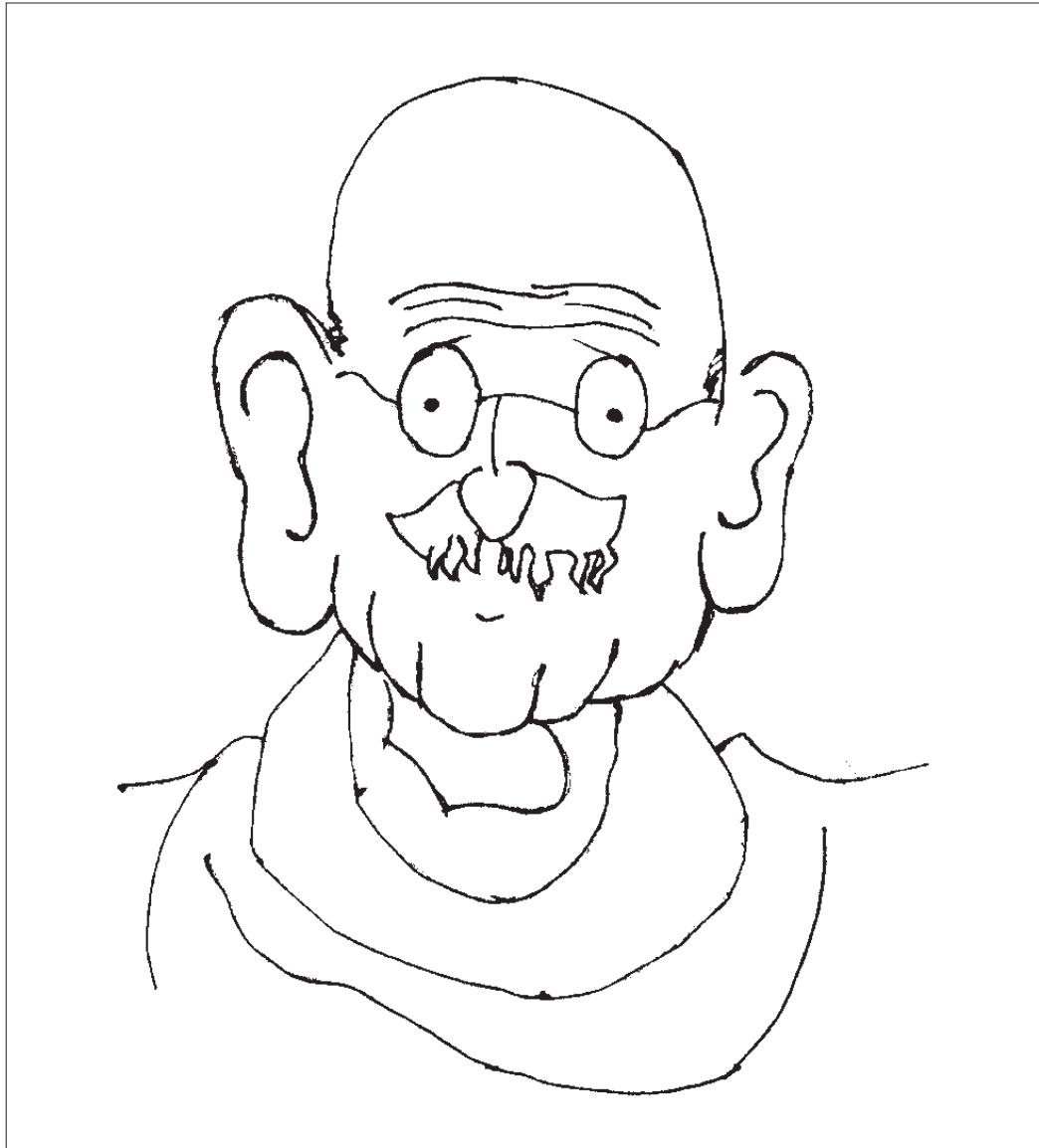
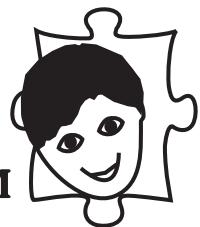


autism network

AUGUST 2010 VOL.5 ISSUE 2



ACTION FOR AUTISM



autism network

AUGUST 2010

VOL 5 ISSUE 2

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

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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'.

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Cover Illustration

Gandhi Ji
by Swastik Prabhakar, 9 years old, Karnal

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PAGE ONE

This August 2010 issue of Autism Network is somewhat unique in that every contributor to the issue is a parent to a child with autism. These are all parents who are also professionals in varied fields including special education, sociology, anthropology, and so on. And that brings a certain flavour to the issue. It is also somewhat ironic because, in our country, if you have a child with a specific need, and especially autism, then you are 'only a parent'. It does not matter if you are a nuclear physicist, or a top policy maker. Just being a parent makes your intellect, your ability, your capability in learning to be a good teacher to your child, suspect. This is the reason why the bedrock of the work that Action For Autism does is the de-mystification of professional knowledge and skills; and AFA has succeeded eminently in proving the effectiveness of this strategy through the many – not just parent support groups but – excellent services that have been set up and run by parents.

Even as we go to press, a new disability legislation that will be in synchrony with the UN Convention for the Rights of Persons with Disabilities is being drafted. It is, as it should be, an event that is marked by discussions and debate; as all of us who are members of the drafting committee, bring to the table different points of view, from different areas of various disabilities that we work in. One striking aspect that comes through at the discussions is the urgent need to increase information and understanding about autism, even amongst those members who have now added individuals with autism to the population that they work with.

While on the topic of understanding of autism, it is pertinent to mention that somehow, success and expertise with a child with autism is still erroneously measured by success in getting a child into a mainstream school. It does not matter that this success owes much to the fact that such experts only pick the more 'high functioning' child for intervention. And it does not matter that the child in the mainstream classroom is learning everything by rote. There is no understanding that the boy topping in math has no understanding of 'place value', and the girl 'excelling' in English thinks that the history lesson on 'Early Man' will be about the man who gets up early in the morning. It does not matter that the child had way more potential than what either the 'expert' or the mainstream

classroom has been able to harness; and finishes school with a degree and no interpersonal skills to navigate the social world. Just somehow putting the child in a mainstream classroom is deemed to be the sole aim of 'inclusion'. Ironically, the interest of the individual has to genuflect to the ideology.

Autism is such an individualistic condition; it is an uphill task getting this understanding across. And that is why it is important for parents to first begin to understand their child 'from the inside'. To not dismiss a child just because he or she is not able to fulfil parental academic aspirations. Let us not allow them to be poked and prodded with unproven needles and machines, have concoctions put down their throats in the hope they become 'alright'. Let us not allow them to be beaten, tied up, yelled at, threatened, locked away, and deprived of their basic needs and human dignity in the name of academic learning. To not buy into the popular perception of these 'violent' children 'who deserve no better'. To acknowledge that our children with autism have the same rights to a real education (not literacy), a right to achieve their potential, employment, and human dignity. If parents do not stand up and fight for the rights of the autistic community, then no power on earth can help our children. Let this Independence Day be a day when all of us, parents and professionals who deeply care for our children with autism, decide to take a stand for our children's rights.

Happy Independence Day!

Mark your Calendars

WORKSHOP FOR ADVANCED TRAINING IN STRUCTURED TEACHING

Action For Autism announces a five-day training programme on Setting Up Structured Teaching Classrooms by Autism ACTION, Chicago, in early December 2010.

Seats limited to 30 participants only.

More details on page 17

Autism and Cinema

Professor Stuart Murray

University of Leeds, United Kingdom

In the wake of this year's high-profile release of Karan Johar's *My Name is Khan*, with its depiction of its central character's autism in its outlining of Islamophobia in the US, it is worth remembering that the very notion that the condition might be recognised, let alone understood, on screen is still a relative novelty. Anyone regularly attending the cinema 25 years ago would not have been able to see a representation of autism, simply because knowledge of the condition was so limited that, beyond those who worked in medical or educational contexts, or had autism in the family, there were very few who knew of its existence. Disability did make it to the screen of course, especially blindness, deafness and physical disabilities, and some films – Alfred Hitchcock's *Rear Window* (1954) or Randa Haines' *Children of a Lesser God* (1986), both critically acclaimed and award winning, placed the issue of disability as a central feature of their plots. But for the most part, cognitive or learning disabilities were either absent from mainstream films entirely or, where they did exist, were present in the generalised figure of the 'backward', 'idiot' or 'retarded' character, a figure rarely given any specific detail. With such a history in mind, it should be stressed that, in Johar's film, autism is presented in a manner that assumes that its existence, and to some degree the ways in which it manifests itself, will be known to the vast majority of people who see it.

