek continual assistance from the families, therapists, or assistive devices. On the other hand, a child with mild CP may have relatively little motor deficiency and not require much special support. [1]

The types of CP can be classified into:

A) According to the movement (tone) disorder

1. Spastic (Pyramidal) - Increased muscle tone with damage occurring at the Pyramidal Tract. The muscles become overactive when used and produce clumsy movement. Normal muscle works in pairs: When one contracts the others relax. Spastic muscles become active together and block affective movement. It Accounts for 70-80% of CP cases. Lesions to the brain's cerebral cortex are generally the cause of it.

2. Non-Spastic (Extra pyramidal) - decreased or fluctuating muscle tone divided into two categories:

(a) Hypotonic/ Ataxic - affects balance and coordination. It is the least common type of CP. This type of patient has poor muscle power poor balance, problem in depth perception and co-ordination. Damage to cerebellum is the cause.

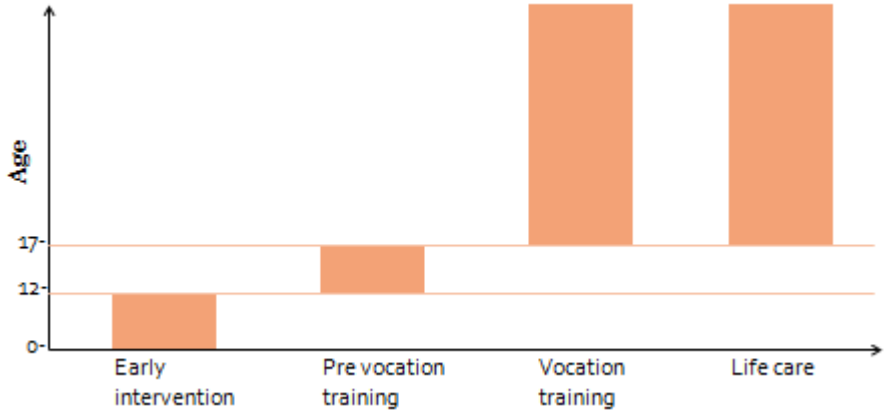
(b) Athetoid/ Dystonic - characterized by continuous or intermittent muscle torsion and abnormal posturing. Fluctuating tone, leads difficulty in controlling tone and co-ordinating movement. They may have involuntary movement and are constantly in motion. It results from damage to Basal Ganglia.

3. Mixed - a child may have mixed symptoms from both categories.[2]

B) According to number of limbs affected:

1. Monoparesis — One leg or one arm
2. Paraparesis — Both legs
3. Hemiparesis — One arm and one leg on either side of the body
4. Tetraparesis/Quadriparesis — All four limbs

Activities at the centre



Picture 2: Activities at the centre

Picture 3: Mr. Rupesh teaching a deaf and dumb child

1. Early childhood intervention

The age of students in this group is from 6 months to 12 years. Their activities include:

1. Gross motor activities: like jumping, playing, swinging, hopping, football etc.
2. Fine motor activities: drawing, painting, clay modelling
3. Communication activities: vocabulary development, sentence formation, greeting others
4. Activities of daily living (ADL): eating, bathing, Toilet training, dressing, wearing shoes etc.
5. Social activities: interacting with others in group, play, learn and share.
6. Therapy: play therapy, physical exercises, Audio-video, speech therapy, eye-hand co-ordination, behaviour modification
7. Pre- academic activities: Concept development (recognizing animals, vegetables, parts of body, numbers etc). Parents are also trained to conduct these activities at home along with counselling for positive attitude. [4]

Picture 4: Children working on different activities

Picture 5: Children learning to make sculpture

2. Pre vocation group

The age group of students in this program is from 12 -17 years. The individual action plan for each student is made during the assessment session, taking into consideration his/her disability and the past level of training and education. Those who have not received any kind of intervention need to be attended to from the early intervention stage. The activities include:

1) Communication activities:

a) vocabulary development,
b) sentence formation,
c) Greeting others by shaking hands, waving hands, folding hands, smiling etc.
d) Understand and respond to question like 'what, where and when'
e) Using gesture, sounds, words to indicate hunger, thirst, etc.

2) Activities of daily living (ADL): eating, bathing, Toilet training, dressing, wearing shoes etc.

3) Social skills:

a) Playing in pairs or small groups
b) Using social conventions of gratitude like please, thank you, sorry etc.
c) Group activities focussing on area of social interaction.

