

autism network

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INFORMATION

For information on receiving the Autism Network write to: Sector 5, Jasola Vihar, Behind Sai Niketan, Opp. Gate 6 Sector 8, SFS Flats, New Delhi - 110025. Tel: 40540991/2

YOUR CONTRIBUTIONS

Do you have any comments, suggestions to offer? Information and experience to share? We look forward to our readers' participation. Send letters, articles, illustrations to: The Editor, Autism Network at the above given address or E-mail: actionforautism@gmail.com

Editor: Merry Barua

Editorial Board: Indu Chaswal, Nidhi Singhal, Indrani Basu

Design & Production: Bindu Badshah, Sudhir Pillai

In referring to the child with autism, Autism Network often uses 'he', 'him' and 'his', not as a prejudice against the girl child with autism, but for reasons of simplicity and because the vast majority of children with autism are male. However, many articles also use 'she', 'her', and 'hers'.

Website: <http://www.autism-india.org>
Helpline Email: helpline.afa@gmail.com

Cover Illustration
'Rabindranath Tagore'
by Kaustav Gayen, 9 years, student at Pradip: Centre for Autism Management, Kolkata

WISHLIST !

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PAGE ONE

Since TEACCH, the approach that was developed by the late Dr Eric Schopler in the early 1970s and carried forward by Dr Gary Mesibov, gained prominence and was adapted by schools across the western world, many other approaches have come into prominence. Each has something to offer. The smartest practitioner, whether a parent or a special education teacher or any other professional, knows how to take what is best of each and relevant for each individual child, for a truly eclectic approach.

I recall when I had gone for my first training in structured teaching in the early 1990s, the introduction included a discussion with parents of five or six of the youngsters on the program. What struck me was their positive attitude which was very much in sync with our own philosophy. These were not unhappy parents desperately seeking someone or something to blame for their child's autism; these were parents aware and accepting of their children's autism, aware of their children's strengths; and respectful of them as individuals.

Over the years as new approaches evolve, and are available to parents, some of these have a similarly positive outlook. But alongside, many promote despair in order to win over followers: My approach is the one you must adopt. If you don't follow this approach your child is doomed to a life not worth living. If you don't follow this approach you are not a good parent. Or, worse, you are a fool!

Parents often leave introductions to such programs shell-shocked in the erroneous belief of having wasted years of their child's life on an approach other than the one being promoted.

Often programs promise exceptional results in return for considerable investments from parents either in terms of finances, time, or other resources; sometimes promising unrealistic results. Parents are so emotionally invested in their children's wellbeing that they willingly buy into these promises. It is hard for them to be objective in the face of the hardsell that they are subjected to. It requires a resolve of steel for parents to be able to objectively

evaluate claims in the face of 'proof' of effectiveness that is skewed in favour of the approach being advocated.

Each child is different. How effective an approach is, is also determined by a number of other variables: such as the skills of the person delivering the program, and the amount of time that the child receives the program. A program, that is delivered one on one by a skilled practitioner for six to seven hours a day for seven days a week, has greater scope of being effective than when it is delivered for four to five hours only during school hours.

**Rehabilitation Council of India
CRE Programs on Autism:
*Fundamentals of Structured Teaching***

~ ~ ~

29th and 30th November 2009

See Page 17 for details.

In a country where there are less than a hundred schools and just a few hundred trained professionals for a school-going population of around two million children with autism, suggesting that a time and resource intensive approach is the ONLY route worth considering, fails to respect the

constraints that parents function under.

EVERY approach that is based on an understanding of autism can be, and indeed is, effective. The effectiveness varies from individual child to child, and the skills of the practitioner: for every exceptional practitioner there are several poor practitioners.

The most valuable approach is one that views the individual with autism as different but not necessarily inferior; that respects the 'culture' of autism.

Disclosing one's own, or ones child's, autism to the world flows from this acceptance and respect. It also allows one to see the lighter side of living with autism. This issue delves into the 'who', 'how' and 'when' of disclosure as well as of living and laughing with autism. We also carry Jim Sinclair's classic piece 'Don't Mourn For Us'. Despite the many years that have passed since it was written, the piece has not lost any of its validity.

With this issue Autism Network completes 15 years of publication. We look forward to the next 15 and thank our readers for their feedback and encouragement.

We wish each one a Merry Christmas and a splendid 2010 ahead!

Disclosure - Telling Others

Merry Barua

Stigma

There is the story of the British American actress Merle Oberon who struggled through life to hide the Indian part of her Welsh-Indian origins. The stigma of being black in a white world was more than she felt she could handle. Many individuals of mixed parentage in white-dominated societies acted similarly in those times of strong racial discrimination and segregation. Ms Oberon's action stemmed from the stigma attached to being of an Asian and of non-white parentage. Many of the opportunities that came her way would undoubtedly not have done so had it been known that her mother was Indian. It would not have mattered that she was talented, beautiful, and did her job well.

PERHAPS it is facetious to compare origins and ability, but the parallel can help us understand why there is such a strong tendency to hide disability when one can. Traditionally disability carries stigma in most places in the world: certainly in South Asia; and definitely in India. People with disabilities through time were usually portrayed as villains. Or to put it differently, villains in modern times as well as in our epics are often portrayed as having some form of disability, like Shakuni in the Mahabharata and Manthara in the Ramayana. This tradition has been carried over in our literature and our popular cinema.

HINDI cinema which has a huge impact across the country has mostly shown people with disabilities as villains or for providing comic relief. Villains in Hindi films typically have a limp, or are one-eyed, are overweight, or have a speech impediment. Conventionally Hindi films always had a comedian. The latter was someone who had a disability which was supposed to be 'funny'. If the character with disability was neither the comedian nor the villain, then the audience was expected to feel sorry for the character. So one was expected to either laugh at the person with disability, or feel sorry for the person. Especially where a person with disability is the protagonist, the storytelling is programmed to raise 'sympathy' for the 'sorry' state of the person with disability. Furthermore, in many films the person with disability defeats all odds and emerges a 'winner' with some special skill or ability. It is almost as

if the person with disability must redeem himself or herself by demonstrating a special skill. Even an otherwise well made film like *Taare Zameen Par* which has created a great deal of awareness falls into the trap of Bollywood formula with the central character emerging with outstanding artistic skills which helps him to win the competition.

THE stigma is such that disability is a condition that no one wants to be identified with and it is even more difficult if one is an 'ordinary', 'normal' person with disability, if one has no exceptional ability.

WHEN the condition is physical and therefore visible, disability cannot often be hidden. So when one has a family member with a locomotor condition or a visual impairment there is little possibility of 'hiding' –if one wanted to – from one's friends, neighbours and relatives. Also, here the individual with the condition is often the one taking the decision though that decision may be coloured by perceptions of others in the immediate environment.

IT is a little different in the case of those with mental conditions. With a physical condition, when disclosing, a rider is often added, that despite the disability there is great intelligence. A phrase like 'an intelligent mind in a disobedient body' has the capacity to fire people into support and action. But this again feeds into this belief that there has to be something – in this case 'intellect' - to redeem the fact of the disability. Interestingly it is the disability sector itself including those with disability themselves who see nothing wrong in propagating this construct. An oft heard comment especially when referring to governmental departments is: They cannot get away treating us like this; we are disabled but we are not stupid. Implying of course that if intelligence was less it was understandable that government departments would treat such individuals without respect.

ADD to this the male's perception of the child – particularly the male child - as an extension of their masculinity. We find that many fathers have significant difficulties in admitting to having a less than 'perfect' child. When the child has a mental disability, then that

becomes even more difficult to accept.

In a world that glorifies the one who 'tops', who comes 'first' in everything, the stigma of a 'mental' disability is that much harder to accept.

Disclosure

- Do we tell others?
- Who do we tell?
- What do we tell?
- How do we tell?

HOW do parents come to terms with their child's autism, much less explain it to their parents, their extended family, to the outside world. Autism? What is that? A 'mental' disability? The stigma of mental disability, of being 'paagal' the universal term of derision for all those who perform differently in everyday life again has several layers of discourse that cannot be covered in this short piece.

WHETHER to disclose one's own or one's child's autism to the outside world is a debate that is laden with strong emotions on every side. However for this, disclosure to the person with autism, something that was discussed in the April 2009 issue of the Network, has to be considered. If the individual with autism is not aware of his condition, then informing the outside world gets that much more complicated. However the reverse has been known to happen, especially in cases where, in the typical underestimation of the individual with autism, the family wonders: Will he even understand? So what's the point in telling him?

