

autism network

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INFORMATION

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YOUR CONTRIBUTIONS

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

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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

'Tree' by Sutirtho,
trainee at Adhaar Skills training Unit, AFA

WISHLIST !

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PAGE ONE

With the approach of adolescence, individuals with autism as well as their families often go through a challenging phase, given the different worldview of the autistic individual including their differences of social understanding. But while it is true that their social understanding may be quite different from the norm, their physiological development is often at par with their peers.

For the individual with autism as with their typically developing peers, adolescence is a complex period in the life, when she is neither child nor adult. The individual often finds confusing the physical, emotional, psychological changes taking place. There is simultaneously a growing sense of self and an increase in self identify. At the same time there is a certain guilelessness and innocence that mark the autistic individual so that parents often do not expect them to mature with age; often viewing them as eternal children.

It is therefore a difficult period for the child as well as the family. Typically, parents tend to anticipate every need of their child and have either little expectation of ability or else an over-expectation. A child who was so far compliant may start showing signs of independence and assertiveness that families sometimes find unsettling. Rather than seeing the natural progression in their child and understanding the behaviours in the light of their approaching adolescence, they are instead seen as challenging behaviours. There is also difficulty on the part of carers in acknowledging the development of a self identity as well as an acceptance of sexual development in the autistic individual.

In this, as well as in the following issue, we try and touch on a few of these areas that those living and working with autism have to address.

ANNOUNCEMENT

Training in
Fundamentals of Structured Teaching

By Christopher Flint and Team

In January, a lucky few had the invaluable opportunity to attend a Training Workshop on the Fundamentals of Structured Teaching conducted and supported by **Autism Awareness for Campaign Through International Organisations Networking** from Chicago. Seats were limited

Nirmaya Health Insurance Scheme under the National Trust

The National Trust had launched Nirmaya, a health insurance scheme for the welfare of persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities in select districts of India in March this year. This has now been extended to to all districts (excluding J&K).

The Nirmaya Scheme plays a significant role since health insurance schemes are not easily available for persons with disabilities. The scheme will provide affordable Health Insurance to persons with Autism, Cerebral Palsy, Mental Retardation & Multiple Disabilities; encourage health services seeking behaviour among persons with disability; and improve the general health condition & quality of life of persons with disability. The scheme will provide services ranging from regular medical checkup to hospitalization; therapy to corrective surgery; transportation, among others.

The scheme is designed to deliver 'Community based' cover which will have a single premium across age band; provide same coverage irrespective of the type of disability; provide insurance cover upto Rs One Lakh; and will include all persons with disabilities.

The premium amount for those other than BPL will be Rs 250. For BPL category of persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities will be shared by the State Government/ Central Government/ the National Trust.

The entire scheme will be implemented and monitored by the National Trust through a Third Party Nodal Agency with the active participation of the Local Level Committees.

and we had to turn away many disappointed participants. We had promised at the time that we will do our best to arrange for the training one more time. We are delighted to share that Christopher and his team will be back for another two-day training in Delhi in January 2009. The two-day training is mandatory for anyone wanting to join the five-day trainers programme.

For more information on this workshop send a SASE marked 'Structured Teaching Workshop'. Once dates are finalised, the information will be on our website: <www.autism-india.org>.

Meeting the Challenges of Adolescence

Nidhi Singhal, PhD, Clinical Psychologist

Adolescence is full of challenges for any child and the people who love them. Youngsters with autism spectrum disorders bring their special flavour to adolescence, making it a more complex journey. The change is fast, everywhere, and hard to keep up with: The body changes in response to increasing levels of sex hormones; the cognitive development moves from concrete to abstract and so do the social expectations. Many of them already have difficulty coping with any type of change, and therefore there is even greater importance in adequate preparation for the physical and hormonal changes that comes with adolescence. Society also expects more from those with an adult-like appearance, and individuals with autism spectrum disorders also need preparation for the new social expectations that accompany their body transformation. Yet the individual needs to deal with every single one of these changes, all at the same time!

OVER the years, parents have voiced various concerns regarding their child with autism reaching puberty. Some of that worry is related to loss of acquired skills; building on self-esteem and friendships; and exploring sexuality. As with all children, the individual with autism will need to be prepared for the changes that will take place. So, how can we prepare the individual? Recognizing the complex and sometimes conflicting needs of an adolescent is a good point to start.

Regression in puberty

Parents have often wondered if their child will regress as s/he reaches puberty. On the issue of regression, while there is reason for concern, the situation may not merit panic. Many changes happen around puberty and these changes can certainly affect behaviour, including in areas where the child has taken important strides. As with all adolescents, the youngster may regress in some areas even while s/he continues to move forward in others. Moreover, these changes can be unexpected and unpredictable.

RECENT research and anecdotal reports of parents indicate that while some youngsters face a clear setback in puberty, most of them are able to recover from that regression. It is therefore reasonable to conclude that a youngster with autism can learn to cope with the challenges of puberty and adolescence.

Building self-esteem

Many adults assume that puberty is a time of inevitable low mood for the adolescent. Some even think that depression is an expected part of going through puberty. However, depression is different from the normal mood fluctuations that are a part of puberty. The fluctuating hormones that are part of the physical changes of puberty can lead to changes in mood. It is important that the adolescent with an autism spectrum disorder understands that good and bad feelings will come as part of changing into an adult body. Having a collection of ideas to help adolescent boys and girls when their mood is low is recommended. It helps further if these are represented visually. Girls who are interested in logic and facts may be interested in charting their own mood on a calendar to see if there is a cyclical pattern coinciding with their menstrual cycle.

DEPRESSION is characterised by low self-esteem, a feeling of worthlessness, and withdrawal from previously enjoyed activities. In addition, depression may be expressed by an adolescent with autism spectrum disorder by disturbances in eating and sleeping, increased agitation, or extreme lethargy which contrast with the individual's usual behaviour. Depression is not a 'normal' part of transitioning to adulthood, and the above symptoms should be discussed with the adolescent's general physician as a starting point. In addition, behavioural efforts may be directed towards building the person's self-esteem. For instance, most adolescents with autism tend to accumulate a lot of information on a subject of their interest and the more verbal ones may enjoy talking about it over and over. Unfortunately, after a point, it is neither healthy for the individual nor interesting for the audience. However, rather than absolutely avoiding the subject, devising ways to structure the topic in a different way to engage and challenge the youngster in the subject may help the person realize his/her mastery on the subject and may boost his/her self-esteem.

