

 **ASTHA**

ANNUAL REPORT 2003 – 2004

THANK YOU !

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Mr. Arun Seth and the entire DOXA family (Delhi Old Xaverians Association)
Ms Sangeeta Suri
Sourav Nandi and his team of 'Make a Child Smile' from Cadence Design System
Mr. & Mrs. Shekhar Gupta of Indian Express
Dr. Neelam and her team from Venu Eye Institute
Dr. Mathew Verghese, Director, St. Stephen's Hospital
Mr. Sreekant Khandekar
IIM Ahmedabad's batch of 1971
Ms Rupali Dutta of Batra Hospital
Dr. Anita Bakshi
Dr. Anjali Masodkar

Organizational Support

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The year 2002-2003 was a year of intense activity for ASTHA. Apart from its usual programs, the agency took on two year long projects. The HPS foundation project focused on creating education based opportunities for children with multiple disability in the community. The GIVE Foundation funded ASTHA to conduct training in disability for community workers of different organizations.

Both programs added significantly to the organization's expertise and enriched our work. ASTHA was able to link and learn about many different organizations through both projects. Our interaction with community workers from different organizations added to our deep respect for their work.

As the understanding of disability changes within the sector and many new schemes and opportunities develop, ASTHA is beginning to redefine its policies and rethink its work. From aiming to be a caring organization that provides quality services we are now moving towards being an organization that works in partnership with persons with disability and their families with a rights perspective

The shift in our service provision has been from focusing on the condition of the child and management of the disability to recognizing children and people with disability as individuals with rights and abilities, understanding the barriers that they face and working towards their inclusion in society in partnership with them and their families.

This has meant a re-negotiation and change in every aspect of our work, including how we conduct assessments, plan programmes and the kind of information we share with families and children and persons with special needs. It has meant a re-negotiation of our understanding of the concepts of partnership and quality.

Information dissemination and advocacy has always been an important element of ASTHA's work. This year we took the plunge and worked hard to gather information and then organizations to work on the very important subject of the disability certificate. It was heartening to see that many organizations shared our concerns.

CENTRE FOR CHILDREN WITH SPECIAL NEEDS (CCSN)

Location	Tughlakabad Village
Number of Persons with Disabilities	24
Multiple Disabilities	16
Mental Retardation	5
Autism	3

Aims

- To provide quality services to children with multiple disabilities
- To focus on children with moderate to severe disabilities and their families
- To become a resource center for information and training in multiple disabilities

Based in Tughlakabad village, this is one of the very few centers that provide services to children with a range of multiple disabilities. For these children who face many challenges, ASTHA's task is to provide the services and opportunities they require to develop their abilities. The Centre for Children with Special Needs does this by providing services like physiotherapy, education and speech therapy, counselling and information and opportunities for growth and development.

There are four classes. Children in each class are unique in terms of the challenges they face, their abilities and have different learning styles.

In their respective classes, children learn from their educators and go for therapy sessions. The team carefully assesses each child and an individual programme is designed within a broad curriculum for that class. Attention is given to how a child must be positioned, what aids to be given and how the child learns best. Each child has a special chair and a table/tray and, the seating is reviewed from time to time and alterations made accordingly.

The children are taught both individually and in groups. Learning takes place through fun filled activities, music, clay work, drama, celebrating festivals, outings and through practical situations.

Over the 11 years that this Centre has been running we have learned, without doubt, that every child has the potential to learn.



It is with this spirit and belief that this year too, the Centre has bubbled with activities. The ever growing opportunities created by different organisations in the city have been seized by us.

A First Time for Everything

There is first time for everything. Our children had several new exciting experiences this year.

On 15th August, Sushmita Burman, was selected to travel by air to Amritsar to participate in **Independence day celebration** at Jalianwala Bagh. Sushmita was awe struck and euphoric with her experience.

This was the first time that the children participated in **Special Olympics Bharat**, held in February 04. It was heartening to see children who had learnt to walk holding on to our fingers, competing confidently on the track, all alone.

Himanshu and Punita were proud winners of the gold medal, while Sushmita carried home a bronze.

In March 04 our children participated in a **quiz competition** organized by Four Steps. For Kedar it was special experience. When people meet Kedar they do not believe that he has high intelligence. For Kedar, who communicates through a board and head gestures, it was a challenge to communicate in front of so many people and in a competitive environment. But he did it and won two prizes!!

Talking through Drama

Children with special needs are always seen as recipients of information. It is time we turned the tables. We saw drama as one of the best mediums of doing that.

Seven senior children along with their teacher worked on a skit on how to celebrate Diwali, safely. The skit was performed at St. George's School, Alaknanda, one of the leading schools in South Delhi. The play was well received by the students and staff members of the St. Georges School. Another first, which we hope to perform in many more schools!!

Sports Day

'Meri bari kab ayegi' was the common refrain we heard at the second Annual Sports Day held on 12th February. The event was held at the government school in the neighbourhood. Children from all the three projects participated in the various sports activities. Several events were organized so as to ensure that all the children, however severely disabled, participate in at least two events.

Some of the new races included the rolling race, the bottom-shuffling race and the innovative hurdle race.

Another important feature of the sports day was the participation of the government school. The school not only allowed us to conduct the event, but also supported us by providing about 10 student volunteers who assisted us in all possible ways. This way the event also provided an opportunity for mutual interaction.

Exposure Visits

Taking children on outings has always been among the most important activities at ASTHA. Every year children are taken to several exciting places, enriching their knowledge.

Some of the interesting places that we visited this year include :

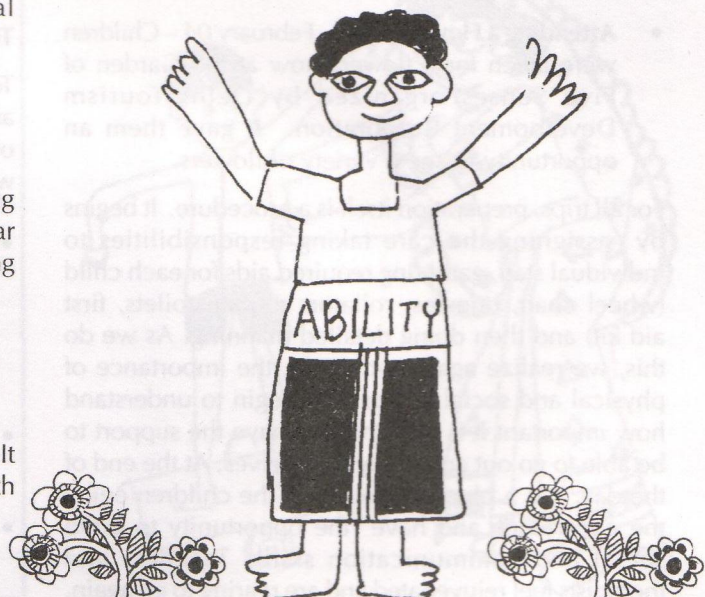
- Visit to the **Garden of Five Senses** – August 03. It gave the children an opportunity to interact with nature and enjoy rides in the solar run buses.