THIS is a long journey in a relatively short space of time and – as we shall see – it is one made all the more remarkable because of the central place that film itself has had in the wider acceptance of autism. At the same time, the manner in which mainstream film has depicted autism is not to be seen as a progression from unenlightened ignorance to subtle and nuanced realistic portrayal. Rather the condition has prompted filmmakers to produce what we can best understand as a peculiar form of fascination – with its difference, its problems but also its potential – that has rarely worried about either whether the version of autism on screen is true or not, or what the ethics are that surround this question. Often, looking at the history of autism on film over the last 30 years, it is more what the condition *might be* than what it really is that has commanded attention, both of

filmmakers and the public. To that extent, *My Name is Khan* sits at the end of a sequence of autism films that have varied from the sensitive to the ludicrous in their ruminations on what life with the condition entails.

BEFORE thinking about specific features or productions, it is a good idea to give some consideration to what the representation of autism on film actually involves. Unusually for a disability, autism is not always apparent visually. Where physical disabilities have obvious markers that display the difference of the disabled body, the same is not true for a condition like autism. While it is true that autism can be very visual (every parent of an autistic child will know about those moments in public when their child, overloaded perhaps with too many sensations or stimuli, will react physically) it is also the case that, for long periods, autism remains unseen, and any person with autism can, and frequently does, go unnoticed in a crowd. As a result, it is not automatically the case that the condition is one that can be easily filmed – after all, whatever the cause of autism is, whatever function of the brain is involved, it is not something that can be portrayed on screen. Ultimately then, film depictions of autism have to rely on representing *behaviour*, and this idea that the condition is best understood through thinking about its behavioural characteristics has become the norm in nearly all narrative-based accounts of anything to do with autism. In terms of film, of course, this consideration makes for an easy link with *performance*, and here we can see that the logic surrounding autism and film begins to fall into place: if autism is seemingly best understood as behaviour, and behaviour can be captured in performance, then it is the acting of autism that becomes paramount. And since we all understand that acting skill, the capabilities of the central performer, are central to any film's appeal, we can see how to 'perform autism' is often understood as a test of ability, of how 'good' an actor really is.

THERE is little doubt that the film that is responsible for all subsequent cinematic representations of autism is Barry Levinson's 1988 feature *Rain Man*, in which Dustin Hoffman played Raymond Babbit, an autistic

savant capable of prodigious calculation and memory feats. Both Levinson, as director, and screenwriter Barry Morrow wanted to make a film that displayed their understanding of 1980s greed and selfishness, and it is intriguing that they chose autism to act as a metaphor for their subject precisely because they thought that a number of its characteristics – perceived ideas about isolation, lack of emotion and difficulties with communication – worked to fit with the film’s wider themes. At the same time, Levinson and Morrow were aware that, up to the mid 1980s, films dealing with cognitive disabilities had paid little or no attention to the specifics of the condition a character might have, and so they went out of their way to consult as many autism experts as possible in order to be as faithful to medical knowledge of the time as they could. Firstly, Hoffman (who famously spent the best part of a year researching the role) based his character in no small part on real individuals with autism, the most important being Kim Peek, a figure who would go on to achieve fame of his own after the film was released; secondly, the filmmakers worked with a number of ‘Consultants on Autistic Behavior’ (as the film’s credits termed it) in trying to achieve a precision in the depiction of the condition. At a time when disability rights more widely were the subject of increased discussion, Levinson and Morrow knew that any story that simply reverted to the ‘retard’ figure of the past would be out of step with contemporary thinking.

RAIN MAN was, of course, a huge success, winning multiple Oscars and other awards and drawing particular praise for Hoffman’s performance, which both critics and the public hailed as a masterpiece by one of the greatest actors of his generation. The other major consequence of the film was the sudden attention autism received. A condition that was largely unknown before 1988 suddenly had a global platform, but what is worth remembering here is that it was a film – a cultural product – and not a medical breakthrough, piece of scientific research, or government health drive that was responsible for such exposure. Without meaning to, *Rain Man* became the foundational marker of autism for a global audience, the seeming guide to what the condition actually was.

A result of this, which persists to this day, is that the version of autism depicted in *Rain Man* became, for many, the reality of the condition. Here the central feature of controversy lay in Hoffman’s portrayal of Raymond’s savantism. Raymond’s abilities to perform

huge mathematical calculations in an instant, or to know the precise day of any given date (both skills Kim Peek had), not only lead to the film’s crucial scenes in Las Vegas, in which he and brother Charlie (Tom Cruise) are able to win considerable amounts of money, they also established what seemed to be a normal link between autism and savant skill. In the immediate period of *Rain Man*’s release, television programmes in particular scrambled to find savants who could perform similar feats, and autism became known to the public as a kind of freak show set of performances, with audiences amazed and fascinated by what seemed to be wondrous and other-worldly talents of calculation and recall. The fact that any kind of savant ability only exists in 10 percent of the autistic population, and that it is not at all typical of the condition, was lost on the majority of people. One particular consequence of this came in the fact that now, for many, autism was perceived as a condition that had a built-in compensation that worked to offset the difficulties that also came with it. Yes, the logic of this argument ran, there were clearly hardships surrounding being autistic, real problems with communication and understanding the world, but there were also amazing skills – as if autism achieved some kind of balance, with its deficiencies counterpointed by amazing abilities.

RAIN MAN also – inadvertently – established Raymond Babbit’s autism, a fiction designed to work for a character in a film, as the form of *the* condition. In 1988, before Asperger syndrome had properly been elevated to either clinical or public understanding, and before the idea of autism as a spectrum condition had been defined, it was thought by many that all those with autism were more or less alike. So, Hoffman’s portrayal of Raymond, in terms of the way he held his body, the tone of his voice, his aversion to eye contact and touch, became the template for what one might expect to find if introduced to someone who was autistic: Raymond’s behaviour was an exact version of autistic behaviour, or so it seemed. And, in addition, Hoffman’s mannerisms certainly became the guide for subsequent *performances* of those with the condition – watching Shahrukh Khan in *My Name is Khan*, it is clear to see the traces of Raymond Babbit (along with Forrest Gump, another hugely influential depiction of learning disability) in the representation of the central character of Rizwan. Khan holds his head and body as Hoffman did, and often uses his voice in a similar fashion. His performance is full of homage to Hoffman’s acting some 20 years earlier.

AUTISM had, then, gone from being an obscure medical condition, thought to be very rare, to a topic of global conversation in just a matter of months, and it had done so based on one particular narrative version of what the condition might be. That this is not ideal goes without saying and in many ways the resulting story of autism on film is a battle surrounding how to deal with these complex origins. Certainly in film industry terms, the success of *Rain Man* meant that characters with autism became far more prevalent as the 1980s turned into the 1990s, as filmmakers and production companies saw opportunities to develop the market that viewed the condition with such fascination. In Hollywood, a number of A-List films with autistic characters appeared – including *House of Cards* (1993), with Kathleen Turner, *Silent Fall* (1994), with Richard Dreyfuss, and *Mercury Rising* (1998), with Bruce Willis. In many ways, what is noticeable about these films is that they nearly always contained their depiction of autism within certain generic forms – family melodrama, detective story, and action film for the three above titles for example. Autism, it seems, worked best in film when it could be combined with something familiar and recognisable, and this is probably best understood as one way in which the difference of the condition, the threat it might pose, was negated and made safe. Audiences, so this logic runs, might be disconcerted if there is too much emphasis on the difference that comes with autism, too much focus on the ways in which those with the condition manage their lives. It is easier to place the story of autism within another, more traditional narrative, to give an audience a familiar plot with which it might identify in order to offset any fear. No filmmaker, after all, wishes to alienate an audience.

IN this sense, it is useful to understand that films depicting autism are often like those representing other forms of disability in that the narratives that inform them frequently work to stress what are thought of as positive values. Because disability is so often associated with negatives – absence, loss, lack etc. – the temptation to see a disabled life as one that requires ‘improvement’ is dominant. In terms of film narrative, this most commonly takes the form of the ‘overcoming narrative’ in which a disabled individual struggles through hardship to achieve some measure of success or ‘victory’ over their condition. More often than not, such films are sentimental, reflecting the ‘journey’ that a protagonist takes and, as genre features, they are usually melodramas. Among Hollywood’s autism films, a feature such as *House of Cards* typifies this model, with a daughter

supposedly ‘lost’ to autism somehow ‘recovering’ thanks to the force of maternal love. Another, non-autism, example might be Sanjay Leela Bhansali’s 2005 film *Black*, with its focus on the relationship between teacher and pupil and concentration on the improvement in the lives of both. Often, those with disabilities find these films misrepresentative, patronising and offensive, and point to the fact that the real audience for such features is, in fact, a non-disabled majority that wishes to see a heart-warming or life-affirming story which ultimately uses disability themes to achieve this end.