THE topic of disclosure comes up first when a diagnosis takes place. Disclosure of course has to be preceded by acceptance of the diagnosis on the part of the family. Autism with its diagnosis in childhood forces parents to come to sudden terms with a difficult situation. Here is a child that they thought was like any other. Maybe not speaking like other children but knowing every colour in the rainbow and more. Maybe a little 'naughtier' than others. Maybe much 'smarter' than others, so much so that there is no interest in toys but instead maybe interest and aptitude in computers. And then to be told that there was this complex condition that the child has, and that, this very aspect of unevenness of skills and interests is one of the key markers of autism.

FOR many parents overcoming this bump is the big one. To make that shift and acknowledge that a behaviour one thought was clever was also a characteristic of autism.

That the difficulties the child has cannot be explained away because there are no siblings, because there are no playmates, because the grandparents moved away; but because the child has a specific condition. Sometimes, especially with children who develop age appropriate communication or cognition, parents can find it hard to acknowledge the diagnosis sometimes for many years. For many parents their child with autism, most often perfect in every physical aspect, seems like a puzzle for which if they could only find that one crucial 'missing' piece then things would fall in place. Added to this is the cacophony of voices propagating cure, there is the aching hope that the autism will go away. So if my child can be cured and may not remain autistic, then why tell anyone! Once the parent has accepted the child's diagnosis of autism, the question 'Do we tell others?' looms large. Interestingly, for parents who are part of a family or community where there is little stigma attached to having a child with a disability, the notion of not disclosing the diagnosis of autism does not occur. Sharing what is a difficult situation comes naturally. For others, a reason for not wanting to disclose is the fear of being stigmatised by relatives and acquaintances. Families fear that when extended family and neighbours get to know about the diagnosis, they might be shunned. They feel that they would be excluded from the life of the community once it gets known that their child has a disability. As a result many try to keep the child out of family gatherings. Others participate, but avoid any reference to autism, skirting any issue about their child that might come up, leaving family members to draw their own conclusions.

SOME prefer to not disclose to avoid being pitied. When disability is disclosed the common reaction is 'poor things'. Many families naturally find this irksome; they would rather not disclose than have people pity them for their child's condition.

HOWEVER what often encourages secrecy and an unwillingness to disclose is that when the child with autism is very young, the unusual behaviours do not seem too atypical. As a result more families are tempted to keep the diagnosis from their families, almost expecting the diagnosis to 'go away' if it were ignored long enough. They may go for several years without any reference to autism. However as the child grows older, and the different developmental trajectory becomes more and more obvious, it gets harder and harder to ignore the diagnosis, or to pretend that there is nothing that is different.

ACTUALLY having a child with autism one learns to live with a leitmotiv of questions through life: Why is he doing this? Is he 'paagal' (mad)? The unusual behaviours invite constant scrutiny, curiosity, and comments. Certainly this is an experience shared with other conditions, but nothing like the constancy with which it accompanies autism. (As for the term 'paagal'; having a psychiatric condition is as much of a disability as any other. And if my son had a psychiatric condition would being called 'paagal' have made it better? Or worse? Because it is not the term 'paagal' that is important but the construct of the difference and what it means to the speaker).

HAVING a child with autism is not a situation any parent is prepared for. Faced with the situation, many are often not sure who to tell. And what to tell others about the child's condition? We tell our parents. But do we tell our sister-in-law's in-laws! Do we or do we not tell our colleagues? What about our neighbours? What will my colleagues think of me if they find out my son has autism? Whichever perspective and route a family wishes to take is a legitimate one for that family given their beliefs and their situations.

THE author's perspective is one that supports disclosure: disclosing to family, friends, neighbours, colleagues, acquaintances, people on the street, in short anyone who shows curiosity of any sort. While yes, it can be irksome to be constantly asked what is wrong with one's 'paagal' son, one can also take the perspective of the questioner and understand that the questioning does not necessarily come from a judgmental perspective. The questioning can also simply be a need to know. Curiosity. And that is human. If we see a blue-coloured human being we would be curious. I would wonder if the colour was for real or painted on. I would have questions. My questions would not necessarily be because I think the blue being is a terrible, bad, unacceptable being, but simply a kind of being different from ones that I am used to. Similar are the questions that people have about autism. It is often just a need to know and understand.

WHEN we hide our children and do not tell the world about autism, then people do not see autism and therefore do not understand autism, leading to more curiosity and questions. So when people ask: Why is he doing (whatever he is doing!)? rather than hide, or avoid, or see it as an affront, we can view it as an opportunity to create awareness. To turn and tell people "Oh, he's doing this because he has autism." A few will then ask: what is

autism? Another opportunity to create awareness; to say a few things about autism, to sensitise one more person about autism.

How do we tell?

Disclosing to the world is not merely about telling them that our child has autism. It is about making a statement that says: **Yes**, he has autism. **Yes**, he is different. And, **Yes** he has as much of a right to a fulfilling life as you or me.

AND that is why 'how' we disclose is important. In the work that Action For Autism does, an important aspect is helping parents come to terms with their child's autism. When asked many parents explain: my child has a 'problem'. If we believe our child has a problem, then why would people see them as anything other than problematic, rather than being 'different'. It is the 'problem' that will remain in the forefront in people's understanding. When people ask, we can perhaps instead say: My child has a condition. He has autism.

OUR acceptance levels and our feelings about our child come into play here. If we view our children as a problem, as an embarrassment, as a shameful situation, it comes through in the way we speak about them. And if we ourselves view our children in such a negative terms, then can we blame others for doing the same? Hence when we speak about the child's condition to the outside world, it helps the child as well as the family to disclose with positivity. That does not mean using positive language with a negative feeling. Both have to be in sync.

DISCLOSURE flows from acceptance. Acceptance is sometimes confused with resignation and inaction, whereas it is the opposite.

ACCEPTANCE is saying, yes he has autism, and I will do all I can to help her learn and grow. Acceptance is being aware that people will ask questions, that often the questions will seem insensitive. Acceptance is understanding that questions come from ignorance, curiosity, surprise, and a desire to know. Acceptance is viewing questions as opportunities to dispel ignorance and myths; to inform and create awareness. Acceptance empowers both the person with autism and the family.

WHEN there is acceptance, a decision to not disclose comes from a position of strength not weakness. When an accepting parent decides not to disclose the diagnosis to the school, she does it not because she is ashamed of her

daughter, but because she is aware that the school is not the enlightened place that it should be.

G is an accounts person and IT trouble shooter. He lives with ASD that was hidden from all but one member of his family and from all acquaintances as well. It was not spoken about. After he joined an organisation that understood and accepted his condition he 'came out'. He speaks on national TV and at international conferences. He has informed his organisation's bankers –with whom he has frequent dealings – that he has ASD. He speaks to the media. Most of his family has learnt about his diagnosis from these other sources. G is comfortable about his condition. Autism for him is no longer the dirty 'A-word' it was before.

DISCLOSURE that flows from acceptance can take a measured decision about where, when, and to whom to disclose.

OF course, there is no one uniform way to go about this: at school, college, place of work or elsewhere. Disclosure will be different in different places, and even in each place will have to adapt to differing situations.

A tricky area for instance is school. For children going to special needs schools, disclosure to the school is evident. However, for children who are in mainstream schools the circumstances can be varied. Some have been attending from a very young age much before a diagnosis of autism. Others may have joined later after two or three years of intensive one on one in special needs classrooms. All of the children have continuing concerns with social understanding. Parents face the dilemma: Do we tell the school that the child has autism? A few mainstream schools with inclusive classrooms are quite comfortable with a diagnosis of autism. Most – despite the rhetoric and apparent inclusivity – are not willing to admit children with autism except for a few functionally able children who have almost no unusual behaviours. Where there are any concerns about the school's policy regarding autism, parents may understandably opt to omit a mention of autism and instead just say that their child has language difficulties, or that there are attention issues.

IF school is difficult, college is more difficult. School in India is a more structured system. There are periods of specified activities that are each regulated by a teacher except for recess. But college is somewhat unstructured. Classes may or may not be attended. One is expected to take oneself to a class one chooses. There may be large

chunks of free time when the student may choose or not to attend library or other activities. It is just the kind of environment that some students with autism find challenging. Non autistic students soon figure out that this is a vulnerable person and create situations to exploit that. Students with autism in college therefore prefer to keep a low profile and keep their diagnosis under wraps, at least from fellow students. College students with autism report being picked on even when their peers do not have information of their diagnosis. Their feeling is that if other students get to know that they have a diagnosis of autism then their time in college would become unbearable.

