"autism network"

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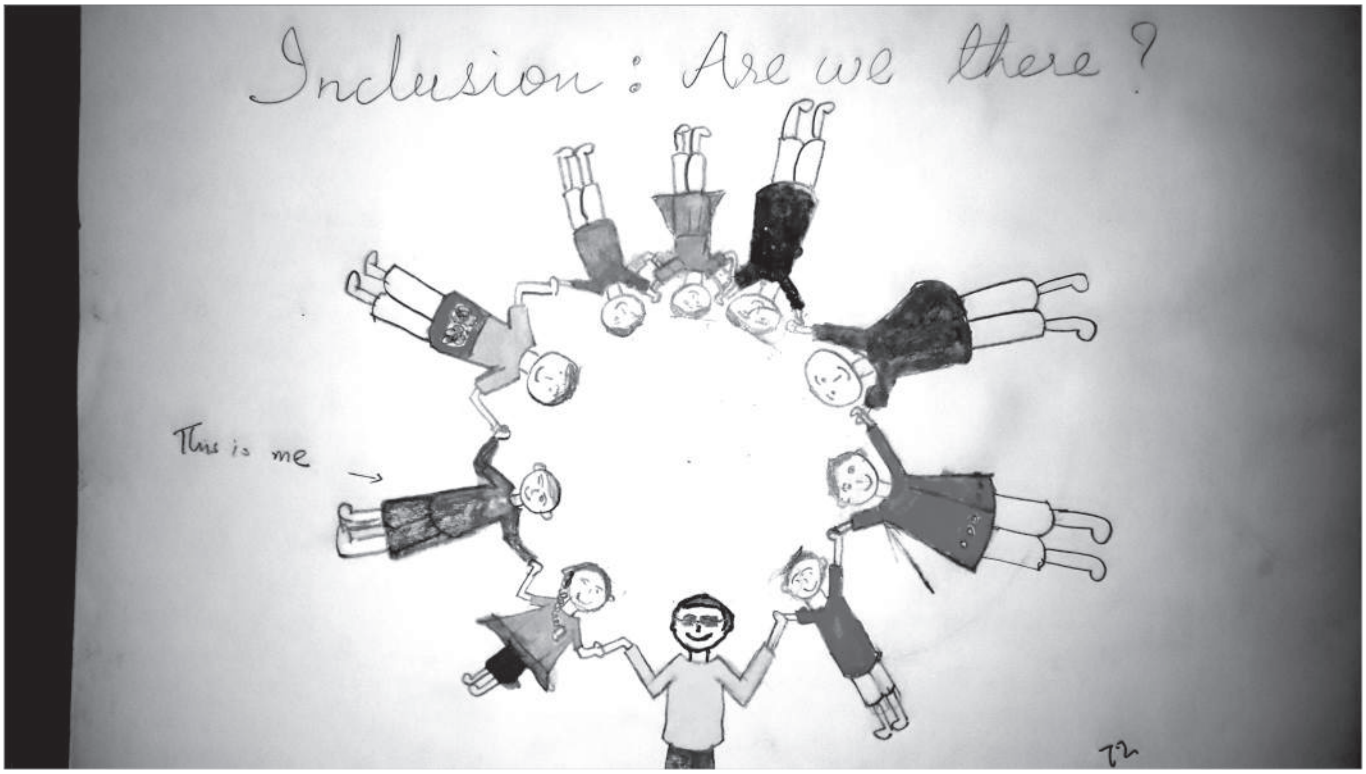

ACTION FOR AUTISM

autism network

APRIL 2014 **VOL 9 ISSUE 1**

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

Editor: Merry Barua
Associate Editor: Indrani Basu
Editorial Board: Indrani Basu, Dr Nidhi Singhal, Dr Vibha Krishnamurthy
Design & Production: Bindu Badshah, Sudhir Pillai

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

Cover Illustration

'I want to be included- Circle of friends'

By Ujjwal Sharma, 18 years old. Ujjwal lives in Gurgaon and has appeared for the NIOS SECONDARY.

WISHLIST !

- Apartment/House for Residence for people with Autism
- Playdoh, pull along toys, light and sound making toys, Lego
- Pretend play toys like: Dolls, doll house,doctor's sets, furniture sets, grooming sets, kitchen sets, tea sets etc.
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- Head phones
- Coffee vending machines
- Volunteers: For Yoga, Art & Craft, Music, Respite care

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

- AFA: 40540991/2
- Reeta: 9811103702

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

PAGE ONE

Suresh Kumar* has been running from pillar to post trying to find out how to get a disability certificate for his son Kaustav. Kaustav* will be appearing for his 10th Boards. Kaustav has motor difficulties and needs extra time to complete is papers. As a student with autism, he is entitled to the extra time. However, he has been asked to submit a disability certificate in order to avail of this entitlement. That is when they approached Action For Autism.

This is a dead end that AFA is often faced with. No government hospital (authorised to issue disability certificates) will issue one for autism. They will give one for mental retardation and might mention autism there. But Kaustav will not be eligible for a certificate for mental retardation as he 'maxes' the tests with ease. The only alternative is to plead with the authorities to allow him the extra time on the basis of a proof of diagnosis from any reputable institution or authority.

This is still a work in progress.

The situation is not much different for Gambhir*. Gambhir's family travels down to Delhi once a month or two, for a consultation at AFA. While their time at AFA is sponsored, they can ill afford the train fare for three. But without a disability certificate they have no option but to manage out of their meagre earnings.

Action For Autism India fields new queries from families every day. These range from those seeking information on services in or closest to their hometowns, sharing concerns about schooling, seeking information on accommodations that their child should rightfully have access to, requesting support with behaviours that the family had difficulty understanding and find challenging, as well as many seeking support for grievance redressal.

Another kind of query we often field is to do with a disability certificate. These are usually to do with entitlements, where the certificate can act as a passport to ensuring rights.

But, of course as most of our readers are aware, there is currently no such thing as a disability certificate for autism. Yes some have obtained disability certificates for intellectual disability. Others have not been successful in this. And still others have decided as a matter of principle to either get a disability certificate for autism or do without certification and suffer the consequences.

It is several years now that an assessment tool – the Indian Scale for Assessment of Autism - expressly for the certification of autism has been approved. But the Persons with Disabilities Act 1995 that mandates certification does not include autism in its list of disabilities. The National Trust Act which includes autism does not have anything on certification. Despite several efforts to bring about a brief amendment in the National trust things have not changed.

This is one of the very many reasons why the autism community is so strongly in support for the passing of the Rights of Persons with Disabilities Bill (RPDB). It is three years since the RPDB 2011 of which the writer was a member of the drafting committee, was finally submitted after wide consultation with stakeholders.

An important aspect of the RPDB is the inclusion of many new disabilities, Autism amongst them, that were missing in the PWD Act 1995. The drafting process of this bill to ensure people with disabilities their rights as citizens of the country, brought into focus the sharp differences of perspectives and opinions within the disability community.

With three years having already passed since the initial submission, if the bill was allowed to lapse before the elections, then a whole new process would have to start after the new government came to power. That would mean an indefinite wait especially for the newly included disabilities to access any smidgeon of rights. Keeping this in mind, through the last year, and especially towards the end of 2013 there has been a concerted campaign to pass the bill.

The 2011 bill went through two avatars and the current RPDB 2013, is undoubtedly a much-diluted version of the earlier bill. Early this year the disability sector was split right down the middle between those who felt that

(cont on page 18...)

Behavioural '*Problems*' and Autism

Merry Barua

This article is reprinted from AWARES CONFERENCE 2010

To even the most loving of carers, the individual with autism 'has a problem'. So even when helping the child with autism, the premise is that they have a 'problem' that needs to be fixed. If we want to truly help, and enable persons with autism empower themselves, the journey has to perhaps start with trying to understand autism; and more importantly by changing the way we view people with the condition. This paper expands on why we need to move from the perspective of viewing individuals with autism as people with problems; to seeing them as people with a valid way of being.

AUTISM is one of the most complex conditions for us to understand. By 'us' I refer to those of us who do not have autism – the non-autistic population. Of course to those who have autism, their condition is something that is neither complex nor strange – it is what it is. Autism, for those who have the condition is just a 'way of being'. Just like being Indian is 'my way of being'. If I went to live in the Netherlands, I might have a home like most of the native people there, I might dress just like them, I might even eat the same foods they eat. But my sensibilities will remain uniquely Indian. So will my responses to many situations. For instance, having my 30 year old autistic son living at home with me will seem perfectly okay to my Indian sensibilities. But to a native of the Netherlands it will seem odd that someone beyond the age of 20 still lives with his mother. My wanting to cook the occasional dal and rice will not be the novelty that it will be in their homes. Neither will my wanting to 'prepone' a visit to India. Only Indians 'prepone' as we all know! And no amount of dressing 'Dutch' is going to take the 'Indianness' out of me.

