

autism

N E T W O R K

DECEMBER 2006

VOL 1 ISSUE 3

Action For Autism is a registered, non-profit, national parent organisation. Autism Network is published by Action For Autism to provide information on education, therapy, care, and to provide interaction for families and professionals across the country.

Autism Network is a forum for expressing diverse opinions. Action For Autism does not hold itself responsible for opinions expressed by individual writers. Publication of any information does not mean support of Action For Autism.

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Cover Illustration

'Aeroplane over the Monument'
By Aditya Aiyar, age 4 years, student of Scottish High
International School, New Delhi

WISHLIST !

FOR THE SCHOOL

- o Swing
- o Plastic indoor slide
- o Board markers
- o Permanent markers
- o Art materials such as :
Water colours, Acrylic paints,
Cartridge paper, Canvas
- o A4 sheets
- o School Exercise books
- o Compact Discs
- o Lady Bird Reading Series
- o Sensory toys that give off light /
make a noise
- o Musician to teach music
- o Artist to teach art

FOR THE WORK SKILLS TRAINING UNIT

- o Twin tub manual washing machine
- o Plastic-bag sealing machine

FOR THE TRAINING AREA

- o Two airconditioners
- o A collar mike

If you want to help, write to AFA or call:

- AFA : Tel. 40540991/2
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PAGE ONE

It is fifteen years since Action for Autism took off; nearly ten years since the first step towards the National Centre for Autism was taken. It is with a sense of quiet accomplishment that we contemplate the huge distance that the autism community has traversed in these eventful years.

Action for Autism (AFA) is more than an organisation: it is a movement. It is a matter of great satisfaction that this movement has been the catalyst for everything that is happening in India today in the area of autism. In the process, somewhere along the way, we have also gained a formidable reputation as an organisation of impeccable integrity and quality of work.

Yet AFA started as an informal parent support group, with a focus on creating awareness and supporting each other. But a growing understanding of Autism, and living experiences with individuals with autism, sharpened the direction of the organisation towards inclusion and empowerment, and a movement for creating an equitable society.

The founding philosophy behind AFA was quite contrary to the commonly held perceptions of disability. AFA did not view autism or disability as a tragic condition, but rather as a different way of being, as 'normal' for the person with autism, as the worldview of a neuro-typical person is 'normal' for her. This philosophy was in many ways unique given the typical scenario prevalent in society.

As a result the AFA family of parents is enabled to look beyond their own children and at the wider community, and its exceptional professionals imbibe the AFA philosophy of loving and accepting without judgments, and from that perspective enable individuals with autism to empower themselves.

AFA has been fortunate in achieving many important gains for the broader autism movement. From focusing attention on the dire need for services, to advocating for the rights of persons with autism and their families. But perhaps most importantly, AFA has pioneered the demystification of professional expertise. AFA has been able to train parents as confident and competent professionals: educating and training their children, being a support for other families, acting as instruments in the spread of awareness, and advocates in legal issues in the disability sector.

None of all this would have been possible without a dynamic partnership between parents and professionals, of members that extend beyond even the boundaries of India, and the many hundreds of wonderful individuals with autism that it has been our privilege to know. But this is just the beginning.

On 8 September 2006 Mrs Sonia Gandhi dedicated the National Centre for Autism in New Delhi to individuals with autism, and all those who love them, share their lives with them, and teach them. On this auspicious occasion, in the presence of an august gathering that included the CM of Delhi Mrs Sheila Dixit, the Minister of SJE Mrs Meira Kumar, the CM of Haryana Mr Bhupinder Singh Hooda, and others, individuals with

(...cont on page 4)

THE INAUGURATION



Parent as Researcher

– A personal narrative –

Shubhangi Vaidya

Shubhangi is a PhD Scholar at the Centre for the Study of Social Systems,
School of Social Sciences, Jawaharlal Nehru University in New Delhi.
She can be contacted at : vaidya_shubhangi@gmail.com

I am the mother of an autistic child. I am also a student of Sociology, presently engaged in PhD research on the topic 'A Sociological Study of Families of Autistic Children in Delhi' at the Jawaharlal Nehru University, New Delhi. The last two years have seen me negotiating these cross-cutting identities; researching into an issue of which I too am the subject matter, building relationships and arriving at understanding myself, my family and other families like my own.

RESEARCH in the Social Sciences was traditionally modelled on the natural science; it had to be 'objective' and 'value-neutral' to be any good. Over the years, this rather blinkered understanding has changed; it is now acknowledged by most social scientists that values imbue every aspect of our work, right from topic selection to interpretation of our data. Moreover, our "subjects" are not things, they are flesh and blood human beings with desires, motives, ways of thinking, acting and feeling that are at once unique and universal. As a parent of an autistic child wanting to study other families of autistic children, I came into research with my own baggage of assumptions, beliefs and judgments which I had to systematically unlearn, as I got into the thick of my work. This article attempts to chronicle some of the issues and dilemmas dealt with during the course of my fieldwork with families.

LET me begin on a personal note. My younger son, Vishu, was diagnosed with autism at the age of three. He has since then been attending Action for Autism's Open Door School. At 9 ½, he is a bright, cheerful, very verbal little boy, fluent in both Hindi and English. When Vishu was six, and his elder brother eight, my husband died. This traumatic event led to a complete reorganization and reconstructing of our lives; most of the difficult decisions I had to take at the time were anchored around Vishu's disability and how to protect

him from the pain and confusion of the situation. I experienced a tremendous sense of 'liminality', a sense of being completely out-of-sync with the world around me; a feeling that my reality and that of the rest of the world don't quite fit. I also understood how this liminality is so much part and parcel of the lives of families with disabled people who have to constantly negotiate a reality that others never quite understand.

I decided to do research that focused on the lived, day-to-day experiences of families of children with autism; how they "made sense" of their child, how they "presented" him to the world; how cultural understandings of mental disability and social support (or lack of it) caused families to "remake" their world so that they could go on with the business of living. Clearly, the work had to be a "qualitative" study, namely, that uses a small sample but is rich in detail, and works at several levels, the inter-psychic, interpersonal and social. I wanted to get into the lives and participate in the experiences of my respondents and paint as vivid a picture as I could of the day-to-day experiences, joys, sorrows and irritations of parenting and living with an autistic child.

I did not expect to have difficulty in recruiting families for my study, and I was proved right. Most of the families I approached willingly gave their consent I was greeted as a friend, a 'co-sufferer', rather than a nosy, pesky research student who was probing their wounds to earn a degree. Most of my families said they were happy that one of their "own" was articulating their voice. I often got to hear the phrase..."you are a mother too, so you understand.." Although my location as a parent made for easy access, it created ethical and academic dilemmas. The people talking to me so freely, frankly and trustingly were friends. Their stories of loss, pain, fear and hope were not mere 'data', and I could not treat them as such. Each "fact" had an emotion underpinning

it, each emotion was something I too had gone through. Could the stories of these lives, so close to mine be reduced to the dull drabness of a PhD thesis? Could these stories be recounted dispassionately? Wouldn't 'sanitising' them for academic purposes be doing a grave injustice to the rawness of their pain? Then there was the issue of anonymity, of course. I have changed all names and details that could reveal identity. I also had to exercise tact and caution at what information I include and exclude. A father of an autistic child confessed to me that he had many extra-marital affairs to help him escape the reality of his child's disability. Do I include this information? Will his wife recognize his identity? Will it break up their home?

