autism network

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YOUR CONTRIBUTIONS
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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

Cover Illustration

Merry Christmas with a 'Christmas Tree'
says Adit Manning

WISHLIST !

- School furniture: desks, chairs, cabinets
- Crayons, white board markers, pencils, pens
- White boards
- Black boards
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Financial donations to the Corpus Fund for the school

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

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**On 19 November 2007
the
United Nations
formally designates:**

**2 April
as
World Autism Awareness Day**

“If autism was always there, then where are all the adults with autism?” This question was put on an Indian autism elist by a fractious middle-aged gentleman who identified himself as a parent as well as a person with autism. He evidently forgot to look at himself when he asked the question! UnderstabUnq ploky bUnq ploky ndable though, since his query was made largely to illustrate that autism is a recent phenomenon, and more to the point that it is caused by vaccines.

And recently another parent of a young boy insisted that genetics notwithstanding that was the case since, according to her, there was absolutely no one in either her or her husband’s family who had autism.

I found her assertion worthy of note because for many years I and many other parents I know were certain there was absolutely no one in our families who had autism.

As our understanding of Autism has grown, neither I nor many others are so sure any more…

There are a few individuals working at The National Centre for Autism who are adults on the spectrum. It is interesting to note that if I had met any of these individuals 15 years ago, when I believed myself as fairly knowledgeable about Autism, I would never have been able to identify them. Neither could any of my colleagues.

Yet 15 years down the line we can identify the ‘quirks’ that put them on the spectrum.

Many of us have gone on to identify members of our own extended families who are on the spectrum; something we would not have had the exposure or understanding to do earlier.

Catherine Lord had put it well many years ago when she said something to the effect that you got to see at least a hundred individuals on the spectrum to be able to identify a child with autism accurately.

At the National Centre some of us have had the opportunity to have seen a 1000 children from every part of the spectrum. An increasing number of these are persons with Aspergers Syndrome who contact us for help on a variety of issues. A recent contact was from someone who was getting married and urgently needed help with his social difficulties. A mail a few months ago was from a young man who wanted to ask a girl he knew to marry him and was concerned that after they were married the girl in question would find him difficult to live with.

All very understandable concerns.

I recall one young man in his 30s who we had occasion to interact with on some work. Within a short while we were certain he was on the Spectrum. Remarkably, many months later, after we had got to know him well he confided the information that he had received a diagnosis of Aspergers Syndrome 25 years ago when he was 14!

So the adults with autism are very much there if we know what to look for!

The South Asian Regional Conference on Autism to be held in January 2008 in Delhi, will be hosting a few such speakers. Adults who have Aspergers Syndrome and who lead meaningful lives that give us neurotypical people a window to their world. Most importantly, these are individuals who are functionally independent, and are learning to self advocate, and who do not believe that they are autistic because some vaccine turned them so.

(cont on page 7...)

My Brother Has Autism

(…or my sister)

T C Daley

In the August 2007 issue of Autism Network, we provided an overview of sibling issues in families with children with autism, with particular note of the Indian context. In the same issue, we also shared the thoughts and experiences of several individuals who have siblings with autism. In this issue, we conclude our article on siblings with a focus on important issues and ways to facilitate positive sibling relationships.

Telling the truth

Having a child with autism impacts the entire family. One cannot hide, or 'protect' the other children from the knowledge that their sibling has autism. Besides, when we hide the information it sends out a message of negative judgments about the condition. Hence disclosure is important. When explaining the child's autism to the sibling it is best not to give too much information to a small child which might just confuse the child. Neither does information have to be given at one solemn sit down major event, but through lived experiences – when the child with special needs does not play with his sibling, when he has difficulties with sleep, when a visit to a special needs school is planned, and so on. Siblings can play an amazing role in the development and growth of a child with ASD, but they cannot be expected to do so if they don't understand the nature of the condition.

IT is also important to make sure that the typically developing child is absorbing the information that you give. One should not assume that a child's nodding head means he understands everything you have said; it can also mean, "Yes, I'm listening to you," "Wow, this is serious," and "Am I in trouble? Maybe if I keep nodding yes then I won't be." This is why having a conversation *with* your child, rather than talking *at* him, will be the best approach.

How as much as *what*

When parents give information on the disability to he special needs child the how will matter as much as the what. As noted by Jenie Mathews and her colleagues, "In your eagerness to inform your child, don't make the mistake of giving too much information at one time. You have an entire childhood to help your child understand what he or she needs to know to feel confident of his/her factual information, to become accepting of themselves and their brother or sister, and to handle the curiosity and ignorance (whether intentional or accidental) that he or she is likely to encounter on the journey through childhood."

FOR instance, if the child asks why the sibling with autism will not play with him, the parents can tell him: "He does not know how to play with you. He has autism. So we will have to teach him how to play." At other times this can be extended to, "Your brother does not know how to play with his toys. Just like he also does not know how to call you 'Bhaiya'. But we can try and teach him. Would you like to help me do so?" This is also a great opportunity to make the child feel special! You can explain, "You know your brother cannot do things the way you can. He cannot play the way you can. So we got to teach him how to do so." It is important that we then do not put pressure on the child by telling them "You *must* play with him," rather we give him a sense of importance. And every child loves that!

ONE question that many young children are likely to ask is: Will he get better? This too is a great opportunity to give more information on the disability in a comfortable and non judgmental manner, as well as to make the regular child feel special. "Yes he will get better. But it may take time. And we will all have to help him a lot. And you know what! You are such a great guy! You can help me teach him so that he can learn how to get better." So we refer to the disability in a matter of fact manner, make the child feel special, and also get him to help without any resentment or pressure.

NEVER, even in moments of great exasperation, do we tell child "if you don't do this your brother will never get better." The burden of responsibility is too much for any healthy sibling relationship to flourish. In fact, an important aspect of giving information is also the assurance that the disability is something that the sibling is born with, and that the typical sibling did not cause.

Children can believe they caused the autism through many ways; as one sibling wrote in the previous issue:

‘This is all my fault,’ I used to think. “If I hadn’t insisted for a sibling none of this would have ever happened.”

Siblings have reported to us that they never knew what their brother had and has spent their whole life wondering if they were somehow responsible.

Check your own attitude

As noted in the previous issue, how children perceive their siblings condition will depend to a great extent on how the parents perceive the condition. If parental perception of the special needs is one of a ‘problem’ so will be the sibling perspective. However, if children learn that their special needs sibling is ‘different’ they can learn to accept and celebrate that difference in the same manner as they accept other human differences. If parents want their typical children to be caring, thoughtful and loving toward their sibling with ASD, then they must, above all, model this behavior. Much therefore depends on parental acceptance of the child with special needs.

Parents love their children – special needs or not. But often, there is an underlying embarrassment, a sense of shame, of how the world views the child. Parents also may express irritation, resentment, exasperation, of the child with autism, over and above normal parenting blues, due to the repetitive behaviours, difficulty in teaching, unusual mannerisms of the child with autism. As a result, sometime parents may not take the special needs child out in the community at all. Or they may do so, but their embarrassment and judgments of the special needs child is evident in the manner in which they ask them to modify their behaviour when in public.