IN terms of autism, this kind of narrative is interesting, as although *Rain Man* is indeed a film that has a focus on family and contains a noticeable degree of sentiment, it is not a story that contains an overtly sentimentalised ending. At the film’s close, Charlie is unsuccessful in his attempts to have Raymond come live with him, and Raymond returns to the institution in which we first met him near the story’s opening. Especially instructive here is the knowledge that the original ending written for the film was indeed one in which the brothers were allowed to live together, but this (which we might view as an ‘orthodox’ generic ending) was rejected because it was felt it was unrealistic and contrived. The generic codes are very different in the US and India of course, but it is noticeable that, in *My Name is Khan*, the narratives surrounding romance, family and marital love are central to the film. As Rizwan makes clear, his journey to meet the President, and to make his central proclamation – “My name is Khan and I am not a terrorist” – is prompted more than anything else by his desire to win back the love of his wife Mandira (Kajol) following the traumatic death of her son. As such, for all the public nature of the film’s themes, those of religious tolerance, politics and indeed of understanding autism, it still works by appealing to a core dynamic that is, at its heart, domestic.

ARGUABLY, the representation of autism in film could now be seen to stand at a crossroads. The spate of films that, post *Rain Man*, depicted autism in such misrepresentative and offensive ways in the 1990s could no longer be made, as now too much is known about the condition for these to be effective. Recent features, including Belgium’s *Ben X* (2007) and Australia’s *The Black Balloon* (2008), show that it is possible to combine strong storylines with convincing portrayals of autism, and it is noticeable from such films that it is no longer the case that autism and savantism are linked in ways that presume such a connection is somehow ‘natural’.

It is not the business of cinema to educate of course, but it can be argued that any film that depicts disability carries with it a certain responsibility. This responsibility involves not increasing, through problematic and misguided portrayals, the prejudice and misunderstanding to which people with disabilities are often subjected. There are signs that filmmakers now understand this, and the real achievement of depicting autism in film may well be when an audience watches a film with an autistic character and is confident enough in comprehending the condition to feel that the narrative does not have to be ‘about’ autism necessarily, but rather that, as an everyday part of the world, autism can be an everyday part of

cinema too. This may seem over-optimistic to some, and there is no doubt that there is a lot more basic consciousness raising to be done, but it is now a position that is maybe in sight, and certainly this was nowhere near the case even 25 years ago.

Stuart Murray is a Professor of contemporary Literatures and Film, in the School of English, University of Leeds, U.K. He has two sons with ASD, Yann (12 years) and Lucas (11 years). Amongst his many literary works is Representing Autism: Culture Narrative, Fascination (Liverpool University Press, 2008).

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FORWARD MARCH

Chitra Raman

A week before her scheduled appearance on March 13 at a piano festival, Divya suddenly began making mistakes.

True, the piece was difficult beyond anything she had attempted thus far. It involved chords, hand movement across the piano, pedal work, and dynamic range (changes from soft to loud and the opposite). But until that point, she had been playing it beautifully.

I left a desperate phone message for her instructor Diane Stanard, explaining that Divya was making errors that no judge could miss. “What would you suggest I do?” I asked, “When I point it out it seems to get worse!”

I came home to find Diane’s response on my answering machine: “I want you to sit back and relax. Don’t put any pressure on Divya that she’s not already putting on herself.”

Now, Diane is one of the most tactful individuals I have ever known, but I’ve learned to decode. What she was really saying was this: “Back off, (s) mother!”

I knew she was right. But how, after months of hard work, could I resign myself to the possibility that Divya might perform a rockslide on the piano? How might that affect Divya?

And how had Diane been so sure, anyway, that Divya could handle this piece?

I mulled over Diane’s message, and changed my approach. Instead of snapping – “Pay attention! Focus!” – when Divya slipped, I said “Relax. Breathe. Slow down.”

Divya slowed down significantly until she recovered her accuracy. I praised her lavishly. Encouraged, she began to get back to her old speed.

The annual piano festival is organized by the Michigan Chapter of the National Federation of Music Clubs (NFMCC). Participants play two pieces from memory. A judge rates them individually on different aspects of performance and assigns an overall score.

As I stood outside the performance room listening to Divya play for the judge, I thought she had done better at home that morning. But I knew also that it is hard to clone the same sound on a different piano. It’s like getting used to an unfamiliar gas pedal. And Divya is not one for “warm-ups;” she cannot see the point of it. She just plunges headfirst into the piece, for better or worse.

Diane called later that evening with the result. She said “Are you sitting down?”

Divya had scored a perfect 100 marks.

I made unintelligible noises.

Then she said Divya also was awarded a little gold cup for getting a Superior (the highest possible) rating three years in a row. As a special gesture, Diane said she was going to engrave Divya's name on the base before presenting it to her.

That got me ...oh all right, I confess, I blubbered a little bit.

I pulled myself together and called my husband Shankar, who was out grocery shopping. Talk about a gruff, bored tone of voice changing into an eardrum-bending bellow in an instant!

That night, Divya got her trophy ice cream and also lapped up all the long-distance love flowing through the phone lines from her grandparents in Mumbai and Delhi.

But it was a temporary respite. The following week, Divya would prepare to tackle the next frontier: the State Solo & Ensemble festival on March 27.

Each year, the Michigan School Vocal Music Association (MSVMA) holds Solo & Ensemble festivals at the District and State levels. Divya qualified for State Solo & Ensemble by winning a first division rating at the District – level event in January.

For State S & E, Divya was presenting "Hark the Echoing Air" by Henry Purcell (1659 -1695) and "Flow My Tears" by John Dowland (1563-1626).

On March 27, we waited in the cafeteria at the Festival site with teacher Jodie Mellos and voice instructor Sloane Thomas. As an accommodation to Divya's autism, Sloane and Jodie were permitted to accompany her and interpret the judge's questions for her if necessary. In all other respects, Divya was subject to the same standards as her neurotypical peers.

I was worried only about the sight reading segment, in which students are required to interpret and sing a written exercise. I explained to Sloane that Divya would not ask for help if she was unsure. Rather, she would likely just blurt out her best guess based on how she had processed the judge's question.

I suggested the best way to help her would be to *direct* her attention to the sheet music and *point* to the element that the question was about. Divya's language – processing difficulties can put her anxious mind in gridlock when communication gets too word-intensive for her.

Fortified by all the moral support, Divya strode into the performance room with Jodie, Sloane and piano accompanist Richard Wolf, while Shankar and I waited in the hallway. After the faint notes from of Divya's second song subsided, I heard something that made me sit up in alarm – loud peals of laughter!

When they emerged and headed with Divya to the sight-reading room, I scurried along anxiously. I eventually managed, in a hesitant undertone, to inquire if Divya had done something inappropriate.

Sloane looked surprised. "Oh, not at all!" She and Jodie smiled at each other and took turns narrating what had happened.

Apparently the judge had really liked Divya's rendition of "Flow my Tears." She asked Divya "Are you in your school choir?" Divya said "Yes".

She then asked "Are you the Star?" Automatically, Divya responded "Yes!" Jodie added "And she's real modest about it too!" – which was what produced those peals of laughter!

After the final sight-reading gauntlet was run, the door opened and Sloane greeted me with a reassuring smile. "She did great," she said, and described what had happened.

Divya has "Perfect Pitch," which means she has the ability to sing a specific note without any auditory

prompts. This is distinguished from Relative Pitch, which is the ability to sing in key, given a starting pitch.

After Divya answered all the judge's questions about the musical notations on the sheet music that she was handed, he asked her to first "say" the notes out loud. (That is, identify them as do, re, mi, etc. after identifying the key signature as C Major, F Major, etc.). He was trying to make it easier for her to sing the exercise.

But to Divya's "literal" mind, you're supposed to *sing* the notes, not *say* them.

So she apparently went ahead and *sang* the whole thing, without waiting to get the starting pitch on the piano! When she was done, the judge looked around at the others in the room and said – "Well, I guess we're done here!"

We would find out later that Divya secured an amazing 24 marks out of 25 in this segment.

I've replayed what followed many times in my mind.

I watch the results go up on the bulletin board, room by room. I stare for a moment at Divya's column – and run back to the cafeteria. Divya sees me walking in with two thumbs up, smiles and rubs her hands in glee. Shankar looks delighted. Jodie's calm smile suggests she is not surprised.

Divya leans across the table, our foreheads touch, our arms garland each other, and we say nothing. Her eyes shining into mine are lamps of elation. She knows she's won First Division.

For Divya, this means her favorite roasted potatoes for dinner and another round of joyful exchanges with her grandparents.

For me, it represents a fitting coda to Divya's school choir experience.

Divya was excluded from Choir in elementary school. That is, she was included in choir class – but she just

stood there, not singing a note. And for months, I was never told.

The social worker finally mentioned it to me hesitantly. Perhaps she thought I'd get mad at Divya – because anyone who knew my daughter knew that she would rather sing than speak. I told her to give Divya word processed lyrics instead of sheet music. She seemed skeptical that it would make any difference, but agreed to try it out.

When I walked into her office the next day, the social worker looked awestruck and incredulous. "I put those words in Divya's hand, and she sang along beautifully!"

Despite this revelation, nothing changed. For reasons unfathomable to me – though school staff seemed kind enough – Divya continued to be denied appropriate support through middle school. I invariably ended up word processing lyrics myself so that Divya could enjoy at least limited participation in school concerts.