4) Functional Academics:

a) Sequential concepts like

i) Remembering at least six objects in sequence
ii) Days of the week, months in order
iii) Should be able to use 'before' and 'after'
iv) Counting 1-50 forward and backward. Recognising numerals
v) Reading time from clock
vi) Concept of money

b) Problem solving: Defining right and wrong in simple problems

The levels of the activities are as per the understanding of the students. All training activities are imparted in form of games and entertaining activity with emphasis on visual programs to keep their interest.

GODs Saagarika at Gorai

The internship started with first two weeks at the GODs Saagarika centre. This centre is located at Gorai. The centre is a two floor bungalow in which the ground floor is kept for activities and dining area. The first floor residing is for teachers and students who are admitted as life-care members.
There were three special educators who took care of the students. There were 18 students of which 6 were girls and participated at day care centre. The males were all aged 18 to 65 years. They all were residents of the centre. One of the educators along with a care taker always stayed with them.

Information on Mental retardation was provided as Module on Training of Resource Teachers[3]
It defines IQ as

$$IQ = \frac{\text{Mental age}}{\text{Actual age}} \times 100$$

Observations:
Assisting students in their day care activities helped in making observations. At Gorai centre, they were making carrying bags out of newspaper. They were working to complete a consignment of the paper bags. They used three full size newspapers, stuck them together and formed one bag. Most of the students were part of the team which would glue the newspaper together. The teachers would then fold it appropriately and then staple the thread so that it can be used as carry bag.

Picture 6: Kelvin making paper bags

Kelvin (Picture 6), a paraplegic with Mental retardation had problems in applying the glue. The care takers told that he was hyper active as well as aggressive when he first came in. But now he has been participating in the activities, became calm and works enthusiastically. While he was working, it was observed that he could understand that he had apply glue at the edges of the paper but could not repeat the same process in order to optimize the time. He needed guidance to tell him where exactly to apply glue. Also, he could not apply glue linearly. He would often deviate from the edges and apply glue at the table beneath.

Picture 7: Uday making paper bags in the centre

Uday Garodia (45) is a person with CP. He stays quiet for most of time; speaks extremely slowly. He is completely dependent on the care takers for his daily needs. He is very well versed with English, hindi and gujarati. He reads newspaper regularly. His responses are extremely slow. He is capable of activities like holding cup, having food and drinking water. But even these activities take a lot of time. His lunch time duration extends to one hour. Also, while having lunch he requires constant observation from care takers if he didn't drop any utensil. Only caretakers could understand easily what he wanted to say.

Picture 8: Holy magi church. Gorai has catholic community

Cecil de mello, the person in charge at the Gorai centre spoke about objectives of their organisation. Their objective was to provide a sustainable economic development through social enterprise. He said that they have to look at the local needs and supply them to people.
He says, "We don't want people to buy our products because of charity, but because they actually need them". Realising a local need he has now decided to go ahead with his plan to make his centre financially sustainable. Since the community in Gorai is Catholic, they extensively use candles for their religious rituals. Therefore they have been marketing candles made by the students here to churches and families which come there to pray.

Cecil along with all the staff had gathered for a meeting to discuss their plans and targets for next year.

Amongst the meeting agenda, were the issues of pre vocation training. They discussed that:

• If students could learn to count at least till 100 they would be capable of doing many activities and can reduce a lot dependency on the care takers. Be it, counting paper bags, candles or phenyl bottles.
• It was important for the students to understand why they were celebrating an occasion or festival. By using various mediums student can understand about the essence of festivals.
• If speech therapy could be provided at early intervention the child would grow up to be less dependent on others.
• They set their priorities to sell their products. They discussed about their logistics in coherence with their other centres at thane, powai and chembur. They planned to make a presentation and go to churches in the vicinity.

Problems faced by the centre

The problem they faced was, people still perceived an NGO to be not for profit and when they see them selling products they doubt their intentions. Therefore, a thorough presentation was needed so that people could understand what the intention of the MBA foundation was. They planned to look at more profitable products and increase its production.

• They faced problems with accounting for the products as well as day to day expenses. The teachers had to double up for the job of administration.
• They lacked basic exposure to ICT (information and communication technology) training.
• Another barrier was the teacher's disinterest in computers. This is understood as their majority of time is spent in taking care of the students. They said it's a 24X7 job and sometimes they don't even get enough sleep. But an up gradation on their computer skills would definitely be fruitful for the NGO.