Understand, affirm, and legitimize

At every age, your typically developing child will have a range of feelings toward his or her sibling: love, hate, protectiveness, resentment, jealousy, and so on. These feelings are part of growing up in normal sibling relationships as well. When the child has a sibling with special needs, when he experiences ‘negative’ feelings towards his sibling it is then often accompanied by feelings of guilt. Parents have to be aware of and understand that a mix of positive and negative feelings is normal in sibling relationships, and as parents assure their child that it is ok to have such feelings; and that it does not make them ‘bad’ people, bad brothers or sisters.

Equal doesn’t mean the same

Many families report that while their typical child is fond of their disabled sibling, they also resent the time and attention given to the special needs child. “You are always spending time with him,” is a common complaint. No one can fault a parent for spending more time with a child who is disabled, and even children without ASD understand this. One way to explain this to your typical child is that being ‘fair’ to everyone in the family doesn’t necessarily mean treating everyone the same. Even two typical siblings in a family do not usually receive perfectly equal attention from their parents. What is important is the quality of time you spend with your other children, rather than the quantity. Some families make a point of setting a special time, such as an hour or half hour on a weekend afternoon, where the parent will just focus all attention on their non-ASD child. This should be a time where there are no interruptions from either the sibling with ASD, work issues, or phone calls. Your willingness to set everything aside—including the child with ASD—signals to your typical child that they are an important and interesting person whom you like to spend time with. It will go a long way not only to alleviate resentment of the sibling with ASD, but help your typical child’s sense of self-worth.

Siblings are individuals too

We all define ourselves in part by our relationships to others—as daughters, sons, brothers, sisters, aunts, and so on. For a sibling of a child with autism, it is important not to lose sight that everyone has a need to be also recognized as individuals, apart from their role in the family. This is particularly relevant to siblings who happen to be exceptionally giving, caring people. Such children must of course be recognized for the sacrifices they make for their siblings, and their important role must be acknowledged. Yet they must have an identity beyond their sibling. Parents have to be sure to recognize the talents, skills, and traits that make the sibling unique without reference to his brother or sister. It is the difference between saying “Reeta has always been such a thoughtful, caring child. I remember that even when she was little, she used to run and get Sahil’s favorite book for him when he was upset,” and saying “I love Reeta’s drawings. Have you seen the lovely drawings she made last holiday? I have put some up in the hallway.”

The pressure

Parents typically have their own hopes and aspirations for their children. Many parents have expectations that their child will study in their old school, take up their mother’s profession, study management which their father wanted to but could not. Parents often look to fulfilling their aspiations and ambitions for their family and their own selves through heir children. As their child with special needs grows, they learn to discard such expectations.

HOWEVER, these unfulfilled expectations of this child get transferred to the neurotypical sibling. Siblings of children with disabilities can often feel a subtle – and sometimes overt - sense of pressure to fulfill all the dreams and aspirations that their parents may have had. Particularly in a family with just two children and one of whom has a special need, parents have to be aware not to push the typical sibling too hard. The pressure will likely just cause resentment—towards the parent as well as toward the sibling with ASD. Alternately, typical siblings also try to overcompensate by striving to be a 'superkid' or the 'perfect child'. While it can be fulfilling to have a child who tries so hard, it can often be detrimental especially for a child who somehow 'fails' to square up to heightened parental aspirations. Parents have to convey to their typical children that they are wonderful as they are, and that what is important is not that they achieve what their parents hope they do, but that they put in their best effort towards it.

FURTHER, most siblings who try to compensate for their special needs siblings are usually the sort that feel obligated to take care of their sibling on behalf of their parents. These are children with an overwhelming sense of responsibility. More pressure is something they can do without! Such children need to learn that they help out only when they need to: they don't need to do so regardless.

Troubles shared are troubles halved

Just as parents benefit from talking with other parents, so too can siblings. Setting up meetings between siblings of children with ASD is relatively easy, and tremendously rewarding for everyone involved. Most siblings have a sense of isolation. Meeting others who are going through similar life experiences as themselves can give one an amazing sense of relief. Among other siblings, your child for the first time is in a group where she or he can feel understood. Talking with a group of siblings provides children with the opportunity to discuss certain feelings which they may be reluctant to express to family members.

IN addition to the strategies enumerated in the preceding which may be helpful for siblings of children with special needs, Powell and Ogle (1985) present several strategies suggested by non-disabled siblings themselves for parents to consider in their interactions with their non-disabled children. These siblings suggest that parents should:

- Be open and honest
- Limit the care giving responsibilities of siblings
- Accept the disability
- Schedule special time with the non-disabled sibling
- Let siblings settle their differences on their own
- Welcome other children and friends into the home
- Praise all siblings
- Recognize that they are the most important, most powerful teachers of their children
- Listen to siblings
- Involve all siblings in family events and decisions
- Require the disabled child to do as much for himself or herself as possible
- Recognize each child's unique qualities and family contribution
- Use professionals when indicated to help siblings
- Teach siblings to interact
- Provide opportunities for a normal family life and normal family activities

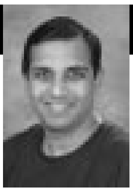
Conclusion

Autism is a family disorder. It does not merely affect the child – autism is a condition that impacts on the entire family. Growing up with a sibling who has special needs is not easy for most children. When the sibling has autism, it is far more difficult given the complexity of the condition. Even most parents and grown ups have a difficulty in understanding autism; for a child getting a handle on the concept of autism is exceptionally difficult. Most children when asked to define autism in their siblings do so only through the behaviour manifestations: few truly understand the condition. That makes things more difficult for both siblings – the non-autistic as well as the autistic.

In conclusion, it is important for the heath of the family to support the non-autistic sibling as much as the child with autism. In conclusion children have to be helped to not feel ashamed of their special needs sibling, as well assured that it is okay to feel frustrated, angry and jealous at times. Ideally, siblings have to learn about the disability in a casual manner so that they are comfortable about answering questions from their friends and peers about their sibling's condition. The information about

(cont overleaf on page 4...)

ROHAN'S COLUMN



Who shall we label as being different?

Satish & Bhavana Sonalker

Persons with autism are seen as different and those who are ‘normal’ are apprehensive of befriending them. But are they really different? We believe that they are not ‘different’ but are only protecting their inborn values from a society that wants them to change to fit into society's norms.

ROHAN, our son, spent his childhood in Assam, where he was as familiar with the elephant as the frog in the garden pond. Both befriended him in their own way: The giant by his trumpet at receiving a fruit or vegetable, and the other by his antics when little fingers tickled the water. Maybe, that is what struck in him a chord of equality and respect, for these remained his hallmark throughout life.

AFTER moving to Pune, Rohan's world began to take in teachers, uncles, aunts, and domestic animals; each of them introducing him to a new ‘hierarchy’ which he did not quite grasp. He could stop the chief guest's car at the school gate, and escort the ‘dignitary’ to a shocked Principal, with as much aplomb and impartiality as he would help little children to climb down the steps of the school bus. After being introduced to a minister, on seeing him the next time he would wave out his loud autistic “Hello Vijaydada !” without disrespect to anyone; yet frightening the sycophants around the ‘dignitary.’

WITH a strong belief in every person's esteem Rohan ‘handed down’ his clothes properly laundered, gift-wrapped and labelled.

Our washerman shares: “For all these years everyone knew me only as ‘Dhobi’; but not Rohan. He always remembered to call me ‘Srinivas’; respecting me as an individual”. At yoga, Guruji BKS Iyengar found him to be positively ‘different’ and would tell his disciples, “Among my thousand of students, he is the only one who learns at the first instance. That's because he does not consider even the smallest instruction to be trivial”. And it was artist Bal Wad's comment before one of Rohan's art exhibitions:“When at work, he reaches a stage of meditation when nothing can distract him from what he has taken in hand”.