Ishaan Roy Chowdhary is an 8 year old boy with Autism spectrum disorder. He joined ASTHA in the year 2001. Both his parents are highly qualified. He has a sister who is younger to him.

Ishaan is a bright and intelligent child. He has a special interest in maths. His family is very supportive. Their main concern for Ishaan was to build his social and communication skills. While he worked beautifully in one on one situations, he did not like to participate in group activities.

Now, with systematic exposure and family support, Ishaan is able to participate in group activities both at class and school level for a short period. He has begun participating in school celebrations, sports day, theatre and performing under supervision.

His interaction with others has also improved. He reciprocates greetings with a quick shy smile that lights up his whole face and has begun to convey short messages.





- **Enthralled by Jazz** – October 03 – the children at ASTHA were invited to attend a Jazz programme organized by the British Council Library, held at Delhi Public School, R.K. Puram. Children had a wonderful time and they joyfully participated in the chorus.
- **Visit to Bal Mela** – November 03. On 'Childrens Day', children from all projects were taken on a trip to Balmela, which was organised by 'The Deaf Way' at Indira Gandhi Indoor Stadium. Some children won prizes in the games and many enjoyed the camel and elephant rides. Some did not want to leave the dance floor.
- **Attending a Flower Show** – February 04 – Children were taken for a flower show at the Garden of Five Senses organized by Delhi Tourism Development Corporation. It gave them an opportunity to see a variety of flowers.

For all trips, preparation itself is a procedure. It begins by assigning the care taking responsibilities to individual staff, gathering required aids for each child (wheel chair, buggies, rollators mobile toilets, first aid kit) and then doing detailed planning. As we do this, we realize again and again, the importance of physical and social access. We begin to understand how important it is that children have the support to be able to go out and enjoy themselves. At the end of the day, it is a pleasure to watch the children enjoy the experience and have the opportunity to build social and communication skills. Teachers and therapists feel rejuvenated and are rearing to go again.

The Nutrition Project

As a part of her project 'Nutrition problems in children with CP, MR and Autism', Mrs. Veenu Seth – Reader, Lady Irwin College, approached ASTHA with a proposal. Since nutrition plays a very important role in the health and development of the children, ASTHA readily agreed to the project. With permission from parents, Mrs Seth studied diet patterns, correlated it with height and weight of the children, shared her findings with parents and the staff members and framed a specific diet programme for each child.

Training : Keeping Pace with Change

To keep pace with change and evolution in this field, at ASTHA we make it a point to constantly upgrade ourselves through attending training programmes and workshops

- Inclusive education – June 03. One Staff member from the centre attended a ten day training workshop called 'Joyful Inclusion' a course conducted by CBR network (South Asia), Bangalore
- One staff member attended and completed a three month course run by RCI July 03 – Sept 03
- Three staff members completed their B.Ed in Special Education from Bhoj University M.P (Distance Education mode) in December 03

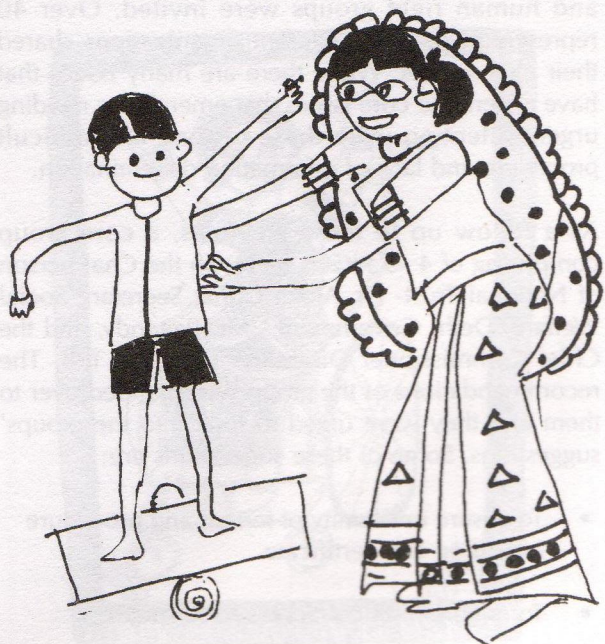
Himanshu, 13 years old, has been attending ASTHA's Centre for the last seven years. Over these years he has worked hard at many different skills. He is being given training in independent living skills i.e. training in independent mobility, fine motor skills, speech for clarity and articulation and functional academics.

At ASTHA, Himanshu does many exercises to strengthen his ability to balance. He is now able to take about 10 steps without support. Because of difficulties in balance, he also has a tendency to fall frequently. So a helmet was suggested. With the helmet and an increased ability to balance, he moves around the school confidently.

Himanshu has tremors in both the hands and this comes in the way of several hand activities such as colouring, painting, cutting, pasting, writing; activities which he likes very much. With weighted bracelets around both wrists the tremors have greatly reduced and he is able to learn and use simple painting techniques. With the bracelet and an adapted pencil, his writing has also become more legible.

Himanshu is a confident boy. In spite of his challenges he does not hesitate to participate in dance, music, outdoor games, art competitions and, compete with others. He won prizes in a painting competition. He is also a recipient of a gold medal in the Special Olympics Bharat, Delhi chapter, in 25 metre assisted walking.

Growing up with few friends, Himanshu has had to depend heavily on his family for companionship. For a young adolescent and his family this can be very difficult. Recently, ASTHA put Himanshu's family touch with Ishwar, an organisation that has organised weekend sports for children with special needs. Being out every weekend, making new friends will, we hope, make all the difference in this young man's life.



INFORMATION, COMMUNICATION & COUNSELLING UNIT

Aims

- To generate information in the area of disability relevant to the Indian environment
- To reach out with information to people with disability and their families
- To conduct research on issues that directly affect the lives of people with disability and their families

The unit does this by constantly collecting information, conducting workshops and sharing sessions.

Disability Certificate

ASTHA has always believed in researching issues that arise in our work and then taking action on them. Over the years we have been witness to the great difficulties that persons with disability and their families were facing in getting the disability certificate. The disability certificate being an extremely important document, we felt that we must act to change the situation. Our first step was to research, discuss and document our own experience.

Then, in September and November ASTHA convened two meetings to discuss the issues surrounding the disability certificate. Representatives of NGOs, legal and human right groups were invited. Over 40 representatives from different organizations shared their experiences. While there are many issues that have arisen, the core issues that emerged as needing urgent attention were those of long and difficult procedure and lack of information dissemination.

As a follow up to these meetings, a core group comprising of 4 -5 NGOs met with the Chairperson of National Trust- Dr. Alok Guha; Secretary Social Welfare, Delhi Government - Mr. Paitandy, and the Chief Commissioner Disability- Dr. Uma Tuli. The recommendations of the group were handed over to them and they were urged to look into the groups' suggestions. Some of these suggestions are:

- To ensure uniformity of format and procedure forgetting the certificate.
- To enable physical access to hospitals.