It was in the eighth grade that we finally worked with a choir director who believed in Divya. That year, Divya participated for the first time in two adjudicated chorale festivals and accompanied her class on a field trip to the Heritage Music Festival in Chicago, where her group won a Gold ranking.

Unlike the Indian model, children in America do not attend grades 1-12 in the same school building. Each transition – elementary to middle school and middle to high school – brings a new setting and new teaching personnel. In high school, Divya faced new challenges. Though she was strongly supported by some staff members, she had to prevail against a strong undertow of indifference, condescension, and even transparent scorn.

But you see, Divya shows me by her example that the best way to respond to negative and bigoted people is not by finding ways to return the hurt they inflict – but by making them *irrelevant*.

And *that's* the main point of this article over and above Divya's accomplishments in music.

Though it is incredibly hard to cultivate, this attitude is the vital thread linking the stories of those who have overcome. We who strive to help the person with autism transcend certain limitations must first deal with our own. We must believe in possibility, respect uniqueness ... and *take it one step at a time*. There was nothing in Divya's behavior or the feedback from school over the years that suggested she would come this far.

Perhaps that was just as well. Because if I had started at the very outset determined to *make* Divya achieve what she has, I might have ended up *making her escape* from music altogether.

People say "You must be so proud of her!" Well, yes. However, Divya also reminds me that life constantly

tests one's ability to stay on the middle path while it swings between extremes. All it takes from her – is one meltdown!

As Divya nears the end of school, we hope to find new avenues for her passionate love of music.

All I know is that even when we have no idea where we're headed, fearful of the future, and unsure of the outcome – we must never stop moving – someplace, somewhere, *anywhere* but here.

Chitra Raman lives in the Detroit metropolitan area with her husband and daughter. She is a published writer whose interests include philosophy, anthropology, astronomy, theater and music.

ACKNOWLEDGMENTS

As parents of challenged kids, we endure bleak periods when it seems no one understands us or cares enough. But that's precisely when we must look harder for people who inspire, support, nourish, and validate. They exist; but we have to find them.

Given Divya's setbacks and the questionable attitudes from certain educators, she would not be where she is today without the following individuals, whom it is my pleasure to introduce.

Diane Stanard, Piano Instructor

Diane has taught piano for some 25 years. A passionate dog lover, birdwatcher and nature enthusiast, she compares the joy of helping students achieve a performance milestone to experiencing a beautiful sunrise. The sun is the same, but the canvas is always different. When Diane entered Divya's world in October 2004, she had no prior experience in teaching persons with autism. Diane says it has been a transformative experience for her – as I know it has been for Divya.

Kelly Holst, Voice Instructor

Dr. Kelly Holst, a coloratura soprano (specializing in music requiring great vocal agility) is a professor at Adrian College, Michigan. An active performer on the concert circuit, Kelly began teaching Divya in September 2007. As a teacher, Kelly has a presence quite out of proportion to her petite frame. She intuitively understands that Divya is best helped by a "show, don't tell" instructional method. Divya has blossomed under her firm, yet encouraging approach.

Sloane Artis Thomas, Voice Instructor

Sloane is a classically trained soprano with a Master's of Music from Indiana University. Sloane relates to Divya with effervescent affection, and positive reinforcement. Having

started teaching Divya in October 2009, she will soon move on to begin PhD studies at the University of California, Santa Barbara.

Richard Wolf, Piano Accompanist

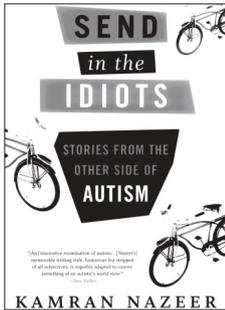
Richard is a graduate of Ball State University, Indiana. He has directed music theater productions, performed with the Detroit Concert Choir and the Meadowbrook Festival Chorus, with such noted conductors as Neeme Jarvi. Considering his accomplishments and crammed schedule, Richard has been astonishingly generous in his support of Divya. His indulgent and attentive piano accompaniment over Divya's last three years of Solo & Ensemble appearances gave her the continuity and security upon which to build her performances.

Jodie Mellos, Special Education Teacher

A teacher for the last 13 years, Jodie has a Masters in Special Education with an endorsement in Autism from Oakland University, Michigan. Jodie's hobbies include reading, researching, and inspired bursts of poetry-writing. Her commitment to helping Divya earn and maintain her spot on the school choir even when the odds seemed stacked against it – reflects personal qualities that no specialized degree can bestow.

BOOK REVIEW

By Shubhangi Vaidya



“Send in the Idiots”
 — Kamran Nazeer
 Published by Bloomsbury
 USA, New York
 (First Edition – 2006)

How does one review a book as complex and textured as Kamran Nazeer’s ‘Send in the Idiots’? Is it possible to blandly discuss themes that are so deeply moving and thought-provoking? Let me try. The book chronicles Nazeer’s search to track down his classmates from the school they attended two decades ago as preschoolers. The twist in the tale—they are all autistic, and the school a special centre working with kids on the Spectrum which eventually shut down due to lack of funds.

HE manages to connect with a few of them, and the book, essentially tells their stories. Andre, a computer engineer who uses hand puppets to convey complex, difficult emotions; Randall, a bicycle courier with a flair for writing poetry, in a potentially exploitative relationship with another man; Craig, a graduate in Law and Philosophy, who works as a political speechwriter, whose echolalic obsession with the phrase ‘send in the idiots’ gives the book its name; and the tragic Elizabeth, a gifted pianist who eventually submits to depression and ends her own life. The thread that links these individual lives is Nazeer, into whose own remarkable story we gain insights and who, contrary to the stereotype of the ‘disengaged autistic’ engages with these stories with astonishing sensitivity and empathy.

BUT this is more than a ‘class reunion’ or a typical ‘rough times to happy times’ feel good memoir. It engages with the fundamental debates regarding the autistic condition from the ‘idiot-savant’ binary understanding to the hip ‘neurodiversity movement’, from ‘refrigerator moms’ to MMR bashers. It brings home the fundamental need of autistic persons for ‘local coherence’; to block out those aspects of the world that disturb their fragile sense of order while simultaneously raising the fundamental issue of ‘bringing them in’,

helping to ‘ease’ their autism through engagement with the world, through careful teaching, training and support.

IN a remarkable passage in the epilogue, Nazeer writes: “The notion perpetrated on Andre, Craig and me has been that our minds are singular, glowing, remarkable and untouched by others. We are expected to be brilliant with figures, or computer programs or abstract ideas... And then there is a view that autistic people can’t be reached, or that they shouldn’t be, that their self-enclosure is or ought to be permanent...As Ira and Rebecca (his teachers) believed, with the evidence provided by their working lives, other people...do make a difference to autistic people... Our autism eased, in each case, because of other people, our parents, friends, and teachers of course. This realization sometimes expands in side me until I feel as if my organs are going to bruise one another.”

AND it is this “organ bruising’ realization that for me was the greatest takeaway from the book; as a parent continuously trying to make my son a part of the world, I feel vindicated and empowered.

BOOKS

It had been startling and disappointing to me to find out that story books had been written by people, that books were not natural wonders, coming of themselves like grass.

— Eudora Welty

There’s many a bestseller that could have been prevented by a good teacher.

— Flannery O’Connor

Never lend books, for no one ever returns them. The only books I have in my library are books that other folks have leant me.

— Anatole France

ऑटिज़म में बौद्धक कठिनाइयों का स्वरूप

प्रत्यक्षीकरण (PERCEPTION) %

ऑटिज़म में ऐसा पाया गया है कि व्यक्ति अनियमित और अस्थिर प्रत्यक्षीकरण अनुभव करता है। कुछ ऐसे काबिल व्यक्ति/जिन्हें ऑटिज़म है जिन्होंने अपने व्यक्तिगत अनुभव एवं अनुभूतियों का वर्णन किया है, इन्होंने अपने लेख में प्रत्यक्षीकरण संबंधित कठिनाइयाँ और सांवेदिक समायोजन की कठिनाइयाँ बतलाई हैं। तेज आने वाली संवेदनाएं कठिनाई पैदा करती हैं और व्यक्ति उनका व्यावहारिक अर्थ नहीं समझ पाते। “ध्यान” देने में और “मनोभाव” समझकर सही प्रतिक्रिया करने में कठिनाई के कारण ऑटिस्टिक व्यक्ति सामाजिक अकेलेपन का शिकार होता है और इसके फलस्वरूप संसार को समझने और सर्वांगत करने में असमर्थ रहता है।

यदि हम समझ पायें कि अति संवेदनशीलता के कारण ऑटिज़म से प्रभावित व्यक्ति अत्यधिक प्रतिक्रिया (जैसे ऊंची आवाज सुनकर डरना या कान बन्द करना या स्पर्श के प्रति अवहेलना) कर सकता है तो उसे समझने में आसानी होगी और बहुत से व्यवहार-दुर्व्यवहार नहीं लगेंगे। यह भी समझना आवश्यक होगा (सभी शिक्षकों को) कि प्रत्यक्षीकरण एक समान नहीं रहेगा। अत्यधिक से अत्यधिक स्तर पर संवेदनशीलता अलग-अलग समय पर हो सकती है। ऐसे तेज बदलने वाली संवेदनशीलता का समाधान कठिन होता है। शिक्षक को इस बात का ज्ञान आवश्यक है कि प्रेरकों (stimuli) का एकीकरण केवल कठिन ही नहीं होता, इसके लिए समय भी लगता है।