WHY am I starting my piece with this introduction? Because I want to, at the start, establish a few things. One, autism is not a 'problem'; it is a 'way of being'. It is a condition that people have. Just because someone wants to view autism, or any other condition, as a problem, does not make them so. Just as my being Indian in the Netherlands or Australia does not make being Indian a problem. Two, being autistic is not a tragic situation. I deliberately use the term 'autistic' here. Being autistic defines the person. People with autism are fine with being called 'autistic'. They don't care what you call them. What matters is what our feelings are behind whatever we call them. We may say "persons with autism" and think "goodness, what a sad tragic weird guy!" and we may say "autistic" and have no negative notions about the condition. So the terminology does not matter. What matters is what is in my mind.

WHEN a professional acquaintance suggested initiating a discussion on 'Behavioural Problems and Autism', I thought this was exactly what we need to address. Everyone working with people with autism, whether caring professionals, or loving parents, we all tend to see behaviours in people with autism as 'problems'. And then we all end up creating more 'problem behaviours' in order to deal with the 'problems' we want to get rid of in the first place! Instead, the education of children with autism needs to shift its focus towards not just 'treating' autism, but rather towards an effort to understand autism, to understand the culture of autism, and what life experiences are like for a person who is on the spectrum.

WORKSHOPS that address behaviours that the non-autistic world perceives as challenging, usually start with a segment on 'understanding autism'. But most of us skip that session because we all feel that we know what autism is. What we actually do know is the clinical definition of autism: that it is a 'social communication impairment that is pervasive, with repetitive actions and behaviours'. Actually that tells us very little about autism, and mostly a deficit-oriented point of view. It does not help us understand the person behind the definition. It does not help us see that the autistic person's communication as 'different' from non-autistic communication, or the very unique and distinct understanding of the social rules of the neurotypical world.

AS a result when we start from the very clinical and deficit oriented understanding, then we start off from viewing the autistic worldview as not valid.

SO when we see a child flapping and jumping, our first desire is to somehow 'stop that behaviour' because it is embarrassing for 'us'. We do not see it as valid for the person with autism; as perhaps the child's way of coping with a new situation. Or maybe an expression of happiness. Or perhaps a bodily need that the child is fulfilling. Or any other of a range of reasons.

SO some of us 'punish' that 'unwanted behaviour' of jumping to make it go away. Or look for biological reasons for that behaviour and dive into diets and medication in order to get rid of the behaviour. It does not occur to us that there could be validity in the child's behaviour. That we need to understand autism, the child, and thereafter the behaviour. Our focus remains firmly on the behaviour that makes us, the non-autistic uncomfortable. Rarely do we consider what it means for the person with autism.

If we want to help our children with autism, we have to start by first understanding their world.

WHAT we perceive as behaviour problems are most often an effort to communicate different emotions, feelings and wants. So the child jumping and flapping could at different times have any one, or a combination of the reasons stated above. Let us explore a few typical scenarios.

SHEILA is waiting for her mother to pick her up. Her mother usually comes in at 1:00 pm; its 2:00 pm already. No one has told Sheila that her mother will be late today. Her teacher has mentioned it in passing, but too swiftly for Sheila to retain that piece of information in her mind. No visual instruction has been given – and we all know that people with autism thrive in visual environments. So now Sheila is a little stressed. Mother has not come in yet. It's long past the time she comes in. When is she coming? Will she come at all? And in order to cope with this disordered world Sheila does the only thing she knows, she jumps and flaps vigourously. (Some of us in a similar situation would have lit up a cigarette; bitten our nails; walked up and down; all considered 'accepted' behaviour in the non-autistic world).

RATNESH has made great efforts to sit quietly in class all day. Now his body feels numb and out of synch. Its break-time and he needs to unwind. The only way he knows how is by either sitting on a swing, or rocking and flapping. The swing is not available, so he does the latter.

TEACHER is saying: "Tarun get your snack and sit down". Tarun opens his bag but today the blue box with his snack is not there. He is distressed and is flapping to get someone to address this issue. Instead his teacher keeps saying: "Tarun stop acting stupid. Behave your age." Tarun gets more and more distressed, flapping and jumping with greater vigour. (If Tarun's younger brother Raskhit were in the same situation he would have said: "Teacher my snack box is not in my bag. I think someone may have taken it out". But then, Rakshit does not have autism. Tarun does).

WHAT was the response of the non-autistic world in these situations?

SHEILA has been told: "If you don't sit still you will not go home when mother comes." Just the response that would get Sheila more stressed and flap with greater vigour!

RATNESH who has controlled his desire to rock right through the morning has then been told not to do so in his free time as well, as "it is not smart": Without the release this gives him, he would be more wont to rocking and flapping when class resumes after break; and as on earlier occasions will probably then be sent out of class for 'disturbing' the others.

TARUN has been told: "Okay you don't want your snack. Then come and sit down." In frustration he whacks the boy next to him, ensuring that he had a bigger 'problem behaviour' because of course he DID want his snack.

AM I then saying: let our kids rock and flap all day long? (Well, if they are not harming anyone by doing so - except our egos! - then why not)! But no, that is not what I am suggesting. What I am saying is to try and understand what they are doing and why, and providing them with answers, alternatives, explanations, strategies, anything in short, that would enable us – the autistic and the non autistic - to meet each other half way.

THE only way to help children with autism who have so-called behaviour problems is by understanding them, teaching them how to communicate with our world, helping them learn to negotiate our social world, and being what I can only term cross-cultural interpreters.

I can think of no better way to end this than to narrate a small incident.

LAST week when Jatin finished his chores, as a special treat Mira said to him: "Let's go for an ice cream." Usually they buy their ice-cream when they visit their neighbourhood market. Today, since they are home, Mira leads the way to the ice-cream vendor on the main road, which is in the opposite direction from the market.

Jatin is confused. He wonders: Why are we taking the road we take when we go to school? Mama had said we will get an ice cream. But now we are going to school! A non-autistic individual in his situation would have queried: "Why are we going to school?" Or, "Are we not going to have an ice-cream?" Or any number of variations. Jatin communicates with phrase speech. But he is still not asking these questions. Instead he is stressing about what seems to him a change in plan.

MIRA senses his confusion and says, "We go this way to school. Are you wondering where we are going now? You could ask, 'Where are we going'?"

JATIN gives a quick sideways look at his mother and repeats, "Where are we going?"

MIRA explains, "We are going for an ice-cream. We will get the ice-cream from the ice-cream vendor on the main road."

NOW Jatin's smile is back.

In another scenario Jatin might have got confused, and then distressed, that instead of the promised ice-cream he was going to school. The distress left unaddressed, in his frustration the six-foot-two youngster might have pushed – something he tended to do when confused and / or frustrated. And depending on the way Mira handled that, the whole situation could have spiralled out of control.

THAT none of this happened was only because Mira respected and acknowledged her son's autism and his different understanding of her world; and acted as a cross-cultural interpreter.

SO what am I saying? I am saying that the norm is to expect the person with autism to understand our world and 'act non-autistic' so that we who do not have autism can feel comfortable. If they cannot, then we label them as having 'behavioural problems'. We, who teach children with autism, we know our world, the world of the non-autistic.

WE can also make the effort to learn to understand the autistic world. With our understanding of both worlds, we can help persons with autism navigate the complex social world that we inhabit.

The Rights of Persons With Disabilities Bill, 2014: An Opportunity Lost for the Autism Sector?

Shubhangi Vaidya

We have to educate ourselves about the issues that concern our children's rights and entitlements. Until such time as our children are able to lobby for themselves, we, their families must stand united and try to secure for our children their rightful place in the sun.

31ST December 2013 was a cold evening, at the peak of Delhi's winter. Undaunted by the chill, a large gathering of people with a range of disabilities assembled at the JantarMantar to demand the passage in Parliament of the Rights of Persons with Disabilities Bill which had just been approved by the Cabinet. Similar demonstrations were taking place all over the country.The Bill was the result of years of consultations and discussions across the disability sector and was seen as a major moment in India's disability rights movement.

THE Bill was intended to replace the existent Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995(PWD Act) whose most crucial provisions pertain to rights to education, employment, rehabilitation and reservations for persons with seven identified disabilities including blindness, low vision, leprosy, hearing impairment, locomotor disability, mental retardation and mental illness. Persons certified by a medical authority as having at least forty percent of a given disability are eligible for benefits, and the 'Disability Certificate' is a crucial document that opens the doors to access, opportunities and inclusion.