- To review assessment procedures, especially for persons with mental retardation.
- To ensure camps for giving disability certificates in all zonal areas of Delhi, on a regular basis.

Understanding Insurance

Furthering our endeavour to meet the need for medical and life insurance for persons with disability we met with various representatives of the insurance sector.

While medical insurance does not seem to be a very viable proposition for insurance agencies, life/general insurance policies do exist. We have had five meetings with representatives of National Insurance Company, Royal Sundaram, Bajaj Allianz, Life Insurance Corporation and HDFC Standard Life Insurance Company Ltd together with parents of children with disability. Through these meetings we have tried to understand the views and needs of both sides.

With the help and guidance of experts in the field we hope to facilitate a better understanding of the different insurance schemes available.

It was October and Sanjay's son, Ravi had his Class-X board exams in March. Ravi was finding it very difficult to cope with his studies. In his mid-term exams he had averaged just 30%. Sanjay came with Ravi's papers and assessment reports. Ravi had a learning difficulty. This was detected three years ago, but no intervention had been initiated. "What can we do now?" was Sanjay's question. "This is a very crucial year for Ravi."

A multi-strategy plan was worked out with him. It included:

- Getting a formal assessment done to certify Ravi as having a learning disability.
- Finding out concessions offered by the CBSE.
- Seeking the help of a special educator.
- Discussion with the school on the various avenues and options available.
- Exploring the National Open School examination system.

Referrals were provided.

Follow-up support was provided and Sanjay was urged to take necessary steps.



Rina has mental illness and lives with her mother.

Her mother is now too old to look after her and feels that a residential facility will now need to be found. She sees that as the only available option. She asked Rina's cousin Ajay to call us and get information on residential homes in Delhi.

Together with Ajay, many other options were explored:

- Could a person be trained to look after Rina's care taking needs?
- Could a trust be formed to look after her financial needs?

These, along with many other possibilities, set Ajay thinking. He definitely decided against sending Rina to a residential facility - nothing like home!

Helpline

ASTHA's telephone and walk-in-helpline has now been operational for over three years

Between April 2003 and February 2004 ASTHA's Helpline touched the lives of 151 persons.

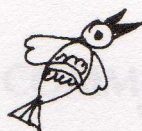
The calls we received ranged from the need for information regarding special schools to courses in special education. The overwhelming need for information on residential facilities was reflected again.

Helpline calls were received in the following areas:

- 1) ASTHA related information
- 2) Adoption
- 3) Assessments for children with disability
- 4) Dyslexia
- 5) Education
- 6) Employment
- 7) Legal Information
- 8) Media
- 9) Mental Illness
- 10) People wanting to volunteer time
- 11) Referrals
- 12) Residential homes for adult and children
- 13) Training in the disability area
- 14) Vocational training facilities



Information Dissemination



Articles written:

- 'Autism and Legal Rights' - an article was written for Tamana's newsmagazine.
- An article on 'Disability Certificate' was written for NCPEDP.
- A concept paper on 'Foster Care' was presented to the Ministry of Social Justice and Employment.
- A leaflet was done in Hindi highlighting the rights and benefits extended to persons with disability.

Legal

- The Persons with Disability Act was simplified and translated into Hindi. It is proposed to publish it with illustrations so as to enable people to read and understand the law. We hope to demystify and simplify the provisions of the law to an extent that the book can be used as a workbook and reach out to people in the community.
- The schemes and facilities extended by the Government, to persons with disabilities, were also compiled and translated into Hindi. This set was used along with graphs and pictorial illustrations to conduct a training workshop for professionals from various community based organizations.

Linkages

Linkages were made with various organizations working in the area of law and advocacy. We have had constant interaction with representatives from:

- Human Rights Law Network
- Social Jurists
- National Centre for Promotion of Employment for Disabled Persons

CBR Network

This year, ASTHA has entered into partnership with CBR Network (Bangalore). ASTHA will be looking at the North India region and attempt to link organizations here. The focus will be on collating and disseminating information, looking into the training needs of organizations and facilitating referrals.

Research Project

An ever-present need of families and persons with disability is that of accessing medical services. 'Access to medical services for persons with cerebral palsy' - is the subject of research ASTHA has been involved in for the last couple of years.

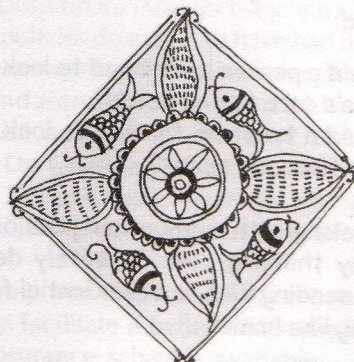
Detailed interviews with persons with disability, their parents and doctors formed the basis of this research. Medical information about visual, hearing and orthopaedic impairment, seizure disorder -has been simplified and concerns of both parents and doctors have been highlighted. An analysis of problem areas and recommendations to overcome them has also been done. The aim is to publish this information and disseminate it among parents, organizations and hospitals.

Different Strokes : Building the Library

An integral part of ASTHA's work is collecting information. As our interests widen and our work and concerns become more inclusive, we need to collect information on subjects other than disability..

- A series of booklets on legal rights was procured from MARG
- A set of publications on legal rights, was bought from Indian Social Institute
- In the area of education, books were sourced from Digantar, Jaipur
- Books on Cerebral Palsy were bought from Indian Institute of Cerebral Palsy, Calcutta
- All the schemes and programmes of the Ministry of Education were collected.
- A copy of all schemes for the girl child was also added to our information material.

All this material along with books in many areas of disability was put together to enhance the library in ASTHA.



CENTRE FOR CHILDREN WITH SPECIAL NEEDS : OUTREACH PROGRAMME

Number of Persons with Disability	55
Multiple Disabilities	10
Mental Impairment	23
Vision Impairment	2
Hearing Impairment	9
Orthopedic	11

Training Workshops

- 1) Educating children with mental retardation by NIMH
- 2) Home based management of children with cerebral palsy
- 3) Mental retardation and management
- 4) Postural management and adaptation at home
- 5) Strategies for feeding and toileting
- 6) Behaviour Management
- 7) Information on disability certificate

Aims

- Creating access to specific services for children with special needs
- Training, information and support for parents in relation to their child with special needs

Focus of the Year

- To increase the number of children and persons accessing the programme
- To share information and management strategies with parents for better implementation of home based programme
- To maintain regular contact with parents through meetings, training and information workshops

Achievements: Increase in Numbers

Thirty three new people accessed our service this year, with the majority of them being children. This increase was due to the regular visits to homes and through interaction of ASTHA members with the Primary Health Centre and other institutions in the community. Regular visits to children's homes also ensured that they did not drop out.

Regular Contact with Parents

During this year, there was a regular contact with parents. One of our major challenges in a programme like this is to share assessments and programme planning with parents. An attempt was made to share information visually with parents, involving them more in the process. As always, a concerted effort was made to reach out to groups of parents with information. This was done through seven training workshops and three meetings. An attempt was made to get the feedback of parents regarding the programme and the meeting gave us many pointers from the parent's perspective.