Building friendships

Regardless of the individual developmental route, most persons with autism are aware that they are not quite like others their age. While this awareness is there from an early age, it is at some point in their adolescence that

this knowledge gains sharper focus. For some, this may propel a higher level of insight into their personal difficulties in social interaction. When the adolescent realizes that s/he has significant difficulties in making friends, s/he may benefit from help to deal with this loss, just like dealing with any other loss. Considering this coping process in a few stages may make the job easier: Anger; Denial; Depression; Acceptance; and Adaptation. Most commonly, the adolescent will not go through these stages one after another, but rather display a larger or smaller aspect of each at any given time. This is a painful process for not only the adolescent but for those who care for him/her as well.

IT is important to encourage the adolescent to express herself and talk about his/her anger and frustration and move closer to the acceptance and adaptation. In this process, understanding the thoughts, feelings and behaviour of an adolescent with autism could be the necessary first step. Another way would be to help the adolescent find her *identity* in autism. Individuals who have had the opportunity of open discussions about their autism can move to this much easier. In addition to talking to them about their autism it also helps the individual to get in touch with other youngsters with autism. Given the ease and anonymity of the Internet, many persons with autism find it useful to join online networking websites, chat rooms and blogs. The medium provides them with an opportunity to interact with other people with autism, and can often provide support in developing a better understanding of autism and themselves, their strengths and difficulties. The internet of course also provides a forum for interacting with non-autistic individuals as well and share experiences and interests, without the social pressures of direct interaction.

Understanding romantic interests

Adolescents with an autism spectrum disorder, due to social immaturity, may show romantic interest in others somewhat later than their peers. However attraction does take place, and the adolescent can be taught that feeling tingly when being near another person, and thinking about that person a lot of the time shows that this is happening. Talking to the adolescent, even if they are not experiencing this themselves can help demystify for them the change in their classmates' behaviour from mainly same-sex interaction, to mixed interaction, with flirting, touching, and showing off for the benefit of potential girlfriends/boyfriends. This may help them make sense of what is going on around them. This may

also help them to understand that behaviours such as teasing, playful punching, etc. may be an indication that one classmate is flirting with the other, rather than an offence needing to be reported to the teacher, and punished!

AN adolescent may on occasion begin to be interested romantically in the opposite sex or same sex (same sex romantic interest occurs with at least the same frequency in people with autism spectrum disorder as those without). Just like their obsessive interest in other matters, this interest too may lead to becoming obsessed with another adolescent. The difference between this scenario and any other adolescent 'crush' is that the person with ASD may not be able to 'read' the cues from the other person so as to judge whether the interest is reciprocated or not. The person with autism will have to learn that: firstly for pursuing a relationship the other party too has to be interested; and secondly, to read the cues that will indicate such an interest.

Acknowledging sexuality

For an adolescent with an autism spectrum disorder, the physical changes that indicate increasing maturity can be quite at odds with where the individual is at in other aspects of their development, such as academic and social skills. It can be a shock for parents to recognise that their child will have an adult's body, without all the adult capabilities to accompany this.

THE physical changes in boys usually begin around age 13 with secondary characteristics including growth spurts, bigger hands and feet, increased muscle mass, deepened voice, pubic, facial and underarm hair, and developed penis and testicles. At puberty, boys may begin to ejaculate semen or may have erections at odd or unplanned times. The physical changes in girls usually begin between ages 7 and 14 with growth spurts; developing breasts, pubic and underarm hair, and vaginal discharges. A girl's menstruation cycle usually follows within a year or two of these changes at an average age of 12 or 13 years, but some girls may start as early as 9 years.

IT is sometimes hard to imagine that our children, who have significant problems carrying a simple conversation, may have sexual needs or curiosity. Many parents and even professionals often believe that the developmental delay of the individual with autism would mean s/he would escape any sexual stirring. This is not true, no matter how one might wish it to be so. Sexual arousal occurs in both children with autism who speak, as well as

non-verbal individuals. It is one of the basic urges of our species. Talking about sex, especially the sexuality of our children makes us feel uncomfortable and we all wish that this issue gets resolved by itself, or at least somebody else takes the responsibility of resolving it. We may find it comforting to believe that our children don't have sexual needs and feelings, and avoid bringing up the subject in any shape or form. We may feel uneasy about sex education, believing that ignorance will prevent sexual activity. However, it is important to acknowledge that teenagers with autism are sexual beings just like the rest of us. In contrast with their rather slow social development and maturation, adolescents with autism develop physiologically and sexually at the same pace as their peers.

SOME parents want to delay discussions because they feel advance preparation may contribute to their child's anxiety. Because it is never certain at what age puberty will begin, some parents don't want to confuse their child with information that may not be applicable for a while. However, it certainly helps to think in a more positive and developmentally oriented way. The absolute latest time to begin discussions about puberty is when the child first begins to show the early physical changes of puberty, such as breast buds in girls, or in boys, acceleration of growth (the boy appears to have 'gangly' arms and legs). If children with an autism spectrum disorder are not prepared for the changes, they may become confused or frightened that they are very ill because things are changing with their body.

IF a youngster shows an awareness of how older people are physically different to them, this may be a great starting point for discussion. Noticing a beard, breasts or underarm hair is a very tangible visual sign for a person with autism spectrum disorder about difference to themselves. For young children start to link these visual signs with 'having an adult body'. For instance a young girl may be initiated with "The girl has those bumps on her chest because she is turning into an adult". "The woman has the bumps because she is already an adult". Showing pictures of a parent at different ages to see how the parent looked different can also be useful. As a more clear visual cue, line drawings of the body and how it looks at different ages can be used. The child's awareness of the differences can then be gradually added to. For example, the next level of information about 'the bumps on the woman's chest' could be discussing that these are called 'breasts', and the other alternative names for them. The child will also learn that breasts are a private area

and are not able to be touched without permission. Depending on the level of understanding of the child, the final piece of information would be discussing that breasts develop for feeding babies when the woman is an adult. It is useful to explicitly teach the adolescent about the changes to expect in their own body. Because, an individual with an autism spectrum disorder sees how things are for others, doesn't necessarily mean they will generalise this to their own situation. Therefore make clear statements like 'as you change into an adult, you will also have underarm hair'.