THESE traits – common to autistic children – made us proud of our son. Let us give these special children their due for an innocence that is often lost in trying to make them ‘normal’.

(...cont from page 4)

the disability when put forward as a ‘difference’ versus as a ‘deficiency’ can have more positive outcomes. Children have to be encouraged to talk about the disability with parents, counselors, anyone who can help. They also have to be helped to understand that they are not alone, and wherever possible introduced to sibling groups. Finally, siblings have to be assured that it is okay for them to have a life where the special needs sibling does not hold centre stage, and that they do not have to live with a sense of guilt for wanting a life of their own.

References and further reading:

- **Harris, Sandra L. and Glasberg, Beth,** *Siblings of Children with Autism*
- **Lobato, D**. *Brothers, sisters, and special needs.*
- **Mathew, J., Leong,S., & White, S**., *Helping Siblings Understand Autism and Encouraging Positive Relationships*
- **Meyer, Donald J**., *Living With a Brother or Sister With Special Needs: A Book for Sibs*
- **Powell, Thomas H. and Gallagher, Peggy A.,** *Brothers and Sisters*
- **Siegel, Bryna**, What About Me?: *Growing Rowing Up With A Developmentally Disabled Sibling*
- **Thompson, Mary** *Andy And His Yellow Frisbee*

http://www.sibs.org.uk/

LETTERS

I am very impressed to see the work that you are supporting in India! Your Web site and thoughts on how to make the lives better for individuals with autism in India are really good.Thank you for your leadership.

SHARI KRISHNAN

I live in Austin, Texas in USA and I have an autistic son who is now 9 years old. Firstly, let me commend your team on bringing so much awareness on the subject.

My son was diagnosed with infantile autism when he was just one and a half years of age. Luckily for us the doctor who diagnosed him knew of a child in his family with similar symptoms and behaviors. According to him, there was complete lack of awareness on the subject, let alone resources to help the child. We met with psychologists, pediatricians, therapists at AIIMS who not only gave us in writing that our son was not autistic, but just slow - they also made jokes about him. Last resort for us was to somehow manage to come to the US. Today it's been six years that we are here. He has made progress although slow. He goes to a communication classroom which has five kids and four teachers, along with which a therapist comes home everyday for two hours to work with him.

After learning a little bit about your work I wanted to share my experience and am hopeful of one day coming back to my home town and maybe settling down.

RICHA NARANG

We received your Autism Network of August. We find it a very useful magazine. The article about brothers and sisters of children with disabilities is very good. We are so stressed with out autistic son that we do many wrong things with our other child and we do not know that we are making mistakes. We do not know what we should do. The article was helpful because it showed me where I am going wrong and how I can help our child. I think I have to first not be sad that my autistic child cannot go to school like other children and will not marry and have his own children. I feel sad for him and so am always being too strict with my daughter. I forget to see what a good child she is. You are so correct. I forget to tell my daughter what a wonderful girl she is. The article by Susmita Kurup on her brother Sujit is too good. It made me cry. I think my daughter is like that, only she never tells me these things. Vibhu Pratyush is also very good. What he feels for his brother Vishu is very sensitive. I think we parents have to begin to see our autistic child differently. Sometimes we have wonderful children and we do not realize that because we are so unhappy ourselves.

I request Action For Autism to hold workshops for siblings. Your workshops are famous. Parent and teachers find them very useful. If you could hold workshops for brothers and sisters of children with disabilities you will help them all a lot. You could also help parents to start a sibling support group. Please take the initiative to do this.

PK KUMAR

I wish to congratulate you for the excellent articles you publish in your journal month after month. The siblings column in the Journal helped many families of Autistic children. I thank you and your team for your dedicated work.

D. VIJAYAGOPAL REDDY

Namaste!
Chri-mati Indu Chaswal aura Chri-mati Merry Barua

Hum log shub Christmas aura naya saal do hazaar so aath mubaarak bolte-hai.
Shubhkaamnay.

(I have written in English if ever my Hindi is not good)

Hello Mrs Indu Chaswal and Merry Barua
I would like to wish you a merry christmas and a happy new year 2008.

Best wishes
GILLES TREHIN & CATHERINE MOUET
France

(...cont from page 1)

Of course the possibility of environmental factors contributing to a rise in diagnosis is possible. Just as there is a rise in a host of conditions including cancer and diabetes. The environmental factors do not have to be medical ones that are thrust on us; rather many are those that we embrace as a part of our contemporary lifestyle. We make extensive use of cellphones, cook in microwaves, spend hours in front of our computers, many more hours glued to the TV screen, get ultrasounds done at the drop of a hat, to just list a few. Do we even begin to have an idea of what the long term impact of these are?! So of course autism may have an environmental origin in the combination of causal factors.

That many families look exclusively for environmental and other external causal factors is understandable, because if that could be true then the possibility of finding a medical 'cure' is that much more possible. But on the other hand many also refer to and think of autism as a 'dreaded condition that must be stamped out at all costs.' Not a very comforting thought for the person who has autism and for whom the condition defines the person he or she is.

And that is why it was a revelation to recently receive a call from a mother in Pune. The mother called to say that her son's psychologist had told her that her husband was on the Spectrum and she agreed. She added that her husband was a very nice man, was exceptionally well educated, but has not been able to hold a job. She agreed with the psychologist's assessment and now wanted to know how to discuss this with her husband. As she put it: "I have to deal with two people with special needs. If I could discuss my husband's condition with him, he would be able to help me deal with our son." She wanted to know the best way to go about it.

And a fellow professional forwarded me a mail from another mother who wrote that she suspected her husband was on the spectrum. So she got him to take an online test that definitely placed him on the spectrum. She actually looks forward 'with relief' to her son growing up to be someone like her husband; a person with some 'weird' behaviour and who cannot lie, never bad mouths anyone, does not have an opinion on others. She describes her husband as unsocial, very uncomfortable at parties and other social gatherings, but warm hearted and a gem of a guy.

What a refreshing change from all the head banging parents who want to 'tear the autism out of our children.'

Hopefully the South Asian Conference on Autism with its presentations from persons on the spectrum will bring forth a more positive approach to autism and build bridges between the Aspies and the Neurotypical.

In this issue we carry articles on intelligence and autism, and on ability, particularly one on Heather Kuznich, a young lady with Aspergers Syndrome who had a successful run of several weeks on a reality show!

We also continue our article on siblings. What we have very little of in India is support for siblings of children with special needs and particularly autism. Perhaps this is something all of us in the field need to consider.

For several years now, December has been observed in India as Autism Month ever since Action For Autism initiated the observance in 2001. Now, thanks to the efforts of the nation of Qatar, the United Nations has designated 2 April as World Autism Awareness Day. That calls for some celebration!

On that note we wish all our readers a Happy Eid, Merry Christmas, and a Joyous 2008!

Look forward to seeing all of you at the South Asian Regional Conference for Autism in Delhi.

SENSORY INTEGRATION THERAPY

Sensory Integration Therapy sessions for individuals with developmental disabilities available from :
2:00 pm – 4:00 pm
Monday to Friday
at the National Centre for Autism.