S is a young man who attended special needs classrooms, moving to inclusive classrooms in his senior years. After school he has finished college without either his peers or the college authorities knowing about his condition. S is very comfortable about his diagnosis. He enjoys coming to AFA for events. Most of the people on the spectrum he meets here are nowhere near his level of functional ability. It never occurs to him to 'look down' on them. For him AFA is a place where he feels people understand him and accept him without judgements. His college, he learnt was different. Even without information on his diagnosis, other students sensed he was different. During his college years he lived a world of such extreme discrimination against the minor oddities of his behaviour - he was picked on almost every day of his college life - that he knew instinctively that this was not a place to reveal his autism.

ADULTS with autism who are in employment, are individuals who have grown up at a time when it was common for families to conceal the diagnosis. For them to come to terms with and reveal their diagnosis to others requires a process of de-stigmatisation and acceptance of their own condition. It is only then that they can disclose their condition to others like G has. As a self advocate G discloses his diagnosis to organisations he interacts with; a situation that has not led him to being disrespected as many feared. On the contrary, A is another young man on the spectrum, who works in the same organisation as G. A's parent's have not disclosed his autism to him or to the people in his immediate environment. Despite being in an environment that understands autism and appreciates differences, A finds it extremely difficult to accept his own autism. Consequently, strategies that are suggested to help him negotiate the work place better are met with unwillingness and thus preventing him from developing appropriate work behaviours.

FOR the individual with autism who successfully graduates to college, from then onwards - and sometimes earlier - disclosure is a personal decision. For this will be an individual who not only has the ability to express in a manner that the non autistic world understands, but is an adult and able to take her own decisions. However, autistic self advocacy is still in infancy in India since in reality the decision often still remains in the parental domain.

IGNORANCE breeds discomfort and discrimination. One of the strongest arguments for disclosure is the awareness it creates. The more individuals with autism that the community is exposed to, the greater will be the comfort that people will show around people with autism.

T is a young man who likes rocking when unoccupied. He has learnt to not hum or flick his fingers when in public but he needs to at least rock in order to feel grounded. His father is mortified each time T rocks when they are out together. The more he tries to stop T, the more stressed T gets and more does his need to rock increase. The more uncomfortable T's father gets, the more people notice them. People keep asking him about T: What is his problem?

WERE T's father more comfortable about T's rocking, he could focus better on teaching T alternative or control behaviours and respond with comfort to people's curiosity. His obvious discomfort leads observers to feel that T's rocking is something to be uncomfortable about, regardless of the function the rocking serves for T. When they see T rock they react with criticism and negativity, a direct reflection of his father's attitude towards T's rocking.

OF course we care what other people say and think about our children. But do we really care about what someone who we will never see again says about our child. We cannot really change that; but we can change the way we feel about what people say!

FINALLY, whether we disclose or hide our child's autism, others find out! They may not know it as 'autism', they may not have a 'name', but they know that the person is different. B is a 12 year old on the spectrum attending a mainstream school. His school and extended family, all know about his diagnosis. His family moved to a new locality where some of the children in the park figured he was different. One day a particularly not-nice

child tried to pick on him. 'Don't play with him. He is paagal.' A confident S turned on his tormentor matter-of-factly and said: "You say that again and I will whack you on the head," And carried on with his game. B is aware and comfortable about his autism. It has never occurred to him that it was something to hide or be ashamed of. And he responded from that perspective.

A common refrain of a lot of parents is that the world does not understand our children. We live in dread of "What after us?" As parents, we all dream of a world that would accept and nurture our children for who they are, provide them with the possibilities that would make their lives as fulfilling and happy as possible. If we sweep the 'autism' under the carpet, the world is not going to go peering for it. If we forsake countless opportunities to tell the world that our child has autism and that its okay.....the world does not have the time to delve further into this. If we want to make the world a better place for our children, then it is time to move to a new and a more positive understanding of what it means to have a disability, to have autism, to be different.

Don't Mourn For Us

Jim Sinclair

Jim Sinclair is an autism rights activist who, together with fellow autistics, Kathy Lissner Grant and Donna Williams, formed Autism Network International in 1992. Sinclair wrote 'Don't Mourn for Us', an essay with an anti-cure perspective on autism. (Wikipedia)

This article was first re-printed with the author's permission in the December 1999 issue of Autism Network.

THIS article was published in Our Voice, the newsletter of Autism Network International, Volume 1, Number 3, 1993. It is an outline of the presentation I gave at the 1993 'International Conference on Autism' in Toronto, and is addressed primarily to parents.

PARENTS often report that learning their child is autistic was the most traumatic thing that ever happened to them. Non-autistic people see autism as a great tragedy, and parents experience continuing disappointment and grief at all stages of the child's and family's life cycle.

BUT this grief does not stem from the child's autism in itself. It is grief over the loss of the normal child the

parents had hoped and expected to have. Parents' attitudes and expectations, and the discrepancies between what parents expect of children at a particular age and their own child's actual development, cause more stress and anguish than the practical complexities of life with an autistic person.

SOME amount of grief is natural as parents adjust to the fact that an event and a relationship they've been looking forward to isn't going to materialize. But this grief over a fantasized normal child needs to be separated from the parents' perceptions of the child they do have: the autistic child who needs the support of adult caretakers and who can form very meaningful relationships with those caretakers if given the opportunity. Continuing focus on the child's autism as a source of grief is damaging for both the parents and the child, and precludes the development of an accepting and authentic relationship between them. For their own sake and for the sake of their children, I urge parents to make radical changes in their perceptions of what autism means.

I invite you to look at our autism, and look at your grief, from our perspective.

Autism is not an appendage

Autism isn't something a person has, or a "shell" that a person is trapped inside. There's no normal child hidden behind the autism. Autism is a way of being. It is pervasive; it colours every experience, every sensation, perception, thought, emotion, and encounter, every aspect of existence. It is not possible to separate the autism from the person-and if it were possible, the person you'd have left would not be the same person you started with.

THIS is important, so take a moment to consider it: Autism is a way of being. It is not possible to separate the person from the autism.

THEREFORE, when parents say:

"I wish my child did not have autism," what they're really saying is, "I wish the autistic child I have did not exist, and I had a different (non-autistic) child instead."

Read that again. This is what we hear when you mourn over our existence. This is what we hear when you pray for a cure. This is what we know, when you tell us of your fondest hopes and dreams for us: that your greatest wish is that one day we will cease to be, and strangers you can love will move in behind our faces.

Autism is not an impenetrable wall

You try to relate to your autistic child, and the child

doesn't respond. He doesn't see you; you can't reach her; there's no getting through. That's the hardest thing to deal with, isn't it? The only thing is, it isn't true. Look at it again: You try to relate as parent to child, using your own understanding of normal children, your own feelings about parenthood, your own experiences and intuitions about relationships. And the child doesn't respond in any way you can recognize as being part of that system.

THAT does not mean the child is incapable of relating at all. It only means you're assuming a shared system, a shared understanding of signals and meanings that the child in fact does not share. It's as if you tried to have an intimate conversation with someone who has no comprehension of your language. Of course the person won't understand what you're talking about, won't respond in the way you expect, and may well find the whole interaction confusing and unpleasant.

IT takes more work to communicate with someone whose native language isn't the same as yours. And autism goes deeper than language and culture; autistic people are "foreigners" in any society. You're going to have to give up your assumptions about shared meanings. You're going to have to learn to back up to levels more basic than you've probably thought about before, to translate, and to check to make sure your translations are understood. You're going to have to give up the certainty that comes of being on your own familiar territory, of knowing you're in charge, and let your child teach you a little of her language, guide you a little way into his world.

AND the outcome, if you succeed, still will not be a normal parent-child relationship. Your autistic child may learn to talk, may attend regular classes in school, may go to college, drive a car, live independently, have a career - but will never relate to you as other children relate to their parents. Or your autistic child may never speak, may graduate from a self-contained special education classroom to a sheltered activity program or a residential facility, may need lifelong full-time care and supervision - but is not completely beyond your reach. The ways we relate are different. Push for the things your expectations tell you are normal, and you'll find frustration, resentment, disappointment, maybe even rage and hatred. Approach respectfully, without preconceptions, and with openness to learning new things, and you'll find a world you could never have imagined.