LANGUAGE concepts are difficult for many individuals with autism spectrum disorder as are social rules. When talking about boy and girl body parts, we can use the medical terminology and get used to saying words such as penis, testicles and pubic hair for boys and vagina, breasts, and menstruation for girls. However this will have to be tailored to the individual child. With many children we may use alternate – and innocuous - words that the youngster may use to express his/her needs, which are known only to significant people in his life.

IF the youngster has moderate to severe difficulty with intelligence, or language development as part of their autism, they may not be able to understand the abstract concepts related to puberty, such as mood changes, or the reason for menstruation. Preparation for them will have to focus not so much on when and why the changes will occur, rather more around teaching appropriate responses to the things that happen during say menstruation and masturbation. There are plenty of teachable moments in every day life. Indeed for the conscious and aware, more often than not, children teach us as much or more than we teach them.

THE internal 'clock' for each individual's sexual awakening appears to be an entirely personal affair. Some parents have been concerned that their child was having erections and masturbating at the age of eight. (There are children who do so at a much younger age, but the act appears to be related to stimulation of a sensory nature rather than connected to, for example, being near the opposite sex). Others spoke of arousal appearing in later years, even as late as the early twenties. The items which cause arousal also vary: the opposite sex, pictures of women in lingerie, metal bowls, feet, specific vegetables and so on. Many of these items seem rather odd, even bizarre to the non-autistic, but they should not seem too surprising given the varied sensory involvements, in general, of individuals with autism.

A few children may show behaviours like touching their private parts in public; stripping in public; masturbating in public; touching others inappropriately; staring at others inappropriately; and talking about inappropriate subjects. However, we can teach them appropriate responses and thereby make sure that our children express sexuality in socially acceptable and legally permissible ways, avoiding harm to themselves and others. The key is in addressing the issue of sexuality squarely, versus avoiding it. Since early education surrounding these issues is so important, an open rapport between families and professionals is crucial. This will ensure that even if matters related to sexuality crop up in later years, they can be addressed easily.

PARENTS are often at a loss on how to go about educating their children with ASD on issues of sexuality. Here are some of the things they could do. Set up a specific time to talk to the child about sexuality, rather than making a few comments about it when the issue is hot, right after an incident, when everybody feels quite emotional about what just has happened. Seeing the parents level of comfort around the issue, the child will get the message that it is OK to have sexual feelings and it is OK to talk about them. Getting this message alone will bring the tension around sexuality a few notches down. Your child may have questions regarding sexuality, and it is important for everyone working with him to be able to identify what he might be asking for.

IT is important to help the individual learn what behaviour is appropriate and what is not; which behaviours are private behaviours and not to be exhibited in public; and where the space is where private behaviours may be indulged in, and when; - for instance, masturbating in a public place. This is a lesson that ideally starts at a very early age. For instance, a child with autism may be considered 'cute' if he hugs people indiscriminately, or sits on their laps, but this rapidly becomes inappropriate and carries the threat of being misinterpreted if it continues into adolescence or adulthood. Items like the value of comprehending correct 'social distance' when standing near someone, are all part of the basic social skills that need to be begun while the child is young.

WITH the girl child, as parents see their daughter developing physical changes of puberty, they have to begin talking to her about menstruation and practising the steps of wearing a pad and changing it regularly before the important day actually happens.

TO illustrate with a behaviour such as masturbation in a public place, it might be decided that the individual needs to be redirected to some form of physical activity. At other times, the young person might be redirected to the appropriate place and time that has been designated for self-stimulation. Each scenario, and the strategy which is to be used for that young person, must be decided individually. The ability to decide what might be a correct strategy can often be gleaned from closely observing the young person's behaviour over a period of time. For example, does self-stimulation occur when the child is bored at a certain time of day? (redirect to an activity scheduled into that time slot); when the child is anxious? (attempt to eliminate or address the cause of the anxiety); when the individual sees a certain object? (Reduce the individual's exposure to that object) and so on. It is important to also examine the individual's communication system to see if s/he has the correct selection of visuals, gestures and opportunities in order to express the need, for example, to go to a private place - which might be the photo of a particular washroom or his bedroom.

GIVEN the difficulty of individuals with autism spectrum disorder with perspective taking, the person may not be able to identify a private place - as a place where other people cannot see you. Therefore, making a list of public versus private places, in order to consolidate the concept may be recommended.

USING this format, other behaviours that must be done in private can also be listed, e.g. undressing, urinating, scratching private parts, and all other behaviours as generalisation often does not occur naturally. The individual with autism spectrum disorder may also need to be told that it is not necessary to masturbate every time you are in a private place. Wendy Lawson recounted in one of her entertaining presentations several years ago the story of a young gentleman who had been informed as part of his sex education that masturbation was to be done in private places, such as the toilet. The same young gentleman became very unhappy and sore when he interpreted that to mean that each and every time he went to the toilet, he should masturbate!

ALTHOUGH inappropriate touching of self in public is of concern, parents will also need to help their child understand where it is inappropriate to touch others. Additionally individuals with autism spectrum disorder

(...cont on page 18)

Preparing Richa for the Onset of her Periods

A mother

A cheerful and lovely child, my 13-year-old daughter has autism. She was diagnosed at the age of three years.

AS with any other mother of a growing girl child, I was also quite worried and apprehensive of her impending puberty. My worries were more acute because of the special condition of my child.

AS simply worrying about the impending situation would not have helped, I chalked out a plan of action. I discussed the various issues related to puberty, especially onset of menstrual cycle, with her teachers.

AS a first step towards preparing her for periods, whenever I had my periods, I took Richa (name changed) along with me to the bathroom and demonstrated to her how to remove soiled napkins, how to wrap it up in a newspaper or (toilet paper) and throw it in the bin. I also demonstrated to her how to stick a fresh napkin in the panties. I told her that mummy will change 'whisper' after about three hours and when it was time to change I repeated the above process with her.

FURTHER, I marked the date of onset of my periods on the calendar and showed it to Richa. I also told her that mummy's periods would last five days and they would come again next month around the same date. The above procedure I repeated continuously for many months.