AUTISM is not included in the PWD Act; it is one of the four conditions along with mental retardation, cerebral palsy and multiple disabilities that come under the purview of the National Trust Act of 1999,which is basically concerned with issues of guardianship and protection to persons with high support needs. Over the years, it became apparent that the PWD Act, a landmark legislation for its time, had a number of gaps and failed to include many disability categories. However, attempts to introduce amendments met with little success.

ONE of the major international developments that had a great impact on disability rights and legislation all over the world including India was the adoption of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) by the UN General assembly in December 2006. India ratified the UNCRPD on 1 October 2007. The UNCRPD is a human rights instrument which aims to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities.

AS such, it is to function as the guiding principle on the basis of which signatory countries are expected to structure their laws, programmes and policies for persons with disabilities. In order to harmonize the existing disability legislation in the country with the UNCRPD it was decided to draft a new, comprehensive disability law rather than merely amend the existing one.

ONE of the important points to bear in mind is that the global disability discourse has moved from the 'medical model' to the 'social model'. While the medical model views disability as an individual problem or deficit that is defined in terms of what is 'wrong' or 'lacking' in an individual's mind or body, the social model views disability as the product of social practices which exclude and isolate people with 'impairments'. In other words, disability is socially produced. For instance, a person with 'impaired' limbs is disabled by society because she/he cannot use public spaces and facilities which are made only with 'able-bodied' people in mind. So the onus on integrating persons with disability into the mainstream falls on society. It is this fundamental philosophy of the social model that is reflected in the UNCRPD. It was expected that the new law would reflect this understanding of disability and focus on disabling environments rather than just medical measurements and diagnoses of disability.

THE Ministry of Social Justice and Empowerment constituted a committee comprising stake-holders across the disability sector to draft a new Bill in compliance with the UNCRPD. The Centre for Disability Studies, NALSAR Law University, Hyderabad, compiled a Draft Rights of Persons with Disabilities Bill in June 2011.However, it drew a great deal of criticism from many quarters. It was subsequently replaced by the draft Rights of Persons with Disabilities Bill 2012, which was by and large acceptable to most of the stake-holders in the disability sector.

IT was believed that the Draft Rights of Persons with Disabilities Bill 2013 approved by the Cabinet would be substantially similar. However, when a copy of the draft appeared in the public domain, it became apparent that it was a considerably watered down version, with a number of provisions that were unacceptable to the disability sector as a whole. The sector which had lobbied in unison in December 2013 was split down the middle. One section argued that the RPD Bill 2013 was in total violation of the letter and spirit of the UNCRPD and a betrayal of the aspirations and hopes of the disabled community; another section felt that it could be salvaged by including a list of 'non-negotiable' amendments and that it should be passed in the forthcoming session of Parliament which would be the last one of the present government.

THE stakeholders in the 'developmental disabilities sector' which included the autism sector, by and large supported the second viewpoint as the Bill was far more inclusive in its scope than the PWD Act and included a number of hitherto neglected disabilities including autism. They agreed that it was by no means a perfect Bill, but lobbied hard in its favour, because so much time had been spent in bringing it to this critical stage. A national election was round the corner, and disability, always a marginalized issue in the public realm, would once again disappear from the public radar and those unrecognized disabilities which were on the verge of finding inclusion in a rights based legislation would be out in the cold.

AS matters panned out, the Bill was not passed in its present form in Parliament and was referred to a Standing Committee. Multiple controversies and acrimonious debates between senior activists and leaders of disabled people's organizations, vociferous protests and *dharnas* for and against the passage of the Bill exposed the sharp cleavages within the sector.

SOME of the contentious issues in the Bill include the clause that says, "no one can be discriminated on the basis of disability..unless..it is a proportionate means of achieving a legitimate aim". Activists argue that this clause can be misused to discriminate against persons with disability as it is not clear what these 'legitimate aims' actually are.

THE clauses related to legal capacity and guardianship in particular have led to serious differences of opinion, with the autism sector arguing that adequate measures must be in place to ensure support and guardianship. A balanced and nuanced view on the subject is critical as there are people who will always need a high degree of care and support and for whom ‘full legal capacity’ means little or nothing.

THERE are also debates on the issue of reproductive rights. There is a sub clause in the Penalties and Offences section of the Bill which states that anyone performing a medical procedure to terminate the pregnancy of a disabled woman against her consent will be punished except in severe cases of disability. Activists argue that this can be misused as it does not specify what is ‘severe disability’ and therefore, all disabled women potentially stand to lose their reproductive rights (see AmbaSalelkar’s article ‘No Piecemeal Change Can Fix Our Terrible Disability Bill’, Grist Media, dated 4th February 2014 at http://in.news.yahoo.com/no-piecemeal...).

ACTIVISTS are also very disappointed that the Bill does not state that the Chairpersons of Disability Commissions must compulsorily be persons with disability. If the National and State Commissions for Women, for example, are headed by women, why is disability treated differently? This is certainly a valid question.

WITH regard to reservation of posts for employment, the Bill says that posts would be identified in establishments for different categories of disability, which will lead to ‘ghettoizing’’ (to use Amba Salelkar’s term) them in certain kinds of jobs and not enabling them take up work of their choice by making reasonable accommodations. The entire Bill, it is argued smacks of a ‘welfarist’ approach in which the Government is doling out charity rather than ensuring empowerment and rights.

WHILE these objections certainly merit serious attention, there is no doubt that the Bill also includes many progressive and positive aspects. A group of cross-disability activists (Rama Chari and others) in a document titled “Why are we in favour of passing The Rights of Persons With Disabilities (RPD) Bill?” (http://deoc.in/pwdbill.pdf dated 19th February, 2014) persuasively argued for the passage of the Bill while simultaneously highlighting the work that needs to be done regarding its contentious points. Amongst the positives is the inclusion of nineteen disabilities in its ambit with the provision for including more in future. Reservations in educational institutions and in Government jobs are raised from 3 % to 5% thus widening the net of beneficiaries.

THE Bill mandates governments to take special measures to protect the rights of women and children with disabilities; it provides rights equally with others to own or inherit property and widens the ambit of social security schemes and the quantum of assistance that can be provided. Despite these positive features and the real urgency expressed by a section of the stake-holders, the Bill could not be passed.

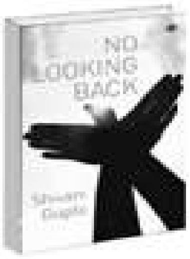
THE events of the past few months have highlighted the need for stake-holders in the autism sector to be aware of and conversant with the on-going debates and engage actively with them. As the caregivers of persons with complex disabilities, we are naturally just too busy with our routines and managing from one day to the next. However, we also have another major duty as activists and advocates for our children.

WE have to educate ourselves about the issues that concern our children’s rights and entitlements and make our voices heard as loudly and clearly as those of the vocal self-advocates who are able to articulate their concerns and issues and get policy makers to listen to their voices. Until such time as our children are able to lobby for themselves, we, their families must stand united and try to secure for our children their rightful place in the sun.

BOOK REVIEW

'No Looking Back'
by Shivani Gupta

Rupa Pages 272 Price: Rs 295



Triumph over Tragedy...

Reviewed by Shubhangi Vaidya

What do you say about a 22-year-old girl whose spine is shattered in a car crash? That her life is over before it has even begun? That she will lead a life of dependence and misery and become a 'burden' on her family? That she will be seen as a deficient, unattractive being who can never hope for romance, love and conjugality?

SHIVANI Gupta's autobiographical account challenges these deeply entrenched cultural stereotypes about people with disability. The author takes us through the trauma after the accident that found her flat on her back, paralysed, and the harrowing experiences of the public hospital where she spent weeks staring at the dingy ceiling, inhaling the overpowering odour of disinfectant and hearing the moans of fellow patients. Shivani chronicles her 'rebirth' as a wheelchair user and takes us through the everyday realities of her new life — personal appearance, clothing, body image, dependence upon a personal attendant, bowel and bladder control, going out and shopping , re-negotiating personal relationships — with compelling candour.

HER narrative highlights the transient, fragile nature of the bodies we inhabit and the way society and culture 'disable' people far more than their impairments do. Converting adversity into opportunity, Shivani embarks upon a career in rehabilitation and counseling at the newly established Indian Spinal Injuries Centre. An opportunity to visit and train in the UK empowers. There is a realisation that people with disabilities do not have to live life on the margins and that society must be responsive to their needs.