MOST research relationships are hierarchical; there is the all-knowing researcher 'up there' and the 'subject' s/he is trying to study on the other side. Fortunately, this was conspicuously absent during my fieldwork. In the tradition of feminists interviewing, these were dialogues between equals. Often times, I would be the interviewee rather than the interviewer as respondents sought details about my life and my experiences as a parent. Most of the interviews were conducted in the homes of my respondents, in as natural a setting as possible, with the cooker whistling in the kitchen, kids demanding more Maggie, telephone ringing.

ALTHOUGH I did carry a notebook to jot down points, I purposely avoided that life-line of the interviewer, the tape recorder. This was a conscious and very difficult decision. Unlike the West, we Indians are not yet a "tape recorder culture"; we are not comfortable revealing intimate details of our life in a machine. After the meeting, I would tear off home and furiously scribble down notes of every word, every gesture, every action I could bring to mind. My Research Supervisor will testify about those bulky notes in scrawling longhand! My children sometimes accompanied me, particularly if the meetings were on a holiday. The sessions then became family get togethers, excellent opportunities for observing interactions between siblings and autistic children themselves. My son Vishu would look forward to visiting a child's home, and would say an enthusiastic hello to everyone. After that, both children would drift off to separate corners, never once looking at each other

until it was time to say good-bye. Later Vishu would say "X" se milkar bahut mazaa aaya!"

MY one-to-one meetings with mothers proved excellent. We would gossip, cook, eat, look after the children, watch TV together, opportunities for female bonding. I realized how little opportunity some of them had to share their feelings, take interest in them and their lives. Bound as they were to the daily grind of household chores and the demands of their child, some of these women had retreated into an inner world of silence and suffering. However, some of them had actively broken the shackles of domesticity and dependency and emerged as fierce guardians of the rights of their child; in the process, acquiring an identity and sense of purpose for their own lives.

BARRING the odd exception, the interviews with fathers were more formal encounters. As a woman, and a single one at that, there were certain 'Lakshman Rekhas' in place. And yet I was heartened at how frankly most of them spoke. I realised that whereas women tend to bond with each other and participate in each other's

"If a man does not keep pace with his companions,
 perhaps it is because he hears a different drummer.
 Let him step to the music which
 he hears, however measured or far away."

Henry David Thoreau, 1817-1862 ~

joys and pain, men hardly get the chance or the social sanction to talk about their deepest feelings. They are supposed to maintain a facade of control which undoubtedly puts great pressure on them. I also interviewed some couples together. This was very challenging because I also had to decode the 'couple work' that was going on; read their silences, their gestures, see through the 'fronts' that each erected for the other. Interviews with grandparents too were challenging, as one had to encounter their views on modernity, parenting, women's work and their impact on child development. This would bring back uncomfortable memories of how my child's condition was attributed to my bad parenting and the fact that I was a career woman!

INTERVIEWS with siblings of autistic children were very interesting too. The way these children made sense of their siblings difficulties would put many adults to shame.

I will never forget the unstinting hospitality I was offered by every single family; the generous giving of time, (often, scarce and precious family time) encouragement,

food and endless cups of tea. Some of them told me I was the first person who had taken so much interest in their lives and that they had come to consider me like a family member.

WHEN my research proposal was first put up for consideration at my University two years ago, one of the professors asked me how I was going to keep myself from getting emotionally involved. I had anticipated the question and had a glib rejoinder ready. I said, rather pompously, that I hoped my training would enable me to walk the fine dividing line between research and autism. Fine words, but so hard to put in practice! I found myself getting angry, upset, helpless, pitying, revolted in turn; I became judgmental of people's attitudes and behaviour; I had the strong impulse to tell some people that they were doing it all wrong and give unsolicited advice.

I also experienced 'survivor guilt' because of the fact that my own autistic child was so high functioning and I had a regular one as well. I felt immense humility in my encounters with the families of severely impaired children who did not have much by way of education and access to facilities, but displayed unconditional acceptance and immense love for the child. Often times I felt so bogged down by the force of my own feelings that I wondered what had ever possessed me to take up

this project. How could I produce a piece of research when my own feelings and emotions were so intense, so conflicting?

THESE are not easy admissions for a researcher to make. I realised, however, that my own feelings and emotions were also data. I recorded them as honestly as I could in the section of my field notes that I called "Headnotes". I realise they provide a prism through which to understand the way in which society at large responds to disability.

IT would be premature to discuss my findings, as much thought and reflection are as yet required on the narratives I have collected. Having said that, the overriding impression that I have gathered is the sheer resilience and resourcefulness of the human spirit when faced with adverse circumstances.

ON the flip side, of course is the reality of modern, urban living, the rapid disintegration of traditional social networks and the absence of new ones to replace them. The rejection, the relegation of 'non-person' status to a person who's mind works differently from the rest. And, of course, the children themselves. The real heroes, who try bravely to accommodate to a world that is so difficult to understand. Whose 'voices' we do not have the insight to hear, yet who probably apprehend, better than most of us, the madness of the human condition.

(...cont from page one)

autism played important roles in organizing the event, welcoming guests, participating in the lighting of the lamp, offering an invocation to the almighty, and giving the vote of thanks to everyone for joining us on that special day.

The National Centre for Autism is a dream that has been in the making for many years. This centre will bring together persons with autism spectrum disorders, parents, professionals and researchers. It will carry forward its work on rights-based issues. The National Centre has much to do in ensuring education, employment, and life itself, in inclusive environments.

AFA has set up an infrastructure for the timely diagnosis of children at risk, runs a model school for their intervention, and trains parents and

professionals. Our next step is to build on their future: making available an infrastructure to strengthen our young peoples existing work skills by setting up model training units, and build residential care units, and thereby direct/guide youngsters towards independent living.

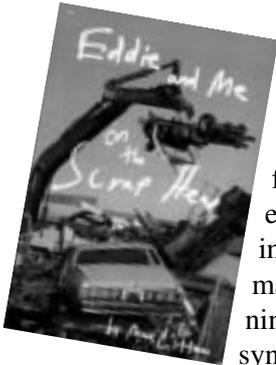


The National Centre will expand and extend the many activities already underway, and will allow a level of integration and coordination that otherwise would not be possible.

The inauguration of the National Centre marks a milestone in the relatively short but remarkably vibrant history of the autism movement in India. We know that we still have very far to travel indeed. The road ahead is long and difficult, but each of us knows, with certainty, that WE WILL DO IT!

BOOK REVIEW: LAURA BAXTER*Eddie and Me on the Scrap Heap*By Mark Littman

Published by BookSurge, LLC



Mark Littman was inspired to write “Eddie and Me on the Scrap Heap” by his experiences with his own son, who has autism. Littman’s first-hand experience of autism enables the reader to gain a unique insight into the world of Eddie, the main character in the novel. Eddie is a nine-year old boy, who has Asperger’s syndrome. His story is told via the narrative of his uncle, Natie, and by descriptions of Eddie’s interactions with an eclectic mix of characters.

Eddie affects all of the characters in the book in some way. When we first meet Eddie it is through his Uncle Natie, who has come to Eddie’s home in Los Angeles to act as his nanny, after an unsuccessful stint in New York. Natie wants to be a reggae star, wears his hair in dreadlocks and speaks with a Jamaican accent, although he has never actually been to Jamaica! Natie’s goal is to start a reggae band, which Eddie becomes involved in due to his remarkable musical ability. Throughout the novel Natie becomes more than a nanny to Eddie; he is his friend and mentor. The relationship between Eddie and his uncle is a special one that impacts on both of them in ways that they did not expect.