I also explained to her in simple words about periods. I did not go into much detail but simply told her that once a month girls bleed between legs. The bleeding lasts for about four to five days. And we use 'whisper' during those days. Sometimes, there is pain in the back or tummy and we take medicines for that.

AS a preparatory step, I kept a packet of 'whisper' and some old newspapers in her cupboard drawer and told her that we would use them when her periods start

LAST year as Richa turned 12, her periods started and I was quite amazed at her reaction to the onset of her periods and the way she coped with the situation. I had to be present with her in the bathroom, but everything starting from wrapping the soiled napkin, throwing it in

the bin and sticking a fresh 'whisper' on her panties was done by Richa herself with very little help from me.

I marked the date of onset of her periods on the calendar, crossed each day of periods and told her that next month; her periods would be around the same date.

IT is almost a year since Richa's periods started and she has been managing it well. I am working towards making her more and more independent in this matter.

SO, it was not as bad as I feared and the reason why it was all so smooth was because Richa was informed and prepared well in advance. She had a fair idea about periods. She knew what to expect and therefore, coped so well.

(The author prefers to remain anonymous)

Preparation for Adulthood

Urmila Taneja

Adolescence is really a very crucial stage of life. At this stage the growing child needs special attention and guidance. It is a difficult stage for any child, but when the child has special needs it may be little bit more difficult; and if the child is autistic and a girl child then the challenges may be even greater. Every mother of a growing autistic girl has a deep concern regarding her daughter's periods. She is in constant worry whether her daughter would be able to deal with various complexities when confronted by the situation, particularly for the first time. This worry is understandable as there are many things one needs to consider, not the least of it being informing and preparing the girl and enabling her to cope with the situation.

ALL these worries were in Ananya's (name changed) parents' mind when their daughter crossed the age of nine. Ananya, a very sweet and cheerful girl had a lot of tactile issues. She took a long time to learn to keep her clothes and sandals on. So her parents' worry was obvious. They discussed the matter and I suggested few simple things to prepare Ananya for her periods.

- Make sure that Ananya understands the difference between 'private' and 'public'; and that she understands what behaviours she can do in public and what things she can do only in private.

Thorkil Sonne receives IT Award 2008 for Extraordinary Entrepreneurship

Thorkil Sonne, an extraordinary father to a young child with autism and the 47-year-old founder of the company Specialisterne ApS was earlier this year honoured with the **IT Award 2008**. The award is the Danish IT Industry's celebration of Thorkil's outstanding contribution to originality in the IT industry in Denmark.

THORKIL is a father whose autistic son caused him to become an entrepreneur. When his son received a diagnosis of autism, Thorkil was impelled to look towards creating a future job opportunity for him. In the process he founded Specialisterne which in its own way is about changing the world and improving the situation for people with autism.

THE business concept of Specialisterne is simple. One per cent of the world's population would be diagnosed with an autism spectrum disorder. These highly individualistic people require special support to get on in society. Specialisterne seeks to do so via their particular logical skills and sense for precision which he uses in the IT industry.

IN Denmark, the knowledge industry faces a scarcity of labour. Thorkil Sonne has taken the industry by surprise by finding labour among people who had been written off by society, thus fundamentally challenging our perceptions of talent, disability, and handicap.

INTERNATIONALLY acknowledged for his company which has two offices in Denmark and is expanding globally, Thorkil's concept for Specialisterne which combines good business sense while using the strengths of autism, has been used as a case study by the Harvard Business School. Specialisterne is now part of the HBS executive management program thereby giving many future top managers a more positive approach to autism, viewing the abilities of those who are different.

~ Inspired by Thorkil Sonne, Action For Autism is exploring the creation of job opportunities in the IT sector for individuals with Autism. The concept is at an early stage. But AFA has many years experience of preparing autistic individuals for the work environment; there are such individuals on the AFA staff; hence we are excited to explore the possibilities.

- Start talking to Ananya about the changes that her body was undergoing like her height, hair on various parts of body, and so on
- Talk about periods with her like what happens in those days, its duration, what is expected from Ananya
- Make it reassuring for her; that periods are a regular and normal event in a girl's life
- Give the sanitary napkin to Ananya to touch and feel
- Modelling the use of the sanitary napkin is also useful. I suggested to her mother that when she gets her period she can tell Ananya and show her how to use the napkin, and also the concept of changing every few hours
- Show her how to fix the napkin in her panty
- Sometimes make Ananya wear a napkin as practice. Sometimes a child may not want to wear the napkin and that is absolutely okay. Just keep on trying and shape the behaviour
- Create a book describing periods
- Once Ananya gets all the information clearly and step by step, over a period of time she will be familiarized in advance, and will be prepared to welcome her period.

ALL these simple suggestions were followed by Ananya's parents. Ananya did not want to practice wearing the napkin, and her parents did not insist.

ANANYA'S parents started preparing her right from the age of nine years since they could not tell when her periods might start. When she eventually got her period in June this year, she was eleven years old. She was quite comfortable with the situation and most importantly she was happy and excited. Her mother told me that she willingly put the napkin on when she started. Moreover, Ananya was absolutely fine changing the napkin several times a day. She wanted to change her clothes each time too, and her parents allowed her to do so.

HER mother was very relaxed and was happy with the success of the tips.

NOW Ananya is well adjusted with her periods every month. We hope she will be similarly happy in every new situation that comes up in her life.

BOOK REVIEW

How to Support and Teach Children on the Autism Spectrum

Author: Dave Sherratt • Publisher: LDA, Cambridge • Reviewer: Indu Chaswal

Children with Autism have a different ‘thinking style’ and therefore they see the world in a different way than the majority of us. This means sometimes their behaviour may seem odd and difficult to understand. Children with this thinking style are seen in all educational systems and mostly teachers find it difficult to understand them and hence apply the correct remediation procedures. In fact, it is very common that the behaviors are misinterpreted and the child may as a result face more difficulties than the others around him. The same situation may occur at home and therefore there is a need to educate and make everybody in the child’s environment aware of the appropriate education and support Autistic children may need so that they can communicate and function effectively in their environment.