YES, that takes more work than relating to a non-autistic person. But it can be done - unless non-autistic people are

far more limited than we are in their capacity to relate. We spend our entire lives doing it. Each of us who does learn to talk to you, each of us who manages to function at all in your society, each of us who manages to reach out and make a connection with you, is operating in alien territory, making contact with alien beings. We spend our entire lives doing this. And then you tell us that we can't relate.

Autism is not death

Granted, autism isn't what most parents expect or look forward to when they anticipate the arrival of a child. What they expect is a child who will be like them, who will share their world and relate to them without requiring intensive on-the-job training in alien contact. Even if their child has some disability other than autism, parents expect to be able to relate to that child on the terms that seem normal to them; and in most cases, even allowing for the limitations of various disabilities, it is possible to form the kind of bond the parents had been looking forward to. But not when the child is autistic.

MUCH of what the grieving parents do is over the non-occurrence of the expected relationship with an expected normal child. This grief is very real, and it needs to be expected and worked through so people can get on with their lives - but it has nothing to do with autism.

What it comes down to is that you expected something that was tremendously important to you, and you looked forward to it with great joy and excitement, and maybe for a while you thought you actually had it - and then, perhaps gradually, perhaps abruptly, you had to recognize that the thing you looked forward to hasn't happened. It isn't going to happen. No matter how many other, normal children you have, nothing will change the fact that this time, the child you waited and hoped and planned and dreamed for didn't arrive.

THIS is the same thing that parents experience when a child is stillborn, or when they have their baby to hold for a short time, only to have it die in infancy. It isn't about autism, it's about shattered expectations. I suggest that the best place to address these issues is not in organizations devoted to autism, but in parental bereavement counselling and support groups. In those settings parents learn to come to terms with their loss - not to forget about it, but to let it be in the past, where the grief doesn't hit them in the face every waking moment of their lives. They learn to accept that their child is gone, forever, and won't be coming back. Most importantly, they learn not to take out their grief for the lost child on their surviving children. This is of critical importance

when one of those surviving children arrived at the time the child being mourned for died.

YOU didn't lose a child to autism. You lost a child because the child you waited for never came into existence. That isn't the fault of the autistic child who does exist, and it shouldn't be our burden. We need and deserve families who can see us and value us for ourselves, not families whose vision of us is obscured by the ghosts of children who never lived. Grieve if you must, for your lost dreams. But don't mourn for us. We are alive. We are real. And we're here waiting for you. This is what I think Autism Societies should be about: not mourning for what never was, but exploration of what is. We need you. We need your help and your understanding. Your world is not very open to us, and we won't make it without your strong support. Yes, there is tragedy that comes with autism: not because of what we are, but because of the things that happen to us. Be sad about that, if you want to be sad about something. Better than being sad about it, though, get mad about it - and then do something about it. The tragedy is not that we're here, but that your world has no place for us to be. How can it be otherwise, as long as our own parents are still grieving over having brought us into the world?

TAKE a look at your autistic child sometime, and take a moment to tell yourself who that child is not. Think to yourself: "This is not my child that I expected and planned for. This is not the child I waited for through all those months of pregnancy and all those hours of labour. This is not the child I made all those plans to share all those experiences with. That child never came. This is not that child." Then go do whatever grieving you have to do, away from the autistic child, and start learning to let go.

AFTER you've started that letting go, come back and look at your autistic child again, and say to yourself: "This is not my child that I expected and planned for. This is an alien child who landed in my life by accident. I don't know who this child is or what it will become. But I know it's a child, stranded in an alien world, without parents of its own kind to care for it. It needs someone to care for it, to teach it, to interpret and to advocate for it. And because this alien child happened to drop into my life, that job is mine if I want it."

IF that prospect excites you, then come join us, in strength and determination, in hope and in joy.

THE adventure of a lifetime is ahead of you.

LOOKING INSIDE . . .

On Autism... As I See It

Rohini Mitra

I first met Nano when I was six years old. He lived in Chennai at the time with his parents and we were going to visit them for a few days. Before we started on the trip to stay with them and on the train as well, my mother explained to me that Nano was different from me and the other children I had met. She explained clearly, in so many words, that maybe in the beginning, I would not understand him and that maybe, I might even be a bit scared of him. I admit that when I first saw him when we got to his house, I was a little scared. I didn't know what to expect. But whatever I had imagined, it was certainly not what Nano turned out to be. At that time though, I tried to stay out of his way, thinking he would probably not like me intruding on his life.

AS a result, even he stayed out of my way and I never really got to know him. The next time I met him was when I was 10 and he was 14. They had come to our house in Kolkata. That was when I first started understanding him properly. After that he visited our house almost twice a year whenever he was in Kolkata. With each visit, I got to know him better.

IN the summer of 2007, I got a Labrador called Sukie. On Nano's next visit, I noticed Sukie's reaction to Nano. It was as if she could sense that the person she was confronted with was different from the other humans she knew, and yet in some ways more in tune with her. She saw that he was human as the rest of us but he was also like her in a way. I am, in my family, the one who interacts the most with Sukie (I being the only child). But, I feel, Nano understands her much better than I. I can give her what she needs and stop at that. To give her what she wants, is not something I am at liberty to give her. And I doubt even if I was at liberty to give her what she wanted, I would still not do so. An incident which took place on Nano's last visit proves that.

NANO and Sukie were left outside on their own devices while the rest of us sat in the living room. We all supposed that Nano would look after Sukie, and Sukie would look after Nano. After ten minutes, we all went outside to find that Nano had happily opened the gate for

Sukie and was even holding it open if she might want to come back. After that incident, Sukie has remained ever grateful to Nano for siding with her and for being the first person to really understand her.

SO, autism is not a state of mind or a disease, it is, in many ways, a gift. Nano is autistic, and at first glance you might call him mentally retarded but all in all, he is the most positive minded person I have ever met.

. . . . THE LIGHTER SIDE OF AUTISM

A Day in The Life...

Sunday afternoon. The kids were doing their own thing: Seven year old Saumya playing with her toys, and Tarun, who has autism, sitting next to his father who was surfing TV channels. I was clearing up odds and ends when suddenly I heard an ear splitting scream and Saumya was yelling "NO! Don't-don't-don't!!!"

I went running in to behold my husband stuck to the TV screen, Saumya jumping around agitatedly, and Tarun feeding a grape to a tottering rat on our dining table. Plague!

THE house had been hosting a rat for some time. I was worried about a disease the rodent might bring in, and had heartlessly used 'Rat Kill' to try and eliminate the pest.

THE rat in question had obviously partaken of the generous quantities of 'Rat Kill' that had been put out. It was unsteady on its feet, like a drunken matron on heels. It was also obvious that the rat had not got onto the dining table on its own. Tarun must have spotted this unsteady rodent, lifted it up by its tail, and deposited it on the dining table before taking action to revive it with a grape.

SO there was my kindly son feeding a grape to an unsteady rat on the dining room table, head bent close to the rat's, while he blew on its tail and head in an effort to revive it. There was my daughter – the concerned sister - shrieking and hopping from foot to foot, frantic with worry that the proximity of her brother's face to that of the rat might transmit some of the poison from the rat to her brother. And there was my husband: oblivious and lost in his manly world of sports and television while this 'life and death' drama was playing out right behind him.

DID I hear a voice say: "Ah that sounds so familiar?"

