

AARTH - ASTHA
Quarterly Report July to September 2008

Administration

- ◆ Checking and sending mails.
- ◆ Updating files related to incoming mails, outgoing mails, Education, Child Rights, Proposals, Telephone, Computer, Meeting-Workshop and all other administration files & Registers like Attendance, Inventory, Helpline & salary register.
- ◆ Keeping a Master file for the entire current project proposals.
- ◆ Checking and maintaining the working of computer / Internet /printer / telephone etc.
 - Helpline phone was faulty for two times. Complained the same and rectified.
 - Telephone at Govindpuri was out of order for several times. Complained and rectified. Also trying to get a codeless instrument for Govindpuri centre.
 - Installed a new printer cum scanner cum copier.
 - Disconnected one of the telephone lines (No.26449028) with broadband connection.
 - Printer (Asta) was out of order for two times, the same was complained and rectified.
- ◆ Keeping the accounts: Preparing vouchers & keeping a daybook and submit the same to the Centre by monthly basis.
- ◆ Maintaining the inventory system i.e., requirement of stationeries / provisions and purchasing the same and keeping and updating inventory register.
- ◆ Payment of bills telephone, water, electricity, printer cartridge, courier etc.
- ◆ Making & issue of salary cheques
- ◆ Supporting all the computer related works
- ◆ Have got two bookshelves, one computer table & 6 chairs from National Trust funding for the resource centre.
- ◆ Have got two-newsletter holder and one CD bag for the resource centre.

Information Collection

Resource Library

- ◆ Maintaining the system & updating resource materials / books / newsletters / newspaper clippings:
 - Setting up Resource Centre, sorting and arranging of books/ Journals /Reports etc under different sections
 - Keeping list of books/periodicals
 - Keeping lending details of books /periodicals
- ◆ **Collection of books in this quarter:**

- **Building as learning aid** – Kabir Vajpei
- **YUVA school life skills programme** –Vol-I, II, III, IV Handbook for teachers (draft material April-2008) Department of Education, State council of Educational Research and Training, Government of NCT of Delhi
- **Guidebook for CRC review audit and reporting---Measuring progress of children** -from rights to realisation-Alternate report on India's CRC performance: 2002-08 —IACR July 2008.
- **First Findings** –For alternate review and report of CRC implementation. — IACR, July 2008
- **Preparation for Fundraising** –Quick Guides
- **Management Mission and Vision statement** - Quick Guides
- **Indian Journal of Gender Studies**, Special issue: Disability, Gender, Society –May-August 2008
- **Good Times for everyone** (Sexuality, Questions, Feminist Answers) – **Radhika Chandiramani**
- **Just Dial yellow pages.**
- **A source book on Learning Assessment at the Primary Level.** - July 07, Draft Discussion and Trial, Department of Elementary Education.
- **Country Report** –India, Mainstreaming persons with disabilities – India's Initiatives –**Amar Jyoti Charitable Trust, India**
- **NCERT – 1st to 5th standard - English, Hindi, Environmental studies and Maths text books**
- **Art Education** : Teachers handbook for class I, Class II & Class III & Teachers' Handbook on work experience class - III – NCERT
- **Let's Sing Together** – NCERT
- **Language Development for children with hearing impairment** - Handbook for Teachers –NCERT
- **Children with low vision-** A handbook for primary teachers
- **Inclusive Learning Friendly Environments**
Booklet 1 : Becoming an inclusive learning friendly environment
Booklet 2 : Working with families and communities to create an ILFE
Booklet 3 : Getting all children in school and learning
Booklet 4 : Creating inclusive learning friendly classrooms
Booklet 5 : Managing inclusive learning friendly classrooms
Embracing Diversity: Toolkit for creating Inclusive Learning Friendly Environments.

Meetings & Workshops: Conducted & Attended

- On **29th of July**, Radhika Alkazi and Shabnam Aggarwal **had meeting with Secretary Education, Ms. Reena Ray** regarding permission to work with government schools for the inclusion of children with disabilities.
- **Radhika Alkazi conducted 2-day workshop on the 6th and 7th of August, 2008 at Kolkata on Understanding UNCRPD.** This workshop has been organised by Aarth-Astha in collaboration with Sanchar- Kolkatta, VSO & supported by European Commission. It was part of the Aarth project, Understanding UNCRPD supported by VSO.