Eddie’s mother, nicknamed the ‘Ice Queen’, is quite negative about Eddie, often in front of him. Through the descriptions in the novel the reader is able to really understand what Eddie’s mother feels. We are told about her struggle to accept Eddie the way he is, and her experiences with a range of professionals who all claim they can ‘fix’ Eddie in some way. It is these parts of the book that I found particularly well written and relevant to the real life experiences of many families who have children with disabilities. By the end of the novel the ‘Ice Queen’s views and opinions have changed quite dramatically, and witnessing her transformation was, for me, one of the highlights of the book.

Other characters in the book include Sharon an ‘Earth Mother’ who introduces Eddie to holistic healing, Jake

the ‘pirate’ who owns a scrap heap, and Eddie’s extended family, who have little understanding of what it is like to ‘be’ Eddie. A harrowing event affects all of these characters in ways that none of them could have predicted and changes the overall tone of the novel. Ultimately this change in the book allows some conclusions to be made and some major changes in the lives of all the characters take place.

Throughout the book the reader is given descriptions of how Asperger’s affects Eddie’s life and those around him, in both positive and negative ways. The author successfully explains Asperger’s syndrome, but sometimes falls into the trap of describing Eddie by his ‘special skills’, rather than as Eddie the whole person. Despite this I found the book enjoyable in general the author’s descriptions of Asperger’s syndrome and the way it impacts on Eddie’s life were realistic and sensitive.

Letters



MY daughter was diagnosed autistic by Dr Vibha Krishnamurthy in the year 2000. Since then I am in touch with Action for Autism. For more than six years I have been receiving Autism Network. The information we get helps us a lot. It also helps parents like us both in India and abroad to bring up their autistic children in a proper manner.

Each and every copy shows a new light to us - such as what was written in the last copy in ‘Page One’ where you pointed out:

“If parents of high functioning autistic child do not want to send their child in the company of more severely affected ones, then how do we expect parents of normal children to allow their kids to interact with high functioning autistic children?”

Such articles are really wonderful. You and your team mates really deserve appreciation.

N. Saha
MUMBAI

Inclusion Works...If Done Right

By Giselle Lobo

Giselle Lobo is a special educator who has trained in the USA. She has returned to Goa and set up two resource rooms in regular schools: at Holy Cross Convent – Bastora, and Chubby Cheeks School – Pilerne, where children with disabilities (mainly autism) are educated together with regular students. She is also the chairperson of Jyot Society of Parents with Autistic Children, Goa.

TWO and a half years ago an inclusive classroom was started at Holy Cross Convent Bastora, Goa. The starting line-up included 8 parents who decided to fly in the face of convention by admitting their children to this classroom and a group of dedicated teachers truly committed to the belief that it was time for children with all abilities to be educated together.

THE concept of inclusion was new to everyone including the principal of the school, Sr. Pushpika, who nevertheless courageously volunteered the space of a classroom in her school. The concept of inclusion is simple – educate children with and without disabilities together for the maximum benefit of both. The key phrase here is ‘maximum benefit of both’ which means that inclusion is not an excuse to just ‘dump’ children with disabilities into a regular setting and hope that they learn skills. Rather it is a carefully planned program where students with special needs learn various skills, which are functional, while giving them an opportunity to interact with their own peers.

LET us take the case examples of Holy Cross Convent and Chubby Cheeks School, Goa. Both have separate classrooms (Resource Rooms) for students with a variety of disabilities (autism, mental retardation learning disabilities). The curriculum of the classroom is as functional as possible and is divided into 6 main areas:

1. **Communication:** Since the majority of children in these classrooms are autistic, there is a great focus on teaching communication skills. These skills range from teaching the child to request simple needs and following simple instructions to asking for information or conducting a conversation. After the child attains the skills in the classroom setting, the emphasis is on using them in real life situations.

2. **Reading:** Functional reading is yet another skill that is addressed in the resource room. In teaching reading

the aim is to get the child to read as quickly as possible using a structured sight word program. Once the child has a reading vocabulary of 10 words, he/she is moved on to reading easy books. In order to help in the process of inclusion, the child is taught to read from the regular readers of the school. Thus a few children do attend the regular class during the reading period.

3. **Maths:** As with all other skills, the focus here is mainly functional. Activities in functional math range from basic matching and sorting, number identification, sequencing to reading the time and using a calculator for money exchanges.

4. **Writing:** Writing is also taught using a very structured program, viz Handwriting Without Tears. Writing is taught in sequence and the focus is on good letter formation and a neat script. The practical aspects include filling out a form with personal information or being able to sign their name.

5. **Gross Motor:** In this period children are taught Yoga, running a race, ball throwing and a few games like bowling and musical chairs. Since a lot of children have problems with body orientation and muscle relaxation Yoga is stressed on as part of the curriculum.

There is a special emphasis on racing and ball throwing because they are the two sporting events in the Special Olympics in which our students participate every year.

6. **Fine Motor:** This area includes all skills to do with leisure and recreation involving fine motor movements eg cutting, coloring, clay work, painting and sticking, to name a few. The reason for teaching these skills is give the children a chance to meaningfully occupy themselves in their spare time. Once these skills are learned to the level of independence, students have a better chance of integrating in the non-academic classes in the regular school.

In addition to these classroom skills, once a month, these children are taken on a community trip which contributes to their developing appropriate social skills in the community. Some of the places visited have included the Goa Dairy, a movie theatre, the ice-cream factory, the local shop and the supermarket. At all these places children were encouraged to use skills learned in the classroom. Eg those children, who were learning to use money, were allowed to independently go around the supermarket to choose what they wanted and go to the counter and pay for it. Those who could speak were encouraged to go up to the person in charge and ask for help. Future trips will include a visit to a restaurant, beach and an overnight stay at a hotel.

While the students are attaining skills in the resource room, they are also being groomed to participate in the regular classroom. Eg the fine motor period, takes care of teaching them art and craft skills which helps them when they go down for those periods. Other students are taught reading so that they go for the reading period. Those students who have developed a level of concentration participate in assembly.

It must be stressed that the main objective of inclusion here is social rather than academic. When students from the resource room and regular classroom interact with each other, there is growth for both groups. The special needs students learn appropriate behavior while the regular students learn that to be different is not necessarily bad. Both accept each other in a completely natural environment.

Many students in the resource room still do not have the necessary skills to be part of the regular classroom and so in this case students from the regular students are brought into the special class and involved in games, acting or story telling activities. Thus the special needs students get a chance to interact with regular students but in a more protected environment.

In another effort towards pushing greater awareness of disabilities, groups of older students are invited to come to the resource room and interact with the special students. They also receive small lectures on what is autism and mental retardation and what their attitudes towards special students should be. These talks have proved to be very helpful since many students have reported a change in their ideas. As one Standard IX girl said:

"I will never call them handicapped again".

As of now, both groups of students have participated together in all of the school annual day, teachers day and mothers day programs. During these times both groups of students have learned how to get along with each other but more importantly how to enjoy each other. While this program of inclusion is moving forward slowly but surely, there is still much to be done. The biggest challenge is from regular school teachers and principals who believe that inclusion would be detrimental to both groups of students.