दृश्यानुभविक शिक्षा

लेखक – थीओ पीटर्ज़

✕रिमा पंत

हमारे पिछले अंक में हमने "वस्तुओं की भाषा" विषय पर लिखा था। आगे पढ़ें:-

संवर्धी संप्रेषण एवं संवर्धी शिक्षा। एक समय ऐसा था जब मूक बच्चों को बोलने के लिए मजबूर किया जाता था। यदि वाक शक्ति नहीं आई तो उन बच्चों की कोई सहायता नहीं की जा सकती थी। कुछ समय पश्चात् यह आभास हुआ कि भाषा, तो संप्रेषण का केवल एक मूर्त रूप है। अन्त में वे बच्चे जिन्हें भाषा सीखने में मुश्किल होती है उनमें संप्रेषण को सरल बनाने के लिए हम चित्रों और वस्तुओं का सहारा भी ले सकते हैं। इससे संवर्धी संप्रेषण का भाव उन बच्चों के भीतर सीखने की विशिष्ट अंतरदृष्टि को प्रकाशमान करता है। इस प्रकार यह नई आशा का संदेश देता है। इसी प्रकार एक समय ऐसा भी था जब स्वलीन बच्चों को शिक्षा योग्य नहीं समझा जाता था। बाद में यह धारणा बनी कि एक ही प्रकार की अंधिगम पद्धति अपनाकर उन्हें शिक्षित बनाने का प्रयास किया जाए जो कि उनकी अधिगम आवश्यकताओं की पूर्ति नहीं करती।

जब शिक्षाविदों को यह ज्ञात हुआ कि स्वलीन बच्चे किसी भी प्रकार की सूचना को भिन्न तरीके से ग्रहण करते हैं, तब उन्होंने इस तरह की शिक्षा प्रणाली को अपनाकर प्रस्ताव रखा जो विभिन्न प्रकार की मस्तिष्क प्रक्रिया द्वारा अपनाने में समर्थ हो और यह स्पष्ट हो गया कि यह बच्चे हमारी अपेक्षाओं की तुलना में कहीं ज्यादा सीखने की क्षमता रखते हैं।

कुछ बच्चों को भाषा सिखाने के लिए द्विविम प्रतीकों जैसे चित्रों द्वारा पढ़ाया गया जबकि औरों को मूर्त शिक्षा वस्तुओं द्वारा सिखाई गई। संक्षेप में, शिक्षणक प्रणाली ने एक नई चेतना को जागृत किया और नई आशाओं का संदेश दिया। अब हम इस संवर्धी संप्रेषण और संवर्धी शिक्षा के विषय वस्तु को नए धरातल पर विकसित करेंगे। खास तौर पर जब हम स्वलीन शिक्षार्थियों

को छोटे विकासशील अवस्था पर विचार करें तो देखेंगे कि स्वलीन बच्चों की शिक्षा के दो आधारभूत तत्व हैं :

1. स्थान और समय के पूर्वानुमान का सृजन तथा सफलता की भावना को आत्मनिर्भरता पूर्ण कार्यों द्वारा जागृत करना।
2. बच्चों में स्वतंत्र रूप से काम करने की भावना जगाना (पीटर्स 1997) पीटर्स और गिलबर्ग 1999)

मैंने अन्य संदर्भों में अनेक सिद्धान्तों का उल्लेख किया है। अतः यहां मैं उनका सारांश मुख्य बिन्दुओं के रूप में करूंगी : स्थान के पूर्वानुमान की क्षमता विकसित करना, वस्तुओं की भाषा पूर्व सांकेतिक दुनिया में स्वतंत्रता या आत्म निर्भरता बहुत कम या नहीं होती है। व्यक्ति जो आरम्भिक विकास अवस्था में होते हैं, उनके लिए सीखना अनिवार्य है कि यह जीवन अर्थपूर्ण है, तथा विभिन्न वस्तुओं, क्रियाओं तथा परिस्थितियों के मध्य अर्थपूर्ण सम्बन्ध होता है। क्योंकि यद्यपि ऐसे व्यक्तियों की बोध क्षमताओं में लचीलापन विकसित होने में व्यापक समस्याएं रहती हैं, तथापि वह मूर्त सम्बन्ध स्थापित करने में अधिक कुशल होते हैं। कुछ उपाख्यानों द्वारा मैं मूर्त सम्बन्धों के प्रत्यय का सूचित उदाहरण दूंगी।

एक बच्चे ने यह अनुभव किया कि टेलीविजन देखने के पश्चात् खाना खाने का समय होता है। उसने एक दृढ़ सम्बन्ध स्थापित कर लिया था। टेलीविजन देखना और फिर खाना। एक शाम, टेलीविजन पर कार्यक्रम देखने के बाद बच्चे के पिता घर नहीं पहुंचे थे। खाने का मेज़ तैयार किया था, साथ ही टेलीविजन पर कार्यक्रम खत्म हो चुका था, परंतु घर का कोई भी सदस्य खाना खाने नहीं आया था। उसको महसूस हुआ कि उसके साथ धोका हुआ है और उसमें एक प्रकार की स्वाभाविक झल्लाहट उत्पन्न हुई। उसने अपनी असरल/पेचीदा जिन्दगी को समझने की अपनी तरफ से पूरी कोशिश कर ली। परन्तु अन्य लोगों ने उसकी इस समझ की इज्जत नहीं रखी। एक दूसरा बच्चा अत्यन्त प्रसन्नता के साथ अपने कमरे से नीचे आया।

उसकी माँ को उसका व्यवहार कुछ समझ में नहीं आया। उसको अपना नाश्ता पसन्द आया, उसको विद्यालय जाना भी बेहद पसन्द था परन्तु मां को यह समझ नहीं आया कि बच्चा अनोखे रूप से खुश क्यों है। जब उसकी विद्यालय की बस आई तो उसकी हंसी गायब हो गई। असल में उस समय उसको बस में चढ़ाने के लिए कड़ा परिश्रम करना पड़ा। क्या वह एक बुरा लड़का था या क्या वह सिर्फ उसके सोचने का नजरिया अन्य लोगों से अलग था? एक अच्छे जासूस की तरह उसकी मां ने वह खुशी जो अचानक से अप्रसन्नता में बदल गई उसका पता लगाने की कोशिश करी। फिर उसने देखा कि उसने कुर्सी को गलियारे में ही छोड़ दिया था। वही पीली कुर्सी, जो वह पिछले सप्ताह समुद्र के किनारे ले गया था। अब सब स्पष्ट हो गया था। उनके बच्चे ने उस पीली कुर्सी और समुद्र के किनारे के बीच एक दृढ़ सम्बन्ध बना लिया था। उसने इस संसार को समझने का अपना तरीका बना लिया था न कि जिस तरह से हम चाहते हैं।

यही वह सामाजिक अभिप्राय है जिससे हम इस संसार को दृढ़ सम्बन्ध बनाकर समझने की कोशिश करते हैं। इन्हीं दृढ़ सम्बन्धों का प्रयोग हम देखभाल कर्ता भी कक्षाओं या घरों में प्रयोग में लायेंगे, जिससे की यह संसार थोड़ा और पूर्वानुमेय हो जाए। हमें अपने शिष्यों जिन्हें ऑटिज़म है उनको यही सिखाना है कि स्थान, क्रियाओं और व्यवहारों के मध्य एक अनुमानित सम्बन्ध है। **हमें यह आवश्यकता है कि हम स्पष्ट करें कि यह कार्य करने का कोना है, यहां पर विद्यालय का कार्य किया जाएगा, यहां हमेशा अध्ययन के व्यवहार की उपेक्षा रखी जाएगी परन्तु सिर्फ यहां। यह आराम का कोना है, यहां पर हम फुर्सत से बैठ सकते हैं। कोई अध्ययन या एकाग्रता नहीं होगी। यह घरेलू (domestic) कोना है। यहां पर हम अन्य बच्चों के साथ बैठ कर खाना खा सकते हैं, इसी संस्था पर हमें आत्मनिर्भरता की शिक्षा भी दी जाती है। यदि यह सारे व्यवहार अथवा क्रियाएं पूर्वानुमेय जगाओ से संबंधित की जा सके तो इन बच्चों की जिन्दगी में नियंत्रण लाना कुछ हद तक आसान हो जाएगा। तथा उनमें शक्ति और आत्मनिर्भरता भी उत्पन्न होती है और शायद यह अपने बारे में अच्छा महसूस करने की शुरुआत हो, सफलता का पहला कदम। मेरा यहां पर यह सुझाव होगा की सफलता - हम जिस प्रकार से वस्तुओं की भाषा का प्रयोग करें**

उससे भी सफलता पैदा की जा सकती है। उदाहरणार्थ, मैं कार्य कहां करूं इस सवाल का जवाब एक बहुत ही ठोस और मूर्त रूप से दिया जाना चाहिए।

समय में पूर्वानुमय की रचना : वस्तुओं की भाषा। कोई भी समय को प्रत्यक्ष रूप में नहीं देख सकता। समय का विश्लेषण करना आवश्यक है। यदि हम यह स्वीकार कर ले कि अमूर्त, अदृश्य, जानकारी स्वलीन बच्चों के लिए समय के प्रत्यय को समझना एक जटिल कार्य है। समय की यह विशेषता है कि वह अमूर्त, अदृश्य और परिवर्तनशील है। स्वलीन लोग को अक्सर व्यक्त में खोया हुआ बताया गया है। हम अपनी जिन्दगी को थोड़ा और आयोजित बनाने के लिए हमें समय को अपने तिथिपत्री और घड़ियों के अनुसार मूर्त और दृश्य बना लेते हैं। ऐसा करने से हम अपनी जिन्दगी पर थोड़ा नियंत्रण बना पाते हैं। मेरा तर्क/मेरी बहस यह है कि स्वलीन लोगों की आम जरूरतें हमारे जैसी ही हैं और इसीलिए हमें अपने अन्दर ऑटिज़मे घड़ियां उत्पन्न करनी होंगी, जिससे कि हम उन्हें मूर्त, स्थानिक और दार्शनिक जवाब दे पाएं कब ?