When Sanjeet Das and his mother came to ASTHA for the first time the mother's main need was that he goes to school

Sanjeet has a severe hearing loss and tries to communicate through gestures. He has been shown in some hospitals who have labeled him as mentally challenged. However no IQ assessment or any hearing test has ever been done.

Our challenge here was to convince the parent of the need for a proper hearing assessment from an audiologist. Secondly we had to find a proper placement for him as he is 10 years old and had never gone to school. ASTHA contacted Deepalaya and today Sanjit is attending school there. The mother's dream of Sanjeet going to school like his siblings, has come true.

GOVINDPURI : COMMUNITY BASED REHABILITATION

Number of Persons with Disability	104
Multiple Disabilities	9
Mental Impairment	16
Vision Impairment	3
Hearing Impairment	33
Orthopedic	32
Others	11

Aims

- To rehabilitate children and people with different disabilities
- To empower the community to become partners and catalysts in the rehabilitation process

Our focus this year has been empowerment of parents of persons with disability and persons with disability themselves. We aimed to do this through training in various areas of disability and information sharing.

The Govindpuri Urban Slum is situated in the heart of Kalkaji (South Delhi). It consists of three camps- Nehru Camp, Navjeevan Camp and Bhumiheen camp. There are around 5000 households with a population of about 20,000. A large number of people live in



pucca houses with 1 or 2 rooms. Few personal toilets exist with maximum people using public conveniences. The main occupation for men is work in the nearby units as tailors; guards etc while the women finish garments from export units and get paid per piece. Children, if they go to school, attend the nearby government schools.

We were aware that many NGOs had worked in the Govindpuri area in various concerns. None had worked in the field of disability. Our work in the Navjeevan Camp and Nehru Camp started from 1996 in the home of an anganwadi worker. At present we are working with children and adults across disabilities.

Sharing and Learning : Workshops & Meetings

Meetings held with parents over the year to disseminate information regarding 'The Persons with Disability (Equal Opportunities, Protection of Rights and Full Participation) Act 1995.'

Under this information was given regarding

- the right for education for all children between the ages of 6-14 and the difficulties regarding admission for disabled children
- 3% job reservations for persons with disability under which 1% reservation for locomotor, vision and hearing only.

Information was also shared about old age pension, widow pension and dowry.

Workshops and Meetings for Parents



Arun's mother who attended the workshop in the area of locomotor disability, mentioned that earlier when health workers had come to their area for the pulse polio programmes she would join her brother and refuse to let the workers administer the drops due to certain myths regarding the polio drops, impotence being one of them.

After the workshop, she convinced her brother and a few neighbors that giving the child the drops was better than exposing him to polio and all the problem associated with it.

This year the parents interacted with a range of organizations like the Hazard Centre, Mamta, Handicapped Childrens Parents Association, Udyogini and others. Parents also attended the series of workshops that ASTHA had organized this year to give information on various disability areas.

Meetings were held regularly to share with them the strength of groups when a strong need or desire for any objective is to be achieved. During the process of these meetings and interactions two leaders seem to emerge. Aneesha and Salma are both mothers of children with disability. Both actively participated in meetings held by the Hazard Centre in relation to information regarding the Master Plan and changes being planned by the Government. They worked along with other members of the community, ASTHA staff and representatives of the Hazards Centre to give in applications and have helped to some extent improve the water situation in the Nehru and Navjeevan Camp of Govindpuri.

They also attended various meetings conducted by organizations such as Udyogini, HCPA and have now started thinking of forming a self-help group. They would like to start with a vocation with the aim that their children will also participate later.

Local MLA

Parents visited the local MLA and gave him a petition for improvement of the conditions of the 'galis' as it was very difficult for person with disability to come out of their homes. Parents were heard and most of the *galis* are comparatively more accessible now.

Networking with Other NGOs

Our interaction with organisations such as Deepalaya, Bible Believers and Katha Khazana has been strengthened because of the intensive training programme ASTHA has conducted this year.

ASTHA has been able to work closely with Bible Believers who are also situated in Govindpuri. We were able to support them to look more holistically at the child and focus on their therapeutic and educational needs and abilities. Children with disability are now accessing the services of the organization and benefiting from it

Interaction with local MCD School

Regular contact with the MCD Primary Boys School afternoon section has resulted in the principal requesting us to hold awareness talks on disability with the teachers. Three workshops were held with 5

teachers on identification and teaching techniques for children with mental retardation.



Local Doctors

Meetings were conducted with various local doctors where information sharing about ASTHA and its work in the community was discussed. As a result we have regular support of one doctor who has looked after one of our children with spinal injury.

Suman has paralysis and loss of sensation in the lower limbs due to spinal injury.

She has lost control of her urine and bowel movement and is unable to move her lower limbs at all. Suman gets regular bed sores either on her knees and legs if she lies on her stomach and on her bottoms if she sits or lies on her back. Her mother is a widow and presses clothes for earning a living. She is unable to afford treatment for Suman or even spend time looking after her. ASTHA spoke to the local doctor who tried to get the bed sores healed; either by dressing the wounds or arranging for medications. However, Suman's bedsores were too deep and needed specialist attention. Suman was then treated at The Spinal Chord Injury Centre and skin grafting done on her wounds. It has been a long process for Suman but today she is learning to look after herself so that she does not get any more sores. Suman is a bright young 10 year old motivated to study. Our next step is to see that she does just that.

Networking with Venu Eye Institute

Two eye camps were held in which 120 people were screened and 8 went for cataract operations. But even without the eye camp we are now able to refer people to Venu for free cataract operation.

10 year old Shweta goes to school. Two years back she injured her right eye with a nail and lost vision in that eye. She was taken to the hospital where first aid was given but no operation was done as it would cost Rs.10,000/-. She was identified in our camp and taken to Venu where her operation was done free of cost and vision has now been completely restored in her right eye.

LAL KUAN : COMMUNITY BASED REHABILITATION

Number of persons with disability	276
Multiple Disability	26
Mental Retardation	13
Vision Impairment	22
Hearing Impairment	32
Orthopedic impairment	79
Others	27

Aims

- Empowering the community, persons with disability and their families, and groups in the community
- To disseminate knowledge and information about rehabilitation services and medical facilities and facilitate linkages with these existing services
- To provide and create opportunities for disabled children to have access to quality education
- To develop the capacities of persons with disability to the highest efficiency and to make them self-reliant and independent as far as possible.

The Lal Kuan project was started in August 01 with the clear aim of working with people with disabilities. Two and a half years down the line we realize again and again that we cannot look at the disabled child in isolation. We are continuously questioning and discussing how we can continue to focus on the child and also work with larger development issues in the community.

As a result this year our focus shifted towards the larger community issues. We are starting to build up a knowledge base and creating awareness about all development issues in the community and in ASTHA.