But world over, the evidence is clear - *Inclusion works ...if done right.*

Two Day Regional Conference on Autism

24 & 25 February 2007, Dhaka, Bangladesh

'SOCIETY for the Welfare of Autistic Children' (SWAC) is glad to announce that a two-day regional conference on autism would be held in Dhaka, Bangladesh. We are welcoming speakers and participants from India, Pakistan, Nepal, Bhutan and Srilanka.

Accommodation for the speakers and participation in the conference would be free of charge. Interested speakers are requested to send their names and topics so that we can finalize and send the agenda and programme details to all.

Contact:

Anwar Hossain, Chairman, SWAC
Email: swac@aitlbd.net

MUSIC THERAPY

India Habitat Centre, 1 December 2006, 6:45 pm

MARGARET Lobo, a qualified music therapist from London, will give a presentation on Music Therapy and her work with the Otakar Kraus Music Trust in England. Music Therapy seeks to harness the power of music to enable people who find it hard to communicate through traditional channels, to express and fulfill themselves. For the last two years Margaret and her husband Walter have set up the 'Music Therapy Trust' a registered charity in India, and are pursuing the establishing of a Postgraduate Diploma in Music Therapy training programme to begin in Mumbai and Delhi. The presentation will be of particular relevance to musicians interested in exploring the healing powers of music as well as those who work with individuals with psychological, developmental, behavioral, learning or physical difficulties.

So What Does He Learn at School?

Indrani Basu

Director, Autism Society West Bengal

Few months ago my eleven-year-old son Kaustav had to have five teeth extracted under general anesthesia. Of the five teeth, four were milk teeth and one permanent. It meant a one-night stay in hospital. The evening we admitted him a nurse came to give him the usual check up. The doctors looking after my son knew about his autism but the rest of the staff only knew he is a special needs child but how special they didn't know.

THE nurse seeing a young boy proceeded to be friendly and mildly teasing:

"So you've been eating too many chocolates have you?" the nurse said.

HEARING the word 'chocolate' Kaustav looked at me and I could see the question in his eyes. Was he going to get some and I quickly told him that there were no chocolates here.

SO Kaustav reminded himself by repeating "Eating too many chocolates will give..." and waited for me to finish the sentence. So I said "...will give..." and he added, "toothache".

FROM this little exchange the nurse figured out that something was different here. So I told her he has autism. The nurse asked, *"So what is his problem?"* I started to explain while she told Kaustav that he had to change his clothes. Kaustav stood up and started to take off his tee shirt.

SHE looked at me and asked *"What school does he go to?"*. I explained that he goes to a special school.

"And what class is he in?" She asked while she held out the pajama top that he had to wear. I explained there are no 'classes', and that the children get a communication-based education specific to their needs. In the meantime Kaustav had slipped his arms into the sleeves while she buttoned him up.

SHE then handed him the pyjama bottoms and told him, *"Go to the bathroom and take your shorts off and put*

these pajamas on". Before he left I reminded Kaustav "After you have taken off the shorts bring them back here." So Kaustav trotted off to the bathroom.

"Yes but if there are no classes what do they learn? Do they have exams?" She asked. I wondered how to explain to her what we teach and how we teach it.

I was mumbling my way through the explanation when Kaustav walked back with the shorts in his hand. "Good Kaustav" I said "you remembered the shorts."

THE nurse told Kaustav to lie on the bed, which he did and then said, *"Put your arm out,"* which he also did. She then went on to take his blood pressure.

"So no classes," she said. "No..." I went on to mumble some more about what happens when teaching a person with autism.

SHE then told him to open his mouth and popped in a thermometer to take his temperature. And then started to examine him with a stethoscope and gave all those instruction that go with it, *"sit up," "breathe deeply,"* and Kaustav followed them all.

"Yes, but what do they learn?" She said finally packing up all her stuff. *"I don't see what the problem is he understood everything I told him"*.

"That's precisely what he is learning at his school" I said, "He is learning to understand."

JUST to conclude, there are two points to keep in mind:

1. The whole visit went off very well. He went to the operation theatre alone and reports from the doctors were that he coped better than most of their other patients.
2. Kaustav did not understand *everything*. He understood all the direct instructions given. But he did not understand the very first thing she had said, "So eating too many chocolates have you."

ANNOUNCEMENT

Depression and Anxiety Disorders in People with ASD

A lecture by Dr Mohammad Ghaziuddin

India Habitat Centre, New Delhi, 5 January, 2007

Depression in youngsters with Autism Spectrum Disorders is increasingly acknowledged to be of significant concern in India. Dr Ghaziuddin will take the audience through the signifying characteristics of autistic diagnosis and the association of other medical disorders, the mechanism underlying these associations, an overview of common psychiatric disorders that occur in persons with autism, asperger syndrome or PDD and the treatment strategies.

MOHAMMAD Ghaziuddin, MD is Clinical Professor of Psychiatry, Director, Child and Adolescent Residency Program, and Director ADHD Clinic, Michigan State University, with a special interest in children and adults with autism and related disorders. Author of several scientific articles on various aspects of autism, Dr Ghaziuddin has lectured widely both in the US and abroad and in addition is on the editorial boards of several leading scientific journals.

THE lecture will be of interest to medical professionals and researchers, other practitioners and interested parents.

FOR registration please email the following information to: autism@vsnl.com:

Yes, I would like to attend the lecture by Mohammad Ghaziuddin, MD

Name.....

Address.....

.....

TelEmail

Medical / Education Professional / Other (specify)

.....

Note: *The lecture is expected to be at 6:45 pm on 5 January 2007 at the India Habitat Centre. The time is yet to be confirmed. Please call Glenys on 40540992 closer to the date for confirmation, or check our website: www.autism-india.org*

NOTICE BOARD

On Receiving Autism Network

ACTION For Autism takes great pleasure in sharing information with parents, special educators, and other carers of individuals with autism. We have been generous about mailing our periodical **Autism Network** out to even those who are not members of Action For Autism. However, this comes at a financial cost.

We regretfully announce that **starting with the issue of April 2007, we will be able to mail Autism Network out only to our members.** We know that many of our readers value the information they receive in the periodical. We therefore request all of you to support us in continuing to send you the periodical by taking a membership of Action For Autism. We encourage parents to preferably take a Life Membership and others to take a Full Membership of the organisation.

However, individuals may also take an Associate Membership in order to receive Autism Network. With your membership you not only help defray the costs of sharing information, you also contribute towards the empowerment of the autism community.

For those seeking more information, please refer to Subscription on page 20 (back page).



Shovana Narayan Dances for AFA

EMINENT Kathak exponent Mrs Shovana Narayan Traxl will give a performance in support of the National Centre for Autism at the beautiful environs of the Lotus Temple in New Delhi on 20 January 2007.

By invitation only.