इन उत्तरों का तीन भिन्न स्तरों पर वैयक्तिकरण किया जना चाहिए (पीटर्स और गिलबर्ग 1999) चिन्ह का रूप, लम्बाई, चिन्ह का प्रयोग किस प्रकार से किया गया है।

एक सामान्य बच्चा पहले शब्दों को समझता है फिर उसे रोजाना बातचीत में प्रयोग करता है। उदाहरणार्थ, वह बच्चा जो अन्ततः वस्तुओं को देकर संप्रेषण सीखता है, वह पहले उन्हीं वस्तुओं को दूसरे से क्रिया होने से पहले लेना सीखेगा।

वह यह भी सीख लेता है कि वस्तुओं के आगे भी अर्थ है। उदाहरणार्थ जब वह आराम कोने में जाता है तब उसे गेंद दी जाती है, जब वह नाश्ते में कोने में जाता है तब उसे एक कप दिया जाता है, जब वह खाना खाने जाता है तब उसे एक प्लेट दी जाती है, आदि। इस तरह उसे वस्तु और क्रिया के मध्य मूर्त सम्बन्ध बनाने में सहायता मिल जाती है। हालांकि यह बात माता-पिता के लिए थोड़ी चुनौती हो सकती है जो अभी भी यह आशा करते हैं कि उनका बच्चा एक दिन बोलेगा, क्योंकि जैसा

कि प्रोफेशनल ने कहा है की वस्तुओं का प्रयोग, संप्रेषण की शुरुआत है।

अभिभावकों ने अपने बच्चे का मूल्यांकन होते हुए देखा होता है, जिसके फलस्वरूप उनकी आशाएँ कम होती हैं। उन्होंने यह देखा होता है कि उनके बालक ने किसी शाब्दिक अनुदेशन की प्रतिक्रिया नहीं करी, शब्दों की नकल नहीं करी, तस्वीरों को वस्तुओं का मिलाना नहीं किया, शायद ध्वनियुक्त वस्तु की ओर भी प्रतिक्रिया नहीं करी। यह सब तथ्य इस ओर संकेत देते हैं कि वाणी (जो सम्प्रेषण का सबसे अमूर्त रूप है) तत्काल भविष्य के लिए आदर्श सिद्ध नहीं होगी। अपने निजी अभ्यास में, वस्तुओं को आरम्भिक बिन्दुओं के रूप में प्रयोग करने के लाभ की व्याख्या करी है और इस धारणा का प्रयोग किया है कि साधारण विकास में भाषा एक ऐसा द्वीप है जो अशाब्दिक सम्प्रेषण के सागर में अचानक नज़र आता है। स्वलीनता में सबसे बड़ी समस्या भाषा

नहीं वरन सामान्य रूप से सम्प्रेषण है तथा अशाब्दिक सम्प्रेषण के विभिन्न रूप भी। सामान्य विकास प्रक्रिया में बच्चों में शब्दों के विकास से पूर्व ही सम्प्रेषण के कई कार्य विकसित हो जाते हैं। बच्चे को जन्म देने के कुछ दिन उपरान्त ही माँ बच्चे के विभिन्न लक्षणों को पहचानने लगती है, जैसे— बच्ची भूख के कारण रोती है, या भिन्न ढंग से रोकर वह अपनी ओर ध्यान आकर्षित करना चाहती है, इत्यादि। नौ माह का होने से पूर्व ही बालक अपने माता-पिता का ध्यान वातावरण की उस वस्तु की ओर आकृष्ट करने में सक्षम हो जाते हैं जो उसे रुचिकर लगता है। अन्य शब्दों में बच्चा अशाब्दिक रूप से टिप्पणी करने लग जाता है।

साधारण बच्चों को इतने अनुभव हो चुके होते हैं कि वह सम्प्रेषण की शक्ति को भली भाँति समझने लगते हैं और तब सम्प्रेषण के उससे भी अधिक शक्तिशाली स्वरूप का आभास होता है : भाषा।

हेल्प लाईन

मेरा लड़का 12 वर्ष का है और उसे ऑटिज़म है। मैं भारत में निवासी विद्यालयों के बारे में जानना चाहता हूँ, जहाँ पर उचित देखरेख निश्चित है।

नैशनल ट्रस्ट एक्ट (ऑप्टिस्टिक, सेबेरब्रल पॉलसी, मैनेटल रिटार्वरडेशन एवं अन्य बहु-विकलांग अयोग्यताओं से सम्बन्धित बच्चों के कल्याण के लिए) अनेक ऐसी संस्थाओं को सहारा देता है जो दोनों अल्पकालिक एक दीर्घकालिक देखभाल की सेवाएं प्रदान करती हैं। जिन्हें ऊपर लिखित असमक्षताएं हों। ऐसी दो योजनाएं जिन्हें नैशनल ट्रस्ट सहारा देता है वह इस प्रकार हैं –

1. समर्थ संस्था आधारित योजना –

(<http://thenationaltrust.in/newweb/schemes.html>)

यह सस्था आधारित योजना जुलाई 2005 में निवासी सेवाएं दोनों अल्पकालिक और दीर्घकालिक देखभाल सेवाओं के लिए स्थापित हुई थी। समर्थ संस्था की क्रियाओं में शीघ्र आरम्भिक हस्तक्षेप, विशेष शिक्षा, एकीकृत शिक्षा, मुक्त विद्यालय, प्रारम्भिक व्यावसायिक एवं व्यावसायिक प्रशिक्षण, रोजगार सम्बन्धी प्रशिक्षण मनोरंजन, खेल

इत्यादि शामिल होना आवश्यक है। घर में जो सुविधाएं हैं वह रित्रियों और पुरुषों का 50-50 प्रतिशत पर उपलब्ध होगा और नैशनल ट्रस्ट के अंतरगत चारों अक्षमताओं को शामिल करेगा। सभी समर्थ संस्थाओं की सूची ऊपर लिखित वैबसाइड में दी गई है।

घरौन्दा –

(<http://thenationaltrust.in/newweb/schemes.html>)

घरौन्दा, असक्षम व्यक्तियों को सामूहिक घरों में आजीवन शरण और देखभाल के लिए नई योजना है। वह संस्थाएं जो घरौन्दा का हिस्सा है वह इस प्रकार है –

1. ओपन लरनिंग सिसप्टम, भुवनेश्वर, उड़ीसा
2. कारनाटक पैरेन्ट्स एसोसिएशन फोर मैन्टली रिटारडिड चिल्ड्रेन, बंगलौर, कर्नाटक,
3. प्रयास कम्युनिटी लिविंग सेंटर, कोलकाता, दक्षिण बंगाल
4. पार्टनर हुगली, हुगली, दक्षिण बंगाल।

इन दोनों योजनाओं पर अन्य विस्तृत जानकारी इंटरनेट पर उपलब्ध है।

Toilet Training for Babu

Lillian Seenoi Kina

My name is Lillian Seenoi Kina. I am a community development officer, and Women's Rights activist working with Maasai Education Discovery Narok, an NGO working with the Maasai community to empower / improve education and social welfare of the Maasai people and especially the children from Transmara, Kajiado, Marsabit and Narok district in Kenya, East Africa. I am also a member and official of the Rotary club of Narok-Maasai Mara, district 9200. I am a wife and mother, and my seven year old son Brian Ledama is autistic.

WHEN Ledama (Babu) was born nothing out of the ordinary was noted at birth. We took home a bouncing baby boy, with the exception that he did not take to the breast immediately; he did so after five days. Ledama (Babu) was born on the 15 November 2001; He was diagnosed with autism when he was 24 months old.

In October 2008, Babu and I travelled to New Delhi in India to enrol for intervention services at the Action for Autism Centre (AFA) where the diagnosis was re- confirmed by a clinical psychologist.

AMONG other difficulties/challenges that children with autism and their families face, toileting was a major one for my family. Being a non verbal child Babu could not communicate his needs. He neither took himself to the toilet nor asked someone to take him. He didn't even understand the feeling that he needed to go.