BACK home, she learns how to live independently, away from the protective and sometimes overpowering embrace of her family. She makes new friends, and meets the man who is to become her 'best friend, lover, comrade and guide', Vikas Sharma. As opposites are wont to, the two are attracted to each other; as professional colleagues they strengthen each other's hands and go on to do path-breaking work together in the areas of accessibility and inclusive environments.

THEIR partnership, working, studying, travelling, 'learning to fly' — results in the formation of **AccessAbility**, a venture that seeks to 'change the world' and make it fit for persons with disability, and not the other way around. In their personal lives too, a major breakthrough takes place; their families accept their relationship and they marry.

SHIVANI'S reflections on the dynamics of becoming an Indian daughter-in-law and her identity as a woman with disability are poignant. She narrates how she is carried up a flight of stairs to meet her in-laws in their apartment and sits awkwardly in the drawing room as the men have their Scotch and the womenfolk bustle around in the kitchen preparing and serving food!

FOUR months after the wedding, on their way to Manali, Shivani and her family find themselves in another terrible road accident in which Vikas and his father lose their lives. Shivani's account of the days that follow is moving. Her experience of the frailty of the corporeal body carries over to her understanding of loss, sorrow and pain, which are an inescapable part of the human condition. She seeks solace in the knowledge that she was blessed with love that was reciprocated in ample measure, whose intensity she is now able to fully appreciate.

THE callousness of the medical system, the daily indignities of being a person with disability in India, the role of family and friends and the healing power of love. It is a must read.

Courtesy: The Tribune

हाई फंक्शनिंग ऑटिस्म की देखभाल

सामान्य द्रिस्कोल

शाज़ीया फातिमा

Contiued from the December 2013 Issue of Autism Network

जुनून (obsession)
स्पेक्ट्रम पर व्यक्तियों को आमतौर से एक विशेष वस्तु या विषय के साथ जुनून या आग्रह सा हो जाता है। इस वजह से इसे इनकी विशेष रूचि के रूप में देखा जाता है। तो यह चुनौती कैसे है ? सरल है आप अपने बच्चे के साथ घर आते हैं, वो आप से 30 विभिन्न चीजों के बारे में बात करता है। वे अपने दिन के बारे में, अपने दोस्तों के बारे में और अपने सामाजिक नाटक (social dramas) के बारे में बात करता है। मगर जब आपका बच्चा हाई फंक्शनिंग है तो ऐसा नहीं होगा तब आप सिर्फ एक ही चीज़ के बारे में सुनेंगे। यह इनकी बातचीत पर 99 प्रतिशत हावी होगा। आपको एक ही हफ्ते/सप्ताह के भीतर सब पता चल जायेगा, जितना भी वे उस विषय के बारे में जानते होंगे।

वे हर चीज़ का बहिष्कार करेंगे उस एक रूचि के लिए। उनकी रूचि एक शो या फिल्म भी हो सकती है जिसे वे बार–बार देखेंगे। चाहे कुछ भी हो मगर फिर भी आपको बैठना, मुस्कुराना पड़ेगा और बार–बार उनकी बातों को सुनना भी होगा। ये कोई बुरी बात नहीं है, वे बहुत समझदार हैं और इस तरह वो खुद को अभिव्यक्त करने की कोशिश करते हैं, आपके सामने। संचार (communication) खुला रखने के लिए आप सुन सकते हैं और आप खुद भी अपनी कुछ खोज (research) करके उनसे बांट (share) सकते हैं। ये एक रिश्ता कायम करने में सहायक होगा। इसका ध्यान रखें कि आप उनको जो जानकारी दे रहे हैं उसे वे किसी प्रकार का व्याख्यान (lecture) न समझें।

महत्वपूर्ण है कि आप कोशिश करें कि एक बातचीत हो जिसमें वे और आप दोनों ही पूर्ण तरीके से भाग लें। दोषी न महसूस करें (don't be offended) अपनी रूचियों को बाहर लाना भी उनके लिए अपने आप में बहुत बड़ा कार्य है। जिसमें अक्सर उन्हें दिक्कत आती है।

संचार (commnication)
सिर्फ इसलिए कि वे हाई फंक्शनिंग हैं, ये नहीं कहा जा सकता है कि उन्हें संचार में कोई दिक्कत का सामना नहीं करना पड़ेगा। ये भी शरीर की भाषा नहीं पढ़ सकते हैं। ये व्यक्ति से व्यक्ति पे निर्भर करता है कि वो कितना समझ सकता है। कई बार इनके चेहरे पर कोई भाव ही नहीं उभरते हैं या अगर भाव आते भी है तो वे बहुत कम होते हैं। अक्सर उनकी शरीर की भाषा और वे जो वास्तव में महसूस कर रहे हैं वो आपस में मेल नहीं खाता है।

उदाहरण के लिए जब भी वह किसी उलझन में होता है, निराश हैं या परेशान है तब वो हँसता है। कई बार वे अपनी स्वयं की आवाज को नियंत्रण में नहीं कर पाते, कभी बहुत अधिक या बहुत कम हो जाती है। स्वर और टोन पर कोई नियंत्रण नहीं हो पाता। कुछ भी उनके वास्तविक मूड़ या भावनाओं को प्रतिबिंब नहीं करता है। वे बहुत कठोर लग सकते हैं, जब वे बहुत अच्छे मूड़ में है। दूसरा मुद्दा है कि ये भावनाओं को समझते दूसरी तरह से हैं और दिखाते दूसरी तरह से हैं। ये कारण हो सकता है कि आप सोचें कि वे भावनाहीन है जो कि सच्चाई से कहीं दूर की बात है। आटिस्टिक वयस्क (adult) या बच्चों को अक्सर शब्दिक विचाराको की अभिव्यक्ति को समझने में परेशानी होती है।

मगर जैसे जैसे वे बड़े होते हैं इसे सीख लेते हैं। इससे ये भी मतलब है, कि जरूरत है कि आप अपने निर्देष (instructions) में स्पष्ट हो। उदाहरण जैसे आपने कहा कार से उतरो तो वो उतर जायेगा या कहा की दरवाजा बन्द करो तो वो

बगैर उतरे ही कार का दरवाजा बंद कर लेगा। इसकी जगह आपको कहना है, ''कार से नीचे उतर कर दरवाजा बंद करो।''

तब वह आपकी पूरी बात समझ कर, वह पूरा काम करेगा, जैसा आपने उसे निर्देश दिया है। वे आपकी बात को फिल्टर नहीं कर सकते हैं। वह सरल सी ईमानदार प्रतिक्रिया दे देगा, जो भी उसे निर्देश मिलेगा। इसका मतलब है कि वे अशाब्दिक संकेत और शरीर की भाषा पढ़ने या समझने में असमर्थ है। यही कारण है कि वे नहीं बता पाते कि कोई झूठ बोल रहा है या धोखा दे रहा है क्योंकि वे समझ नहीं पाते हैं। यह भी सुरक्षा का विषय है। अक्सर संवाद स्थापित करने में इन्हें मुश्किल होती है और मेल्टडाऑन के कारण ये खुद को संभाल नहीं पाते जो इन्हें गंभीर संकट की तरफ ले जाती है, जैसे कि इस दौरान अमौखिक हो जाना। मेल्टडाउन का कारण संचार भी हो सकता है। यह फिर से एक और सुरक्षा में चिंता का विषय बन जाता है।

आयु उपयुक्त हितों या अभाव क्या है (age appropriate interests or lack there of)

कई हाई फंक्शनिंग ऑटिस्टिक अपने स्वयं के आयु समूह से संबंधित नहीं होते हैं। कई बच्चों को बड़ों या वयस्कों की कम्पनी या साथ पसन्द होता है। और कई लोगों को आप देखेंगे कि वे छोटे बच्चों की चिजों में खुश होते हैं। इनमें से कई की रूचि अभी भी किसी विशेष प्रकार के खिलौने खरीदने में होती है। उनको अपनी उम्र से कम या ज्यादा बड़े शो देखने पसन्द हो सकते हैं। वो अपनी उम्र के हिसाब से रूचियों में शायद रूचि न दिखाये। उदाहरण– एक 20 वर्ष के व्यक्ति को भी आप बहुत खुश पा सकते हैं जब उन्हें खिलौने या किताबें मिलती हैं उपहार (gift) के रूप में, जो उनके लिए बहुत मनपसंद वस्तु है।

नींद (sleep)