For information please contact: Glenys on 40540992

ऐक्शन फार आटिज्म वार्षिक प्रशिक्षण कार्यशाला

रजनी गन्धा, प्रशिक्ष

इस कार्यशाला के अनुभव को बाँटने से पहले मैं अपने उन अनुभवों को बाँटना चाहती हूँ, जो मैंने इस कार्यशाला से पहले अनुभव किये थे।

मैं एक विशेष शिक्षिका हूँ और मैंने "मानसिक मंदता" के क्षेत्र में विशेष शिक्षा ग्रहण की है, मैंने इसमें आटिज्म के बारे में बहुत सीमित ज्ञान ही पाया था, और मुझे व्यवहारिक ज्ञान का अनुभव न के बराबर था। जब मैं आटिज्म से ग्रसित बच्चों के साथ काम करती थी तो मेरे सामने कई तरह की कठिनाइयाँ आती थी, मुझे समझ में नहीं आता था कि उन बच्चों के लिये किस तरह का कार्यक्रम बनाऊँ जिससे उनका कार्यात्मक विकास हो सके। हमेशा मेरे मन में आटिज्म को जानने की उत्सुकता बनी रहती थी।

ग्वालियर में आयोजित मेरी बरुआ जी की कार्यशाला में शामिल होकर मैं बहुत सी जानकारी प्राप्त की, तभी मैंने सोचा कि 'आटिज्म' से ग्रसित बच्चों के लिये मैं आटिज्म से संबंधित पाठ्यक्रम जरूर करूँगी। यह पहली बार था कि मैं 'आटिज्म' को समझ पा रही थी। अब मैं इस क्षेत्र में हूँ और मुझे कई जानकारियाँ व अनुभव प्राप्त हो रहे हैं, जो अब तक नहीं हुए थे।

"ऐक्शन फॉर आटिज्म" ने वार्षिक प्रशिक्षण कार्यशाला का आयोजन किया जो कि अभिभावकों और विशेष शिक्षकों के लिये था। इसका संचालन श्रीमती मेरी बरुआ जी ने किया था। ए0एफ0ए0 संस्था के द्वारा हर साल इस प्रशिक्षण कार्यशाला का आयोजन किया जाता है। यह कार्यशाला नई दिल्ली में भारतीय पुर्नवास परिषद की सहायता से पाँच दिनों तक चलायी जाती है।

इस कार्यशाला में उपस्थित होने के लिये विभिन्न स्थानों से प्रशिक्षक जो मानसिक विकलांगता के क्षेत्र में कार्यरत हैं, और अभिभावकगण जिनके बच्चे "आटिज्म स्पेक्ट्रम" से ग्रसित हैं,

उपस्थित होकर ज्ञान प्राप्त करते हैं, इस कार्यशाला का आयोजन करने का मुख्य उद्देश्य आटिज्म से ग्रसित बच्चों से सम्बन्धित कठिनाइयों को जानना व उनका समाधान कैसे किया जाए, उसके बारे में बताना था। इस कार्यशाला में व्यवहार परिवर्तन, भाषा व संप्रेक्षण में कठिनाइयाँ, संवेदिक कठिनाइयाँ, सीखने की पद्धति आदि की जानकारी दी गयी। बच्चे को कार्य करते समय किस प्रकार से वातावरण व ढाँचा को तैयार करें जिसे बच्चा अधिक सीख सके।

यह कार्यशाला मेरे लिये बहुत ही उपयोगी व महत्वपूर्ण रही। इस कार्यशाला में शामिल होकर मुझे बहुत ही अधिक लाभ हुआ है और मैं आटिज्म को अच्छी तरह से जान व समझ पायी हूँ। जब मैं आटिज्म से ग्रसित बच्चों के साथ काम करूँगी तो उन सभी बातों का ध्यान रखूँगी जो मुझे कार्यशाला से जानकारी प्राप्त हुई है।

इस कार्यशाला में सभी ने अपने-अपने विचारों व अनुभवों का आदान-प्रदान किया जो मुझे आटिज्म से ग्रसित बच्चों के साथ काम करते समय सहायता प्रदान करेंगे। इस कार्यशाला से मेरे अन्दर एक आत्मविश्वास बना है कि मैं अपने बच्चों को अच्छी तरह से समझ सकती हूँ और उनके विकास से सम्बन्धित कार्यक्रम को बना सकती हूँ।

देखा जाए तो यह कार्यशाला सभी के लिये उपयोगी व महत्वपूर्ण रही है भविष्य में इसी तरह की कार्यशाला समय-समय पर होती रहनी चाहिये, जिससे लोगों को नई जानकारी मिल सके, और ज्यादा से ज्यादा लोग आटिज्म को जान व समझ सकें।

अन्त में मैं मेरी बरुआ जी को धन्यवाद करती हूँ कि, जिन्होंने मुझे इस कार्यशाला में उपस्थित होने का अवसर दिया और आटिज्म व उससे सम्बन्धित कठिनाइयों का समाधान बहुत ही स्पष्टता से किया।

अभिभावकों के लाभकारी है वार्षिक वर्कशाप

प्रीती निगम

वो इत्तफाक ही था कि हम (मैं, मेरे पति और बेटी) जिस ट्रेन में चंडीगढ़ से लखनऊ के लिए रवाना हुए उसी ट्रेन में हमारी सामने वाली बर्थ पर चाइल्ड न्यूरो सर्जन श्री नीलेश चतुर्वेदी अपने परिवार के साथ सफर कर रहे थे, उन्होंने ही हमें पहली बार यह बताया कि हमारी बेटी मुस्कान के साथ क्या दिक्कत है। बाद में लखनऊ के जी एम सी में टेस्ट कराने के बात पता चला कि उसे 'आटिज्जम' है। मैं बहुत परेशान हो गई थी अचानक लगा कि दुनिया में अब जागे जीने के लिए कोई राह नहीं रही। तब हमें चंडीगढ़ में एक मानसिक रोग विशेषज्ञ से 'एएफए' – ऐक्शन फार आटिज्जम – के बारे में पता चला। मेरे पति ने वहां से मोबाइल फोन पर मेरी बरुआ से बात की तो पता चला कि साल में एक बार होने वाली वार्षिक वर्कशाप कल से ही होने वाली है।

हमने फोन से ही रजिस्ट्रेशन मांगा और ट्रेन से तत्काल उसी रात दिल्ली पहुंच गए।

वर्कशाप में मैंने ही भाग लिया। पहली बार मैंने जाना की मेरी बेटी को क्या हुआ है। उस वर्कशाप को अटैंड करके सबसे पहली राहत तो मुझे ही मिली क्योंकि मुझे मानसिक सुकून हुआ कि मैं अपनी बेटी के इलाज के लिए सही दिशा में कदम बढ़ा रही हूं।

पहली वर्कशाप और बाद में मदर-चाइल्ड प्रोग्राम से मैंने काफी कुछ सीखा और इस साल 23 से 27 सितम्बर तक चली वर्कशाप में मुझे यह सीखने को मिला कि कैसे सिलसिलेवार मैं अपनी बेटी की देखरेख कर सकती हूं और उसे आगे किस तरह से ट्रेनिंग देनी है कि वो अपने कार्य खुद कर सके।

इस वर्कशाप में मुझे मेरी बरुआ की यह बात सबसे ज्यादा अच्छी लगी कि ऐसे बच्चों के अभिभावकों को अपने बच्चों को सरकार की तरफ से मिलने वाली छूटों और सहूलियतों के लिए संघर्ष शुरू कर देना चाहिए। अगर ऐसा हो पाता है तो हमारे बच्चों का भविष्य सुरक्षित हो पाएगा।

इस वर्कशाप में प्रोफेशनल, थेरेपिस्ट और टीचरों ने भाग लिया। इससे लोगों को अपने बच्चों की समस्याओं के बारे सही जानकारी मिल सकी। इसके अलावा वर्कशाप में आए हुए लोगों ने एक दूसरे से अपने अनुभवों को बांटकर भी काफी जानकारी एकत्र की।