शिक्षण

बच्चों में इस प्रकार की सांवेदिक दुशक्रिया या अति संवेदनशीलता है तो उनका अधिगम परिसर और शिक्षा पद्धति धीमी या नम्र हस्तक्षेप पर निर्धारित होनी चाहिए। तेज़ रोशनी, ऊंची ध्वनि, दीवारों पर प्रदर्शनी या सजावट इत्यादि कम करने होंगे। शिक्षक को यह परिवर्तन बच्चे की प्रत्यक्षीकरण के अनुसार करने होंगे। आवश्यकता पड़ने पर अपनी आवाज को नीचा, स्वर-लाटरी को नर्म करना पड़ सकता है। यह परिवर्तन आरम्भ में करने आवश्यक हो सकते हैं और धीरे-धीरे बच्चा सामान्य वातावरण में ढल जाता है। इसे असंवेदीकरण (Desensitization) कहते हैं। इससे

बच्चे में तनाव कम होता है। वह अधिगम के प्रति अधिक ग्रहणशील होने लगता है।

यदि कठिनाई अति संवेदनशीलता की नहीं परन्तु अस्थिर और परिवर्तनशीलता की है तो उसका समाधान अलग होगा। बच्चे के लिए ऐसे सहायता साधन होने चाहिए जिन्हें आवश्यकता अनुसार बच्चा स्वयं प्रयोग में ला सके। उदाहरण— तेज या ऊंची ध्वनि महसूस होने पर कानों में कर्ण टैठी (Ear Plugs) लगा ले या अधिक रोशनी लगने पर काला चश्मा लगायें। बच्चे को प्रशिक्षण देना होगा जिससे वह अपने आसपास होनी वाली घटनाओं में सही प्रत्यक्षीकरण पर अपना नियंत्रण रख सके। सांवेदिक एकीकरण औपचारिक रूप की चिकित्सा भी होती है। जो ऑटिस्टिक व्यक्ति अधिक कौशल एवं कुशलताएं रखते हैं, उन्हें इस प्रकार के हस्तक्षेप की आवश्यकता होती है, परन्तु पढ़ाई लिखाई पर ही केन्द्रित रहकर माता-पिता एवं शिक्षक भूल जाते हैं कि यदि साथ में सेंसिरी इन्टीग्रेशन (सांवेदिक एकीकरण) भी दी जाय तो बच्चा बहुसांवेदिक प्रणाली से बेहतर सीख सकता है।

अवधान (Attention)

शिक्षक जब यह कहते हैं कि बच्चे की अवधान अवधि छोटी है तो उनका तात्पर्य यह होता है कि बच्चा दिये गये कार्य पर ध्यान केन्द्रित नहीं कर पाता। कई बार यह केवल इसलिए होता है कि क्योंकि ऑटिज़म के कारण बच्चा शिक्षक को ‘खुश करने’ के गुणों में असक्षम होता है और काम के प्रति प्रेरणा भी कम होती है। परन्तु बहुत बच्चों में अवधान की कमी यथार्थ कारण से होती है। यह भी स्पष्ट है कि ऑटिज़म से प्रभावित बच्चे ध्यान को बदलने में कठिनाई महसूस करते हैं। अवधान स्थानान्तरित करने में उन्हें अधिक समय लगता है।

एक दूसरी कठिनाई यह आती है कि अध्यापक प्रतीक्षा नहीं करेगा और अपने आदेश को पुनः अभिव्यक्त करेगा जिसमें शब्दों को भावार्थ वही होगा पर वाक्यांश बदले होंगे। इससे बच्चों में बात पुनः प्रक्रिया में लानी पड़ेगी।

ऑटिज़म साहित्य में ऐसे विवरण हैं जिनमें पता चलता है कि

ऑटिज़म से प्रभावित लोग किसी वस्तु, स्थिति या बात को संपूर्ण रूप से संपूर्ण चित्र के रूप में न समझकर, उन्हें इकाईयों में देखते व समझते हैं। यह ऑटिज़म की बौद्धिक विशिष्टता है। कई बार व्यक्ति एक समय पर दो आदेश या दो सूचनाओं या संवेदनाओं पर ध्यान दे सकता है। ऐसे में उन्हें अवज्ञाकारी कहा जाता है। उनकी कठिनाई को न समझ उन्हें 'अनुशासनहीन' या 'अवज्ञाकारी' कहना सही नहीं है।

सबसे अधिक कठिनाई जो इन बच्चों में पाई जाती है वह है 'संयुक्त या सह-अवधान' (joint attention) जो कि ऑटिज़म में पारस्परिक संबंधों में कमी का मुख्य बिन्दु है। सामाजिक, ज्ञानात्मक और संस्कृतिक बोध की नींव आपस के संबंध, संयुक्त रूप में सीखना और समझने होते हैं। यदि व्यक्ति में ऐसी अवधान क्षमता (joint learning ability) की हीनता रहती है तो वह किसी भी विचार को उसके समाजिक या सांस्कृतिक संदर्भ में नहीं समझेगा और आसपास के ऐसे विचारों पर ध्यान देगा जो महत्वपूर्ण नहीं है। वह ज्ञानेन्द्रियों द्वारा बांध, स्पर्श, स्वाद इत्यादि के ग्रहण में ध्यान और दूसरा व्यक्ति क्या कह रहा है, इस पर नहीं।

शिक्षण

शिक्षक के लिए प्रथम पाठ यह होगा कि वह बच्चे का ध्यान अर्थपूर्ण विचारों एवं संदर्भों पर केन्द्रित करवा सके। इसके लिए शिक्षक द्वारा पढ़ाये जाने वाले विषय पर से ध्यान हटाकर शिक्षक को स्वयं बच्चे द्वारा की जाने वाली क्रिया में रूचि दिखानी होगी। बच्चा जो करता है (शारीरिक क्रिया) या वह जिस विषय को पसन्द करता है, शिक्षक को उसमें सम्मिलित होना होगा। बच्चे को समय देना होगा जिससे वह ध्यान हटा सके, उसे नाम से संबोधित कर उसे कुछ ऐसी दार्शिक सहायता (visual support) देनी होगी जिसके द्वारा उसका ध्यान दर्शाये गयी वस्तु या चित्र से मिल सके। बच्चे को एक रंग का टुकड़ा (crayon) दिखाकर बोला जाये "देखो मेरे पास कलर है" जब वह देखेगा तो उसे रंग भरने के लिए प्रेरित किया जाये। बच्चे में क्योंकि सह-अवधान की कमी होती है, ऐसी शिक्षा विधि से अध्यापक और बच्चे में अवधान बन सकता है।

बच्चा अति संवेदनाओं के प्रति यही ध्यान दे रहा हो तो पढ़ाये जाने वाले सामाजिक, भावनात्मक और ज्ञानात्मक विचारों पर

ध्यान ही दे पायेगा। यदि बच्चे को कुर्सी चुभ रही हो या उसे अपने जूते, मोजे या कपड़ों का स्पर्श परेशान करेगा तो वह शिक्षक क्या बोल रहा है, इस पर ध्यान नहीं दे सकेगा। बच्चा अपने कार्य पर सही ध्यान देगा जब शिक्षक उसके भौतिक वातावरण और उसके कार्य को सरलता एवं स्पष्टता के साथ संरचित करेगा। कार्य-स्थान निर्धारित करना, उसमें ध्यान भंग करने वाली वस्तुओं को हटाना और दिये गये कार्य को दार्शिक रूप से और शब्दों की स्पष्टता से प्रस्तुत करना आवश्यक होगा। शोर को घटाने के लिए फर्श पर नर्म तक लगाई जा सकती है, दीवारों पर कम से कम प्रदर्शनी और अध्यापक की अपनी वाणी ६ मीमी और हल्की रखी जाने से अति संवेदनशीलता से राहत मिल सकती है। प्रत्येक बच्चे को ऐसी संरचना की आवश्यकता न होगी, परन्तु इसका लाभ सभी को होगा पहले ऐसा वातावरण निर्मित किया जाये और धीरे-धीरे बच्चे को एक सामान्य वातावरण में रहने के लिए तैयार किया जा सकता है। संवेदनशीलता को बच्चे के अनुसार नियंत्रित करने से हम बच्चे में उत्तेजना और दबाव को कम कर सकते हैं। इससे उनके सीखने में सहायता और सरलता मिलती है।

परन्तु समस्या कई बार संवेदनशीलता की नहीं होती। परेशानी होती है जब अस्थिर संवेदनशीलता होती है। ऐसे में वातावरण की संरचना किसी विशेष कठिनाई के आधार पर नहीं बनाई जा सकती है। अभिभावकों को और प्रभारियों को बच्चे को ऐसी विधि या साधन देने होंगे जिन्हें वह स्वयं प्रयोग कर सकता है। उदाहरण -