काफी व्यक्तियों को नींद में परेशानी होती है। वे रात को देर तक जागते हैं और अक्सर कुछ ही घंटों में उठ जाते हैं। एक अन्य आम समस्या है कि वे रात के बीच में कई बार उठ जायेंगे। अक्सर पर्याप्त नींद की कमी के कारण मेल्टडाऑन की संभावना बढ़ जाती है और वे आसानी से निराश हो जाते हैं। यह भी माता पिता की चिन्ता का कारण है। इसका ये भी मतलब हो सकता है कि उनकी नींद कम हो। रात में जागना भी एक सुरक्षा में चिंता का विषय है, उदाहरण–जैसे रात में वे निर्णय करते हैं कि कुछ खाना पकाया जाये और शायद वो कुछ पकाने की कोशिश करें जिसके दौरान उन्हें फिर से नींद आ गई तो ये चिंता का विषय बन जाता है।

आहार (diet)

स्पेक्ट्रम पर कई व्यक्तियों का बहुत सीमित आहार है और उनके भोजन के समय के आसपास एक विशिष्ट दिनचर्या होती है। वे केवल एक निश्चित दिन पर एक निश्चित पक्ष के साथ कुछ खाद्य पदार्थ (खाना) खा सकते हैं। वे केवल एक या दो प्रकार का ही खाद्य पदार्थ हर भोजन के लिए या हर समय खाने के लिए चाह सकते हैं। अक्सर इन्हें कोई मसाला या मिर्चे या किसी खास प्रकार का खाना नहीं पसन्द हो सकता है। उन्हें एक नरम आहार की आवश्यकता हो सकती है। स्पेक्ट्रम पर व्यक्तियों के एक बड़े हिस्से (सभी नहीं) के साथ पाचन प्रणाली मुद्दों के कारण उन्हें एक विशेष लस–मुक्त कैसिइन प्री आहार लेने की आवश्यकता हो सकती है। लेकिन कई बार ऑटिस्टिक बच्चों को डाइट या किसी विशेष प्रकार के खाद्य पदार्थों पर डालना मुश्किल होता है। और इसके लिए काफी संघर्ष करना पड़ सकता है। क्योंकि वो अपने भोजन में कोई भी नये खाद्य पदार्थ को लेना पसन्द नहीं करते हैं।

अलगाव (isolation)

ऑटिस्टिक व्यक्ति के माता पिता अक्सर खुद को काफी अलग और अकेला महसूस करते हैं। उन्हें पता नहीं होता कि कहाँ से मदद मांगनी है। वे अक्सर जहाँ से मदद के लिए पहल चाहते हैं और जब वहाँ से उन्हें निराशा मिलती है, तो वे खुद को हताश महसूस करते हैं। वे महसूस करते हैं कि इससे उन्हें अकेले ही झूझना है। स्पेक्ट्रम पर व्यक्तियों के अक्सर कोई दोस्त नहीं होते, वे एक सामाजिक अलगाववाद का सामना करते हैं। कभी अगर कोई दोस्त हो भी तो वो ज्यादा दोस्ती नहीं चाहते हैं। कुछ बच्चे दोस्त चाहते भी हैं परन्तु सामाजिक और संचार बाधाओं के कारण नहीं बना पाते हैं। मुझे याद है कि मेरी चचेरी बहन एलिसा रोती थी जब तक वह सो न जाये क्योंकि उसे अपने लिए एक दोस्त चाहिए था लेकिन उससे दोस्ती करने के बजाये, उसे बहुत तंग किया जाता था।

तंग करना व मज़ाक उड़ाना (bullies)

तंग करना या मज़ाक बनाना ये एक विशेष मुद्दा है हमारे बच्चों के बीच। अक्सर गिरोह बनाकर दूसरे बच्चे इनकी नकल उतारते हैं या फिर तंग करते हैं। कई व्यक्ति बहुत संवेदनशील

होते हैं और हल्की बदमाशी भी अत्यन्त हानिकारक रूप से इन पर मानसिक दबाव बना देती है। मज़ाक बनाना अपने आप में अथक व डराने वाला है। अक्सर बच्चे और वयस्क (adults) भी इतना डर जाते हैं कि वे इस बात को किसी से भी बांट (share) नहीं पाते कि उनका मज़ाक बनाया जा रहा है या फिर उन्हें तंग किया जा रहा है।

आत्म–उत्तेजक व्यवहार (stimming)

Stimming एक छोटा शब्द है आत्म–उत्तेजक व्यवहार के लिए। जो प्रयोग किया जाता है दोहराने वाले व्यवहार की श्रृंखला (series) के लिए जैसे–हाथ फड़फड़ाना, चबाना, बैंगिग, सिर पर मारना, पेसिंग, रौकिंग, किसी वस्तु को लगातार देखना, चक्कर खाना या लगातार घूमना आदि, ये केवल कुछ उदाहरण हैं। ये बच्चे करते हैं जब वे चरम भावनाओं के समय या दौरान (उत्तेजना पर) अपने आप को विनियमित करने में मदद करना चाहते हैं।

वे बहुत सामान्य लग रहा है : स्वीकृति और दया ढूंढना

(They seem so normal finding acceptance and compassion)

स्वीकृति एक बड़ा संघर्ष है माता पिता, परिवार के सदस्यों, अधिवक्ताओं (advocates), करीबी दोस्तों और खुद के लिए। यह समझने और स्वीकारने के लिए हर रोज लड़ना पड़ता है। इसके लिए कई कारण हैं। पहला कारण लोगों का यह मानना है कि (high functioning autism) बिना किसी चुनौती के हैं। वे मानते हैं कि असली चुनौती सिर्फ उनके सामाजिक रूप से अजीब व्यवहार या शर्माना है। अन्य आम समस्या है कि लोग विश्वास ही नहीं करेंगे कि इनको भी ऑटिस्मि है। लोगों को वे बहुत मौखिक लगते हैं। वे धारणा बना लेते हैं और कोई बुरी टिप्पणी व कानाफूसी करते हैं। वे परिवारों के दैनिक संघर्श को समझ नहीं पाते। सबसे ज्यादा चौकाने वाला है कि लोग अक्सर कहेंगे कि वह ऑटिस्टिक नहीं दिखता है। यह इसलिए क्योंकि शारीरिक रूप से ऑटिस्टिक बच्चे बिल्कुल सामान्य दिखते हैं और एक ऑटिस्टिक व्यक्ति को देखकर कोई एकदम से नहीं कह सकता कि यह आटिस्टिक है विशेषतया एक हाई फंक्शनिंग ऑटिस्टक व्यक्ति को।

अधिगम/सीखना (learning)

हर एक अलग ढंग से सीखता है। कुछ को दिखाकर निर्देशित करने की जरूरत है। अन्य बच्चों को सीखाने के लिए उपकरण या चित्रों की आवश्यकता होती है। सिखाने में प्रबलन प्रणाली (reinforcement) बहुत मदद करती है। कई व्यक्तियों को सिखाने के लिए हमें अतिरिक्त समय व धैर्य की बहुत जरूरत हो सकती है।

प्रतिगमन (regression)

प्रतिगमन अक्सर तीन साल की उम्र के बाद हाई फंक्शनिंग ऑटिस्मि के साथ व्यक्ति में दुर्लभ होने के लिए कहा गया है मगर मुझे ये मामला भिन्न लगा। प्रतिगमन वास्तव में कुछ हद तक सामान्य है। कई कारण हैं जो एक व्यक्ति को वापसी (regress) या वापसी के लिए (appear to regress) प्रदर्शित करते हैं। जैसे स्वास्थ्य में परिवर्तन आप प्रतिगमन पाये तो एक स्वास्थ्य जांच करा लें, यहां कोई स्वास्थ्य से जुड़ा कारण भी हो सकता है शायद जिसकी जांच न हो पाइ हो । बड़े बदलाव जैसे स्कूल का संक्रमण (transitioning) या कहीं जगह बदलना या जाना, बीते हुए पूरे वर्ष में जिसका प्रतिगमन के कारण में योगदान हो सकता है। ट्रामा (trauma) भी प्रतिगमन पैदा कर सकता है। प्रतिगमन को इस तरह परिभाषित नहीं किया गया कि वो ज्यादा आटिस्टिक लग रहा है। लेकिन वास्तव में यहां नये अधिगृहीत (सीखे हुए) कौशल का नुकसान हो जाता है। कुछ हमें अधिक आटिस्टिक लग सकते हैं मगर वास्तव में वे नये कौशल प्राप्त कर चुके हैं।

याद रखने के लिए (to remember)

ये ज़रूरी है कि हम याद रखें कि ऑटिस्म हर व्यक्ति को अलग ढंग से प्रभावित करता है। कोई भी दो व्यक्ति अपनी किसी दिक्कत में समान नहीं होते हैं। हर एक की गंभीरता अलग होगी। ये भी आवश्यक है कि याद रखा जाये कि बड़े होने के साथ–साथ उनकी रूचियों में और संवेदनशील प्रतिक्रियाओं में भी परिवर्तन आता है। जब आप एक आटिस्म के व्यक्ति से मिले हैं तो आपने सिर्फ आटिस्म का एक ही प्रकार देखा है। आपको दूसरा देखने पे पता चलेगा कि हर एक अपने आपमे दूसरे से कितना भिन्न है और अगर वे हाई फंक्शनिंग है तो उनके कामकाज का स्तर एक दिन से दूसरे दिन तक में बदल सकता है और कुछ दिनों में वे दूसरों की तुलना में अधिक कार्य करते दिख सकते हैं।

My Life

Tania Melnyczuk

I love people deeply and individually.
I also let friends and family down pretty often.