- **A Partnership Development Exercise held at Astha** on the 12th of August 2008. This was conducted by VSO and Aarth-Astha. Ms. Vijaya and Ms. Rimmi from VSO were participated.
- Aarth-Astha participated in a **two-day meeting organised by Indian Alliance for Child Rights**. This meeting was held for **'Measuring progress of children—update on country performance 2002-2008** on 17th and 18th of July, 2008.
- **Meeting held at Astha with Anjela**, Action Aid (Inclusive Education project) on 22nd August 2008.
- **Aarth(Astha)-National Trust (Helpline) meeting** regarding the Niramaya Insurance Scheme on 13th, 20th & 22nd of August.
- **Disability, Gender and Society contemporary perspectives and challenges** organised by Centre for Women's Development Studies in collaboration with Women's Studies Development Centre, Delhi University on 21st of August. Ms. Radhika Alkazi attended the meeting on behalf of IACR.
- **Meeting with Madhavi Samson (Abhas and rep World Education)** on the 20th August 2008. The meeting was on the basis of working with government schools & community for the inclusion of children with disabilities.
- **NCERT – Two-day programme on Inclusive Schools in Emerging Indian Economy on 18-19th September 2008**. Ms. Radhika Alkazi took a session on **"Theatre in Education"**.
- **Plan India and UNESCO were organised an International Consultation on 'Schooling for All'** as part of Right to Education advocacy initiative on 19th September 2008. Ms. Radhika Alkazi & Ms. Uma Ajit participated on behalf of Aarth.
- **September 22nd – Official Launching of Aarth (Astha)- National Trust Disability Helpline**. The Helpline was launched by Hon Ex President Shri. A.P.J. Abdul Kalam.
- **Meeting with Parents from Centre, Lal Kuan and Govindpuri.**
- **Meeting with students from Lady Irwin College.**

New Projects

A new project on Inclusive Education was started from July in partnership with Action Aid. This six-month project, tries to understand the barriers and enablers in education for children in Govindpuri with a focus on children with disabilities. It involves working at the level of home, community, school and policy.

Project Proposal

Two proposals were written and submitted

1. Concept note on "Creating Opportunities for Children" submitted to Plan India. We have now to submit a detailed proposal
2. Proposal submitted to Sarva Shiksha Abhiyan to work in schools in South Delhi.

UNCRPD Toolkit

Work on Toolkit took a backseat in the quarter with so much other work coming up and illustrator also out of touch. However, now the edit has begun.

Staff

Ms. Uma Ajit joined as Assistant Coordinator Inclusive Education.
Ms. Shabnam Aggarwal left Aarth and will be shifting to Chandigarh

AARTH-ASTHA NATIONAL TRUST ABILINE FOR PERSONS WITH DISABILITIES AND THEIR FAMILIES QUARTERLY REPORT JULY-SEPTEMBER 2008

HIGHLIGHTS :

1. **NIRAMAYA:** With the launching of the Health insurance scheme, 'Niramaya' and the active advertising by the National Trust, the Aarth-Astha National Trust Helpline has been receiving many calls. In the last quarter - July to September 2008- of a total of 214 calls, 79 were for seeking information about Niramaya.
2. Launching of the Aarth –Astha National Trust Abiline formally on September 22, 2008 by the former President of India, Dr A.P.J. Abdul Kalam.
3. Successful completion of text for the Interactive Voice Recording System as a part of the Aarth-Astha National Trust Abiline Programme.
4. Regular upgrading of reading material at the Resource Centre and making it readily available for parents, teachers and staff of Aarth-Astha as well as visitors wishing to use the facilities.

Formal launch of the Aarth-Astha National Trust Abiline by former President of India, Dr A.P.J. Abdul Kalam

- Taking cognizance of the urgent need for a helpline for addressing the needs of Persons with Disabilities and their families, the Aarth-Astha helpline was first launched in October 2000.
- In May 2008, Aarth-Astha entered into collaboration with the National Trust to begin the Aarth-Astha National Trust Abiline. The Abiline is partly funded by the National Trust.
- The Abiline was formally launched on September 22, 2008.

Preparation and formatting of text for the Interactive Voice Recording System (IVRS) as a part of the Abiline Project :

- To make the helpline facilities more accessible to people at all times of the day, the possibility of having an IVRS in place was envisaged.
- The purpose is to make information about various aspects of disabilities available, though briefly, to Persons with Disabilities and their families in the immediate absence of a counselor with a possibility of talking to the counselor later.