DAVE Sherratt, author of the book *How to support and Teach children on the Autism Spectrum*, has been working directly with children with ASD and has lectured and published on Autism for over twenty years at Birmingham University UK. As Sherratt mentions in the introduction this book is for all those who are involved and interested in working with children on the Autism Spectrum. It has seven chapters that lead the reader through an understanding of the spectrum and are full of ideas and guidelines for effective interventions.

THE narratives in the first chapter depicting a Café Scene (Tea and Cake –1 and Tea and Cake-2) are very interesting and even though the characters are not meant to be autistic they give the reader a sense of the lack of perspectives among people who are in a common situation and how they can come to a common understanding to adapt to the situation for Social Purposes. From here Sherratt brings out the different understanding of such skills that characterize social communication with someone on the spectrum. In the same chapter Sherratt addresses seemingly difficult questions in a simple and subtle manner. These questions are related to dietary interventions, cure, education etc.

IN the first few chapters Sherratt outlines very clearly the fact that children on the spectrum learn about the world in a different way and their understanding lacks the shared and common foundation for learning ‘from’ and ‘with’ others. The latter part of the book has practical strategies

to enhance skills that will enable them to get around these difficulties. In chapters four and five one finds innovative yet simple ideas that can be easily executed and achieved. As Sherratt notes, ‘Effective relationships and a sense of connectedness can be built on sharing information that is of interest’.

THEREfore Sherratt suggests role-play activities, creating situations for social understanding and drama around familiar stories and routines as very useful in developing social comprehension in children on the Autism Spectrum.

THE concluding part of the book provides the readers with more specific guidelines and suggestions to make the teaching-learning process as simple and least complicated as possible. Page 60 carries Inclusion exercises that are designed to sensitize professionals who work in the mainstream schools and these also draw their focus on how mainstreaming can bring about a difference for children with autism.

TO give an example Sherratt poses the question: ‘Rupert feels lonely in the playground and does not attempt to join in the games with other children. How might his interest in television and computers be used to help other children play with him?’ In the very framing of the question itself, Sherratt advocates a more inclusive and positive approach by helping the teacher think of how the non-autistic child can be helped to play with Rupert using the latter’s strengths, and not necessarily what Rupert must do to ‘change himself’ to fit in.

THE book also contains resource sheets for use with children, carrying the author’s permission to reproduce through photocopying or other means.

‘*How to support and teach children on the Autism Spectrum*’ is an effective guide that is reader friendly. The activities included have all come out of real classroom practice. The book not only explains very concisely and clearly the consequences of deficits in the spectrum but also leads one through a variety of practical strategies that can be implemented in all environments and at all levels. It is a useful one for those wanting to help children with Autism learn better..

LETTERS

We would like to thank everyone at Action For Autism (AFA) for helping us with our son. The work that is being done at AFA is commendable and I really wish that similar efforts by parents and professionals could be carried out in other parts of India. For this, proper awareness and training of parents and professionals is really required. I am speaking from my experience in Guwahati for the past eight years. Thanks to AFA once again. Please keep up the good work.

Anumita Paul
GUWAHATI

This is just in case any of you thought the US is monolithically 'progressive' ...there remain areas in the South that are repugnantly backward in terms of social values. And some of the stories that do make it into the media in the North demonstrate how much remains to be done in bringing disability awareness to all.

A few years ago, a Chicago couple were in the news for using a cattle prod to shock their adult son with autism into compliance. Until recently, an institution for autistic individuals in New York State was putting their wards in total seclusion in the equivalent of a box with holes, and — get this — administering electric shocks to them *to curb their self-injurious behaviors* ! Some of the parents of those children knew about this, and *defended the school's methods*!

Stories like that make me wonder how much of what is happening in India we never get to hear about, and hear about in a manner that helps us process its meaning and significance, in a way that makes us comprehend that people that look and act differently because of circumstances beyond their control are not *objects* — but rather, reflections of *ourselves* as we might look if *we* had a closed-head injury tomorrow, or were resuscitated from a drowning accident, or survived any number of other afflictions.

When I was in Gurgaon last year, I witnessed television coverage of a story about a deranged woman that turned my stomach. This woman was absolutely terrified, she was in the street begging people to save her because she

believed some people were trying to kill her. An enormous crowd had gathered around, television cameras covered her every facial grimace, and they were conducting this back and forth question and answer session between the studio and reporter on the scene as though she were a cornered animal in the wild, not a person.

Not that I would treat a cornered animal in that manner either. I would have liked to be on the scene to tear-gas those crowds, give the cameraman and reporter a concussion, and comfort and calm the woman.

Chitra Raman
USA

Ryan's Law

On the last day of the legislative session of 2007, the South Carolina legislature passed what is known as Ryan's Law. The law is named after Ryan Unumb, a six-year-old who has autism. Ryan's mother Lorri is a lawyer who wrote the bill that became Ryan's Law, and she counts this as her finest professional accomplishment.

Typical of the autism movement everywhere in the world, parents of autistic children have achieved more rights for their children than any government is willing to concede.

Married to Attorney Dan Unumb, and with two younger children, Christopher and Jonathan, Lorri fought a two-year battle to ensure that insurance companies will pay for autism treatments.

Since the passage of the Law at the end of last year, over 20 other states in the United States have subsequently introduced bills similar to Ryan's Law in their legislatures and families hope most of these will be passed into law.

अतीत का क्रन्दन

अनुराग श्रीवास्त

2002, 19 अगस्त, ऑटिज़म का अर्थ देखने के बाद मैंने छुपा दी। खुद को सम्हालने के लिये मैं बाहर चला गया। हाथ मुँह धोने के बाद जब कमरे में घुसा तो पाया गरिमा राब्दकोश हाथ में लिये रो रही है। आज सुबह अपोलो गया तो पता लचा कि मेरा मिलेनियम बच्चा सुन सकता है, मगर उसको षायद आटिज़म है जिसके लिये हमें मेहनत करनी पड़ेगी। हम बहुत खुषी खुषी घर लौटे। घर पर कुछ और विडम्बना हमारी प्रतीक्षा में थी। ममता मोम की तरह, बच्चा कपड़े, असु धार में अविरल बह रही थी। मैं इतना कमजोर हूँ ये मुझे नहीं मालूम था। सब मिथ्या है। ये पराक्रम वो पौरुश का रंज, गौरवमयी अतीत, स्वर्णिम भविष्य की कल्पना –सब मिथ्या। मृत्यु सत्य है। काष आज कुछ हो जाये जिससे हम तीनों धरती की गोद में समा जायें। हृदय क्रन्दन कर उठा।