वर्कशाप में आए हुए काफी अभिभावकों को लगता था कि जब हमारा बच्चा बोल सकता है तो उसे सम्पर्क विधि क्यों सिखाई जाए लेकिन वर्कशाप के दौरान ही अभिभावकों को पता चला कि ए.ए.सी. विधि से ही वो आगे चलकर बच्चों को दैनिक जीवन में होने वाली जरूरतों के लिए बोलना सिखा पाएंगे। वर्कशाप में प्रश्न-उत्तर सत्र काफी अच्छा था और अभिभावकों को यह सबसे ज्यादा पसंद आया क्योंकि इसमें उन्हें अपनी समस्याओं के समाधान का पता चला।

वर्कशाप के दौरान मैंने देखा कि शुरुआत में लोग यह मानने के लिए ही तैयार नहीं हो रहे थे कि उनके बच्चे को आटिज्जम है। उसके साथ एक बच्चे जैसा ही व्यवहार करना है, उसके साथ खेलना है उसे समझना है। वर्कशाप में विभिन्न तकनीकी मैथेड सिखाए गए कि बच्चे को किसी बात के लिए न नहीं करना है बल्कि उससे सकारात्मक बात करनी है। बच्चे के बदलते हुए व्यवहार को किस प्रकार से डील करना है, उसे सही तरीके से खेलना सिखाना है। यह ऐसी बातें थी जिनसे अभिभावकों को बहुत कुछ सीखने को मिला।

वर्कशाप में उदाहरण देकर समझाने की विधि से लोगों को बातें बड़ी आसानी से समझ में आईं और उदाहरणों के कारण कभी-कभी माहौल हल्का भी हो गया।

अंत में मैं यही कहूंगी कि जब तक हम यह नहीं मानेंगे कि मेरे बच्चे ही मेरी पहचान है तब तक हम उन्हें सही तरीके से न समझ पाएंगे और न ही उनके लिए कुछ कर पाएंगे।

खेल और संवेदिक एकिकरण (भाग—दो)

'खेल में परिवार की भूमिका'

यह समझना जरूरी है कि परिवार में असमान्य बच्चे के होने पर भी वह सबसे पहले एक परिवार का बच्चा है और अन्य दूसरे परिवारों की तरह इस परिवार के भी कुछ उत्तरदायित्व है क्योंकि ऐसे परिवार में स्पेशल बच्चा है, तो कुछ जिम्मेदारियां बढ़ जाती है। यदि परिवार के सदस्य बच्चे के साथ खेल और मनोरंजन से पूर्ण ऐक्टिविटीज में भाग लेते हैं, तो उनपर जो तनाव रहते है वह कम हो जाते है और स्थिति का सामना करना सरल हो जाता है साथ बच्चा अन्य गुणों को विकसित करता है जैसे जानात्मक गुण जिनमें सामाजिक व्यवहार में सुधार होता है।

निम्नलिखित कुछ एक्टिविटीज है जो कुछ खेल और मनोरंजन प्रदान करने वाली है:-

. एक विकासशील बच्चे के लिए यह बहुत जरूरी है कि उसके साथ घुमने-फिरने वाली क्रियाएं की जाए। और उसके लिए कुछ समय ऐसी क्रियाओं के लिए निर्धारित किया जाए जिसमें झुला-झुलना, स्लाईड पर जाना, घोड़ा बनकर खिलाना और गोल-2 घुमना हे।

. कुछ ऐसी क्रियाएं जो उसके प्रीप्रायोसेप्टेव प्रक्रिया को चालु करती है जैसे:- खींचने वाली/धक्का देने वाली क्रियाएं, कुदने और ऐसी क्रियाएं जिसमें वजन उठाने वाली, अधिक दबाव या हल्के दबाव से घुने वाली क्रियाएं आती है।

. कुछ ऐसी क्रियाएं जो घर की दिनचर्या में काम आती है जैसे - एक पंक्ति में लगे हुए तकिये उठवाना या उसकी पक्ति बनवाया और कुर्सी को इधर से उधर ले जाना और उसके साथ टग ऑफ वार खेलना जोकि इन प्रक्रियाओं के लिए प्रोत्साहित करती है।

- टरम्पुलिन पर कुदना।

- बच्चे के स्तर के अनुसार कुछ आकृति पज्जल कराना।

- लकड़ी के बलॉक्स या प्लास्टिक के बलॉक्स ले कर कुछ डिजाईन बनाना।
- ज्यामीतिय आकृतियाँ बनाना।
- मोतियों की पद्धति को धागे में डलवाना।
- चॉक और बोर्ड के साथ खेलना।
- चित्रों को काटना, मोटे मोमी रंगों से रंग भरना। या चॉक से भरना।
- प्ले डॉ जैसी चीजों को प्रयोग करके उसकी कुछ आकृतियां या एल्फाबेटस बनावा सकते है।
- कुछ और फन् एक्टिविटीज की किताब लेकर कार्य करना।

उपरोक्त सभी क्रियायों का सांराश यह कि इससे आपको और आपके बच्चे के लिए अत्यधिक सहायक है। और यह सभी क्रियाएँ आपके बच्चे के पूरे विकास में सहायता देते है। इसलिए इनकी शुरुआत किजिए और उसके बाद आपको अपने बच्चों से अच्छा परिणाम प्राप्त होगा।



• Young people with ASD participating at the inauguration of the National Centre for Autism



How Much TV is Good TV?

A question parents frequently ask is: My child loves watching TV; how much TV can I let him watch. This is a difficult question and there is no straightforward answer.

MOSTLY parents have to use their judgment in determining the value of any programme that their child watches. Children can learn a great deal from watching TV. But not all TV programmes have content that benefit children.

SOME children spend up to six or seven hours a day watching TV which parents often use as a tool to keep their child with autism occupied. The same goes for the computer. Children largely watch song and dance routines or cartoons on TV. For children with autism, the movement, colour and music of such programmes act as an attraction. However, such programmes do not teach the child anything worthwhile.

IF a child must watch TV, try and introduce content that is stimulating, that the child can learn from. When children get too addicted to song and dance routines or endless hours of cartoons, it is then very difficult to get them to watch educational programmes. Its like feeding your child a packet of chips just before lunch: he would be so full of junk that it would be difficult to feed him his rice and dal.

CHILDREN who are introduced to stimulating programmes at an early age, such as those on nature or wild life, enjoy such programmes immensely and learn

- The Inauguration plaque unveiled by Shrimati Sonia Gandhi



from them as well. Many go on to watching the news and do so on a regular basis. TV time can also be a great opportunity for a parent to spend time along with the child, providing opportunities for communication and sharing.

AS for computers, their predictability of operation ensure that children with autism often excel at their use. Many teach themselves how to turn on and operate a computer without ever having been taught. There are wonderful educational computer games available that children can learn from. These range from games on the environment, on reading, numbers, and so on. Children with autism often become adept at using and learning from these programmes. However, it is important to be alert and move on to more challenging games once a child has mastered one. Children can become addicted to a game and then it ceases to be a learning tool. A game can turn into an obsession and sometimes it can be very difficult to wean a child off it.

BECAUSE the computer can be such a wonderful learning tool, and because our children can grow their cognition through computer games, parents often allow their children many uninterrupted hours on the computer. However, while computers can teach our children many things it does not help develop their social understanding. So it is important to ensure that the opportunity for human interaction is not usurped by time on the computer.