Picture 9: Students and educators at Gorai centre

The task given was to make a presentation which would make an impact on the local people. It included collecting information about the centre, organisation and the products they make, their history, their present work and future plans.

Since it would be shown to people at church, candles would play an important part in this business pitch therefore it must be presented well. The presentation was made and it included photographs of all the candles they offered. The photographs of all the candles were taken at the centre and the studio environment was arranged at the centre itself.

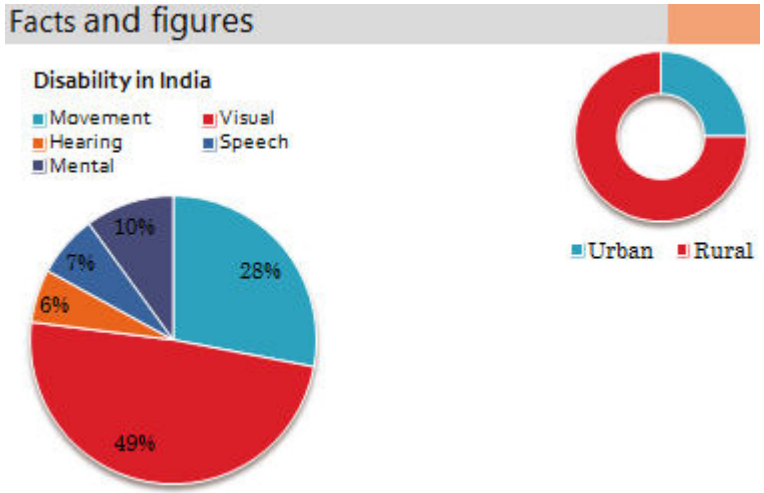
Picture10

Picture12

Picture11

Picture13

Picture 10-13: Photographs of candles made by students to be used for makrket-ing.



Picture 14: Info graphics made for the presentation.

The other task was to work on a presentation which would be used for business pitch for the foundation. The objective was to highlight the history of foundation and efforts that the children were putting in to continue with their living.

GOD's Heaven Powai

The powai centre is also the head office of MBA foundation. Two weeks were spent here. There was opportunity to work on the marketing side of the foundation here. While working in this centre I got opportunity to meet CSR manager of MNCs, attend exhibitions held by the foundation, work on brochure design, attend CSR events and assist children in their activities.

Picture 15: Nilesh making a sculpture

The first day was to observe and get to know students at the centre. A group of students were filling Phenyl bottles. They were not using any reference for the volume to be filled. The group had distributed the task, namely of filling the bottle, collecting the empty bottles, putting the cap, washing it and then packaging.
While observing them, it was evident that they faced problem while aligning the funnel with the bottle opening.
This could be due to weak control over the muscles or problems in spatial ability.

Picture 16: Brochure design for new centre at Airoli


Picture 17: MBA's exhibition at kamani Oil Factory, Sakinaka

Observations of people with Cerebral Palsy (CP)

1. Akshat Gambhir, 24, Male

Diagnosis: Athetoid CP with mild spasticity, multiple spastic contractions, currently wheel chair bound with problems in speech, epilepsy.
Dependency: Completely dependent on care takers
Health: Good physical health and personal hygiene
Social: Good interpersonal skills. He likes to interact with everyone and shows good participation in group therapy. But due to physical limitations he gets restricted with few activities.
Motivation: needs to be motivated
Activities: pasting paper bags, gifts envelope with help an aggarbatti packing

Treatments from past:
1. Extension and flexor muscle movement
(extension is a movement of a joint that results in increased angle between two bones or body surfaces at a joint. Extension usually results in straightening of the bones or body surfaces involved.
Flexor is a joint movement that decreases the angle between the bones that converge at the joint. For example, a person's elbow joint is flexed when the hand is brought nearer to the shoulder) (wikipedia)
2. To teach co-ordination movements
3. Trying to sit and balance
4. To improve speech, Om chanting, tongue exercise, breathing exercise
5. Activities like cycling, pulley, putty and rowing.
Results from the treatments:
1. Stiffness and pain is reduced.
2. Enjoys exercise
3. Sitting posture is improved
4. He can speak letters of the alphabets, days of weeks and months but not with clarity

Observations of Occupational therapists

1. He has history of CP. He is able to communicate his needs but it is difficult for people around him to understand him, especially if someone is new.
2. Conversation is very limited. Conversations are not initiated at all
3. During sessions, he explained that "papa loves him" but was unable to express himself in more detailed manner so as to why and how.
4. He needs more time to explore how to express emotions and relations

2. Rohit Gambhir, Age: 38 Male

Diagnosis: CP with Athetoid (severe), mental retardation, Epilepsy
Dependency: Completely dependent on care takers
Activities: pasting paper bags, gift envelope, gift envelope, aggarbatti counting.
Extra curricular activities: yoga, physiotherapy, painting.
Overall: Social but limited by speech. He likes painting and is enthusiastic to learn new activities but due to severity of his disability he is restricted.