For appointments contact:
Neeru Sharma
Tel: 40540991 and 40540992

''ऑटिजम और खेल'' कला का विकास

इन्दु चसवाल

प्रथम खेल जो एक बच्चा सीखता है, वह होते हैं ''झॉकी'' (पीक–अ.बू.) या दूसरे के चेहरे पर से कपड़ा खींचना। ऑटिजम से प्रभावित बच्चे इन खेलों में रुचि बिल्कुल नहीं रखते। परन्तु इनके साथ यदि कुछ संवेदनशील क्रिया जोड़ दी जाये, जैसे गाना, गुदगुदाना इत्यादि तो ऑटिस्टिक बच्चे के रुचि हो सकती है।

सर्व प्रथम पारस्परिक खेल स्वयं रचाये जा सकते हैं। यदि बच्चे को गुदगुदाये जाने पसन्द हो तो आप 1–2–3 गिनती बोलकर, या स्वर में गाकर गुदगुदाये, कुछ बार ऐसा करने पर आप पायेंगे कि जब अब गिनती बोल ही रहे हैं तो बच्चा खुश होने लगता है। यदि 1–2 बोलकर आप रुक जायें तो शायद बच्चा स्वयं ही आपका हाथ अपनी ओर लाने का प्रयत्न करे। इस तरह की सन्धित नित्यक्रम जैसे बुलबुले बनाना, गुब्बारे उठाना, गाने सुनाना, बच्चे को आनन्द प्रदान करते हैं और भविष्य में दूसरों के साथ खेलने की कला सिखाते हैं।

एक और प्रकार का सामाजिक खेल है – ''अनुकरण'' या ''इमिटेशन''। एक ऑटिस्टिक बच्चे के लिए बहुत महत्वपूर्ण होता है कि दूसरा व्यक्ति उसके खेल या उसकी रुचि में सन्धित हो जाए। बजाये उसे जबरदस्ती वे खेल खिलाए जो बच्चे के लिए कोई मूल्य नहीं रखते। जब हम बच्चे के अपने खेल में उसके साथ सम्मिलित होते हैं, तब बच्चा भी कुछ समय बात दूसरे का अनुकरण करेगा।

खेल के समय कुछ बुनियादी बातों का ध्यान रखें :–

1. बच्चा विशेष रूप से खेल को आनन्दमय महसूस करे।

2. लेनल क्रिया (बारी लेना या टर्न टेकिंग) बच्चे के लिए लाभदायक होता है।

3. खेल की सैशन (अवधी) कम हो।

4 ऑख से सम्पर्क बनाने को या अन्य प्रतिक्रिया के लिए जबरदस्ती न करें। यह कोई कार्य–समय (वर्क टाइम) नहीं है, मजे का टाइम है।

5 शोर या अन्य संवेदनाओं को ध्यान में रखें और बच्चे की बरदाश्त के अनुसार रखें।

खिलौनों के साथ खेल

अभिभावक और अध्यापक अक्सर कहते हैं – ''हमारे बच्चों को खिलौनों से खेलना नहीं आता।'' यह सत्य है, ऑटिजम से प्रभावित बच्चे खिलौनों में या तो सीमित रुचि रखते हैं और या अटपटे ढंग से खेलते हैं। गाड़ी की चक्की चलाना, या आगे–पीछे करते रहना, गुड़िया की ऑख को छूते रहना या कपड़ों को उतारना–चढ़ाना या पटकना। आम तौर में यही देखा जाता है।

बच्चों को यदि हम आम वस्तुओं से स्वॉग करना सिखायें तो आगे चलकर प्रिन्टेड खेल या 'काल्पनिक खेल' सीखे जा सकते हैं।

सरल ऐक्शन जैसे गिलास से पानी पीना, घंटी बजाना, कंघी करना, ब्रुश करना, चम्मच से खाना इत्यादि टेबल टॉप ऐक्टिविटी से रूप में पहले सिखाये जायें जिससे खेल संबंधित भाषा का विकास होगा। बच्चे के सामने गिलास, कंघी, चम्मच, घण्डी रखकर सरल निर्देश पालन सिखायें (पानी पियो, चलो खाना खायें) इत्यादि। इसके बाद गुड़िया के साथ यह निर्देश दें। धीरे–धीरे बच्चे को उसकी जिन्दगी में आप घटने वाली स्थितियों के आधार पर स्वॉग रचायें। जैसेः– ''चलो, डॉल को साइकिल पर बैठाऐं, थैला दें''। फिर उन्हीं सब क्रियाओं को दोहरायें जो बच्चा समझ सकता है। डॉल साइकिल पर बैठकर सब्जी के बाजार (कुछ सब्जियों के छोटे छोटे ढेर लगाये), पैट्रोल पम्प (पाइप और डब्बा जिस पर भारत पैट्रोलियम लिखा हो) जा सकती है। याद रखें कि पहले भूमिका हमें बनानी होगी और स्वॉग भी हमें रचाना होगा। धीरे–धीरे बच्चे को शामिल कर, नये आइडिया डालकर प्रिन्टेड प्ले, सिखाना होगा। इसप्रकार ''जन्म दिन'', ''खिलौनों की दुकान'', ''डॉक्टर क्लिनिक'' इत्यादि प्रिन्टेड सिखाये जाते हैं।

खिलौनों से आरम्भ करके हम और ज्यादा ऊॅचे स्तर के स्वॉग खेल रच सकते हैं। इनसे केवल खेलक्रिया ही नहीं, परंतु भाषा का विकास भी होता है। साथ–साथ कुछ मुख्य व महत्वपूर्ण सामाजिक स्थितियों में उचित व्यवहार दिखाने का ज्ञान भी मिलता है।

शिक्षा में समावेश सफल हो सकता है

गिजेल लोबो

गिजेल लोबो एक स्पेशल शिक्षिका हैं, जिन्होंने संयुक्त राष्ट्र अमरीका में औपचारिक ट्रेनिंग ली। हिन्दुस्तान लौटकर इन्होंने दो मुख्य धारा स्कूलों में स्पेशल कक्ष (रिसोर्स रूम) खोले। यह जोत सोसाइटी ऑफ पेरेन्ट्स ऑफ ऑटिस्टिक चिल्ड्रन की मुख्य अधीक्षिका हैं।

तीन वर्ष पहले गोवा के होली क्रॉस कान्वेन्ट में एक समावेशक कक्षा की स्थापना हुई। यह अभिभावकों की रूढ़ीवादी शिक्षा प्रणाली का सामना करने की वजह से हुआ। उनका साथ दिया। एक बहुत ही प्रत्यतशील शिक्षकों के गुट ने जो सही रूप से मानते थे कि अब समय आ गया है जब हर एक प्रकार की कुशलताऐं रखने वाले एक साथ शिक्षा ग्रहण करें।

समावेश (इनक्लूजन) का यह विचार सभी के लिए नया था पर स्कूल की महाआचार्या सिस्टर पुश्पिका ने हिम्मत कर अपने स्कूल में स्पेशल शिक्षा के लिए जगह दी। इनक्लूजन का तात्पर्य सरल है – आम और विकलॉग बच्चों को एक साथ शिक्षा देना जिससे दोनों को लाभ हो। यहॉ पर महत्वता इन शब्दों पर दी है ''दोनों को लाभ''। अर्थात् इन्क्लूजन केवल बच्चों को आम स्कूलों में जबरदस्ती घुसाकर उम्मीद रखना कि वह कौशल सीखें, ऐसा बिल्कुल नहीं है।