IT is my unquenchable conviction that when I die, I should - through the proliferation of friendship and love - have left behind a fabric of relationships that becomes ever wider and stronger, that can swell as a wave does and move forward with a power that far exceeds any input I may have made as an individual, and does not need me at all to drive its direction or to see to it that it reaches the shore.

IT is extremely important to me that autistic children and those who love them should get the help and encouragement they need to live meaningfully on this planet. Many parents of autistic children have had so many struggles related to their children's autism, that for them, autism is defined solely by the things that they hate. Their vision is contorted by the fundraising efforts of autism charities that perpetuate a bleak and pitiful picture of suffering in order to solicit donations, dotted here and there with inspirational stories of isolated heroes who have 'overcome' autism to achieve something worthy of a smile and a sentimental tear.

I want to give these parents hope; I want to help. I understand what a meltdown is like, I know what it is like to be full of bruises, I know how horrible sensory overload feels, what it is like to be unable to talk or to make eye contact; I know what it is like to feel left out, I know what it is like to vomit at the smell of certain foods, I know the desperate feeling of being misunderstood. I have seen the pain of the other side, of the person who experiences a meltdown as an attack, who reads your lack of eye contact as disregard, who feels manipulated by your insistence on masking the clutter on the computer screen, who cringes with embarrassment when you do something associated with the bathroom in the presence of others, and who has the inconvenience of having to plan around your taste in food in a society where communal participation is not merely efficient, but also seen as a sign of love and respect.

I have also experienced the height and depth and breadth of the ecstasies of being autistic, and I live in gratitude for these unsurpassable joys. My brother's wife, who works in the healthcare industry, told me that the reason why so many people take recreational drugs is that the magnificent feelings I experience simply from dancing and stimming and looking at typography and designing classification systems, cannot be experienced naturally by most non-autistic people. The celebration within me, knowing that I have friends, and the dissipation of that feeling throughout my body when they say something that is both extremely astute and extremely funny — that full, systemic catalytic exciting realisation of their intelligence, and the potential future that it creates for them in my mind — it is wonderful. When I look at a crane, when I look at cogs, my heart beats differently. It costs me nothing to experience this intense pleasure — even the thoughts in my mind can bring it forth in part, without me even being there. When I read the sensitively accurate sentences composed by the patent attorney, describing the convolutions produced by the baffles in a static mixer — something so difficult to explain in words — my mind breaks my body into tears at the poetic beauty of his craft, and I am in awe. When a non-speaking autistic child comes to me, unsolicited, when a person who is afraid of people bestows her trust in me without my insistence, when I work with people who are completely unlike me towards a common purpose, when my autistic friends, haphazardly, rise up to help non-autistic people who cannot get help or understanding from anyone else, and when my joy becomes the joy of others, when their joys are mine, I am so happy. I am so grateful.

I love being autistic. I want people to have this joy. I have friends whose facial expressions mask their devotion from people who live in the mainstream of society, whose manner of communication hides their autistic brilliance from those who are disabled by the disorder of being unable to see it. I have the privilege of knowing them, of rocking with them, of having access to their savant skills and their helpful obsessions in practical applications where I have no skills of my own.

MY world is filled with these surprises, these paradoxes, these exclusive experiences, these rare privileges. Who would not want such a life?

Tania Melnyczuk is a self advocate with Aspergers Syndrome. She lives in South Africa. Tania is the Director: Programme Design at ProjectManagement.co.za. She participates in conferences, conducts workshops on autism and actively advocates for the rights of people with autism.

CGPA Score of 10...a Cakewalk?

Sudhanshu Grover

My son Drishaan secured a CGPA score of 10 in his CBSE board exams in 2013. So what?! What is unusual about it?! Every year lakhs of children appear for CBSE class X board exams. The year 2012-2013, itself, saw 86162 students accomplish this score, across the country. So what's the big deal if Drishaan was one of them? Well, this is our story…….

WHEN the nurse handed me this soft, rosy pink, baby wrapped in a clean crisp sheet the first time, he had placed his index finger on his chin, as if he was in deep thought...A thinker!! I told myself, he'll surely make me proud one day. We named him Drishaan, the learned Shiva...a sage, a scholar.

DRISHAAN was an extremely happy and satisfied child. Once he was well fed, he rarely asked for my attention. Sure, there seemed to be some things that were a bit different about him. For instance, he never crawled and he did prefer to play with the TV remote and pens, instead of traditional toys. He could assemble and dissemble watches and mobiles in seconds. He would hold my hand and lead me to his blocks and get me to make models for him.

WHEN other children his age were making their parents ecstatic by calling them 'Papa' or 'Mama, Drishaan was labelling everything 'Kyku'. He was clumsy, frequently bumping into things and resisted physical activity, but had a strong inclination for music.

AT the age of two and a half, Drishaan was misdiagnosed as hearing impaired. A few months later, when his twin, Drishabh was diagnosed with autism, fortunately Drishaan was accompanying him. And, it was ***then*** that Drishaan received his accurate diagnosis, that of being on the autism spectrum too, like his twin. At that time, this did come as a surprise to me, that the boys were so very different from each other and yet happened to be diagnosed with the same condition. But, I did not take long to recover. Reading up on autism, I understood why Drishaan was the way he was. He, like each one of us was bestowed with ***his*** unique strengths and challenges. I decided to focus on his assets, on his strengths. Drishaan has a very strong affinity for music. So, I started playing nursery rhymes in the background at home. As a result he picked on humming tunes and then started speaking new words. Throughout the day, describing them, but, never testing him. Word by word, his vocabulary blossomed and strengthened; and within no time he was speaking in phrases and then sentences. I read stories to him every night and from that, he developed a desire to read. This also helped little Drishaan vary his tone while speaking.

PRINT fascinated Drishaan and I realised that he could read. He was hyperlexic, which meant that he could read volumes, but, without comprehension. So, I worked on his understanding ability by starting with easy passages and then moved on to more complex ones. We did our math experientially in the environment; counting numbers and learning various operations whilst eating, walking, climbing steps, swinging and so on. I used nature to teach him other concepts like that of sizes, colours, shapes and many more...We performed experiments to understand the various phenomena in science. I taught him to solve his own problems as and when they arose. I helped him 'learn to learn'.

OUR aim was always, learning for the sake of learning - to gain information, to understand what was being taught, because learning in itself was so enjoyable. Learning was never forced and there were no unrealistic expectations. Probably this was what generated a keen interest in academics and Drishaan continued to be an eager participant to learn more and more. The aim, per se was not to move to a higher class. And when Drishaan did get promoted every year to a higher class, that was just the bonus!

DRISHAAN was lucky to have accepting, loving and encouraging teachers. Year after year he excelled. I made him aware of his uniqueness early and encouraged him to appreciate differences. I did not use one particular intervention approach to teach him, but instead used the best of all the strategies I knew of.

DRISHAAN'S success was due to the contribution of a positive and healthy atmosphere and his strong learning base. But, most importantly, this success would have been impossible without Drishaan's own effort, his willingness and passion to learn.

If an individual can be so motivated as to find academics as enchanting as Drishaan does, it is easy to secure a CGPA score of 10 in the Board exams.

Getting a CGPA score of 10 in the Board exams may actually seem to be a cake walk.

And wouldn't all our children, whether autistic or neurotypical, scale new heights, under similar circumstances, given similar passions?

So really, what is so unusual about Drishaan's CGPA score of 10 in the Board exams?

Interactive Classes at the National Centre for Autism

Action for Autism is delighted to announce a range of interactive classes for children and youngsters on the autism spectrum for the 2014-2015 academic session, at the National Centre for Autism, Pocket 7 and 8, Jasola Vihar.