Community Mobilization & People Centered Advocacy

In community programs ASTHA sees itself as a catalyst in promoting community development. We aim to

- Disseminate knowledge
- Facilitate linkages
- Sensitize members of the community

An information center has been started where books and pamphlets have been collected on disability and other developmental issues. This center is also a big hit with the local children who like to come here after school to play and read books.

The Focus on Information Sharing gains Momentum

The information sharing sessions with the parents on various disability issues like the Disability Act, disability certificate, importance of early intervention and different disabilities has brought about a change in the families attitude not just towards their child with disabilities but other children with disabilities in the neighborhood. Groups of mothers are now starting to access services by themselves supporting each other.

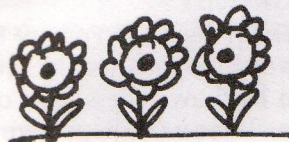
For the community information sharing sessions have ranged from development issues like electricity, water, health issues like TB, epilepsy and issues of education, thrift and saving groups, work opportunities in the community...

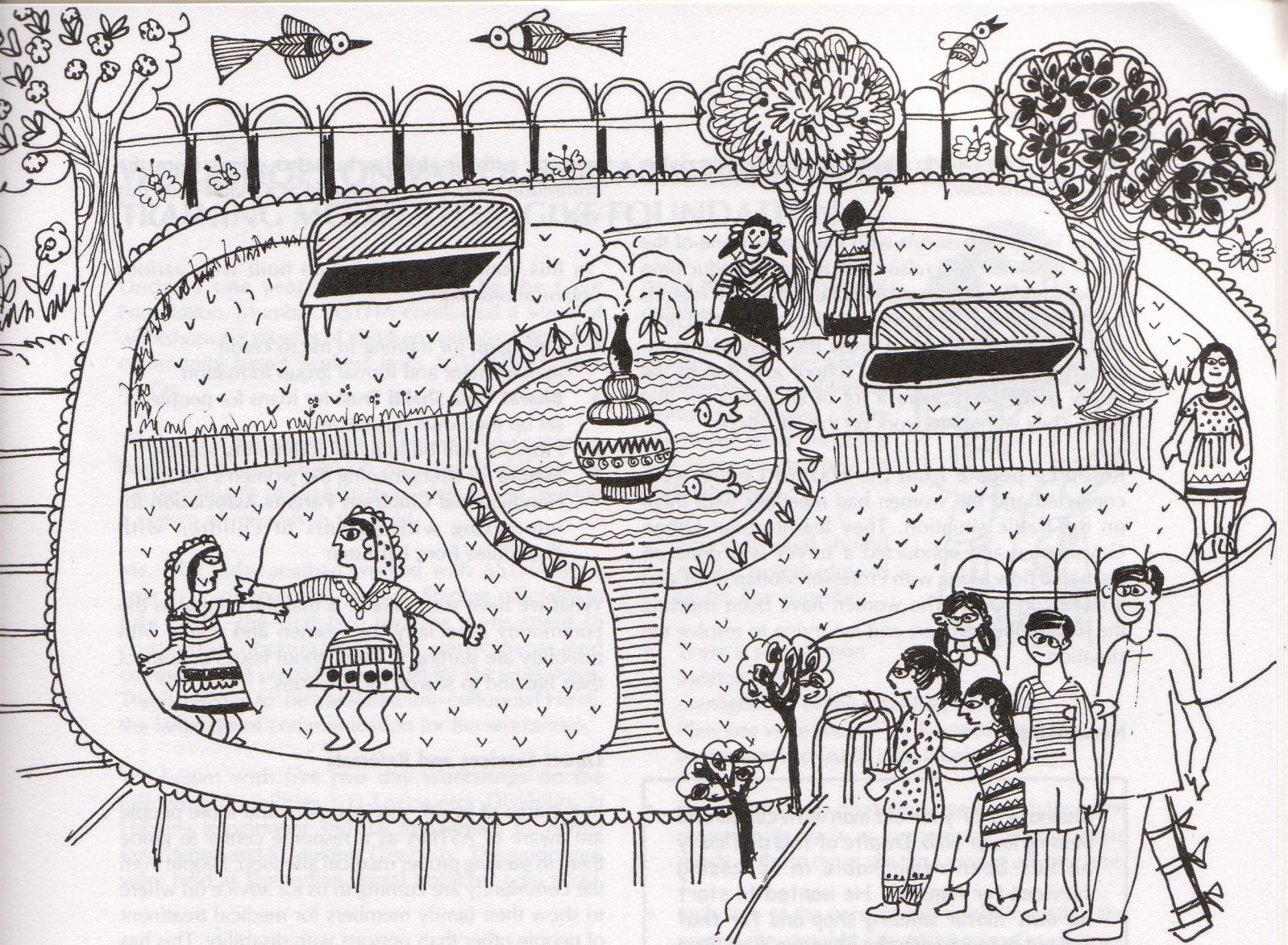
Parents and members from the community have also taken part in a series of workshops organized by ASTHA at the Indian Social Institute on various types of disabilities.

Going to School; Nukkad Natak in Lal Kuan

Children from the community: disabled and non disabled and the staff of ASTHA worked with a professional theatre company on a 'nukkad natak'. The play examined the attitudes of the community and advocated the importance of education for all children, especially children with disability. Filled with songs and music it was enacted many times in various parts of Lal Kuan.

It has been heartening to see people enjoying the play and starting to discuss the issues raised in the play.





Strengthening Groups

Our main focus this year has been strengthening of groups in the community.

An informal association has been initiated with 5 people all of whom, especially the women, have a zeal to make Lal Kuan a better place.

A group that plans with ASTHA and evaluates its work is now beginning to take shape. We have begun by sharing information with them about ASTHA's work and vision for the future. And now, we hope to involve them in planning the next six months of our work in Lal Kuan.

The Parents Groups and People with Disability Group are meeting regularly, getting sensitized to disability issues and starting to understand the larger development issues that effect disability in the community. Young adults with disability have had the opportunity to participate in the World Social Forum, taken an active part in the celebration of

World Disability Day and participated in ASTHA's attempt to advocate on the issue of the disability certificate.

The main thrust this year has been on the strengthening the women's group. We started by having to literally beg, force and cajole the women to come for the meetings. Slowly they felt that it was not so bad to go and listen to what was being said. In the beginning it was very common for us to hear the statement "We will do whatever you tell us to do". But that has changed in this year as the women have become better informed and as a group supported each other to become stronger. The women's group went to the local police station and forced the policemen there to take action against a man in B Block who was beating his wife and children.

As the women start to organize themselves, meet to discuss vocational issues on their own they begin to take decisions on what they want to do. The previous

refrain of "We will do whatever you tell us to do" is seldom heard now.

In our initial discussions with the women one of the issues that was often raised was that of the education of their children. They said that one of the main reasons why the children were not sent to the secondary school was because they had to cross the busy Mehrauli-Badarpur road to get to the school and due to the heavy traffic there were a lot of accidents on that road. They wanted to work on this situation.