इसका अर्थ है स्पेशल जरूरत रखने वाले बच्चों को एक सावधानी से बनाये गयी योजना के माध्यम से आयोजित कार्यक्रम सिखाऐं ओर साथ उन्हें अपनी उम्र के बच्चों के साथ घुलना–मिलना सिखाऐं।

अब हम होली क्रॉस कानवेन्ट का केस उदाहरण लेकर इनक्लूजन को और समझते हैं। हम होली क्रॉस कानवेन्ट के साथ–साथ चब्बी चीक्ज स्कूल का भी उदाहरण लेंगे। इन दोनों स्कूलों में अलग कक्षाऐं हैं (रिसोर्स रूम) जिनमें अन्य प्रकार की विकलागता से प्रभावित बच्चे हैं (ऑटिजम मन्द बुद्धि, लर्निंग डिसेबिलटी इत्यादि) पाठ्यक्रम जोकि इन कक्षाओं में सिखाया जाता है, वह बहुत ही कार्यशाली ओर बच्चे के जीवन में काम आने वाला रहता है। यह पाठ्यक्रम 6 भागों में बॅटा रहता है।

1. कम्यूनिकेशन :–

इन कक्षाओं में अधिक बच्चे ऑटिस्टिक है, इस कारण अधिक ध्यान कम्यूनिकेशन या संप्रेक्षण सिखाने पर दिया जाता है। इसके अंतर्गत बच्चे को सरल निवेदन करना अपनी आवश्यकताओं को व्यक्त करना और सरल आदेशों का पालन करना सिखाया जाता है । दूसरों के साथ सूचना बॉटना व लेना ओर वार्तालाप संबंधी कौशल सिखाये जाते हैं। कक्षा में यह गुण प्राप्त करने के प्श्चात् बच्चा इन्हें अपनी सहज वातावरण में प्रयोग करना भी सीखता है।

2. पाठन :–

पाठन भी इन कक्षाओं में सिखाया जाता है। पहले बच्चे को पूरा शब्द पढ़ना सिखाया जाता है। इसे साइट रीडिंग कहते हैं। जब बच्चा 10 साइट शब्द पढ़ना सीख जाता है, तब उसे सरल पुस्तकों द्वारा रीडिंग सिखाते हैं। कुछ स्पेशल बच्चे जो रीडिंग सीख पाते हैं, उन्हें दूसरे बच्चों के साथ आम क्लास में रीडिंग पीरियड में भेजा जाता है।

3. गणित :–

इस विषय में भी ध्यान का केन्द्र कार्यात्मक ज्ञान है। मैचिंग, सॉर्टिंग, अंकों की पहचान, अंकों का और समय का ज्ञान अथवा समय को घड़ी पर पढ़ना सिखाया जाता है।

4. लेखन :–

लिखना एक बहुत ही संरचित ढंग से सिखाया जाता है। साफ लिखाई, वर्णों का सही आकार बनाना मुख्य एक्टीविटी हैं। वास्तविक रूप में लाभकारी एक्टीविटी जैसे फार्म भरना जिसमें अपने बारे में सूचना हो। अपना नाम लिखना या हस्ताक्षर करना भी कुछ बच्चों को सिखाया जाता है।

इस कक्ष में 'योगा', 'दौड़', 'गेंद फेंकना' और अन्य खेल जैसे म्यूजिकल चेयर सिखाये जाते हैं। बहुत से बच्चों को शारीरिक 'गेंदबाजी' और 'दौड़' पर विशेष ध्यान दिया जाता है क्योंकि 'स्पेशल ऑलम्पिक' के यह दो मत्वपूर्ण प्रतियोगिताऐं हैं जिनमें गोवा के इन स्कूलों के बच्चे प्रति वर्ष भाग लेते हैं।

फाइन मोटर :–

बहुत सी मनोरंजक और फुरसत में करने वाली एक्टिविटीज जैसे रंग भरना, कटाई, पेन्टिंग, क्ले कला इत्यादि भी सिखाये जाते हैं। इनका लक्ष्य है बच्चे को ज्यादा से ज्यादा कार्य सिखाना जिससे वह अपने खाली समय में स्वयं को सही ढंग से व्यस्त रखेगा। इन कार्यों में स्वतंत्रता होने पर वह मुख्य धारा के आम बच्चों के साथ सम्मिलित हो सकते हैं।

इन छ' कौशल के साथ–साथ माह में एक बार बच्चों को सम्प्रदाय दौरे के लिए ले जाते हैं। इसके फलस्वरूप इनके सामाजिक यवहार और गुण विकसित होते हैं। गोवा डेयरी, सिनेमा हॉल, आइसक्रीम फैक्ट्री, पास की दुकान और सुपर बाजार – कुछ ऐसे स्थान हैं जहॉ यह बच्चे जाते हैं। जो स्किल कक्षा में सीखे हों, उन्हें अपने जीवन में भी प्रयोग करते हैं। उदाहरण के लिए – जो बच्चा पैसे का हिसाब या सिक्के पहचानता है, वह पैसे निकाले जो बच्चा बातचीत में सही हो, वह दुकानदार से सामान मॉगे।

जैसेकि पहले बताया गया है, इन कक्षाओं का महत्व या लक्ष्य पढ़ाई–लिखाई नहीं है, इनका लक्ष्य है सामाजिक रूप से बच्चों का विकास। जो बच्चे स्पेशल हैं, उनका गुणात्मक विकास होता है और वह आम बच्चों के आचरण को ग्रहण कर पाते हैं। कक्षा में आम बच्चे या विकलांगता रहित बच्चे हैं, वह सीखते हैं कि विकलांगता को बुरी चीज नहीं है और स्पेशल नीड्ज़ बच्चों को अपनाना भी वह सीखते हैं।

एक और प्रभावशाली प्रयत्न है, मुख्यधारा के आम बच्चों को ग्रुप में विकलांगता के बारे में बताना, उनके साथ विचार विमर्श करना। अन्य प्रयास द्वारा विद्यार्थियों को ऑटिज़म और मानसिक विकलांगता के विषय में जानकारी दी जाती है और बताया जाता है कि स्पेशल विद्यार्थियों के प्रति कैसा रवैया रखना चाहिए। इन बातचीत द्वारा बहुत से विद्यार्थी लाभ उठा पाये हैं और विकलांगता के बारे में उनके विचार परिवर्तित हुए हैं। एक नवीं कक्षा की बच्ची का कहना है :–

''अब मैं कभी भी इन्हें हैण्डिकैप नहीं कहूँगी''।

अभी तक दोनों ग्रुप (स्पेशल और दूसरे) बच्चों ने एक साथ स्कूल के 'सालाना दिवस' (एनुअल डे) 'शिक्षक दिवस' और 'मदरसा डे' मनाये हैं। इन प्रोग्रामों में बच्चों ने एक दूसरे के साथ काम करना तो सीखा पर जो सबसे महत्वपूण्र बात रही वह है कि इन्होंने एक दूसरे के साथ को आनन्दमय पाया और एक साथ मनोरंजन का अहसास किया। यह एक धीमी गति में चल रहा सफल प्रयास है। और बहुत कुछ होना है। सबसे बड़ी चुनौती है – मुख्य धारा के अध्यापकों और प्रधानाचार्या को बदलना जो समझते हैं कि समावेश या इनक्लूजन दोनों ग्रुप (''स्पेशल व नार्मल'') के लिए हानिकारक हैं।

पर संसार भर में सुस्पष्ट है कि समावेश या इनक्लूज़न एक सफल प्रयास है यदि सही ढंग से किया जाये।

HELPLINE

Q *My ten-year-old son attends a mainstream school. He has been going there for the past three years and the staff there has been very nice. Of late he has developed behaviors like running away from the class, throwing notebooks and bags on the floor etc. I then started taking him for remedial teaching at a center for children with Autism. His work behavior at the center is very good. He shows compliance and sits happily for work. But it has not helped him show similar appropriate behaviors in his own school. What can we do?*

A First of all it is good to know that the teachers at his school are nice and that he has been there for three years. Regarding the behaviors mentioned by you there are a few things that need to be seen from his perspective. The fact that he sits with the special educator during remedial classes and works well explains very clearly that he does like to work.