SO how much TV should a child watch, and how many hours can a child reasonably spend on the computer. While parents can determine what length of time they consider suitable: an hour, an hour and a half, less or more, they can ensure two things. One, that the TV programmes children watch and the computer games they play are ones that they learn from, that challenge their intellect, and that which are not mere obsessions. Two, that the length of time that the child spends in interacting with 'people' is definitely more than what the child spends in watching TV or on the computer, and with a greater component of 'fun' than what either box provides.

BOTH TV as well as the computer are wonderful teaching tools when well used. How they are used is completely up to the parents.

HELP LINE



Q I have a son who is three and is an autistic child. We live in Surrey in British Columbia, Canada. My son gets IBI treatment based on behaviour analysis at a school which has been supported by the provincial government. He has been showing some improvements in his behaviour.

The reason for this mail is to inquire about any schools, organisations in India that offer IBI to children with Autism. As we have decided to settle in India in the very near future, but as informed earlier, we are looking for schools/ organisations that have professionals trained in behaviour analysis so that my son keeps getting the intervention therapy.

A There are a few schools in India that have IBI based teaching methods – more specifically Verbal Behaviour based. The ones we have information on are:

Dikshan

Autism Society West Bengal Kolkata
<autismsocietywb@hotmail.com> Contact: Indrani Basu

SAI

Mumbai
<kamini108@rediffmail.com> Contact: Kamini Lakhani

We Can

Chennai
<wecantrust@rediffmail.com> Contact: Gita Srikanth

Q I am a government servant working in UP cadre. My son is 10 years old and has mild autism. He is hyper and lacks wisdom. He has delayed speech and repeats words. He always carries an empty bottle in his hand which he hits against things. He sleeps in the day and wakes up at night. He watches a lot of TV. Please suggest relevant therapy, institutions, and hostel (if available) in India.

A We understand your concern for your son and hope to guide you as much as we can. First, a little about the Autism Spectrum. As you may already be aware, Autism is a lifelong developmental disorder, which is characterised by three core difficulties. The concerns you have identified fit these three difficulties. For instance, delayed speech can be quite typical of children on the

spectrum. This may be accompanied by odd or formal speech or unusual use of words and phrases. Holding on to bottles, banging them on surfaces (preoccupation with, and non-functional use of the item, or fulfilling a sensory need by hitting the bottle), and different sleep patterns may be considered a form of ‘inflexibility of thought and behaviour’ which is again, a core deficit seen in individuals with Autism. Thirdly, a different quality of peer interaction and social interaction in general is also a core difficulty.

It is quite subjective to classify Autism into mild, moderate or severe as each individual shows a different skill profile. So while your son may excel in one area, he may be behind on others such as speech and language. Another child with the same diagnosis may have great language but may score differently on other abilities. It may therefore be more useful to isolate each strength and difficulty and to see how to use those strengths to push your son’s development further.

As you mention, the next step for you would be to find a trained autism therapist with sound understanding of your son’s difficulties and to begin a training programme based on his individual needs and strengths. In UP we know that the King George Medical Hospital in Lucknow has a programme for children with autism. We currently do not have information of other institutions and therapists from UP, though there may be a few others.

You may also arrange to visit us in New Delhi for a three day extended programme to assess your child’s abilities and to start you off on a basic programme.

While there are not many residential facilities in India for young children, we will send you the list of facilities we have with us. We however recommend highly that parents and families are fully involved in their child’s educational programme, whether at home, school or at any other facility.

Q My son is 23 months old, but he has not started speaking. But on his own he has learned certain things by observing other family members. He is very active, enjoys playing with other children, loves music and watching TV and builds with blocks at a good level. He feeds himself.

He tries to copy and do what others do. He is healthy and has achieved all milestones except two:

1. His speech is not clear except a few words like 'bye', and 'ma', and that too not meaningfully sometimes.
2. He follows only a few commands like 'do', and comes when called. But if we show him something he does not pay attention. He prefers to do what he wants: like he will bring rotis and serve you if he sees that you have finished your roti and your plate is empty. When he wants to eat something he will try and get it or he will point to the objects and take us to the kitchen. He is able to make us understand all his wants: whether he wants to go to the toilet or to the market.

I have no doubt about his intelligence as he learns very fast by observing others. I just want to know what the real problem with my son is. Are these the symptoms of Autism?

Finally, can I undertake the proposed two year bio-medical programme of chelation and HBOT for my son.

A It is difficult to say on the basis of your description whether your son has autism or not, as for that it would be essential to make an observation of your son's behaviours and have an interview with you and your wife. Receiving a diagnosis for your son's condition should be of top priority, as that would help direct you to an appropriate treatment approach. If we know where you are based we could refer you to a competent diagnostician, ideally a developmental paediatrician or a child psychiatrist with extensive experience of autism.

As for undertaking the advised bio-medical programme, perhaps you want to first arrive at a diagnosis for your son's condition before you can consider whether to go for it or not?

Q My child is now six years old. She is suffering from childhood autism and taking treatment at Tamil Nadu. My wife is taking her to Speech Therapy classes daily and giving her physiotherapy also. Please advice what type of puzzles and toys would be suitable for her.

A We do not have any list of toys specific to children with autism because each child is different. Though many children with autism do not show much interest in conventional toys, toys that provide sensory input are liked by most of them. These days there is a wide variety

of such toys available. Cause and effect toys that produce sound / light/ movement on pressing a button are easily available and at very affordable prices

Get your daughter simple toys that can enhance her learning in various areas. Play dough, colourful blocks, activity centres, cushion balls, beads, are things a child can play with and they also enhance motor skills.

Many children like to build blocks, scan through books. Picture books like the ones in the Lady Bird 'Learning to Read' series, Children's Book Trust and National Book Trust, may be useful as these have simple pictures that the child can identify with.

Jigsaw puzzles can be fun if the child can fix them. Some would enjoy playing with educational puzzles such as the ones on 'opposites', 'things that go together', etc – that often come in interlocking sets. However a child with autism may just follow the pattern of the interlocking cut-outs and fix the correct pieces together without ever following the concept. Therefore in the latter case you can get cards that are simple square pieces (brands such as Creative and Funskool have them) and come in interesting sets such as:

- what comes next picture sequencing
- match and learn
- opposites

Every child with autism is different and so are their interests. The best toys or equipment would be the ones your child likes and finds exciting. It is not what the toys are but how they are used that is important. Even a simple ball if rolled at a line of empty upright plastic bottles that get knocked down could be great fun provided the entire process of rolling and knocking down is done with cheering and excitement.

Initially let your daughter lead the play. Join her in her kind of play and then slowly modify and model play for her to imitate. Use toys like dolls and kitchen sets to enhance pretend play through imitation. These can be used by the speech therapist as well.

You mention in your letter that your child has 'childhood autism'. It is important to be aware that though the term 'childhood autism' and 'early infantile autism' is sometimes used, autism is not a childhood disorder that 'goes away' as the child grows up. It is a lifelong condition. Of course it is also a condition in which there

can be often great progress if the intervention is appropriate and early.

Q I have a question regarding the Turn Taking procedure that you have outlined on your website – I find it incredibly helpful and was hoping for some clarification around what the visual should look like for turn taking between two or more children.