Resource people from the Hazard Centre were contacted and the women had meetings with them on the traffic situation. They learnt about Urban Governance and conducted a survey was done on the traffic flow along with Professor Mohan of IIT and a report prepared. The women have been meeting the local police officers and are trying to resolve the situation.

Networking

Munna is a 27 year old man with congenital missing lower limb. In spite of this difficulty he has been remarkable in accessing services for himself. He wanted to start his own motor winding shop and for that was put in touch with the Bhartiya Yuva Seva Trust (BYST). He had to run around a lot facing hurdles at every step from opening a bank account in the local bank to getting estimates from his various clients. ASTHA staff supported him in getting information and arranging for meetings. Pleading, cajoling and fighting all became a part of his arsenal as he went about getting all the documents in order. Finally all the hard work paid off and BYST has recently approved his loan. He then went a step further and was empowered to arrange for an STD booth from the MTNL office by himself with support from ASTHA and the Vocational Rehabilitation Centre in Rajindar Nagar.

Right from the start ASTHA has worked to build up strong links with different organizations to be able to bring in resources to create awareness about the issues raised in the community. The focus of networking has been looking at vocation opportunities not only for

persons with disabilities but also others from the community since that appeared as a major need this year.

In this connection links were built with various organisations like

- **Udyogini**, for training in micro credit management and formal group formation
- **Bharat Yuva Shakti Trust** for loans for people to set up their own businesses
- **PRIA** for skill building of community leaders
- **Mamta** for strengthening the women's groups
- **Handicapped Childrens Parents Association** for interacting with parents of children with disabilities from Lal Kuan

What we have seen clearly is that the people in the community especially the women and adults with disability are starting to think about issues that affect their life and to search for solutions..

Direct Services and Referrals

In the area of health services more and more people are aware of ASTHA as a resource center to guide them in seeking proper medical attention. People from the community are coming to us for advice on where to show their family members for medical treatment of people other than persons with disability. This has been a challenge for us, as we have to be updating ourselves on diseases and other health issues.

Direct services are being given to children and persons with disabilities in physiotherapy, education and speech therapy. We have also been working with the local government and private schools conducting workshops for the teachers there to build up their skills and teaching practices.



WORKSHOPS ON VARIOUS DISABILITIES AND DEVELOPING TRAINING MODELS FOR GIVE FOUNDATION

Under a one year project funded by the Give Foundation, Mumbai, ASTHA conducted a series of workshops for parents of children with disability, and community based workers from ASTHA and other NGOs.

The focus of the workshops was to provide a common baseline of information on different disabilities for the participants and to help them identify and develop a system of referrals in the field.

Ms. Lilly Vishwanathan worked with ASTHA for a year to co-ordinate this project. Starting officially in July 2003, the first two months were spent in contacting organizations for participants and compiling and preparing material for the workshops. These needed to be translated into colloquial Hindi, the language of communication for the workshops.

We began with five two day workshops on the following disabilities : 1) Locomotor Disability 2) Hearing Impairment 3) Visual Impairment 4) Mental Retardation and 5) Multiple Disability. The workshops were held at The Indian Social Institute, Lodhi Road.

A total of 124 participants from around 9 organizations including ASTHA attended the initial workshops held in September 2003. Organizations that participated in the workshops were those already working in the field of disability or those involved in community based development projects that included or planned to include disability in their mandate. The organizations included were Aradhana, Butterflies, Bible Believer's Church, CASP-PLAN, Chetanalaya, Katha Khazana, Mamta, Prayas, Parents' Association, Chattarpur .

A core group from ASTHA planned and conducted a large part of the initial workshops. For some specialized areas, expert resource persons from outside the organization were contacted.

The participatory methodology used in the workshops, focused on building on the existing knowledge base and using existing skills and knowledge to enrich the learning process. Thus ample time was provided for discussions, sharing of experiences and debating on

issues that raised divergent opinions.

While the technical components of individual workshops differed, there were some basic principles that were emphasized in each workshop :

- The individual should not be overshadowed by his /her disability
- There is no common method for management of the disabling condition. Planning varies based on the needs and environment of each individual.
- The persons with disability goes through the same stages of life cycle as anyone else. His/her basic needs at these times are the same as anyone else.
- Inclusion of the person with disability within the community should be the primary goal at all times.



Following the initial workshops there was an ongoing contact programme that extended upto June 2004. The contact programme includes i) individual placement for all the participants in one of the three ASTHA centers at Tughlakabad, Lal Kuan, Govindpuri ii) contact sessions at the individual organization level and iii) tutorials on relevant subjects. To date, we have reached 50 more individuals through the contact programme apart from the original 124 .

One day follow up workshops on Autism conducted by Action for Autism, on Hearing Impairment conducted by National Institute for the Hearing Handicapped (NIHH), Orthotic and positioning aids, Auditory Training, Paediatric Visual Problems and Counselling have been conducted by March 2004.

The positive response from the participants, their enthusiasm in participating in all the activities, and their keenness to share their knowledge has been a great source of encouragement to ASTHA.

EDUCATING CHILDREN WITH SPECIAL NEEDS IN LAL KUAN : HEWLETT PACKARD SOCIAL WELFARE FOUNDATION PROGRAM

ASTHA's experience of working with children with multiple disability shows that very often the educational needs of children with sensory impairment, physical and multiple disability get ignored in the effort of the family to access medical rehabilitation. For the overall development of the child it is extremely important that educational opportunities of the child go side by side with medical and other rehabilitation activities.

A one year program was started with the aid of HPS Foundation to provide intensive services to children with severe or multiple physical disabilities who have cognitive potential in the Lal Kuan area.

Aims

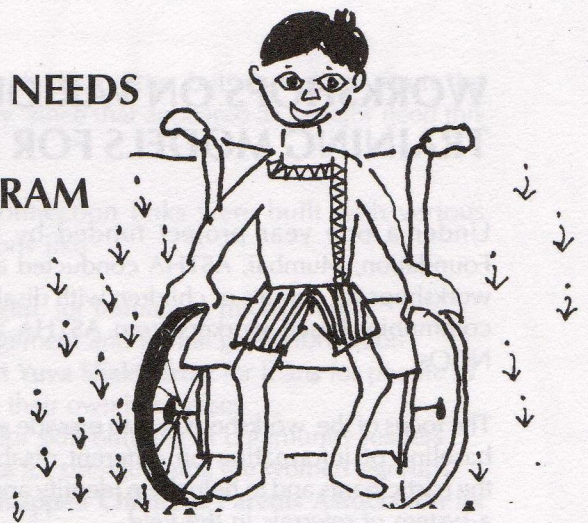
- To provide opportunities to children to access quality education through the provision of services, awareness and interaction with educational institutions
- To create access to and an understanding of rehabilitation services through direct services and facilitation of linkages
- To research techniques of working with children

Children in the age range of 3 to 19 participated in the program. The breakup according to disabling conditions is as follows:

Cerebral Palsy	8
Polio	5
Multiple Disability	6
Orthopedic Disability	3
Speech and Hearing	4
Visual Disability	1
Developmental Delay	6

The program involved intensive work with children and their families as well as educational institutions in the community. Each child has been assessed in all areas and programmes have been made in consultation with parents. The team visits each child weekly and more if required.