Physiotherapist's observation:
• Hip muscle are tight,
• knee muscles are tight,
• hyper active,
• no balance while sitting
• Can't balance head at upright position
• No co-ordination of limbs
• Drooling of saliva

Treatment suggested
• Flexor and extension muscle movement
• Active assisted movements to all joints
• Try to balance while at sitting position
• Teach co-ordination movements with Proprioception (the sense of the relative position of neighbouring parts of the body and strength of effort being employed in movement.) (wikipedia)
• To improve speech by Om chanting, tongue exercise, mouth exercise and breathing exercise

Long term: He would require spinal brace

Observations of Occupational therapist
• Body symmetry, oral structure and posture are affected
• Speech affected
• Head is not in the middle of the body
• Asymmetry of shoulders and internally rotated
• Elbows flexed and forearms pronated.
• Asymmetric trunk, hips adducted,
• Ankle in plantar flexion (Plantar flexion is the movement which increases the approximate 90 degree angle between the front part of the foot and the shin, as when depressing an automobile pedal or standing on the tiptoes.) (wikipedia)
On examination:
• Voluntary control is poor
• Severe Scoliosis (a medical condition in which a person's spine is curved from side to side. Although it is a complex three-dimensional deformity, on an X-ray, viewed from the rear, the spine of an individual with scoliosis may look more like an "S" or a "C", rather than a straight line) (wikipedia)
• Hand function not properly developed
• Tightness of both upper limbs, hip flexor and knee flexor

Recommendations
• Generalised mobilization and stretching exercises
• Overall motor development
• Proper positioning on wheel chair
Total body contact brace to prevent Scoliosis

3. Manisha, 34, Female

Diagnosis: Triplegic CP with mild spasticity, multiple spastic contractions, currently wheel chair bound,
Dependency: Partially dependent on care takers
Health: Good physical health and personal hygiene
Social: Good interpersonal skills. She likes to interact with everyone. She works in an MNC and also takes care of other students in centre.
Motivation: Highly motivated to work in an MNC
Activities: She works at reception of the office. Attends the calls, operates computer, has basic ICT knowledge. She has problems while using keyboard and mouse due to pronation of hands.
Recommendations from physiotherapist: Regular physiotherapy to maintain flexibility, motivation and confidence.
Computer efficacy:
• She can type at a speed of 32 words per minute.
• She can operate mouse but the wire of the mouse gets entangled.
• For pressing the mouse button she has to align her hands in a specific way
• When given a task to open word processor, she was able to do it using a combination of keyboard and mouse commands. But mostly mouse.
•She faced problem while applying complex formulas in excel.
• She wanted to customise multiple key presses in key boards
Communication: Even though her speech is normal and can communicate well with others, she complains of epileptic seizure during which she can't communicate with others.

4. Ashwani, 35, Female

Diagnosis: Triplegic CP with spasticity, limited hand movement, unresponsive legs, multiple spastic contractions, currently wheel chair bound, spine support, problems in speech, weak eyesight
Dependency: Completely dependent on care takers
Health: Good physical health and personal hygiene
Social: Good interpersonal skills. She likes to interact with everyone. She enjoys doing activities at centre and as is friendly with others.

Motivation: Highly motivated to do activities at the centre
Activities: She likes painting diyas, pots etc. Even though a little help is needed from the care takers she does the job with efficacy. Packing Aggarbatti and counting.
Observations:
• She was able to paint the mud plate in fair amount of time efficiently.
• She could also pick up the paint brush by herself
• She could understand all the conversations and commands given to her and respond appropriately
• She could count till 50 but had problem in remembering the last counted number after 30
• She would salivate excessively

5. Renuka, 42, Female

Diagnosis: CP with mental retardation, spastic Triplegic, operated on both legs
Dependency: Completely dependent on care takers and mother
Health: Good physical health and personal hygiene
Social: Good interpersonal skills. He likes to interact with everyone and shows good participation in group therapy. But due to
physical limitations he gets restricted with few activities.
Motivation: Low
Activities: Threading napkin edges, aggarbatti packing, envelope pasting.