ये तो आम बच्चे की तरह था/ इतना भोलापन था। कई बार हमने एक दूसरे से कहा वत्सल हमेषा ऐसे रहे तो कितना अच्छा हो। षायद कहीं तारा टूटा हो तभी। आज भी उतना भोला है। हम दोनों रो रहे हैं और ये सो रहा है। रात रोते बीत गयी।

*जो घनीभूत पीड़ा थी
मस्तक में स्मृति सी छाई
दुर्दिन में आंसू बनकर
मेरे क्रन्दन में बजती
क्या वीणा, जो सुनते हो
धामों से इन आँसू के
निज करुणा पट बुनते हो।*

जयषंकर प्रसाद

व्यक्ति मन, निर्जीव चित्त दो दिन तक घर पड़ा रहा। कदाचित्त कुछ नेक कृत्य किये रहे होंगे, वर्ना सत्संग कहां आसानी से मिलता है। किसी अभिभावक का साथ मिला, जो व्यथाकी उसी परिकाश्टा से निकल चुका था। उस समय मैं था। उसकी पंक्तियां आज भी मेरा ध्येय बनी हुई हैं। व्यथित मन् किसी

दूसरे के सहारे की आषा करता है जबकि हमारा सहारा हम स्वयं हैं।

ईश्वर ने हमें इतना समर्थ समझा कि वत्सल को हमारा पुत्र बना कर दिया है। परम्पिता के आग्रह को वरदान समझकर स्वीकारना होगा।

हृदय आलौकिक आनन्द से भर गया। ईश्वर की सत्ता पे मेरा विष्वास चाहे पहले उतना ना रहा हो मगर उसके वरदान ने अनगिनत अभिलाशाओं को करवट दे दी है। नीख सी कालिमा रात भी अब कलरव कर रही थी। मेरा पौरुश षायद अब लक्ष्य पा चुका था। रजनी अब अरुणोदय की प्रतीक्षा में थी। व्याकुल मन उस मधु सौरभ से खिलने लगा था।

स्नेह का दीपक आलौकिक प्रेम में प्रज्वलित हो रहा था। छः साल और संघर्ष अविराम। ध्येय यही की विकास हो परिणाम। हर दिन, हर पल मेरा वत्सल कैसे निष्चिन्त सोता है। कैसे मस्त क्रीड़ा करता है; कैसे गेट पर चढ़ता है, कैसे आलिंगन से आनन्दित होता है, कैसे झूले के पेंग से मुस्कराता हुआ धन्यवाद देता है, छोटी सी पन्नी से खुष रहता है।

विचार तन्द्रा की सीपी में रत्नाकर का आभास हो चुका था। भावना सागर की गहराई में छुपे सुःख का आत्मसात् हो चुका है। विचार सुव्यवस्थित हो गये हैं। छः साल का ये पथ अब है आजीवन आषायें असीम उत्साह उपवन, ज्वालामुखी जगत्, मैं काकामें बड़वानल यान्त्रिक जीवन, ममता सजीव अट्हास करता अतीत का वो क्रन्दन।

वत्सल के माता-पिता ने ऑटिज़म को एक बहुत ही साकारात्मक या पोजिटिव ढंग से अपनाया है। उसकी माँने स्वयं वत्सल के साथ काम करने की ट्रेनिंग ली है और अब वह ऑटिज़म से प्रभावित और दूसरे बच्चों और उनके परिवारों के लिये कार्य करने के लिये औपचारिक प्रशिक्षण ले रहीं है, जिसके पश्चात् वह ऑटिज़म शिक्षिका बन सकती है।

मनोदषा सम्बन्धित संकल्पना का ज्ञान

इन्दु चसवाल

आम बच्चे मनोदषा समझना (स्वयं और दूसरों की) स्वभाविक रूप से अपने विकास में सीख लेते हैं, परन्तु ऑटिस्टिक बच्चों को इसका ज्ञान देना पड़ता है और वह भी एक बहुत ही आयोजित ढंग से। मनोभाव समझने के पाँच स्तर या लेवल बताए गये हैं और ऑटिज़म स्पेक्ट्रम डिर्साडर से प्रभावित बच्चों को यह स्तर सिखाने की विधि में साइमन बैरन कोहन नामक मनोवैज्ञानिक और उनके अनेक सहयोगी (पैटरिषिया हॉलिन, और जूली हैडविन) का बड़ा योगदान रहा है।

मनोदषा समझने के पाँच स्तर:-

स्तर-1

फोटोग्राफ देखकर मनोभाव पहचान लेने की क्षमता (प्रसन्न, दुख, भय और रौद्र) इन मनोभावों को हम 'खुश' उदास, डर, गुस्सा जैसे सरल शब्द देकर और फोटो में संबंधित चेहरे के एक्सप्रेशन दिखाकर सिखाते हैं।

स्तर-2

आरेखीय चित्रों द्वारा इन भावों की पहचान करने की क्षमता। मनोभाव से संबंधित रेखा चित्र बनाकर उनकी पहचान सिखाना।

स्तर-3

स्थिति या परिस्थिति के आधार पर मनोभाव पहचान लेने की क्षमता। किसी चित्र को उसके भावनात्मक पहलु से पहचान लेना।

स्तर-4

इच्छा और अभिलाशा के आधार पर मनोभाव पहचान पाने की क्षमता। इसमें बच्चा पहचानता है कि किसी व्यक्ति की

इच्छाओं की पूर्ति होने या ना होने पर, जो मनोभाव व्यक्त होते हैं।

स्तर-5

व्यक्ति की क्षमता जिसके द्वारा वह अपने विचार और यकीन के आधार पर दूसरे के क्या मनोभाव होंगे।

हम पहले तीन स्तर जो सबसे महत्वपूर्ण हैं, उनकी चर्चा करेंगे।

स्तर-1

फोटोग्राफ द्वारा चेहरे के भाव की पहचान

ब्लैक और व्हाइट (श्याम व श्वेत) फोटो लेने होंगे। यह फोटो व्यक्तियों के चेहरे के हों। इन फोटो में स्पष्ट रूप से खुश, उदास, गुस्सा और डर भाव दिखने चाहिए। दूसरे शब्दों में यह कहा जा सकता है - खुश उदास, गुस्सा और डर वाले चेहरों के फोटो (ब्लैक एण्ड वाईट) लीजिए।