Therefore the disruptive behaviors seen in the class situation first needs to be assessed. Find out what happens before these behaviors take place, which are the persons in the situation, what do people in his environment do when the behaviors occur, what does he get after the behavior or is something taken away from him.

For example: when he throws things is he sent away from the class? Or is he punished in any way. If he is sent out of class that could actually be strengthening the inappropriate behavior because he is learning that such behaviors lead to escape from work. Whatever strategies are being followed are perhaps not effective and that is why the behaviors are not going.

Other things to be considered are:
- Can he understand the instructions given in the class? Sometimes even very high functioning children have difficulties in attending jointly in a group situation. They need very specific and individual instructions.
- What is the level of tasks - is it too challenging for him, too abstract or complex? Most children with Autism find it difficult to understand things that are not concrete/ predictable/ have too many aspects in one concept?
- His sitting position in class, noise levels and responses from other students.
- His school as you have stated has a staff that is nice but it does not explain that they understand him as well . They may be trying their best but it is not working, therefore a networking betweenschool , parents and the Special Education team that works with him is very important so there is a consistence in responses and expectations

Q *I wanted to know if anybody has used Melatonin to correct the sleep cycle of their child and if it is available in India.*

A There are a few studies to suggest that melatonin may be useful for sleep disorders in kids with ASD. It is available in India as Melocet 3mg tablets.

Q *I am writing for your advice on the courses that I could study. I have been teaching three to five year olds for the last five-and-a-half years now. I really enjoy working with them. I would also like to learn how to help children who have disabilities and those who have autism. I have not undergone any formal teacher's training.*

At present I work at the Kindergarten in the mornings, in the afternoons I work for a French company and in the evenings I teach French at the Alliance Française.

A You appear to have a very full day. Ideally if you can take time off to do a couple of complete courses, then perhaps you could do a BEd in special Education, or an MEd depending what your current education al level is.

You could then do an additional short training in autism spectrum disorders. Autism is one of the disorders that you do not get a handle on in the BEd course. A good short training can help you learn some excellent behavioural principles that will help you to handle children with a range of difficulties. You can also do a full one year course depending on your time schedule.

Of courese there is no course that trains you to work with every special need. If you cannot take off from work for a complete course, then you can do short trainings on a number of disabilities, and maybe spend some time at different centres to gainpractical experience.

BOOK REVIEW

AUTISM: A Practical Guide for Parents and Teachers

By Prithvi Perepa

Publisher: Prachi Publications

Reviewed by Indu Chaswal

Autism Spectrum Disorders - these words have been often misunderstood in the past. The confusion and myths created by ignorance and lack of knowledge resulted in slowing down the process of evolution of effective treatment. However, in the last two decades there has been a better understanding of the distinctive thinking styles of a person with Autism and the particular ways of behaving that the thinking leads to. Today parents are faced with a variety of choices in the form of teaching methods. However, they are still at a loss because even if they are convinced by a particular method, they find it difficult to get teachers who can carry out the program accurately.

PRITHVI Perapa in his book titled 'A Practical Guide for Teachers and Parents' provides practical and effective strategies to enhance skills of persons with Autism. According to Perapa himself, it is very important for parents and teachers to have a guide that is comprehensive and that can be referred back to at the relevant point of time.

THE theory section of this book has been kept as brief as possible. The terminology is also kept clear. The term autism is used to refer to the entire spectrum, and avoidance of terms like PDD, Asperger Syndrome, ASD, High Functioning Autism, has helped reduce confusion for the readers. The writer has kept in mind other terms that sound like jargon but are actually very important and need to be understood. These have been explained along with a list of abbreviations (like AAC, TEACCH, ABA etc.) decoded right in the beginning of the book.

PRITHVI Peraepa has combined his varied experience in Special Needs Schools, as an advisory teacher in mainstream schools, adult residential places, and as a student pursuing higher studies in Autism. His positive approach towards families that are struggling to cope is reflected with lucidity and sensitivity in Chapter Three where he writes, 'Remember, there is no school that trains us to be parents, grandparents, siblings or an individual with autism. We are all learning, and failure is a part of (the) learning process.'

THE anecdotes in the guide enable parents and teachers to relate to the issues mentioned. The second half of the guide is especially useful as it imparts creative ideas to work with the children. Parents craving for miracles and a normal child are vulnerable to approaches that claim *cure* or *recovery*. Perepa warns parents to be flexible, rational and not averse to the idea of eclecticism in teaching programs. Therefore, he has shared activities for enhancing language, communication and social skills that are based on well established methods like PECS, ABA, TEACCH, SIT, Social Stories, Social Supports etc.

THE writer mentions that using strategies simultaneously may be daunting in the beginning but if the rationale of what one is doing is clear then there will be more moments of happiness than frustration. The illustrations and simple games and fun activities given provide teachers and parents with ideas to work on the subtle as well as vital aspects of learning like turn taking, waiting, joint attention, play and independence.

AS Perepa guides us through the book he makes a consistent and successful effort to remind us that ideas and suggestions are for both teachers and parents. The book is written in simple language with a very positive approach and the examples, anecdotes, ideas and activities mentioned are well within the Indian context. The book does not carry detailed accounts of teaching methods. Rather it serves as a very good resource for understanding the autistic child, starting a useful program and moving forward to enhance the skills of the child.

PRITHVI Perepa concludes the book with the chapter titled-**'Completing the Puzzle'** in which he has covered a wide range of abilities, age groups, and needs through four case studies of Indian children, to *complete the puzzle* by fitting these abilities and needs together for optimum results!

Banking Made Easier for Persons with Mental Disabilities

On Monday, 19 November 2007, the Reserve Bank of India made it easier for persons with disabilities like autism and cerebral palsy to open and operate accounts, by asking banks to accept guardianship certificates issued by local level committees set up under the National Trust Act.

The RBI Notification
Banks are advised to rely on the guardianship certificate issued either by the district court under the Mental Health Act or by the local level committees under the National Trust Act for the purposes of opening and operating bank accounts.

Following the RBI directive, local level committees which have been set up in 499 out of 591 districts under the National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act will be able to issue valid guardianship certificates.

The only state where the local level committees have not been formed is Jammu and Kashmir.

The RBI came out with the notification in response to certain issues raised by the Trust such as whether banks can accept the guardianship certificates issued by the local level committees with regard to disabled persons.

Having examined the matter in consultation with the Indian Bank's Association, the RBI said that guardian, for the purpose of opening and operating accounts on the behalf of mentally disabled persons, can also be appointed by the district courts under the provisions of the Mental Health Act.