Overall progress in past 3 years:
• She goes into depression and indulges in self stimulated jabbering which overshadows her general abilities
• Health condition is deteriorating
• She is interested in participating in activities like yoga and bhajans
• She has been irregular to centre due to illness
Recommendation from doctor:
• She should be allowed to stay in respite care for a few days
• She has to learn to stay independent from her mother and give other care takers a chance

Communication
• Comprehension- poor
• Expression – need assistance
• Reading/ writing – need assistance
• Money value- poor

Social
• Behaves well in group social activity
• Sits quietly without fidgeting in social situations
• Helps others when asked
• Contributes meaningfully in decision making conversations
• Is stubborn, while interacting with other care takers

Future: To make her less dependent on her mother and give other care takers a chance. To continue therapy to increase flexibility of legs.

Veena Advani, 82

Mother of Renuka Advani (CP) and also the trustee and director of Chembur centre of MBA foundation.
Following are excerpts of Mrs. Veena describing her experience about raising a child with CP.

• She knew about her child being CP affected since a year from birth.
Doctors at KEM had told her about the disorder after she was born.
• She ignored at the beginning but her physical weakness started affecting her normal being.
• She was admitted in Wadia hospital till the age of 12. She also underwent surgery on her legs to improve stability while walking.
• After the age of 12 she was shifted to special school at Colaba and physiotherapy at children's orthopaedic hospital at Haji Ali.
• While going to school at Haji Ali her condition improved and she could stand on her own. She was doing well in studies. She was able to speak, read and write.
• After her father's death she couldn't cope up. Her condition started deteriorating.
• She had to carry her child on her back even after she was 12 years old. Due to this she suffered from back ache.
• She started a day care-centre for children with special need in chembur at her own flat. Initially there were 5 students and presently the number has gone up to 22.
• Presently she is 82 and Renuka is completely dependent on her. Even though there are other care takers she prefers to talk to her mother only. This is Veena's biggest concern.

Meenakshi Balasubramanium

Mother of child with special need and founder and trustee of MBA foundation
Following are excerpts of Mrs. Meenakshi describing her experience about raising a child with special need and her experience of training children with special need.

• She believes that child with special need should be taught till an optimum level, so that it balances his/her physical and mental capability. If a person with physical constraints learns more than his capability then he/she might face problems in applying that knowledge.
• She talked about her experience of training children with spasticity. A keyboard with holes for different keys helped the kids in pressing right key. As they have shaking hands.
• She talked about a person who was CP and had a degree of Bachelor of Arts, but could not get a job because of his inability to communicate. He was always depressed because people who were less qualifies got better jobs than him.
• There was another case of girl who was paraplegic but completed her education in the USA and went on to present her research paper in conference. This highlights India's ignorance for universal design and considering.

Survey of assistive devices for people with CP

While no cure is known for any of the subtypes of CP, many of the capabilities of the patient can be improved using a variety of methods. Orthotic devices and mechanical aids can help to improve mobility and posture, while speech therapy and communication aids, such as voice synthesizers and computers, can help to alleviate the affects of communication difficulties.

With the increased feasibility and applicability of robotic solutions to physical problems, rehabilitative therapy for CP has begun to see some benefit. Robotic devices that assist in patient exercises during therapy sessions have been shown to increase positive outcomes, as well as providing other benefits. Robotic devices also show promise as measurement aids to help gauge the abilities of the patient, as well as improvements over time.[1]

Examples of assistive devices:

Picture 18: Arun Mehta with his setup

1. Arun Mehta from Delhi has designed a communication system for a child suffering from cerebral palsy condition. The best part is that the technology can be extended and applied for the benefit of many more such children.
The set-up includes nothing but normal computer hardware, including a PC monitor, CPU, speakers, etc. However, for an input device, Mehta has replaced the traditional keyboard and mouse with a gaming console that we normally see kids playing racing games with. “This is because Arpit cannot control his hand movements, which makes it extremely difficult for him to type or navigate using a mouse.”[5]