A Not sure which article you might be referring to. However, here is an illustration of where two children Tia and Sunny take turns throwing a ball. Each is to take three turns. First Tia, then Sunny, then Tia, then Sunny again, and so on. As each child takes a turn they strike out one of the balls on the illustration (or the facilitator may do it for them). This gives a clear indication of whose turn next and how many turns left etc. Trust this is what you wanted:

Tia	Sunny
	
	
	

Q My autistic grand daughter is 10 yrs old. She attends regular school in Standard Three. Of late her hyperactive behaviour in school has increased a lot and is causing concern to all of us. There is nobody in the school who can keep a watch on her throughout the school hours to prevent this behaviour. The school has no full time Special Educator or Counsellor, and as such the teacher tries to manage her abnormal behaviour whichever best way she can.

My grand daughter attends therapy sessions with the special educator on three days and with a behavioural therapist on two days. She destroys the pictures that are stuck on the wall, or sometimes she throws her tiffin on the floor. She sometimes continues to laugh for a long time or sometimes bursts out crying for no reason. Academically she is very good. She scored 78% marks in the unit test with excellent remarks. Can you offer us some remedial measures which will effectively control her abnormal behaviour?

A Your grand daughter seems to be managing well with the academics as many other children with autism but she appears to have other difficulties in coping with the school situation. Very often these difficulties can act as triggers for challenging behaviors.

One needs to find out what happens before she resorts to tearing paper displayed on the walls or laughing, when these behaviours happen, whether they occur with different teachers or with the same teacher. Similarly it is important to know what the teachers do when she exhibits these behaviors. If despite the intervention behaviors are increasing as mentioned by you then it is very clear that even though her school may be trying its best to support her and deal with the challenging situations, the strategies are not working to reduce the behaviors.

It is rather difficult to comment on the possible reasons and give suggestions without having answers to the situations referred to above. However we can suggest a few things that can be tried out. But most crucially it is important to remember that your grand daughter has autism. Her apparent skills often make us expect far more from her than she is capable of.

In addition, your grand daughter is ten years old and is entering adolescence. For her this is a new phase of life in which she may be confused with her own bodily changes and also the awareness of being different from other children may be setting in gradually. Therefore the family needs to have a lot of patience and acceptance and a positive attitude. We find that families are generally aware of this and surely you may be having the same approach.

Provide her with an environment that is predictable and prepare her about changes if and when they happen. For example in case of a change in the timetable talk about it in advance. Tell her clearly and specifically about the change. Your grand daughter has autism. Despite her communication skills she may not be able to ask “Why are we not taking out our Math book in the Math period,” and get confused and stressed about it.

Try and keep instructions to her brief, precise, and concrete. Do not assume she will follow an instruction that has been given in general to the entire class. The teacher may have to take your grand daughter’s name, pause to get her attention, and then repeat the instruction. For example if the teacher has told the class,

“Take out your work books and give them to the class monitor”; she may have to address your grand daughter by her name: “Shweta, take out your English workbook from your bag. Now give it to Shalini”.

You can practice having your grand daughter learn to pay attention in a group at home, where the mother says, “Everyone, come for dinner”.

Classrooms have a lot of distractions that can be problematic for a child with autism. Teach her to deal with these at home. Expect her to complete her task or follow instructions with the TV or music on. Conceive interruptions that she has to work around.

State clearly what is expected of her. Be concrete. Say and give the child time to process your instruction in her

mind and then carry it through. Avoid verbal overload. Too many instructions may be confusing.

Your grand daughter has to be helped to see that when she does NOT tear paper she gets praise and attention. Catch her when she is good and by and large do not provide too much attention for inappropriate behaviours.

During times like the tiffin time a lot of interactions take place between children and obviously she has difficulties in interacting with her peer group. Therefore she may throw her tiffin in order to either get attention of others or out of confusion. She needs to know what she can do during recess. Assign an area for eating that is quiet and she is in the company of very known and preferred kids. Give her clear indication of what she can do after she has had her tiffin and still has time before the next class starts.

Dr Bernard Rimland

Dr Bernard Rimland, founder and director of the Autism Research Institute, passed away on Tuesday 21 November 2006. Dr Rimland was 78. To many parents whose children have been diagnosed in recent years, Dr Rimland represents the Autism Research Institute, originally known as the Autism Research International, which provides information and guidance on the use of various alternative therapies. But Bernard Rimland’s most remarkable contribution was the publication of his seminal work, **Infantile Autism: The Syndrome and Its Implications for a Neural Theory of Behavior**.

The book was published in 1964 when psychoanalysis for autism, and Bruno Bettelheim’s ‘refrigerator mothers’ theory reigned supreme. When it was believed that cold calculating parents who deprived their children of love was the cause of autism. Based on these theories, Dr Bettelheim advocated the separation of the children from their supposedly unloving parents. Treatment often espoused the use of having the children display abusive behaviours towards dolls and other objects representing their parents. These were theories that destroyed many loving families. The publication of the book was the first and the most significant blow against these destructive beliefs.

Dr. Rimland’s journey with autism began with his son Mark Rimland, who was born in 1956. A barely known condition in the USA at that time, Mark’s autism was identified by his mother Gloria who recalled reading in college about a condition that appeared to mirror her son’s. Faced with the then widely held belief that they, the parents, were the cause of Mark’s autism, Rimland set out

to find all he could about the disorder. In the process he realized that autism was clearly a biological condition, and had no relation to the quality of love and care that children received. This led him to write the book **Infantile Autism: The Syndrome and Its Implications for a Neural Theory of Behavior** which changed the autism scene forever. Parents of children with autism everywhere owe a huge debt of gratitude to the person who ensured that we do not go through life with a burden of blame.

A pioneer who reversed the trend of parent blame, Dr Bernard Rimland’s work led to the development of more appropriate ways of helping children with autism. Along with other parents like Ruth Sullivan, Clara Claiborne and David Park, Dr Bernard Rimland went off to form the Society for Autistic Children in the USA which is now known as the Autism Society of America. Started as a parent support group in the same way as most national societies for autism across the world, it is now a leading organisation for autism advocacy in the USA.

In India as in many countries in the world the nightmare of being blamed for our children’s condition is still not over. Many parents continue to be routinely asked about their family dynamics and relationship between spouses, whether they ever fight; whether the mother goes out to work; and so on, when a diagnosis is made. The greatest tribute that those of us who work with children with autism and their families can pay to the memory of Dr Bernard Rimland is to intensify our efforts to change this destructive belief.

Autism Research Institute
www.AutismResearchInstitute.com

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Diagnosis (if known) _____

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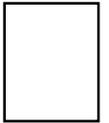
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BOOK POST



If undelivered please return to:

The Editor, Autism Network,
Sector 5, Jasola Vihar, Behind Sai Niketan,
Opp. Gate 6 Sector 8, SFS Flats, New Delhi - 110025

Publisher: Merry Barua
Printer: Ashish Adhikari
Owner: Action for Autism
Editor: Merry Barua

Printed by:

Nyogi Offset Private Limited
D-78 Okhla Industrial Area Phase I,
New Delhi-110020
Tel: 26816301/26813350/51/52 Fax: 26813830

Place of Publication and address:

Action For Autism (AFA)
Sector 5 Jasola Vihar, Behind Sai Niketan
New Delhi-110025 Tel: 91 11 40540991, 91 11 65347422

Email: autism@vsnl.com

Website: <http://www.autism-india.org>