Informing Organizations About the Helpline :

- As a part of an ongoing process, it has been our effort to spread information, not only through word of mouth but also by distributing relevant reading material during meetings and workshops.

Answering Machine Facility :

- The helpline gets connected to the Answering Machine after 4 pm every day and is on till 8.30 am the next day.
- A recorded message in both Hindi and English requests the caller to leave a message –if they so desire.
- The concept is in its nascent stage and has really not caught on in a big way. The callers have more often than not, not left a message.

E-mail Facility :

- Though the facility of getting information through e-mails does exist,we haven't got any such queries .

INFORMATION COLLATION :

- A constant upgrading of the master list of the Helpline Referral List is being done.
- In an effort to make things a little easier, while taking a call,the information on the master list has been copied and categorized into different folders.
- The list also includes the names and telephone numbers of NGOs and other organizations working out of different states as well as SNACs and SNAPs.The information is disseminated as and when required.
- It has been observed that the telephones numbers do keep changing from time to time. An effort is made to include the new numbers in our list for ready referral.
- A list of Inclusive Schools, NGOs and individuals dealing with Aids and Appliances for Persons with Disabilities and their families has been updated.
- A list of hospitals, both Government and Private, providing facilities for PWDs including assessment and issuing of Disability Certificate, has been updated.
- As a part of our information-upgrading programme, when new organizations voluntary or otherwise call us, we have been incorporating their details into a list and is used as and when the need arises.
- We have also been able to collect information on Voluntary Organizations working for the disabled as well as homes/hostels for the same from the far flung seven sister states of North-East India.
- In addition to receiving calls on disabilities, we have been entertaining calls on adoption issues as well as for donations for charity. Though they are not our focal areas,we have tried to keep our information updated on these as well.With this in hand we have been able to forward information as and when required.
- Working with Mr Ranjot Punni,a volunteer working with us has been of immense help.Though a student himself,Ranjot has always found time to analyse our

- helpline calls data for us,often at a very short notice.We would like to acknowledge his efforts and help.
- Additionally,there have been calls from a number of newly set up or even existing agencies who desire to be registered with the National Trust.Though the registration form and required documents' list is available on the National Trust website where we guide them,there are many technical queries which we are not able to answer satisfactorily.

We would like to request the National Trust to set up a help desk to assist such people who look for technical clarifications.

PARTICIPATION IN WORKSHOPS AND MEETINGS

1. Workshop on Mental Illness :

Organized on Saturday August 9 by the Action for Mental Health and the Department of Psychiatry, Dr Ram Manohar Lohia Hospital,New Delhi..

The workshop was organized by a NGO-Action for Mental Health dealing with issues related to mental illness particularly schizophrenia and Alzheimer's disease.

The forum was well represented by parents,professional and individuals with a condition,one of whom put forth her views.Representatives from the Govt .of India(Min.of Health and Min. of Empowerment &Social Justice) also participated presenting the areas of concern,suggestions about dealing with them and the facilities that have been made available for such patients and their families.

The focus of the forum was to bring together the technocrats ,health professionals and parents in an ongoing effort to share and exchange ideas and viewpoints while trying to resolve some issues of basic concern.The purpose of this workshop was also to formally launch the Parent Support Group with the idea of devising an effective information dissemination system while linking up with other groups to help further the cause.

The emphasis was to set up a strong system that would help people with mental illness and their families.

2. Workshop on Autism Spectrum Disorder :

Organized by the Department of Paediatrics,Lady Harding Medical College ,September 27-28,2008 at the India habitat Centre,New Delhi.The cause was supported by the World Health Organization

This was the first of its kind meeting where parents,teachers,experts on Autism,speech and occupation therapists as well as rehabilitation professionals came together for a

two-days session.the basic purpose was to share viewpoints and concerns where this hidden disability called “Autism” .It has, at the best of times been an enigma and it continues to be so even after years of active research have gone into it.

The points that emerged out of this interactive session is as follows :

1. Autism is a hidden disability – an enigma till today.
2. It is a spectrum, where no two affected individuals show the same trends. The skill and behavior profiles are unevenly spread though the three basic areas of core deficit : socialization,communication and rigidity of behavior remain the same.
3. Assessment in autism is very important and despite meaning to do so, the doctors are not able to do justice as they feel that the OPDs are too crowded to give sufficient time. The general grievance was that they could only give about 5-10 minutes and there were no other days allocated especially towards the treatment of autism.
4. The importance of constantly upgrading,improvising and being innovative while devising a curriculum (individual/group) be it for academic,social or sensory issues is a must – keeping in mind their uneven profile.
5. An information link-up between the multidisciplinary team members on a sustained basis is very important. The progress of the case has to be constantly monitored with the therapists who might be dealing with them.
6. Spreading awareness about autism especially at the community level has become essential.Forming respite and support groups from within the community would definitely help the cause.