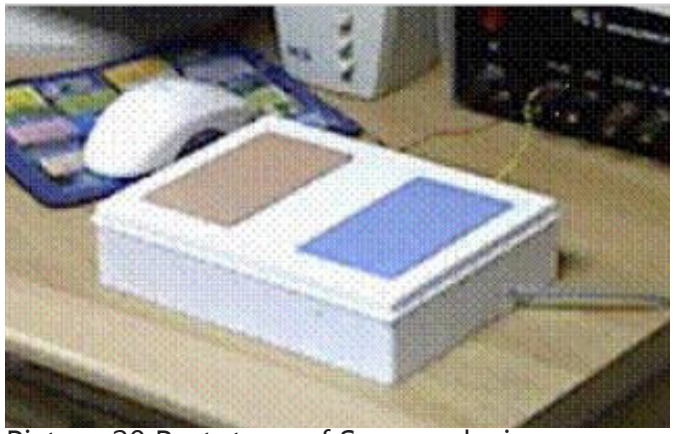

Picture 19: Ajit Narayanan with his invention

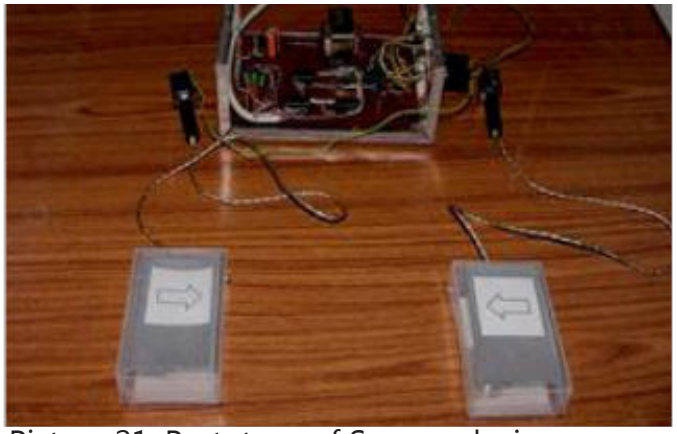
2. Avaz, the speech therapy app for autism and CP, is the culmination of four years of research, involving more than 20 speech therapists and educators. It was also included in MIT's TR35 list of transformative innovators in 2011.

Speech synthesizers have long been used in the West (perhaps most famously by Stephen Hawking), but they are prohibitively expensive to all but the richest in India. Narayanan's Invention Labs, based in Chennai, designed Avaz to be not only cheap but also capable of supporting multiple languages.

Tablets like the iPad are revolutionizing the way children with special needs communicate. To tap the true power of these devices, we need relentless invention: in technology, in special education and in therapy. [6]

3. Sanyog: a low-cost iconic communication system has been designed to aid people afflicted with cerebral palsy and motor neuron disorders. The system is fully portable and has been specially designed to cater to the Indian society. The biggest advantage of the system is its inherent user friendliness achieved with the incorporation of appropriate user interfaces and specially designed accessibility devices. Sanyog is a complete embedded system solution for children.[9]


Picture 20 Prototype of Sanyog device


Picture 21: Prototype of Sanyog device

Picture 22: Foot operated keyboard for Hemant

4. Professor G.G. Ray of Industrial Design Centre, IIT, in cooperation with Happy Hours Centre, a school for children with special needs, had developed a unique type of foot-operated personal computer-based communicating tool for children with cerebral palsy.
The input is through specially developed foot-operated switches in conjunction with specially developed software to cater to the needs of children who can neither speak nor have adequate control over their body movements except a marginal control over their leg and toe muscles.
The foot-operated keyboard and monitor are set on a sturdy wooden stand to enable the child to operate it with ease while seated in a wheelchair.

Picture 23: Professor Anupam Basu from IIT KGP

5. This special device is designed by IIT-Kharagpur professor. It is loaded with a talking keyboard and a series of voice-assisted applications for cerebral palsy patients and others with limited limb mobility. These applications would help persons with disability communicate better with those around them. It is a more comprehensive device, much more affordable than its foreign counterparts. IIT-Kharagpur and the Society for Natural Language Technology Research are also working at designing web browsers for blind users and for those with cerebral palsy [10]