अपने पढ़ाने के या सिखाने-सीखने की क्रिया को आसान व सरल बनाने के लिये, बच्चे के सामने तीन या चार चित्र रखे (चारों भाव दिखाते हुए) परन्तु पहले केवल खुश चेहरे की पहचान की प्रैक्टिस दें। बच्चे को स्वयं आप खुश चेहरे पर हाथ रखकर या फोटो उठाकर, बच्चे को दिखाकर बोले 'खुश'। इस प्रकार कुछ तीन-चार बार करें और फिर बच्चे से कहें "खुश" दिखाओं। बच्चा यदि सही रिसपॉस (जवाब) देता है तो उसे प्रतिबलन (रिइन्फोर्स) करें। यदि वह सही चित्र नहीं दिखाता तो आप स्वयं उसका हाथ "खुश" चेहरे पर रखकर कहें 'खुश'।

ठीक इसी प्रकार आप अन्य तीन मनोभाव उदास, डर, गुस्सा भी सिखाये और फिर बहुत सारे चित्रों द्वारा आप इन भावों

के आधार पर चित्रों की सारटिंग करवाये इसका अर्थ है— बच्चा सारे खुशी के भाव एक ढेरी में, दुख के एक, डर के एक साथ, गुस्से के एक साथ रखेगा।

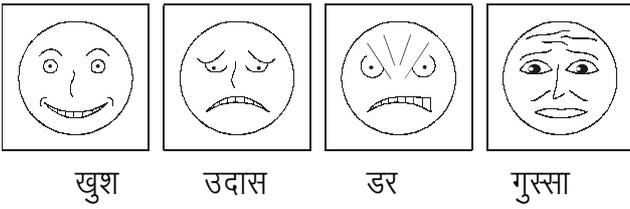
यह चित्र असली के फोटोग्राफ, या मैगजीन से कटे हुए चेहरो के चित्र हो सकते है जिनके कार्ड बना लें।

स्तर-2

चेहरे के भावों के रेखा चित्र की पहचान

जब बच्चा पहले स्तर को प्राप्त कर लेता है, तब हम दूसरे स्तर की पहचान देते हैं। इसके लिये हम चार रेखा चित्र काले मारकर पेन के साथ सफेद कार्ड पर खींचते हैं। यह चार चहरों के रेखा चित्र खुश, उदास, डर, एवं गुस्सा दर्शाते है (चित्र-1)

सिखाने की क्रिया बिल्कुल स्तर-1 जैसी होगी। जब बच्चा इन रेखाचित्रों को पहचानने लगता है तब स्तर 1 में प्रयोग किये गये फोटो और स्तर 2 के रेखाचित्रों की मैचिंग करवाई जा सकती है। उदाहरण फोटो पर खुश चेहरा साथ खुश रेखा चित्र को मैच किया जाये।



चित्र 1

स्तर-3

स्थिति से प्रभावित होने वाले मनोभाव।

यह भाव क्या होंगे, यह सिखाया जाएगा। रेखा चित्रों का प्रयोग यहाँ भी किया जाएगा पर एक ऊँचे स्तर पर।

अब हमारे बच्चे को सीखना है कि किसी स्थिति में क्या भाव हो सकता है। इस क्रिया को सरल बनाने के लिये हम हाथ से चित्र खींचेंगे परन्तु चित्र में जो व्यक्ति है उसके चेहरे की बाहरी रेखा बनाकर छोड़ देंगे।

बच्चे के सामने चित्र द्वारा स्थिति प्रस्तुत करेंगे,

स्थिति :- पवन सड़क पर दौड़ रहा है, उसके पीछे कुत्ता दौड़ रहा है। (चित्र दिखाये) चित्र -2

बोलें:- देखें पवन के पीछे कुत्ता उसे पकड़ने के लिये दौड़ रहा है।

प्रश्न:- पवन को केसा लग रहा है? (चारो मनोभावों की रेखाचित्र पट्टी पेश करें।)

बच्चे का उत्तर:- डर, के रेखाचित्र पर हाथ रखेगा और बोल भी सकता है डर (यदी वह बोल पाता है तो।)

अगर बच्चे से गलत उत्तर मिले, तो उसे सही चित्र पर हाथ रखवाकर बोले 'डर' लगा

अन्य उदाहरण :-

1. जब आपको गिफ्ट (उपहार) मिलता है तब आपको कैसा लगता है?
2. जब आपको माँ म्यूजिक चलाकर देती है, तब आपको कैसा लगता है?
3. जब आप सड़क पर चलते समय गाय देख लेते हो तो कैसा लगता है ?
4. जब कोई दूसरा व्यक्ति आपके खिलौने ले लेता है तो कैसा लगता है ?
5. जब टीचर ने रोहन को झूले पर बिठाया तो रोहन को कैसा लगा ?
6. जब टीना को सोनू ने धक्का दिया तो टीना को कैसा लगा ?
7. आज टिंकू की बर्डडे पार्टी है। उसे कैसा लगेगा ?

समर कैम्प 2008

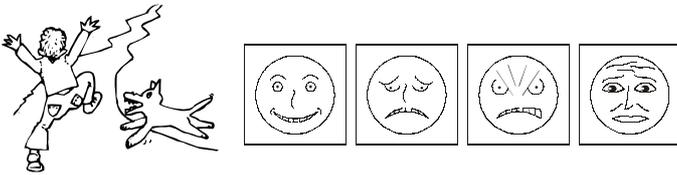
उर्मिला तनेजा

इन सभी प्रश्नों के उत्तर के लिये आप बच्चे से मौखिक उत्तर या फिर स्तर-2, 3 में प्रयोग की गई रेखा-चित्र पट्टी का प्रयोग कर सकते हैं। यदि बच्चा बोलकर उत्तर न दे सके तो सही रेखा चित्र को हाथ लगाकर बता सकता है। स्थिति जो आप प्रस्तुत कर रहे हैं, वह आरंभ में चित्रों द्वारा हो और आगे चलकर यदि बच्चा कर पाये तो मौखिक रूप से पेश करें।