It was agreed upon that a two days workshop was too short a time to set directions- and more such interactive sessions were required to regulate the system – once that is in place

FOURTH NATIONAL MEETING OF HELPLINES :Sustainability :Models that Work:

Organized by TARSHI,September18-20,2008 at the India International Centre,New Delhi.

The national meeting of helplines was organized by TARSHI.TARSHI works in the area of sexual and reproductive health.

The meeting was attended by helplines working on homosexuality,lesbianism, Transgenders,HIV/AIDS,domestic violence,children’s issues and disabilities.

It was a good forum to form linkages across helplines to remain in touch,learn from each others’ experiences and share strategies that they may have employed successfully.The referrals generated form an important link and create awareness through disseminating information among families they work with.

The problems being faced by most attending helplines were as follows :

1. **Reluctance** in accepting the cause.

2. **Rejection** of people working for the cause and ascribing negative reasons to their purpose. This is especially seen with organizations, groups working with homosexuality, lesbianism, same sex issues, domestic violence and HIV/AIDS.
3. **Reaching out** to people is very difficult – be it from the lower or the higher strata of society.
4. **Misunderstanding of intentions** as their causes are considered to be “socially unacceptable”.
5. **Publicity** of organizations through advertisement in the print media especially in widely read ones is not entertained. These are therefore restricted to the local newspapers in regional languages.
6. **Fund raising and sustenance** in some cases is becoming increasingly difficult especially for people working on gender-based issues. There have also been cases where funds have suddenly been withdrawn without giving any reasons.
7. **Retaining of volunteers and paid staff.** A lot of volunteers and paid staff leave once they are trained and gained experience. This constant flux makes the working of the helpline difficult.
8. **Burn out** is where people working on the helpline do not wish to continue as their own state feels threatened after having dealt with adverse circumstances over a period of time.
9. **Inadequate networking and sharing of information and referrals.**

The participating group did come to a decision about forming an E-group which would strive to keep in touch, initiate and maintain dissemination of information proactively, touching base often.

The analysis of calls made over a period of three months (July to September 2008) have shown the following trends :

1. Most calls received were from persons themselves with MR or Physical Impairment or from their family members.
2. There was a distinct rise in the number of calls seeking information on Autism.
3. There was a drop in the number of callers enquiring about home/hostel facilities.
4. Most calls were directed towards information on Niramaya – the newly launched health scheme with persons with disabilities by the National Trust. Initially there were some confusions as regards the requirements and the documents required to be submitted, but that became clearer once the information was upgraded on the net.
5. Calls from organizations from the NCR region as well as from other states wishing to register with the National Trust featured prominently.
6. There were 22 walk-in sessions, where some of them were follow ups.
7. There were no queries over e-mails
8. Number of queries about other schemes of the National Trust have started rising especially about Gyan Prabha scholarship scheme.
9. Some callers have called back and given a feedback about how the information got over the helpline has helped them, essentially touching base with the hope that they would be able to call back when a need arose.

SOME CASE STUDIES

Following are three case studies, which we found interesting:

CASE STUDY I : AABIR'S TALE

Aabir is the youngest of four children. Born late in his parents' life, he is 11 years old, Aabir has been diagnosed with **autism**. He is also non-verbal. Aabir had been sent to a play school when much younger, but had to be withdrawn when his aggressive behaviour began to harm children. He's been at home ever since.

Aabir's father, Mr Roy's call came requesting for **information on homes or hostels** where the child could be sent for the rest of his life, educated and looked after.

Since Mr Roy sounded tired, conversation was guided towards the reason as to why, as parents, were they contemplating such a step! The information came out in bits and pieces. It was revealed that behavioural manifestations had always been an issue in Aabir's case and that he was being treated for it by a paediatrician, who had known him from birth. However, the parents had suddenly withdrawn the medication without consultation with the doctor. Thereafter, there was further worsening of his condition leading to the child becoming violent and given to fits of hitting out and throwing things.

The parents, being elderly, and no other offspring stepping in to support them in taking care of Aabir, they wanted their youngest child in an institution which would essentially take over from them in looking after him. They were not being able to handle the child and feared harm to the child and themselves if his behaviours persisted.