BEFORE I joined the Mother Child Program in AFA, I started training him at home. I tried for four and a half years without any success. I had no idea how to train a child with autism, which made it even more difficult for me to train him. It used to be very difficult to get Babu to sit on the toilet without his trousers; I had no option other than to put him on diapers.

WHILE at home, I would leave him without diapers. Whenever he agreed to go to the toilet he would sit for

half an hour doing nothing., The moment we got him off the toilet he 'went' on the door step. This was very frustrating for me and my family too.

AFTER joining the Mother Child program, toileting was my first priority on the list. After sharing my frustrations and disappointments on my own way of toilet training, I was taken through steps of toilet training. It was very interesting to find out that the toilet itself may be aversive to our children, that we may need to make it a fun place for them, make toileting 'fun', that even before you put him on any schedule you need to take data, you need to note his way of indicating, timings and reinforce him big the moment he does it right when you take him to the toilet.

*"The real voyage of discovery
consists not in seeking
new landscapes,
but in having new eyes"*
- Marcel Proust

WITH the help of a professional, we started intensive, fun toilet training for Babu. This meant no more diapers for him whether travelling, in school or just playing at home. I used to take with me five or more pairs of

shorts and pants for changing in case of accidents, of which I did experience lots of in the first month of training.

TODAY, Babu agrees to sit on the toilet without his trousers, Being patient with him has made him improve, he has been able to communicate his toilet needs through a particular behaviour, he also started by pulling me so that I can take him to the toilet, and in the last few days he has been walking alone to the toilet, and because he still doesn't know how to pull his pants out, with my assistance he has been successful in helping himself in the toilet. In the last three months we have had 20 days of success, which means I have also reduced the number of shorts and pants that I usually take with me whenever I go out, from five to one.

His toilet training is one thing that has encouraged me and made me believe that all is possible with professional training. This is the biggest and most exiting achievement of my journey to India.

HELPLINE



Q A sensory therapist we consult forces stimulus on children who are averse to it. She will hold the struggling, screaming child on the swing or in the ball pool, all the time insisting that this is the only way to desensitize the child. Is this true? A child with hyper auditory sensitivity is tied to the chair and forcibly made to listen to auditory tapes by clamping earphones onto him while he cries. Does such therapy yield positive results for the child?

A Most of us unconsciously learn to combine our seven senses (sight, sound, smell, touch, taste, balance, body in space) in order to make sense of our environment. Children with autism often have trouble learning to do this, since they may be receiving and/or processing the information received by their senses in a different manner. In other words they may be over stimulated (hypersensitive) or under stimulated (hyposensitive) by the environmental stimuli.

When a child is hypersensitive to sensory stimuli, it could mean that the particular stimulus is overwhelming for the child, sometimes to the point of even being aversive. It could feel like being bombarded by sensations, like drowning in them. To help a child function better it may be necessary to desensitise the child to the stimuli he finds aversive and thereby improve the child's ability to cope with the stimuli.

The therapist you are referring to may have the best of interests for her students, since she feels that the only way to desensitise a child is by forcing the aversive stimuli onto the child. However, effective sensory integration therapy has to be child-directed, playful, and pleasant for the child and desensitisation has to aim at increasing sensory tolerance very gradually through pleasurable activities.

You mention that the child is forced to sit on the swing, or in a ball pool, or tied down and forced to listen to auditory stimuli. Let's take the swing example. If a child is fearful of movement and is being forced to sit on the swing, the trauma and the stress can have short term as well as long term repercussions that may not be evident right away. For instance it may result in a rise in challenging behaviors in other situations, or a decline in his ability to learn other things. In a few cases a child may actually overcome a fear, but the price to pay will be too high.

It is also a violation of the child's personhood. As a society, our general perception is that children do not have any

rights, hence such violation of human rights is common, and in fact in many instances is often supported by the child's parents.

If an adult were to say, "I don't like sharp and hot food," and insisted that he would only eat mildly flavoured meals, no one would think of holding him down and forcing a handful of chilly peppers in his mouth in order to get him used to spicy food. Instead, one would occasionally offer a spicy meal, and bit by bit, the gradual exposure might get him to learn to eat and appreciate spicy food.

That is exactly the route one has to go with a child with sensory issues. One could start with movements that the child may feel safer with, like rocking on an adult's lap or in a rocking chair. Once he seems to be comfortable with these movements, he could be put on the swing for an extremely short duration to begin with and then be rewarded for sitting on the swing. Slowly the duration of the time that he spends on the swing can be increased. This will make the desensitisation process a less stressful one for both the student and the therapist and yet be respectful of the child.

The same procedure would be applicable for desensitisation of any kind of sensory stimuli - moving from the least aversive to the more aversive stimuli, increasing the time of exposure to the stimuli very, very gradually and rewarding each effort made by the child appropriately.

Q I shall ask you a question that you might find a little odd. But ask it I must. AFA has the biggest knowledge base on Autism in the country. Open Door appears to be the only school using the soundest of teaching methods for ASD children, namely, TEACCH, ABA and VBA. The school believes in mainstreaming - where it is an option - and works towards it. Then why is Open Door never considered as an option by parents for their children? Is it because the in-take of students is very limited?

Many parents that I spoke with had this to say, "Open Door has profoundly severe cases and your child will learn all the wrong behaviours and probably regress." I am asking you with complete openness, because I don't know who else to ask. Should every parent consider Open Door for their child with autism? Or is it suited only for very severe cases?

My daughter R has just started attending a regular play school. She seems happy, the staff loves her. Will she learn there? Probably yes. Will she reach her full potential there?

No way. She requires much more support. I am totally confused, which school setup will be most suited to her needs. Should I consider Open Door for her?

A Thank you so much for all the positive things that you say about AFA.

We can understand the ambiguity that you are going through about the kind of schooling that you should choose for R, as to whether you should be keeping her in the mainstream or should be considering an autism specific school like Open Door. We will try to address your queries about Open Door School.

Our policy with respect to admission of students at Open Door school is such that parents register for the programme and are put on a waiting list. We accommodate new students in the school depending on a vacancy arising in the particular class that suits the individual's needs and functioning levels. So, it is rather difficult for us to tell parents with certainty when their children may find placement in the School. We are reasonably strict in adhering to this policy because we do not want to dilute the quality of the services that we provide to our students. It is true that our waiting list is long and that parents get anxious since they want placement as soon as possible. In the interim, we encourage parents to seek schooling services elsewhere and welcome them to avail of any of the other services that AFA can provide to help their child progress.

We have a no 'caste' system at Open Door School. We welcome children from every socio-economic background, as well as students across the entire spectrum of autism. Our classrooms are divided according to the age and ability levels of our students, and we cater to the individual needs of all our students with the same degree of passion and commitment, irrespective of whether they are functionally more able or have a more severe range of difficulties. In fact, if one wants to see what it means by autism being a 'spectrum' condition, a day at Open Door School may help one understand it better.

While as a parent, each of us wants our children to be accepted by society, we are often unwilling to show the same acceptance towards children who we perceive to be more severe, and hence 'inferior' to our own.

When people say that children with autism may learn 'all the wrong things' from other children who are more 'profoundly' impaired, on one level one almost wishes that were the case. If that was true, then all we would need to do would be to place our children in the mainstream where they would see other children and learn 'all the right

things' and no special intervention would have been required. But, we do know that this is not the way our children learn, because for most of our children learning through imitation is difficult. I am sure that imitation skills are a key part of R's IEP, as are for a lot of our students, so that we can TEACH them to imitate, so that they can finally begin to learn from the environment. If our children start learning 'all the wrong things' from their peers, I would say that it is reason to celebrate, because it means that they are acquiring the skills to imitate spontaneously and learn from the environment. A small comment: Though, our children may just be learning novel things from the environment, it is our reaction to their actions which will determine whether it will turn into an inappropriate behaviour, whether our children will regress or progress. Since you seem to be familiar with ABA, you would know that attention is often a reinforcer for behaviour. If we see our child doing something 'wrong' that he has picked up from school and give a lot of attention, even negative attention, in all probability our child's actions will be reinforced and he will do more of it.

If we decide to not give any attention to a behaviour we consider to be inappropriate, it is possible that what began as exploration and experimentation, as does in the case of neurotypical children too, will remain at that and not turn into an inappropriate behaviour. So, perhaps it is up to us to choose the specific actions amongst the ones which our children are spontaneously imitating in the natural environment, that we want to react to or reinforce, and hence turn them into a 'good' or 'bad' thing.