A monthly inclusive art session was also devised so that children with and without special needs learn to



Rinku is a 4 year old boy with arthrogyphosis whose parents felt that he will never be able to do anything. Schooling for him was nowhere on their mind. As a part of the HPS project, the special educator started working with him at home and then enthused the mother to bring him into the centre. After just a few sessions where intensive cognitive input was given, Rinku's amazing intellectual ability showed through and his language and communication improved a lot. This motivated the parents to shift their focus on medical rehabilitation to sending him to school. Rinku is now attending the Kalyanam School in Lal Kuan. From being an extremely shy child, he is now making friends and interacting with all his teachers

work and play together. We believe that these sessions can go a long way in creating an awareness about the abilities of our children.

This intensive work has shown remarkable results as more and more children with severe physical difficulties are starting to show progress and parents are beginning to see the potential of their children.

Education

The local private schools have supported the initiative and admitted children with severe physical difficulties in their schools.

ASTHA staff has been regularly interacting with staff from the following private schools:

- Little Hearts Public School
- Siddharth Public School
- Seva Bharti Schools (3 branches)

Simultaneously we have started going into the government schools and started supporting the teachers in working with the disabled children already admitted there.

Workshops

A workshop has been conducted for the teachers of the local private school on teaching aids and how to use them in a classroom situation by a special educator from our Tughlakabad center. This workshop was attended by teachers from Seva Bharti, Manav Kalyan Samiti, Deepalaya and Kalyanam.

In December 03 a workshop was organized with resource people from the National Institute of the Hearing Handicapped on hearing impairment, its causes, prevention and remediation. This was attended by parents of children with hearing impairment, teachers from local schools and members of the community.

Work with Parents

In an effort to reach out to more parents and share work with children a visual method of recording progress was devised.

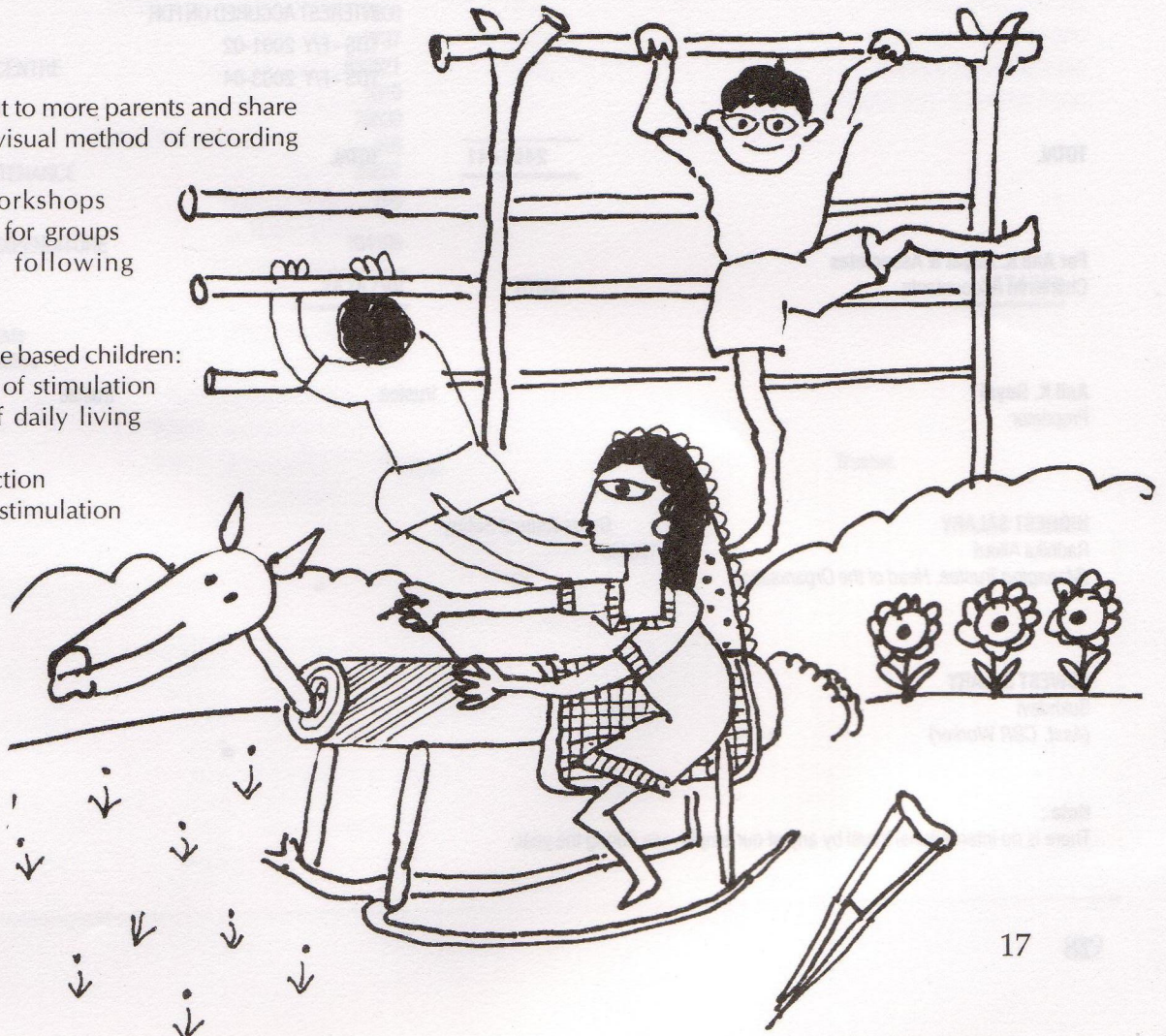
Regular monthly workshops have been organized for groups of parents on the following subjects.

1. For parents of home based children:
 - Importance of stimulation
 - Activities of daily living
 - Positioning
 - Peer interaction
 - Play based stimulation

2. For parents of school going children:

- Importance of extra input
- Importance of contact between parents and school
- Difficulties in school

Ashok is a 14 year old boy with multiple disabilities. He has polio in one leg and low vision in both his eyes. In spite of his difficulties his family has been sending him to the local government school even though the teachers there are indifferent and he has failed in class 5 two times. His brother is very supportive of Ashok and wants him to get an education. Our challenge is to convince the parents of the need for a placement for Ashok in the Deepalaya School in Okhla where he will be studying in an inclusive class but at the same time getting special input to compensate for the low vision.