The decision will help thousands of people suffering from autism, cerebral palsy, mental retardation and multiple disabilities open and operate bank accounts through a legal guardian.

India Ratifies UN Convention on Rights of Persons with Disabilities

India was one of the first countries that signed the UN Convention on the Rights of Persons with Disabilities when it opened for signatures and ratification on 31 March 2007 in Washington. The Convention which aims to promote and protect the human rights and fundamental freedoms of those with disabilities as also respect for their inherent dignity had to be ratified by 20 signatories for it to become International Law.

Now, India has ratified the convention. On Monday 1 October 2007, External Affairs Minister Pranab Mukherjee deposited with the UN the instrument of ratification of the Convention on the Rights of Persons with Disabilities.

The adoption of the convention 'to promote, protect, and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity' followed four years of intense negotiations. The convention marks a major step toward changing the perception of disability and ensures that societies recognise that all people must be provided with the opportunities to lead a life to their fullest potential.

Postgraduate Diploma in Music Therapy

Jointly organised by Action for Autism and The Music Therapy Trust, this one year full-time course covers all aspects of Music Therapy, enabling students to qualify as Professional Music Therapists.

The comprehensive curriculum covers:
• Theory • Observation • Improvisation • Models of Practice • Research • Personal Development • Clinical Work • Psychology

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The Music Therapy Trust
Sector 5 Jasola Vihar, New Delhi

Email: themusictherapytrust@gmail.com
Tel: (91) 22 2869 6552, 22 2868 1525
Fax: (91) 22 2869 1834
URL: www.themusictherapytrust.com

The Puzzle of Hidden Ability

Sharon Begley

This article has been contributed by a parent

Even their parents struggle to draw the tiniest hint of emotion or social connection from autistic children, so imagine what happens when a stranger sits with the child for hours to get through the standard IQ test. For 10 of the test's 12 sections, the child must listen and respond to spoken questions. Since for many autistics it is torture to try to engage with someone even on this impersonal level, it's no wonder so many wind up with IQ scores just above a carrot's (I wish I were exaggerating; 20s are not unknown). More precisely, *fully three quarters of autistics are classified as having below-normal intelligence, with many deemed mentally retarded.*

IT'S finally dawning on scientists that there's a problem here. Testing autistic kids' intelligence in a way that requires them to engage with a stranger "is like giving a blind person an intelligence test that requires him to process visual information," says Michelle Dawson of Rivière-des-Prairies Hospital in Montreal. She and colleagues therefore tried a different IQ test, one that requires no social interaction. As they report in the journal Psychological Science, autistic children's scores came out starkly different than on the oral, interactive IQ test, suggesting a burning intelligence inside these kids that educators are failing to uncover.

THAT failure has lifelong implications. *"If we label these children as below-normal in intelligence, that is how they're treated,"* says Laurent Mottron, who led the study. The disparity between scores on the two IQ tests also makes you wonder who else the tests, which are used for everything from screening military recruits to filling "gifted" classes, are mislabeling.

FOR the study, children took two IQ tests. In the more widely used Wechsler, they tried to arrange and complete pictures, do simple arithmetic, demonstrate vocabulary comprehension and answer questions such as what to do if you find a wallet on the street—almost all in response to a stranger's questions. In the Raven's Progressive Matrices test, they got brief instructions, then went off on their own to analyze three-by-three arrays of geometric designs, with one missing, and choose (from six or eight possibilities) the design that belonged in the empty place. The disparity in scores was striking. One autistic child's Wechsler result meant he was mentally retarded (an IQ below 70); his Raven's put him in the 94th percentile. Overall, the autistics (all had full-blown autism, not Asperger's) scored around the 30th percentile on the Wechsler, which corresponds to "low average" IQ. But they averaged in the 56th percentile on the Raven's. Not a single autistic child scored in the "high intelligence" range on the Wechsler; on the Raven's, one third did. Healthy (non-autistic) children showed no such disparity.

THE Wechsler measures "crystallized intelligence"- what you've learned. The Raven's measures "fluid intelligence"- the ability to learn, process information, ignore distractions, solve problems and reason - and so is arguably a truer measure of intelligence, says psychologist Steven Stemler of Wesleyan University.

THAT presents a puzzle. If many autistics are more intelligent than an IQ test shows, why haven't their parents noticed? Partly because many parents welcome a low score, which brings their child more special services from schools and public agencies, says one scientist who has an autistic son (and who fears that being named would antagonize the close-knit autism community). But another force is at work. *"We often think of intelligence as what you can show, such as by speaking fluently,"* says psychologist Morton Ann Gernsbacher of the University of Wisconsin. *"Parents as well as professionals might be biased to look at that"* rather than dig for the hidden intellectual spark.

THE challenge is to coax that spark into the kind of intelligence that manifests itself in practice. That is something autism researchers are far from doing. Worse, much of the expert advice might be counterproductive. *Many experts dismiss autistics' exceptional reading, artistic or other abilities as side effects of abnormal brain function, "not a reflection of genuine human intelligence, which it is likely to be," says Mottron.* They advise parents to steer their child away from what he

(cont overleaf on page 15...)

Heather Kuzmich: Aspie In The Limelight

Heather Kuzmich, a beautiful 21 year old art student from Valparaiso, Indiana, USA, with a lean and angular look well suited to the fashion industry, is one of 13 young women selected by the supermodel Tyra Banks to compete on the popular reality television show 'America's Next Top Model.'

THE show has been running for four-and-a-half years. It has a format similar to the 'Big Brother' show that made actress Shilpa Shetty famous, and requires Heather to live in a house with a dozen other young girls under the full glare of cameras that record their every activity.
What makes her entry into the show interesting is that Heather Kuzmich has Asperger's syndrome. While many individuals with Aspergers have written about living with the disorder, this is the first time that millions of viewers have a compelling first-hand glimpse into the little-understood world of Aspergers syndrome. Like others with Aspergers, Heather is painfully direct, socially awkward, and has trouble making eye contact. She is also sometimes the target of her roommates' jokes. For a few months now Heather's struggle to cope with her disability has played out on national television in America.

HEATHER says she tried out for the show to 'test her limits,' to see how far she could go despite her autism. Used to being ignored most of the time, to her surprise not only did she get chosen to be on the show, she was chosen the most popular contestant eight weeks in a row. Aware of her own social difficulties, Heather was half afraid of being made fun of, and was instead surprised by her popularity, making it to the top five contestants.Her mother who has seen her struggle with her social difficulties is delighted at her daughter's achievement. She hopes it will bring greater understanding of, and public focus on, Aspergers syndrome.

AS expected on a show of this nature, there is much cattiness and backbiting that ensue. To quote from The New York Times:

EARLY in the show, (Heather) appears socially isolated, the girls whisper about her within earshot, and viewers see her crying on the phone to her mother. One girl is frustrated when Heather, concentrating on packing a bag, doesn't hear a request to move out of the way. At one point, the others laugh when they stake out their beds and Heather has no place to sleep.

"I wish I could get the joke," Heather laments.
"You. You're the joke," retorts another model, Bianca, an 18-year-old college student who is from Queens.

BUT while Heather's odd mannerisms separate her from her roommates, those same traits translate as on-the-edge high fashion in her modeling sessions. In interviews on camera, she often glances to the side, unable to hold eye contact. But Ms. Banks, the '60s-era model Twiggy and the fashion photographer Nigel Barker, who all appear on the show, marvel at Heather's ability to connect with the camera. The pop star Enrique Iglesias is so taken by her haunting looks that he chooses her for a featured role in a music video.