1. ध्वनि को नियंत्रित करने के लिए कानों के डाट (एयर प्लग)।
2. रोशनी को नियंत्रित करने के लिए काला चश्मा या टोपी।

इस प्रकार बच्चे अधिक आवाज और रोशनी से नहीं घबरायेंगे और अपने जीवन में और कार्यों पर अपना नियंत्रण महसूस करेंगे। उनके व्यवहार में सकारात्मक परिवर्तन होगा। संवेदिक एकीकरण कार्यक्रम (सेन्सरी इन्टीग्रेशन प्रोग्राम) भी लाभदायक हो सकते हैं। इनसे बच्चों को ऐसा प्रशिक्षण मिलता है जिससे वह उतनी संवेदनाएं ग्रहण करते हैं जो उनके लिए उचित होती हैं। संवेदिक हस्तक्षेप से व्यक्ति अपने स्वाभाविक वातावरण, एकेडमिक सामग्री, वाक् इत्यादि को सही ढंग से समझत है और आगे बढ़ने में प्रयोग करता है।

हमें याद रखना है कि ऑटिज़म से प्रभावित व्यक्ति को ऐसे अनुभव प्रदान करना अनिवार्य है और उन्हें अपने वातावरण को समझकर ग्रहण करने में दूसरों के मुकाबले अधिक समय लगता है।

कुछ व्यक्ति एक समय में एक ही संवेदिक सूचना या प्रेरक पर ध्यान दे पाते हैं। इस कारण वह पूर्ण स्थिति, बात या व्यक्ति का अर्थ न समझकर केवल छोटी-छोटी (कभी-कभी अनावश्यक) बातों में ध्यान केन्द्रित कर लेते हैं और वांछित कार्य हैं उसे नहीं समझ पाते। बहुत से ऑटिस्टिक व्यक्तियों का कहना है कि 'देखना' और 'सुनना' एक साथ कठिन लगता है। परन्तु यह सारी परेशानियां केवल बौद्धिक या ज्ञानात्मक ही नहीं हैं, यह प्रत्यक्षीकरण, विलम्बित विकास इत्यादि के कारण है। हम बच्चों को अनाज्ञाकारी मान लेते हैं परन्तु उनकी कठिनाईयां यथार्थ होती हैं।

अवधान समस्या का सबसे सही-प्रलेख ऑटिज़म में 'संबंधित अवधान' (ज्वाइंट अटेन्शन) होता है। यह एक केन्द्रीय परेशानी है। ऑटिज़म से प्रभावित बच्चे दूसरों के ध्यान या अवधान को समझ नहीं पाते और उनकी बातों, क्रियाओं के साथ अपने अवधान का अनुगमन नहीं कर पाते। इसी के कारण वह आदेश पालन करने में कठिनाई पाते हैं। साझा अभिदेश (शेयर्ड अटेन्शन) सीमित होने के कारण वह उन सब गुणों में क्षतिग्रस्त रहते हैं जिनकी बुनियाद आपस के निर्देशों पर आधारित होती हैं, जैसे-सामाजिक, बौद्धिक और साहित्यिक, गुणों का विकास। शायद इसी असमर्थता के कारण यह आस-पास की या करीबी संवेदनाओं पर ही ध्यान दे पाते हैं।

अवधान

जब हम कहते हैं कि बच्चे का अवधान सीमित या कम है तो इसका तात्पर्य होता है कि बच्चा शिक्षक द्वारा दिये गये कार्य पर ध्यान नहीं दे पाता या नहीं बना पाता। कई बार यह परेशानी केवल "प्रेरणा" की कमी होती है। बच्चों को कार्य की महत्ता समझ में नहीं आती और उसे शिक्षक को 'प्रसन्न' करने का सीमित बोध है परन्तु ऑटिज़म में यह कोई आवश्यक नहीं है कि इन्हीं कारण से अवधान में कमी रहती है। जब बच्चा छोटा होता है तब उसे ध्यान बनाये रखने में कठिनाई होती है। यह भी साफ है कि बच्चे कई बार किसी वस्तु, संवेदना या विषय पहलुओं पर ध्यान नहीं दे पाते। उन्हें अवधान परिवर्तित या पलटने में कठिनाई होती है। इस कारण प्रायः कक्षा में शिक्षक उनकी प्रतीक्षा

नहीं करते, अपने आदेश को या तो दोहराते रहते हैं या दूसरे शब्दों में बोलते हैं, जिससे बच्चा उलझ जाता है।

ऐसी जानकारी है कि ऑटिज़म से प्रभावित व्यक्ति किसी भी स्थिति, वस्तु व्यक्ति को आंशिक रूप में समझते हैं और एक 'ईकाई' के रूप में नहीं। निर्देश या बात को महत्व न देकर, किसी अन्य आवाज के प्रति अधिक ध्यान देने लगे। इसका अर्थ यह है कि बच्चा शिक्षक की बात पर तब भी ध्यान नहीं देगा, जब वह किसी दूसरी करीबी प्रेरणा की ओर ध्यान दे रहे होते हैं।

उदाहरण- उनके वस्त्रों का स्पर्श, जिस कुर्सी पर बैठे हैं उसका स्पर्श इत्यादि। इसी कारण बच्चे के लिए विकर्ण मुक्त (डिस्टैक्शन फ्री) वातावरण रखा जाये। कार्य करते समय बच्चे से अधिक बात करना भी इसी कारण उचित नहीं होगा। अधिक बात करना भी इसी कारण उचित नहीं होगा। कार्य की संरचना सही बनानी होगी जिससे प्रस्तुत करते हैं कि बच्चों को देखकर स्पष्ट हो जाए- क्या कार्य है, कैसे करना है, कितना है, कब अन्त होगा।

अच्छा अभ्यास यही होगा कि बच्चे का ध्यान इस तरह से आयोजित किया जाये जिससे बच्चा काम करने के और सही संदर्भ समझने के तरीकों को समझे।

स्मृति

ऑटिज़म में अक्सर पाया जाता है कि बच्चों में बहुत अच्छी रटने की स्मरणशक्ति रहती है। वह घटनाओं को विस्मयकारी ढंग से याद रख सकते होंगे, परन्तु जब किसी कहानी या घटना को यादकर और स्वयं संदर्भ में याद करने के लिए कहा जाये तो कठिनाई होती है।

उदाहरण - किसी पारिवारिक त्यौहार में कौन आया, किस रंग के कपड़े पहने इत्यादि याद होगा। पर 'मैंने क्या किया' 'कैसा लगा' इत्यादि नहीं।

वह लोगों की बातों पर, उनके व्यवहारों को सही ढंग से न समझकर केवल उनके स्पर्श, सुगन्ध, रूप, आवाज इत्यादि पर ध्यान देने लगते हैं। कई बार वस्तुओं के सही महत्व को ना समझ, केवल उनके आकार, गन्ध, बनावट इत्यादि पर ध्यान देने लगते हैं।

शिक्षण

सभी शिक्षकों को यह समझना होगा कि ध्यान का अभिप्रेत-केन्द्र अर्थपूर्ण होना चाहिए। इसके लिए बच्चा जिस क्रिया में स्वस्त है, उस पर बात का दबाव न डाला जाये कि वह शिक्षक की क्रियाओं पर ध्यान केन्द्रित करो। बच्चों को जो गतिविधियां पसन्द हैं, जो क्रियाएं वह बार-बार करना चाहता है, उन्हें करने से बच्चे के लिए सीखने में सरलता होगी। जब शिक्षक के लिए जरूरी होगा कि बच्चा उसकी ओर ध्यान दे, तब उसे देखना होगा कि सर्वप्रथम बच्चा किसी अन्य ओर ध्यान नहीं दे रहा और कभी-कभी उसे ध्यान परिवर्तित करने के लिए समय देना होगा। शिक्षक यह नहीं मान सकता है कि केवल 'मुझे देखो, मेरे हाथ में क्या है' इत्यादि कहने से बच्चा आसानी से ध्यान बना लेना।

सामाजिक एवं भावनात्मक संदर्भों को समझने में कमी के कारण आर्टिस्टिक बच्चा शिक्षक के उसके साथ उन्हें अर्थपूर्ण विधियां भी सिखानी होंगी इससे वह केवल कुछ गिने चुने संकेतों पर ही निर्भर नहीं करेंगे और उन्हें पता चलेगा कि किस बात को किस उचित और महत्वपूर्ण संदर्भ में याद रखना है।

उदाहरण – बच्चे को किसी क्रिया को करने के लिए संगीत द्वारा सिखाया जाता है। कोई भी गाना जैसे –