The classes will address different needs and skill areas, and, at all times will incorporate the element of fun to ensure that the learning process remains motivating.

Social skills training classes

This interactive programme, gives participants an opportunity to **develop social skills for school and everyday life, make friends, talk about feelings and a range of other socially appropriate skills.**

- *Age of participants: 5-15 years.*
- *The Social Skills Training Classes commence from 7th July 2014 and will be conducted for a period of 8 to 10 weeks, on every Monday from 3 pm to 5 pm*

Magic Beans Language Classes

The Magic Beans Language classes offer a comprehensive and advanced language curriculum. Through this novel language programme, the children learn different aspects of language. The programme is divided into **four modules**: **listening and memory; sentence formulation; reading comprehension and pragmatics,each module having four weekly sessions for two hours each.** Participants can choose to enrol for one or more modules.

- *Age of participants: 5-15 years.*
- *The Magic Beans Language Classes will be held on every Tuesdays from 3 pm to 5 pm, from 7th July 2014.*

Bubbles: The Social Communication Program

Children who are functionally more able and based in mainstream schools may find it difficult to follow group instructions, comply with daily routines of classrooms like taking out notebooks, copying from the blackboard, sitting during transitions, waiting for their turn in classroom activities, asking for help and even providing answers to questions they may know. **Bubbles: The Social Communication Program has been devised to address such difficulties commonly faced by children with autism in mainstream schools.** This weekly programme replicates classroom situations through fun activities and builds upon social skills necessary to interact with peers and adults.

- *Age of participants: 4 years onwards*
- *Bubbles: The Social Communication Program,will run Saturdays, starting on 19 July 2014, for a period of 8 to 10 weeks.*

Leaps And Bounds

Leaps and Bounds is a unique training program using best practices to help the adolescent and young adult with autism be independent and move towards self-reliance in vital skill areas using learning modes like role modeling, to -do lists ,work systems and power points on the skill being targeted. The program comprises of **four modules: cooking, daily living skills, leisure time and social etiquette. Each module comprises of four weekly sessions for two hours each**.Participants can choose to enroll for one or more modules.

- *Age of participants: 13 years and above*
- *Leaps and Bounds will start from 10 July 2014 and will be held Thursdays between 3 pm to 5 pm.*

For registration or any further inquiries,
please contact Salini at 01140540991/ 01140540992
or email at helpline.afa@gmail.com

HELPLINE

Q Hi. My son, M, is 16 years old. He has always had extremely irregular sleep patterns. However, for the past couple of years he virtually does not sleep at all in the nights. On some days he sleeps for just half an hour in the day and that's all. He seems to be fine. But, we are completely tired. We get no sleep in the nights, since M keeps us up. We keep telling him to go to sleep, but, instead of listening to us, he asks us to do different things for him like give him a snack or to put the TV on and so on and if nothing else to just stay awake with him. Even after we do all of this, he does not sleep. Is there anything we can do to change this?

A Thank you for writing in. One completely appreciates how fatiguing this situation may be for you and your family. There seem to be two issues here: one, M not sleeping at night; two, other members of the family being deprived of sleep due to M's keeping them up.

To address the first: there are some individuals with autism who may have sleep disorders and there are also those who just seem to need less hours of sleep than the non autistic population. From your email, it seems that M may fall into the latter category, since you mention that he seems to function fine even with just half an hour of sleep in a day. However, it may be worthwhile to seek some medical advice on this. For instance, it seems that some individuals with autism may have a lack of melatonin (melatonin regulates sleep-wake cycle) and this could disrupt brain systems and cause sleep disorders. In such cases giving melatonin to the individual may definitely help in regulating sleep patterns.

In addition there are strategies that one could try out, to help M sleep better and / or be more settled in the night which we discuss in the following.

Firstly, try to introduce a 'bedtime routine', in case M does not already have a regular bedtime routine. For instance, if we decide that M needs to be in bed by 10.00 pm, we could start setting up this ritual from as early as 8.00 pm. The routine could start with a hot water bath (hot water baths often help calm the senses) and then he could change into his 'bed clothes'. If M does not have specific bed clothes, you could set aside one or two sets of comfortable clothing that M wears **only** for going to bed and at no other time, so that M associates those garments with 'going to bed'. M could then have his dinner. Since you have mentioned that M tends to ask for snacks in the night, you could give M a slightly heavy dinner, to make sure that he is not hungry in the middle of the night. After this, you could put on some soft music, perhaps instrumental music,without too much percussion. One of the things to avoid at this time would be watching TV or sitting at a computer. Studies show that both these activities that involve looking at a lit screen suppress melatonin and delays the onset of sleep.

This could also be time for some quiet interaction when you can chat with M about the day's activities. The conversation has to be a relaxed, casual discussion, and not about testing his knowledge. Any kind of rough housing or animated play too, is best avoided at this time.

Closer to bed time have M cross off the day on a calendar. If the date is 10 November, you could help M put a cross on the '10' in the calendar, to clearly signify that the day is over. If M uses a visual schedule then place a 'Bedtime' / 'Sleep' card on the schedule that he can take and match to his sleeping area. This would be the last activity on the schedule, so after taking the bedtime/ sleep card the schedule gets finished. This would again help M understand that all activities for the day are over. Once M has checked his schedule and headed to, or been guided to his bed you could introduce a closing ritual. Depending on his functional level, he could read a story or you could read one out to him / sing some songs and/ or say a prayer with him. Whatever it is, it would be a good idea to keep your voice very soft.

Once this is over, say 'good night' to M, tell him that it is time to sleep and then just let him be. Should he get up again, you could guide him back to bed, gently telling him 'It's time to sleep'.

The preceding is just an example of a bed time routine. You may want to tweak it to M's interests and functional level, and what makes sense to M and the family.

Once a sleep routine has been introduced, follow the same pattern of activities daily with no or minimal variation so that for M there is predictability in the activities that lead up to his bed time.

It is possible that despite the bedtime routine M continues to be up and is unable to sleep. Then the next thing to do would be to help structure the night time for him.

If there are any activities, for instance looking at magazines, listening to music or doing puzzles, that M enjoys, you could add these to his schedule for the night. Of course, in that case ‘Bed time’ / ‘Sleep’ will not be the last activity on the schedule. A ‘to do list’ or a mini schedule could have pictures of the activities in the sequence in which they are to be done (eg first, listen to music; then, look at magazines and last, doing the puzzles). Should you feel that M does indeed get hungry in the night, you could also set aside a small snack for him to eat. Further, do make sure that your house is completely safe for M, ie the main door and balcony doors are locked, there is nothing fragile/breakable around etc. Also if there is something that you would rather that M did not have access to, for instance, the kitchen or the TV, you could block the access to the same, maybe by locking the kitchen or disconnecting the TV from the main switch or keeping the remotes away. This will ensure that M is safe as well asdoes not have possibility of doing things during the night that you would rather he did not.

Another strategy that may help would be to write a social story about bedtime. The social story can be a very effective tool to provide M with information of what is expected of him. You could use pictures/ photographs relevant to the situation to illustrate the story. The story would describe the activities that lead up to bedtime and what happens at night. It could provide information about the options of activities that he has in the night, should he be unable to sleep, even as his parents sleep.

You could read this story out to M two to three times in the course of the day, and also as one of the stories that you read to him at bed time.

Along with all of the above, do also try to ensure that M gets ample physical exercise and that he does not nap during the day.

An extremely vital learning for M would be to understand that while it is okay to want to stay awake at night, bed time is not a time to interact with others. For all of us there are those nights when we are be unable to sleep. On such occasions we keep ourselves occupied by reading, watching the TV, listening to music or any other activity that may help us pass the night, and we also know that we cannot wake up the rest of the family. This is what we will have to help M to learn.

From your mail we understand that when M asks you to stay awake with him, or to put on the TV or give him a snack, or when he is just moving around, you invariably interact with him. M has learnt that if he stays awake at night he gets your attention, if he demands a snack you will get up and give it to him, and so on. He has learnt that when he is unable to sleep it is okay for him to wake you up, get attention from you, and get his demands met by you. This is something that we need to help M unlearn.

So from now onwards, once you have wound up for the day and gone to bed, you will need to stop responding to M completely till it is morning. That would include not telling him to go to back to sleep or not getting up to give him something he wants. Instead, continue to keep lying in your bed. This would also entail not looking at him when he makes his demands, or looking annoyed, exasperated, anxious or any of these. Pretend to sleep and if need be, cover yourself tightly with a sheet.