IN Beijing as part of the show, she got hopelessly lost and was unable to keep her appointment with various designers and finally was eliminated from the show in late November.

BUT the very fact that Heather Kuzmich was selected to a somewhat superficial show that is hardly associated with special needs, brings Autistic Spectrum Disorders and particularly Aspergers syndrome into the limelight. The show has seen the transition of Heather Kuzmich from socially awkward adolescent to socially awkward adult in full public glare. By bringing her lack of intuitive ability and single-minded fixations into the limelight, the show gives the world an insight into the differences in human behaviour, and of an awareness that being different is not being without value.

AFTER her elimination Heather Kuzmich has appeared on a few other shows, and now wants to continue modeling and use her position and new found celebrity statusto

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(...cont from page 14)

excels at and obsesses over, such as letters and words and details, and toward what he struggles with, such as faces and the big picture. Dawson, who is autistic, thinks that's a prescription for intellectual failure; *autistics should be encouraged to build on their strengths, as everyone else is.* The problem of a lurking intelligence that won't be coaxed out by the usual education and parenting methods is not necessarily unique to autistics. *It makes you wonder how many other children, whose intellectual potential we're too blind to see, we've also given up on.*

South Asian Regional Conference on Autism: BUILDING BRIDGES & Training Workshop in Structured Teaching

15 - 18 January, 2008, New Delhi

The South Asian Regional Conference will present an interesting mix of a few invited pioneers in their areas of work, as well as papers on work that is going on in different parts of South Asia. *Academicians, researchers, professionals from the UK, USA, Denmark, Germany and India and SAARC countries from a range of fields have been invited to share and exchange the latest in research and practice. In addition the Conference will also feature a number of speakers who have Autism and who will speak on growing up and living with autism.*

Presentations by keynote speakers, invited speakers, and delegates include:

Adolescents and Adults: Community, Work and Sexuality

- Employing strengths, interests, and negotiating relationships in theworkplace: Observations on Promoting Success: *Dr Stephen Shore*
- Employment Opportunities For Persons With Autism: *Thorkil Sonne*
- Qualification Modules for Person-Centered Community Inclusion Networks: *Prof Evemarie Knust Potter*
- Sexual Concerns and Adolescent Issues In Persons With Autism: *Dr Jitender Nagpal*

First Person Accounts

- Sexuality & Intimate Relations For People On The Autism Spectrum: An Inside View For Success: *Dr Stephen Shore*
- Unconventional Strategies for Living with Asperger's Syndrome: The life of an Asperger Savant : *Qazi Fazli Azim*
- Without Disclosure: My Life with Autism: *A Guha*
- My School Days: *A Basu*

Neurological, Diagnostic and Medical Issues

- Medication Issues for People with Autism: *Dr Tom Owley*
- Epidemiology Of Autism and the Influence Of Environmental Factors On Autism: *Dr Shobha Srinath*
- Face Processing In Persons With Autism: *Dr Pawan Sinha*
- Management Of Neurobiological Aspects Of Autism Spectrum Disorders: A Medical Perspective: *Dr R K Sabharwal*

Asperger's Syndrome: Pitfalls in Diagnosis: Dr Vibha Krishnamurti

Interventions

- Creating Structures While Teaching Persons With Autism: *Christopher Flint*
- Role Of Music Therapy In Persons With Autism: *Annie Tyhurst*
- Role of Homeopathy in the Management of Autism: *Rajlakshmi*
- An Initiative in Facilitating Peer-Play in Children on the Autistic Spectrum: *Parul Gupta*
- Social Skills Training for Children with Autistic Spectrum Disorders: *Denise Lai*
- The Effect of Individual versus Group Occupational Therapy Intervention on Social Skills in Children with Autism: *Sadia Merchant*

Family

- The Need of a Communicative Environment for Autistic Individuals at Home: A Case Study: *Dr Nusrat Ahmed*
- A Parent Training Approach for Management of Children with Autism: *A Thakore*
- Enhancing Coping Skills in Parents of Children with Autism: *Dr Ashum Gupta*
- Disability and the Social Construction of Motherhood: Mothering a Child with ASD in Urban India: *Shubhangi Vaidya*
- Anticipating Autism: *Dr Monidipa Banerji*

Living with Asperger's Syndrome: *Indrani Basu*

Country Overviews

- Autism in Sri Lanka: *Hemamali Perera*
- Autism Awareness in Pakistan: *Rukhshana Shah*
- Autism in Bangladesh: *Anwar Hussain*
- Building Community Support In India: *Indu Chaswal*

THE WORKSHOP following the conference will aim to train mainstream teachers, special needs teachers, OTs, SLPs, vocational trainers, Parents, and anyone involved in helping individuals with autism receive an education and life skills training. The training on the TEACCH approach out of North Carolina will address the need for structure in a lifespan perspective, from the classroom right up to employment and future life.
Trainer for the workshop: *Christopher Flint*

Registrations for the workshop are closed.
The ConferenceCoordinationTeam:
Email: actionforautism@gmail.com

Playing to Learn: An Introduction to the DIR/ Floortime for Families with Children with Autistic Spectrum Disorders

Talk by Dr Barbara Kalmanson

Wednesday 9 January 2008 • Time: 1 : 30 – 5 : 30 pm
Venue: The National Center for Autism

Dr Barbara Kalmanson is a psychologist and special educator who has been working in the field for 36 years. She is the founder of the Oak Hill School, a therapeutic education center for children with Autistic Spectrum and related Disorders. Dr Kalmanson and colleagues Stanley Greenspan and Serena Wieder have worked together since 1980 developing the DIR/ Floortime approach to intervention with children and families. Her publications focus on early identification of autistic characteristics in infants and toddlers, relationships as the basis of all interventions with families, DIR as a model for intervention and affective development.

The DIR (Developmental, Individual-Difference, Relationship-Based)/ Floortime approach provides a comprehensive framework for understanding and treating children challenged by autism spectrum and related disorders. It focuses on helping children master the building blocks of relating, communicating and thinking, rather than on symptoms alone.

It is a parent-centred approach that focuses on addressing emotional development, in contrast to approaches that tend to focus on cognitive development. Floortime addresses the disordered development exhibited by children with autism by attempting to teach them how to relate socially, communicate, and think. It teaches parents and carers how to interact with the child to help him learn and move up the developmental ladder, by going with the child’s interest, and building on what the child does, to encourage more interactions.

Registration: Rs 50/-

For more information please contact:
Anuradha Krishnamurthy

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Behind Sai Niketan, New Delhi-110025
Tel: +91 11 4054 0991, 4054 0992,
Email: anurakm9@gmail.com

Detail Thinking in Individuals with Autism

Talk by Hilde De Clercq

Wednesday, 5 December 2007 • Time: 1:30 pm – 4:00 pm
Venue: The National Center for Autism

Hilde, is a parent professional with a background in linguistics who is now the Director of the Centre for Training in Autism in Antwerp, Belgium. Hilde is a trainer, author, and an international associate editor of *Good Autism Practice*.. She gives workshops on subjects such as communication, the cognitive style of people with autism, high functioning persons with autism and people with Asperger Syndrome, and parent-professional collaboration.

For more information please contact:

Anuradha Krishnamurthy
at <anurakm9@gmail.com>

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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.

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Date of birth ____________

Diagnosis (if known) ____________

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