(The author of this response is a parent of a 17-year-old young man with autism.) I have lived in different major cities across India, where I have availed services for him. Two years back, I decided to shift to Delhi because I wanted Nano to get services at Open Door School. (We had registered for the programme way back in 1999.)

Currently, my husband is posted in Antwerp, Belgium and it has been a conscious decision on our part to have Nano to continue at Open Door since the services provided there are at par with most of the good schools for autism across Europe, a decision that was vetted by leading experts in Europe who have visited AFA and seen the services that are provided here. I must hasten to add that this of course is a personal decision.

You have asked in your mail "Why is Open Door never considered as an option by parents for their children?" I am sure there are parents who have concerns such as those discussed in the preceding. At the same time there are parents for whom Open Door is a primary option. So you see there are varying opinions on the matter.

AFA is a parent run organisation and we strongly believe that parents are the key pivots in their children's lives. We believe that it is their prerogative to choose different options for their children. Each parent makes his or her own choices about their child based on their unique circumstances and on what they perceive to be 'right'. You would appreciate that it would be extremely difficult for me to tell you whether you should or should not consider Open Door as an option for R. That is a decision that you would have to weigh by yourself. Being a parent myself, my suggestion to you would be to make an informed choice. You may want to thoroughly explore all the options available to you currently and then take a decision on which kind of environment and services you feel that R would progress the best in.

This query has been responded to by Indrani Basu.

Q I am P, presently residing in USA. I have 9-year-old Autistic son. He goes to special education school in USA. He is high-functioning but can not be part of regular school due to his behaviours. We are considering moving to India so that our son A, can get more social exposure. We are kind of undecided about the move. We are not sure if USA will be the right place for him or whether India will help due to high social interaction. We do not have any relatives or too many friends in the USA. In your experience, which is more beneficial, USA or India for children with autism? Does India have all benefits that USA has for individuals with autism between the ages of 11 and 21? I mean reading/writing programmes, therapies etc? My question is more based on cultural and life style difference in the two countries.

A Any decision to move locations can be a difficult one because there are so many parameters to be considered. The move comes with its own set of pros and cons that are unique to a family and thereby a third person's perspective can be skewed and inaccurate.

If you do decide to move to India, as you mention, there will definitely be a vast cultural and lifestyle shift for your entire family and especially for A and you may want to factor these in whilst you make your decision.

One other thing to consider would be that the west is much more 'structured' and therefore, may sometimes present an environment that our children find easier to function in. On the other hand, children growing up in India may develop the ability to deal with proximity to people, the lack of general structure and the 'chaos' with greater ease than children growing up in the west. For instance, if you take something as simple as environmental noise or the different kinds of visual stimuli that our children have to

cope with in India in the normal course of life, sensory desensitisation, is almost an ongoing process. However, if a child is extremely sound sensitive, the environmental noise can often be extremely stressful for him, even if he is 'used' to it and one would need to use specific strategies to help him deal with the same. This is just an example and there could be many such factors that come into play, presenting both advantages and disadvantages.

Family and friends can of course be a huge support system for both the child with autism and his family. The large number of cousins, extended family and friends in India often provide great opportunities for developing social understanding. But, this is provided that our family and friends understand autism and accept our children for who they are. Often the techniques we use to deal with our children (e.g. putting inappropriate behaviours on extinction, reinforcing desirable behaviours) may seem alien to people who are not familiar with autism, though most of these methods can be and are often used with people who do not have autism, with the very same results. However, if they can understand why our children do what they do, why we interact with them in the way we do and are willing to follow our lead in interacting with our children in a similar manner, providing consistency across all the different environments that our children are exposed to, it can indeed be of immense help to our children. And it is then that our children would be able to benefit from all the myriad opportunities for social interaction that India offers. Of course, our comfort with our child's autism and behaviours are often cues that family and friends follow. Higher our level of comfort, easier it is for our family and friends to be comfortable with our children.

In response to your query about services available in India for the age group between 11 and 21, as of now, there are far fewer services catering to the needs of adolescents and more so of adults with autism compared to services available for the younger age group. However, there are a few organisations who do have pre vocational and vocational work as part of their programmes, Action For Autism being one of them.

With regards to services available in India, you could perhaps check out:

http://www.autism-india.org/afa_otherlinks.html

It has a reasonably comprehensive list of services available across India for people with autism. Some of the organisations certainly focus on cognitive skills like math, reading, writing, depending on the individual child's functioning levels. For a more detailed understanding of the exact nature of services/programmes offered by any one of these organisations, you may need to get in touch with them directly.

WORKSHOP ANNOUNCEMENT

Rehabilitation Council of India CRE Programs in Autism
FUNDAMENTALS OF STRUCTURED TEACHING

————— 29 & 30 December 2009 —————

Action for Autism is organizing a two-day training workshop on Structured Teaching based on TEACCH, by Autism AACTION. It is an approach that is internationally used with individuals with Autism Spectrum Disorders (ASD) and other developmental disabilities. It is a family-centered, evidence-based teaching practice that is supported by empirical research and extensive clinical expertise, and is notable for its flexible and person-centred support for individuals of all ages and skill levels.

Structured teaching fosters the development of independence as well as the development of enjoyable social interactions and meaningful social relationships which are important priorities.

Resource Persons: *Christopher Flint, Lally Daley & Heera Chandani from Autism ACTION.*

ACTION is a Chicago based humanitarian organization dedicated to developing worldwide awareness, support and acceptance of autism through education & training, both nationally and internationally.

Venue: The National Centre for Autism, Pocket 7 & 8 Jasola Vihar, New Delhi - 110025

Childcare will be available during workshop hours for those participants who find it difficult to leave their children at home. However, to avail of the facility, Child care, Registration Forms have to be filled in and submitted *latest by 4:30 pm of Monday 21 December* so adequate Child Care arrangements can be made.

Early Bird Registration

Before 4:30 pm, of Friday 11 December 2009

Registration Charges

Members

- Institutions & Professionals: INR 4,500
- Parents (Life & Full Annual): INR 3,500
- More than 1 delegate from member organisation: INR 4,700

Non members

- Professionals: INR 5,000
- Parents: INR 4,000
- Students: INR 2,500

Childcare Charges

INR 250

Limited Seats

No registrations will be accepted after seats are filled

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PRE-REGISTRATION FORM

Do fill this form in BLOCK LETTERS and mail, with a self-addressed stamped envelope to:
Action For Autism, Sector 5 Jasola Vihar, Behind Sai Niketan, New Delhi 110025

Name _____ (Tick relevant box) Parent Professional

Address _____

Tel _____ Email: _____

If parent, name of child _____ Child's DOB _____

If professional, name of organisation _____

Please find enclosed a Demand Draft No _____

dated _____ drawn on _____ Bank _____

Do you require accommodation YES/ NO

Do you require childcare YES/ NO

MEMBERSHIP TO AFA

To continue to receive 'Autism Network' please complete the application below, cut or photocopy, and return it to us as soon as possible.

MEMBERSHIP DETAILS

Parents: Associate Member – Annual: Rs 150/- Full Member – Annual: Rs 500/- Life Member: Rs 5000/-

Professionals: Associate Member – Annual: Rs 150/- Full Member – Annual: Rs 1000/- Institutional Member – Annual: Rs 2000/- Overseas Membership – Parents \$ 30, Professionals \$ 50

Associate Members receive copies of Autism Network and information on all upcoming events and activities. Full Members, Life Members, Overseas Members and Institutional Members are in addition, entitled to concessionary rates for AFA events and workshops.

New Renewal Date _____

Name _____

Address _____

State _____ Pin/Zip _____

Phone _____ Email _____

I am a: (tick all that apply)

Parent Relative _____

Professional _____

Other _____

If you are a parent of a person with autism, please answer:

Child's name _____ Sex _____

Date of birth _____

Diagnosis (if known) _____

• I wish to become a member of AFA and enclose:

Rs 150/- Rs 500/- Rs 1000/- Rs 2000/-

Rs 5000/-

(Send Demand Drafts Only) Draft No: _____

Dated _____ On Bank _____

Amount in words _____

• I wish to give a contribution to AFA _____

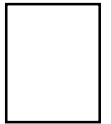
Amount in words _____

Mail demand draft payable to:

**Action for Autism, Pocket 7&8, Jasola Vihar,
Behind Sai Niketan, New Delhi - 110025**

Contributions are tax exempt under Section 80 G of Income Tax Act.

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