ASTHA
ALTERNATIVE STRATEGIES FOR THE HANDICAPPED
BALANCE SHEET

as at 31st March ' 2004

LIABILITIES	Amount	ASSETS	Amount
	(Rs.)		(Rs.)
CAPITAL FUND		FIXED ASSETS(Annexure 'A')	649588
Opening Balance	1564075	AMOUNT RECEIVABLE	
Assets procured in Project Funds	3850	MINISTRY OF SOCIAL JUSTICE & EMPOWERMENT	
Add.: Excess of Income over Expenditure	<u>61032</u>	(SPECIAL SCHOOL FOR MR & CBR PROJECT)	155201
	1628957	HPS FOUNDATION	2226
BUILDING FUND	400000	GIVE FOUNDATION	80427
PROJECT FUND		LOANS & ADVANCES	
PROJECT BALANCE - ACTION AID	235079	STAFF - ADVANCE	10000
PROJECT BALANCE - WOMEN'S RELIEF	5208	PLAY - ADVANCE	26743
PROJECT BALANCE - NFI	40700		
	280987	CURRENT ASSETS	
EXPENSES PAYABLE		CLOSING STOCK	35587
SALARY PAYABLE	129928	CASH	1067
TDS PAYABLE (SALARY)	15830	CORPORATION BANK - 10515	125426
TELEPHONE EXPENSES PAYABLE	5739	CORPORATION BANK - 10221	39869
		CORPORATION BANK - 11745	197
		FIXED DEPOSIT	1288817
		INTEREST ACCURED ON FDR	36350
		TDS - F/Y 2001-02	3153
		TDS - F/Y 2003-04	6790
TOTAL	<u>2461441</u>	TOTAL	<u>2461441</u>

For Anil K. Goyal & Associates
Chartered Accountants

Anil K. Goyal
Proprietor

trustee

Trustee

HIGHEST SALARY

Radhika Alkazi
(Managing Trustee, Head of the Organisation)

Gross Annual Salary

176400

LOWEST SALARY

Sukhdevi
(Asst. CBR Worker)

18900

Note :

There is no international travel by any of our employees during the year.

ASTHA
(ALTERNATIVE STRATEGIES FOR THE HANDICAPPED)
INCOME AND EXPENDITURE ACCOUNT

for the year ended on 31st March, 2004

EXPENDITURE	AMOUNT(Rs.)	INCOME	AMOUNT (Rs.)
FUND RAISING EXPENSES		FUND RAISING INCOME	
OPENING STOCK	15238	SALES OF DIYAS	9150
PRINTING OF CARDS	49140	SALES OF GREETING CARDS	7003
		SALE OF PADS	7500
		CLOSING STOCK	35587
PROJECT EXPENSES		PROJECTS RECEIPTS	
ACTION AID EXPENSES	552401	ACTION AID PROJECTS	787480
GIVE FOUNDATION EXPENSES	193902	MINISTRY OF SOCIAL JUSTICE & EMPT.	313127
PROJECT-HPS EXPENSES	322226	GIVE FOUNDATION	113475
PROJECT-MINISTRY	468328	HPS	320000
WOMEN RELIEF EXPENSES	16192	NFI	40700
		WOMEN RELIEF	21400
TRUST EXPENSES		TRUST INCOME	
BANK CHARGES	851	DONATIONS RECEIVED	367144
CONVEYANCE EXPENSES	2988	USER CHARGES INCOME	299950
INFORMATION & COMMUNICATION UNIT	6480	ASHA FUND RECEIVED	276766
LEGAL & PROFESSIONAL CHARGES	41650	INTEREST ON SAVINGS	20808
MEDICAL SUPPORT	13246	INTERSET ON FDR	56539
NUTRITION EXPENSES	5198	INTEREST ON I.TAX REFUND (F/Y 2002-03)	170
OFFICE EXPENSES	12771		
PLAY-RATES & TAXES	4420		
POSTAGE & COURIER	8730		
PRINTING & STATIONERY	3958		
RENT-CENTRE	146400		
RENT-GOVINDPURI	7500		
REPAIR & MAINTENANCE	7737		
SALARY & HONORARIUM -CENTRE	633521		
STAFF WELFARE	5519		
TELEPHONE EXPENSES	28630		
TRAINING EXPENSES	165		
VEHICLE REPAIR AND MAINTENANCE	24687		
WORKSHOP	756		
EXCESS OF INCOME OVER EXPENDITURE	104165		
TOTAL	2676799	TOTAL	2676799

As per our report of even date
For Anil K. Goyal & Associates
Chartered Accountants

Anil K Goyal
Proprietor

Trustee

Trustee

A S T H A
ALTERNATIVE STRATEGIES FOR THE HANDICAPPED
RECEIPTS & PAYMENTS

for the year ended 31st March, 2004

RECEIPTS	AMOUNT	PAYMENTS	AMOUNT
	(Rs.)		(Rs.)
OPENING BALANCE:			
CASH IN HAND	17313	ACTION AID EXPENSES	526626
CORPORATION BANK - 10221	324737	GIVE FOUNDATION EXPENSES	187902
CORPORATION BANK - 10515	413515	PROJECT-HPS EXPENSES	298726
CORPORATION BANK - 11745	197	PROJECT-MINISTRY	430258
FIXED DEPOSIT	400000	WOMEN RELIEF EXPENSES	16192
		BANK CHARGES	851
RECEIPTS :		CONVEYANCE EXPENSES	2988
ACTION AID	665800	INFORMATION & COMMUNICATION UNIT	6480
MINISTRY	620100	LEGAL & PROFESSIONAL CHARGES	41650
HPS FOUNDATION	320000	MEDICAL SUPPORT	13246
GIVE FOUNDATION	113475	NUTRITION EXPENSES	5198
ASHA FUNDS	276766	OFFICE EXPENSES	12771
NEI	40700	PLAY-RATES & TAXES	4420
WOMEN'S RELIEF	21400	POSTAGE & COURIER	8730
DONATON	303742	PRINTING & STATIONERY	3958
INTEREST ON SAVINGS	27399	RENT-CENTRE	158400
INTEREST ON FIXED DEPOSITS	88817	RENT-GOVINDPURI	6600
TDS REFUND & INTEREST	3448	REPAIR & MAINTENANCE	14737
USER CHARGES RECEIVED	299950	SALARY & HONORARIUM -CENTRE	581924
SALE OF CARDS & DIYAS	23653	STAFF WELFARE	5519
STAFF ADVANCE - RECOVERY	1774	TELEPHONE EXPENSES	22891
		TRAINING EXPENSES	165
		VEHICLE REPAIR AND MAINTENANCE	24687
		WORKSHOP	756
		PRINTING OF CARDS	49140
		ADVANCE FOR PLAY	26743
		PUCHASE OF ASSETS	55852
		CLOSING BALANCE:	
		CASH IN HAND	1067
		CORPORATION BANK - 10221	125426
		CORPORATION BANK - 10515	39869
		CORPORATION BANK - 11745	197
		FIXED DEPOSIT	1288817
			1455376
TOTAL	3962786	TOTAL	3962786

As per our report of even date
For Anil K. Goyal & Associates
Chartered Accountants

Anil K Goyal
Proprietor

Trustee

Trustee