Design Ideas

1. "If we could build a community radio for the people of Gorai, we could spread awareness about people with disability and how to bring them up. We can also promote local music and market the products."- Cecil
2. "We need a network of special educators. Due to various reasons teachers migrate and we take teachers who teach at normal schools and make them undergo training for children with special needs. It would be nice to have contacts of such teachers".
3. A device that could help people with spasticity to practice linear motion, circular motion, figure 8 etc. These would help them in Occupational therapy, thereby making their work more productive.
4. A tangible device which can train them for alignment in 3D space. A tool which trains their spatial ability.
5. For exhibitions, they could use portable computer and projector. This would help them spread the message about the people who make it.
6. A communicative device which can at least respond as 'yes' and 'no'.
7. If Multiple key press can be customised on a specific key it would help in operating complex functions in MS Excel

Insights

1. A person with disability may have combinations of disability due to various reasons. While at NGO, I observed people had physical disability coupled with mental retardation.
2. A person with CP has unique set of disability. To overcome that we have to look at individual case separately. In order to come up with an assistive device a set of tools has to be developed which can be used by them as per their need.
3. CP treatment is an area that has begun to benefit greatly from emerging technologies, warranting further research efforts. Continued work in many areas, such as robotic manipulation, control, biomechanics, and pervasive electronics, will lead to future advances for CP and other disabilities.
4. Sometimes, a little modification in normal devices can lead to great benefit for people with disability, e.g. a key board with holes for key press.
5. For people with disability, working in a normal office environment is dream. If by any means they are able to do it, they would be satisfied.
6. Priority on developing therapy or tools for occupational therapy shall be beneficial for the students. As it helps them to work efficiently.

Suggestions for NGO

1. A good area to work upon would be ICT (information and communication technology), if they could operate the services Google provided, namely drive to share their work, document, spreadsheets, maps, calendar etc. It would be worthwhile if all the documents would be on the cloud and could be shared real time.
2. To have a dedicated social media manager. Presently a facebook page exists. But a dedicated person who updates regularly and communicates with those who follow would help them spread their product's customer range.
3. The web presence for online shopping is presently being tried in associations with other organisations. If that also be linked with social media platform, it would be helpful.
4. Suggestions on Exhibitions

a. The people who already knew about exhibition were interested in buying products but those who didn't knew about the organization just passed by. For engaging people who aren't aware about NGO, a portable projector with a portable small size computer would be fine for showing students who are involved in work.

b. The product range on exhibition were feminine, therefore men bought only aggarbatti. Products from consumer goods range can also be looked upon.

Conclusions

After spending a month at an NGO that works for people with disabilities it is possible to conclude that:

1. People with disabilities can lead life with dignity if they are given opportunity and support.
2. The insights gained out of experience would definitely help in developing design issues for further projects.
3. Technological interventions help in as career enhancements, assistive or therapeutic.

Through the experience of internship it's clear that every person with CP has different tones of disability. In order to come up with an assistive device an individual case has to be taken and worked upon, thereby finding a link which is common to all.

In future, meetings with occupational therapist and physiotherapist would further enhance the findings and help narrow down the concept for the product.

References

[1] Published in: Proceedings of the 5th International Conference on PErvasive Technologies Related to Assistive Environments by Christopher McMurrough, Shahina Ferdous, Alexandros Pa-pangelis, Angie Boisselle, Fillia Makedon Heracleia. A Survey of Assistive Devices for Cerebral Palsy Patients. 2011
[2] Manual for training of physiotherapist, 2010
[3] Training Module on Cerebral Palsy and Locomotor Impairment by Sarva shiksha abhiyan
[4] 10th annual report of MBA foundation
[5] EFY- http://www.electronicsforu.com/electronicsforu/circui-tarchives/view_article.asp?sno=658&title+=+Technology+to+aid+disabled&id=5033&article_type=5&b_type=new
[6] http://www2.technologyreview.com/tr35/profile.aspx?TRID=1097
[7] http://www.zoominfo.com/CachedPage/?archive_id=0&page_id=1048633298&page_url=//www.gulfnews.com/Articles/World-NF.asp?ArticleID=156801&page_last_updated=2005-03-19T01:26:04&firstName=G.G.&lastName=Ray
[8] www.lifecare-disabled.com
[9] An Iconic Communication Aid for Children Suffering from Cerebral Palsy and Motor Neuron Disorders
Authors: Arijit Mukhopadhyay, Soumyajit Dey, Pawan Saraswat, Susmit Biswas, Vijay Srinivas Nori, Samit Bhattacharya, Anupam Basu
[10] http://www.telegraphindia.com/1130516/jsp/calcutta/sto-ry_16904600.jsp#.UdlRG239Uag

Index of pictures