The conversation was steered along the lines of suggesting that the behavioural manifestations, though associated with autism may also have been enhanced because of any other developing medical condition and needed looking into. Aabir's father was requested to get in touch with the paediatrician to re-assess the situation and put him back on medical treatment, under strict medical supervision, that had been abruptly discontinued. It seemed to make sense in trying out this option to see if things would be any better.

The subject of seeking a home/hostel to relocate Aabir was taken up next. It was gently put across that the child was with his parents and in an environment that he felt safe in. To put him away may only make things more difficult, confusing and insecure for him which in long run may delay any progress that Aabir may be capable of making. It was also suggested that they should look for someone in their family or neighbourhood who could provide some respite care to the parents and perhaps have a special educator identify his strong points and guide him accordingly, at home, since funds were not a constraint. Mr Roy, by this time had come around to considering taking him to the closest metropolis to get a proper assessment done and seek a home programme that the child might benefit from.

The last time we heard from Mr Roy was to be told that Aabir had been put back on a strict medical regime and therapy programme and that things were looking up.

CASE STUDY II : HUSSAIN'S CASE

Shahbanoo, a mother of five children, came with her eldest child Hussain who is 15 years old .

She has been running from pillar to post, from one hospital to the other for a number of years seeking guidance and recourse for her child – but to no effect. The doctors kept telling her that her son was weak mentally suggesting **mental retardation** but would eventually get well as he grew. The schools were reluctant to take Hussain on saying that he would not be able to cope. This resulted in the boy staying at home in his grandmother's care while the mother worked to make ends meet.

Only last month, just to keep Hussain from roaming in and around their home aimlessly, Shahbanoo decided to send him to the play school where her youngest son, aged three, was admitted. The school authorities were kind enough to take him on at no extra cost. What surprised the mother was Hussain's ability to learn and interest in music. She came seeking information on schools or institutions which would help further Hussain's **education** or **train him in a vocation** that in future would help him become economically independent.

Shahbanoo's effort at taking that decision of sending Hussain to school was appreciated. She was persuaded to get an **assessment** done, since the last one was done when the child was four years old, so as to identify Hussain's condition and seek recourse accordingly. It was also impressed upon that she should get a **disability certificate** to facilitate a number of things not only for Hussain but also for her family. With the disability certificate, she would be able to seek better educational facilities or pre-vocational training opportunities for her child, apply for a scholarship or a loan to set up a business venture for the family. The certificate would also allow for national and state level concessions. Shahbanoo was surprised to know of the possibilities and promised to do the needful.

Hussain came in with his mother sometime ago. He seemed to be happy going to the same school, has learnt to count till 100 and was learning to recite English rhymes and sing popular Hindi songs ! The mother had started the process of getting an assessment done from a Govt, hospital which would lead to getting a disability certificate in about three months' time.

CASE STUDY III : SNEHA'S STORY

Sneha's elder brother, Satish, was a worried man. His sister, now aged 18 yrs – Sneha had **cerebral palsy**. After their parents' passing Sneha was his responsibility. Since the parents were conservative and feared social ostracization, they did not allow Sneha to leave home to go to a school. But somewhere their mother's wise decision of tutoring her at home had worked and Sneha, being an intelligent and perky child had learnt to read and write, with the ability to tackle Class 8 state level curriculum.

Sneha's brother had just been transferred to a new metropolis and had called the helpline to seek assistance as regards his sister's future.

One query led to the other and it was found that Sneha did not possess a disability certificate,so the first thing that Satish was requested was to do was to get in touch with the closest civil/govt.hospital to ascertain the modalities/assessment procedure which would get Sneha a disability certificate.

The importance of having a **disability certificate** was explained.

A second call followed a couple of days later,seeking **information on the newly launched health insurance scheme –Niramaya** and the process of getting that done.After giving him the details about the scheme and guiding him to download the form from the National Trust website,he was requested to get in touch with the **Local Level Committee or a Non-Govt Organization registered with the National Trust** for further guidance on Niramaya as well as other available schemes.

Since Sneha's brother was a state govt .employee he was also asked to get in touch with the **state welfare department** to seek information on the **state run schemes and concessions** available to Sneha.Addresses and telephone numbers of **SNAC and SNAP members** of the state were given for assistance.

A third phone call from Satish was an update on his efforts to get a disability certificate for Sneha with an assurance to keep us informed on further developments.