राजू केक बना रहा है, वाह वाह वाह

राजू अण्डा और मक्खन मिला रहा है, वाह वाह वाह

राजू ने मिक्स को अवन में डाला है, वाह वाह वाह

जब वापस घर लौटकर या कुछ देर बाद राजू को पूछा जाये, 'तुमने आज क्या बनाया' ? तब राजू को उसी गाने का घुन सुनाकर याद दिलाया जा सकता है। यह घुन ही केवल उसे 'केक' की याद दिलवा देगी।

जिस बच्चे में भाषा के बेहतर कौशल होते हैं, उन्हें हम संरचित प्रश्न सिखायेंगे। शिक्षक द्वारा प्राम्पट (संकेत) का इन्तजार न कर, बच्चे को सिखाया जाता है कि वह स्वयं इन प्रश्नों की सहायता लेकर (कब, कौन, कहां, कैसे) अपनी याद को सहारा दे और स्थिति अनुसार स्वयं सम्प्रेषण को संभाले। इससे बच्चा पूर्व हुई घटनाओं को दूसरों के साथ बांट सकता है। बच्चे को इस प्रकार का प्रशिक्षण देते समय यह भी अच्छा होगा कि हम उन्हें दूसरों के बारे में भी ऐसी जानकारी दें। इससे वह दूसरों के साथ अनुभव और जानकारी बांटते समय दूसरों के दृष्टिकोण भी बता

पायेगा और उस घटना में दूसरों की भूमिका को समझकर बाद में व्यक्त कर पायेगा।

शिक्षकों को बच्चे के स्वाभाविक वातावरण में पाये जाने वाले संकेत भी प्रयोग करने चाहिए। उदाहरण- बच्चे ने मान लीजिए एक पेंटिंग बनाई है। इस घटना की पुनः प्राप्ति (याद करने) के लिए बच्चे के हाथ पर लगे पेन्ट या जो एप्रन पहना था, वह बच्चे को उस पेंटिंग के बारे में बताने के लिए प्रयोग करना सिखाया जा सकता है। इस प्रकार के बाहरी मूर्त संकेत के स्थान पर आगे चलकर आन्तरिक संकेत बच्चे की स्मृति को जागृत करेंगे।

इस प्रकार हम देखते हैं कि आटिज़म से प्रभावित बच्चे को बातों की या यादों की पुनः प्राप्ति में कठिनाई होती है। और ऐसा नहीं है कि वह असहयोगी है और बातें बनाना नहीं चाहते। वह केवल अपने आप से संबंधित वह बातें बता पाते हैं जो उन्हें बताई गई हैं। जैसे-उनका नाम, पता इत्यादि। कई बार वह तारीख, समय इत्यादि अच्चा याद रखते हैं और दूसरे व्यक्ति के साथ भेंट या किसी अतिथि के आगमन का समय व तारीख बहुत खूब याद रख पाते हैं। ऐसा भी देखा गया है कि कुछ विशेष शब्दों को सालों बाद सुनने पर वह किसी घटना को याद करने लगते हैं जिससे वह शब्द सुने हों या किसी स्थान पर बहुत समय के बाद जाकर वहां हुई (पुरानी) घटनाओं से संबंधित प्रतिध्वनि बातें करने लगते हैं (विलम्बित इकोलेलिया)। बहुत से बच्चे तो सामान्य ज्ञान में अच्छे दिखाई देते हैं क्योंकि वह जी०के० (जनरल नालेज) की पुस्तकें रट लेते हैं।

कुछ क्रियात्मक ज्ञान में सही लगते हैं। साईकिल चलाना, कम्प्यूटर चलाना, पियानो या की-बोर्ड चलाने में अच्छे होते हैं। यह सारी गतिविधियां पूर्व निश्चित चरणों पर आधारित रहती हैं, जिन्हें वह याद रखते हैं। इसका तात्पर्य यह है कि दूसरों को उन्हें कार्य पहले सही संकेत और चरण द्वारा सिखाने होते हैं। इसके पश्चात् वह स्वयं याद कर उस क्रिया को करते हैं। परन्तु यदि प्रतिवेश या परिस्थितियां परिवर्तित हो जाएं तो वही कार्य करने में कठिनाई होंगी और व्यक्ति बहुत ही व्यथित हो सकता है। उसे कार्य कैसे करना है, समझ नहीं पायेंगे।

To be continued in the next issue...

HELPLINE



ACTION FOR AUTISM

Q My daughter's special school is part of a larger, regular school. Recently, after I had dropped her off at school, she was molested by a peon of the regular school. The campus watchman intervened and told me about the incident later. When I brought this to the notice of my daughter's school authorities, I was told that they do not have any say over the functioning and staff of the regular school. I am feeling helpless and concerned about my child's safety. What do I do? Please help.

A Sexual abuse is always a concern for most parents whether their children have special needs or not. It is one of those areas that parents feel helpless about, both in terms of prevention and intervention in the unfortunate circumstance of it occurring. As parents, it is this feeling of helplessness that one would probably need to deal with. My plea to you is that whatever else you do; please do not accept this situation, not just for the sake of your daughter's safety, but for all the other students who could be prey to a similar situation if not corrected.

Your daughter's school cannot under any circumstance claim that they do not have a say over the matter. Irrespective of whether they have a say in the management or functioning of the mainstream school that your daughter's special needs school is part of; under these circumstances they have every right to intervene! As a school they have a responsibility towards their student's safety and well being, physical, emotional, sexual, the entire gamut. To absolve themselves of this responsibility would at one level be tantamount to their aiding and abetting this incident. Learning skills and being helped to reach one's maximum potential is an important aspect of schooling, but the student's safety is paramount and is the very basis on which any parent would send their child to a school and trust them with their children's vulnerabilities.

On your end you could offer to directly approach the principal of the regular school. S/He may actually be receptive to your situation and prove to be a sensitive and concerned individual and take corrective measures. It may also be worthwhile to point out that if the peon gets away with molesting your daughter, he may not stop there. Not only may he repeat the act with your daughter, the safety of all the students will be jeopardy.

In addition to the preceding, from now onwards, whenever you drop your daughter off at school you could try to make sure that you entrust her with a teacher. Your child's safety and wellbeing is primary and as a parent you have the right and the power to insist on the same.

Further, teach your daughter to protect herself against sexual abuse using some of the strategies that are given in the next question.

Q Some months back, my friend whose daughter attends a special school told her mother that a boy who is her classmate was feeling her private parts in the school toilet. When my friend brought this up with the school authorities, she was told that this was not the first complaint about the boy and they were trying without success to alter his behaviour. My friend was advised to teach her daughter to be guarded against such exploits, which she has been attempting to do. What could the school and she do in this case?

A Thank you for sharing your friend's concerns. While teaching the young girl to guard against abuse, there are other steps that are as important. For instance, it is extremely important to change the boy's behaviour. Not only is this behaviour damaging for the young girl in question, but it can be a potentially dangerous situation for the boy himself. Following are some of the strategies that could be implemented:

1. Have the school separate the boys' and the girls' toilets, and use clear visuals to indicate the same.
2. Analyse the situation and try to arrive at an understanding of the boy's behaviour. Teach the boy that one can touch only one's own private parts and never other people's. At the same time one may also want to help the boy understand, that only he and maybe one or two primary caregivers (mother/father) can touch his private parts under specific circumstances such as bath time. A social story to address this may also be useful.
3. Make changes in the environment to ensure that there is no opportunity for the behaviour to recur. One of the things that can be done is to make sure that the boy's toilet time is always very well structured. He could be taught to follow a work system which would help him

walk through the precise steps involved during his toilet time. For example: Go to toilet; Use urinal; Wash hands; Go to class; Next activity. The work system would need to be based on the boy's functioning level. Initially the boy will have to be helped to follow the work system till it turns into a positive routine. In addition, it has to be ensured that the boy has no unsupervised contact with your friend's daughter. This would be very important in breaking the inappropriate routine that he has developed with her.

4. Teach the boy to interact appropriately with girls; play turn taking games, watch videos or listen to music together, have little scripted conversations. Praise and reinforce the boy highly for appropriate interaction. The contact time could be short to begin with and then extended slowly to ensure success. Other social skills like keeping an appropriate distance whilst interacting with people, acceptable forms of physical contact with different people etc can also be taught to the boy.

5. Finally teach the boy to take care of his own sexual needs appropriately.

It is wonderful that your friend's daughter had the communication skills to be able to tell her mother what was going on. It is extremely important for us to always keep our focus on teaching communication, in all its functions. In addition to teaching our children to understand language in all its facets, helping them express their needs, another area of focus needs to be teaching them to 'report', as was the case in this instance. This can be done in various ways. For instance, one can begin with reporting at home. Say, when the father comes back from work he could ask the child what s/he has eaten for lunch, and the mother can facilitate the answer. A diary going back and forth between home and school with salient features of activities in each environment is also useful here, where the teacher can ask the child as to what had happened at home whilst being equipped to prompt the child should the need arise and vice versa at home. In this manner we can slowly build up on the individual's repertoire of reporting skills. Needless to say, that it is thereby extremely important for our children to have a formal mode of communication that they can use, whether it is vocals or any form of augmentative and alternative mode of communication.