Initially, both you and M may find this very challenging, but, it is essential for you to be able to do this, for M to learn that even though he is unable to sleep, it is okay for you to continue sleeping. Initially you may face resistance from M; he might try to shake you to ‘wake’ you up, or pull the cover off. Depending on how he reacts to unexpected situations, he might also vocalise or make other sounds or movements. The important thing would be for you to stay consistently non-responsive to his efforts to get you up.

Finally, any night when M has been more settled it will be important to reinforce him the following morning, with a lot of attention / affection / activities or items that he likes; in short anything that hold a big appeal.

The whole process may take some time: for M to settle into his bed time routine; for him to stop trying to make you get up and meet his demands; learn to keep himself occupied if he is unable to sleep and thereby you being able to sleep; and hopefully for M to start sleeping better and longer. However, if you are consistent in the strategies that you follow, and give M time to understand what is expected from him, some of these issues that you are facing will certainly get sorted out. All the best!

Q I am a diplomat with an 11-year-old autistic son. We are currently on a 2-year tour of duty in the US, but will soon be sent overseas again and are looking for the best countries for autism education.

I read with interest your list of international autism organizations. Thank you for compiling such a useful list! Do you have, or are you aware of, any reports that rank countries by the quality of their autism education?

A You have asked an interesting question for which I am not sure that there is an easy answer. To the best of our knowledge, there is no study on the quality of autism education in countries.

There are several variables that I imagine you will have to consider. For instance, is your child included in a regular classroom or does he attend a special needs classroom? If he is in the former, what kind of accommodations does he require for him to be able to learn better and to keep his schooling a positive experience? In addition, does he require the additional support of backup services from a good therapist to bolster all that he is learning at school, as well as teach those concepts for which he may need specialised inputs? If this is the case, then you may need to look at a country where there is ample emphasis on inclusion, and alongside there are those add on services available either through the school itself or through external facilities.

If your son is in a specialised set up, the variable to consider there would be the particular intervention strategy that he learns best with. Whilst there are services in some countries that use a combination of strategies that are considered to be ‘best practices’ for autism internationally, like the Structured Teaching, ABA, VBA, and tailor the programme to the specific strengths and needs of the child in question, there may be others which use only one such intervention strategy.

Given all these factors, I am not sure if there is any country where every service is of the same standard. The percentage of good quality services in each country varies; some higher than others. Of course, there would be countries where the number of organisations/ professionals providing services to individuals with autism may be greater, making those services more easily accessible. However, to reiterate, the quality of services may again vary across organisations and / or professionals.

The key to ‘good’ education for individuals with autism may often be understanding the condition, understanding the unique ways in which children with autism think and learn, accepting their autism as a vital, vibrant part of their being and then approaching the intervention, the teaching of skills, and / or changing of behaviours, from that paradigm of understanding and acceptance. What your son would need is a service that has a rock solid understanding of autism, provides students with structure and predictability and uses good behavioural principles in the teaching.

Hence you may need to widen your quest a bit more: in addition to looking for a country which provides good quality services to individuals with autism, you would also need to delve into the quality of services that are provided by the organisations and professionals in question.

Unfortunately, there are no precise answers that we can give to this particular question. But, we do wish you the very best in your search.

AAKAAR: Early Intervention School Readiness Programme

Action For Autism is excited to launch
the pilot of its newest programme:
AAKAAR:Early Intervention
School Readiness Programme, in July 2014.

Aakaar will run twice a year,
beginning in January and July of each year.

Aakaar is a comprehensive early intervention programme for children with Autism Spectrum Conditions upto seven years. The programme is child centric, play based and family focused. The primary aim of the programme is to help the child ‘learn to learn’ by working on various school readiness skills and prepare the child for a successful inclusion in the mainstream classroom.

Each session will have a group of six children who train together with their mothers (or parent primarily involved in the child’s education) throughout the duration of the programme.

Aakaar aims at helping the mother understand the unique learning styles of the child with autism. This enables her to both teach new skills and help generalize learnt skills in the environment using the most appropriate teaching strategies, as well as empowers her to act as an informed support for the child’s needs in the mainstream classroom. in the mainstream classroom.

For registration or any further inquiries, please
contact Salini at 01140540991/ 01140540992
or write an email to helpline.afa@gmail.com

Upcoming Workshops

At a Glance

Creating Opportunities for Work & Employment

- ***Speaker: PreetiSiwach, Action For Autism***

Thursday, 24 April 2014; 9:30 - 5:00 pm

Like everyone else people with autism too need appropriate work skills and opportunities in order to lead productive and happy lives as adults. Some individuals succeed in open or semi-sheltered workplaces. But for most others, sheltered workplaces or vocational centres are ideal. Preparation for this ideally starts young, should be underway in adolescence, but for someone who has not had the opportunity, can also begin in adulthood regardless of the age. As a parent or professional working with people with autism, the workshop will focus on essential work skills; how to teach them as well as basic pointers on how to set up and run a vocational training centre employing individuals with autism and other developmental disabilities.

Building Bridges through Sensory Integration

- ***Speaker: Dr Anjali Joshi, Director Research and Training, Ummeed Child Development Centre, Mumbai***

Friday, 25 April 2014; 9:00 am- 5:00 pm

Living and working with children with Autism and/or exhibiting Sensory Processing Disorders can be rewarding, but it's also very challenging! It is seen that what people need the most help with is learning how to manage the apparent unmanageable behaviors that get in the way of learning, progress and relationships. The sessions will focus on planning and executing flexible and effective curriculum and learning environments.

Including the Child with Autism in the Mainstream Classroom

- ***Speaker: Indrani Basu, Founder & Director, Autism Society West Bengal, Kolkata***

Saturday, 26 April 2014; 9:00 am- 6:00 pm

The Indian law mandates that schools cannot refuse admission to students with autism. In reality parents are struggling to get admission for their child with autism. One of the chief reasons is that the schools still feel inadequately prepared to meet the needs of people with autism. This workshop will focus on fine nuances of the difficulties that the child with ASD faces in the classroom and the accommodations required to facilitate learning. The workshop will be useful for professionals to facilitate an inclusive learning environment and for parents as they prepare their young ones for mainstreaming.

Empowering my Child: A Training for Parents

- ***Speaker: Action For Autism Team***

Thursday 3 July to Saturday 5 July 2014;
9:00 am – 5:00 pm

Whether you are a parent of a newly diagnosed child, or whether you are a more seasoned parent, the bottom line in helping your children learn is to understand autism beyond theoretical explanations. Here is an opportunity that will help you understand autism and your child better, and empower you to help your child learn more effectively. Professionals wishing to understand the world of autism from the child'sperspective and explore approaches to enjoyable learning are also welcome to register.

For all inquiries, please contact:

Aditi Rao, Trainings Coordinator
Email: anvay.trainings@gmail.com
Mob: + 91 99906 72647
Tel: +91 11 4054 0991-92

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> *" The difference between high-functioning and low-functioning is that high-functioning means your deficits are ignored, and low-functioning means your assets are ignored"*
>
> - Laura Tisoncik -
> (from the 'Circle of Moms' blog)

(...cont from Pg One)

the bill should be completely scrapped and a new one drafted, and those who felt that it was not a perfect bill, but would assure new disabilities some rights.

We believe that with some amendments, the bill must be passed. Before being sent to a Parliamentary Standing Committee, many non-negotiable amendments suggested by the disability community, have already been incorporated. We believe the way to go is in negotiating with the government to strengthen the bill further and ensure the Right of Persons with Disabilities Bill is an Act within the coming year.

The reality is that disability is not a homogenous construct. There is extreme heterogeneity within each disability group, and more so across different disability groups. Yet during disability discourse, unfortunately, the voices of those who need support to articulate their wants and needs get side lined, such as those with intellectual impairment and autism.

The other important point to keep in mind is that there can never be a perfect law. If we wait for the perfect law to come about, we could wait forever. Those disabilities that already have various entitlements to education and jobs and travel etc, can say with great vigour that they would rather not have a new law if it were not a perfect piece of legislation.

But is someone listening to the voices of the Kaustav's and Gambhir's of the country?

AFA has entered the 20th year of its official existence, though unofficially we are a 23 year old. Two decades is a short time in the life of an organisation. We have achieved a significant amount in this short span and fought many successful battles. But there are many battles yet to be fought: it's just that the battles are now different, and many times more complex. But like experienced troopers we gamely marshal our forces, support our children with schedules, organisers, social stories, reinforcers, visuals, etc, sort out our often-difficult family lives, benignly ignore judgemental neighbours, service people, schools, etc that are quick to critique our parenting, and prepare for the next battle.

**Names changed*

B O O K   P O S T

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