Our children are particularly vulnerable to abuse. Hence they need to be taught about safeguarding themselves, about relationships, about how they are supposed to

behave with different people who play different roles in their lives, what kind of behaviour to tolerate from others, what kind of physical proximity in different situations, who can be approached under different circumstances. This is an important for appropriate social behaviour as well as for their safety. Some of the specifics of this are detailed in the following:

1. We need to teach our children to maintain appropriate physical distance from others. Amongst other strategies we can teach concept of maintaining a one-arm distance by actually positioning the child at a one arm distance from others whilst interacting. We can also teach the concept of relationship boundaries by adapting from the ideas in the Circles Program (*Leslie Walker-Hirsch and Marilyn P. Champagne*) to explain what kind of behaviour/ physical proximity is appropriate with whom.

In this a dot is drawn in the middle of a big piece of paper, concentric circles surrounding it. Pictures and/ or names of different people are added to each of these circles depending on the individual's relationship with the different people. You can hang this up in your child's room and add the people (by name or picture) he knows to the different circles, depending on your child's intimacy/relationship with the different people. Using this we can explain to the child (at his individual functioning level) what kind of behavior in terms of physical proximity, conversation or other relevant issues is acceptable with people in a particular circle. As and when he meets new people, they can be added to the diagram.

The different circles starting from the centre represent:

- The private circle/ close hug circle: The circle closest to the dot represents people the child is extremely close to, such as immediate family members.
- The hug circle: This would include the extended family and best friends.
- The far away hug circle: People who are friends but not as close as one's family or best friends.
- The handshake circle: These would be people your child sees at school or people s/he works with (in case of an adult with autism).
- The wave circle: Here one would include people your child passes every day on the street in the neighborhood, but doesn't personally know.
- The stranger circle: These are people one would ignore or not give a greeting to, because one doesn't know them.

2. It would be a good idea for our youngsters to avoid inappropriate hugging and kissing as they enter their teens. A light squeeze on the shoulder can be a hug now, instead of a full bodied hug.

3. It is important for our children to learn how to respond to inappropriate physical contact. As with much else, we can simulate a situation, take the child through the steps, and practice till the skill is in place. For this, there can be a facilitator behind the child who prompts the required responses, and an 'aggressor'. The 'aggressor' can make a move to touch the individual at an inappropriate place, and immediately the facilitator can prompt the child to push the 'aggressor's' hand away with force and say a loud 'No', which our child can be taught to repeat if s/he is vocal. Slowly the facilitator can fade away the prompts until the child is able to do this independently.

Q A male therapist who has done a short six-month 'training programme', from an un-recognized institute has been talking to parents about the need of their adolescent ASD boys to have an older 'Buddy' with whom they can be close and share their fears and anxieties. The therapist offers to be this 'Buddy' on the condition that the parents allow him to interact with their child alone in a room behind closed doors, claiming that this is his method and that it is known to work in getting children who have behavioural and anger issues due to adolescence to become subdued. When this was brought to my attention, as a psychologist I am rather concerned. How do we stop such practices that can lead to abuse? What yardsticks can parents avail of when responding to such claims so as to ensure that their children are in safe hands?

A It is correct that youngsters with autism benefit from having a non-autistic individual as a 'Buddy'. 'Buddies' for autism are an increasing part of school programs, as well as individuals in their home environment. A 'Buddy' is a friend, a chum, who one can spend time with doing something both enjoy. It could be a companion with whom one can spend time having a chat, going for a walk, eating out, surfing the net, listening to music, or simply just 'hanging out'. And yes a 'Buddy' is also someone who one can share anxieties and fears with.

It is also true that there are therapists / schools/ intervention centres that have a policy whereby parents or other caregivers are not allowed to observe sessions, where work is done with the child in seclusion. The reason for this is not clear, given that most intervention strategies agree that an individual with autism learns and

progresses the best when the strategies used in all environments are the same and consistently so. All those involved in delivering services for an individual with autism - school, special educators, occupational therapists, speech therapists, 'buddies', any other, and sometimes parents - have to work as a team, follow similar approaches and be on the same page. One of the best ways for a parent to learn how to teach their child any skill is to be able to observe the experienced professional and replicate the teaching methods at other times, and especially in the natural environment. Of course, there may be some individuals with autism who may not work very well in the presence of others. In this case the decision to work with the child in a secluded environment would be post facto, after having interacted with the child and not pre determined.

However, here the young man is offering to act as a 'Buddy'. It is not clear why it should only be in a closed room with the door locked. The 'Buddy' can sit in the family living room and watch TV, have a snack at the table, sit out in the balcony and talk about the world going by, or go outdoors to kick a ball around. Adolescents with autism benefit from a 'Buddy' who can help them expend their energy in outdoor activities.

We do not want to doubt the intentions of the young man who perhaps truly believes that interacting with the youngsters behind closed doors is the only way to help. However, in terms of ethics of special education this is not an appropriate procedure. Perhaps the young man is not aware of it and would be open to being educated about it. If it is privacy that he seeks, a room with curtains drawn would work equally well.

You have asked how we can stop such practices that can lead to abuse and what are the yardsticks that parents can avail of when responding to such claims so as to ensure that their children are in safe hands. I would think that the only way out is for us to step back and ask ourselves 'Why?' Why does a therapist want to work behind closed doors? Is there any justification for the same? If we were in our child's place, were vulnerable and did not have the communication skills to report about what happened behind those doors, would we want to be in that situation? I know that as parents, we are often desperate for services. But I do not think that we are in a position of 'Beggars can't be choosers'. We need to decide for ourselves what it is that we want for our children. We need to decide whether we would want to barter our children's safety for claims (often hearsay) of miraculous

improvement. Once parents have an answer to these questions, it would probably be easier for them to be able to decide what they feel is the best course of action for their children.

As the psychologist counselling families you want to make it clear to them that the demand of the young man is unacceptable. I would imagine that you have had some concerns regarding this which is why you have chosen to write to us. Please help parents be aware that boys are as susceptible to abuse as girls. Please make it clear to families that while it would be great for their sons' to

have 'buddies', they have to guard against potentially abusive situations.

Young people with autism need, in fact crave 'buddies'. Unlike the former assumptions of people with autism not wanting social contact, we now know that most people with autism do want to have friends, it just that they do not know how to go about it. So it would be wonderful if we could find a safe way to find 'buddies' for our youngsters. In fact Action For Autism is trying to tie up with Best Buddies International (www.bestbuddies.org) to bring a programme that would facilitate this in India.

LETTERS

My son, Akshat is autistic and it was for him that I joined the January to April 2010 session of AFA's Mother Child Programme. I was very excited to have got the opportunity to train at AFA, since it is the National Centre for Autism in India. Within a few days of the training having started, I got a clearer picture on the exact nature of my son's difficulties. Though, I was working with him before attending the programme, at AFA I came to know the difference that my attitude can make towards his learning. Soon I started observing and celebrating each small gain

that my son had started making here, instead of focusing on what he could not do. I also came to know so many important and useful tools like schedules, social stories etc which are helping me a lot in keeping my son's anxiety down and helping him move towards independence.

I think it was a right and extremely timely decision to go to AFA for the training. The valuable support and friendly atmosphere which AFA provides has made me a more confident mother than ever before. I would especially like to thank Indrani Ma'm and Mrs. Merry Barua whole heartedly whose lectures have changed me totally. Thanks AFA

RITU RASSAY
BARODA (GUJARAT)

Upcoming Workshops at a Glance

We announce the much awaited 4-day series of workshops for professionals on **"Understanding and Teaching Children with Autism Spectrum Disorders"** from 27 – 30 Sept. 2010.

The UTCA Workshop is built on an understanding of ASD and works through teaching various cognitive, communication, and daily living skills.

The workshops are illustrated with practical examples based on AFA's hands-on experience and exposure to children with Autism and Asperger Syndrome of varying ages and across the spectrum. The format includes lectures, demonstration classes, video clips, question and answer sessions, and discussions.

This will be followed by a 3-day workshop for parents **"Knowing & Teaching my Child with Autism"** from 19 – 21 November 2010.

The workshop will build on an understanding of the child with ASD and work through teaching communication, play, social, daily living skills, and behaviour modification.

And mark your calendars for the **"Workshop For Advanced Training in Structured Teaching."** Action for Autism is organizing a five-day training programme on **Setting up Structured Teaching Classrooms** by Autism ACTION, Chicago, in early December 2010. Only those who have attended the two day basic workshop on Structured Teaching are eligible to participate in this workshop.

Details about the same will soon be available on our website, www.autism-india.org.

For any further information you could contact Ms. Shikha Bharadwaj (Training Coordinator, Action For Autism) at shikha.afa@gmail.com.

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

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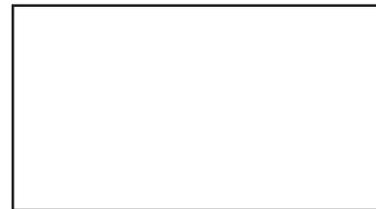
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