इस प्रकार जो बेसिक या बुनियादी मनोभाव सिखाये जाते हैं। इन्हें आम जीवन में प्रयोग में लाने के अनेक अभ्यास किये जा सकते हैं। जब बच्चा स्वयं इन भावों का अनुभव कर रहा हो, तो उन्हें लेबल या "नाम" दें। यदि बच्चा हँस रहा है, जम्प कर रहा या मुस्करा रहा है और आप जानते हैं तो आप स्वयं कहें "राजू (बच्चे का नाम) खुश है"। जब वह किसी विशेष कारण से रो रहा हो या चुप बैठा हो तो कह सकते हैं "राजू (बच्चे का नाम) उदास है। इट इज ओके।" इस प्रकार दूसरे मनोभाव डर, गुस्सा भी लेबल किये जा सकते हैं। धीरे-धीरे स्थिति का भी संक्षिप्त वर्णन कर सकते हैं जैसे-

1. वीना को कुत्ता देखकर डर लग रहा है।
2. दीदी ने रोहन का बॉल ले लिया रोहन को गुस्सा आ रहा है।
3. टी.वी. में ऑटी रो रही है। ऑटी उदास है।

इन बेसिक मनोभावों के समझने पश्चात अन्य और मनोभाव जैसे "हैरान" सरप्राइज भी बताये जा सकते हैं। घर में और स्कूल में प्रिटेन्ड प्ले स्वींग रचित खेल द्वारा हमें इन इमोशंस की प्रैक्टिस दे सकते हैं।



चित्र 2

गर्मी के महीनों का आरम्भ होते ही बच्चों को रहता है छुट्टियों का इन्तजार। इन गर्मी की छुट्टियों में बच्चे अनेक एक्टिविटीज़ का आनन्द लेने के लिये कोई भी समर-कैम्प में भाग लेते हैं। इन समर-कैम्प में वे ऐसी एक्टिविटीज़ करते हैं जो कि आम दिनों में नहीं कर पाते।

ओपन डोर के बच्चों को भी यहां आयोजित समर कैम्पमें भाग लेने की उत्सुकता रहती है। साल 2008 में, ओपन डोर का यह तीसरा समर कैम्प आयोजित हुआ। इसकी अवधि 12 मई से पुरु होकर 10 जून तक थी। चार हफ्तों के इस प्रोग्राम में बच्चों को तीन गुप में बांटा गया। इन गुप को रोज़, ट्यूलिया और सनपलावर नाम दिए गए।

समर कैम्प में बच्चों की जरूरतों को ध्यान में रखते हुए एक्टिविटीज़ को चुना गया। बच्चों ने इन सब में भाग लिया :-

- चित्रकारी,
- खाना बनाना (हल्के-फुल्के स्नैक्स),
- तरह-तरह के खेलों,
- डांस तथा
- संगीत

इसके अलावा बाहर घूमने का प्रोग्राम भी था। जिसमें बच्चों ने सैर करना, मॉल में घूमना, डॉमिनोज़ मिज्ज़ा जैसी जगहों का आनन्द लिया।

समर कैम्प में आक्यूपेशनल चिकित्सा का भी प्रबन्ध था। बहुत अर्धिक मात्रा में बच्चों के साथ इस चिकित्सा द्वारा काम किया गया। समर कैम्प के आखिरी दिन पूल-पार्टी का आयोजन किया गया। इस दिन संगीत, खाने-पीने के साथ प्रमाणता-पत्र भी बच्चों को बांटे गए।

शिक्षकों ने भी समर कैम्प का भरपूर मज़ा लिया। समर कैम्प 2008 बहुत ही उत्साहित कर देने वाला अनुभव रहा। इसमें ओपन डोर के साथ अन्य दूसरे बच्चों ने भाग लिया। आशा करते हैं कि ओपन डोर इसी तरह हर वर्ष समर कैम्प का आयोजन करेगा और अर्धिकतम सफलता प्राप्त करेगा।

HELPLINE



Q I would like to know about cure of autism with the help of medicines as my son is autistic. It is learnt that FRAXA is trying to develop medicine for cure of autism. Can we be hopeful for cure or some reduction in autistic behaviour? Are the researches continuing on Gene/ Chromosomes, that can give us some hope.

A There is a great deal of research underway, and some of it is towards finding a medical cure for Autism. Some of the research follows proper scientific practices (proper documentation, accurate data collection, control groups, placebos, etc), and others may not. There is also research in the area of genetics. Even though there are periodic reports in the media about a researcher having found a 'cure' or a fabulous breakthrough with the tone being that the cure will be marketed tomorrow, they are more hype than fact. Till date, though, there have been interesting insights, no immediate breakthrough have happened and as of now no medication to cure Autism.

There are however some medicines that can be given to an individual with autism for symptomatic relief for some associated behaviours or conditions such as hyperactivity, extreme ritualistic/ obsessive behaviours, anxiety, and so on, if these behaviours come in the way of the individual's learning or functioning in daily living. While some medications are quite helpful, most have some adverse side effects, so it may be advisable to consult your general physician, or your child's neurologist / psychiatrist / pediatrician who has ample experience in dealing with individuals with autism to get a clearer picture vis a vis the medication.

I reiterate, there is no medication as of now, that can 'cure' the core differences in Autism.

However, all people with autism can learn and show progress, irrespective of their age or the intensity of their autism. The most effective and well documented treatment option for individuals with autism is education based on behavioural principles with a focus on the core areas of impairment, i.e. communication and social understanding. Any work with the child will have to focus on helping the individual enjoy social interaction and understand social rules, and on teaching communication. Along with this a focus on activities of daily living is also important.

Consistency in teaching, and clarity and clear structure, while keeping the methods of teaching concrete and literal ensure that individuals with autism learn well.

Q Since long time I have been thinking to open a school and early intervention center for children with cerebral palsy and autism. I am currently working outside India.

Can you please help by giving the following information.

1. What is the legal procedure to get registration of such kind of school?
2. If I want to open the school in West Bengal whom should I contact ? Do you have any contact info?
3. What is the best, safe and quick way to start this?

A Your desire to start a school is commendable. You will of course have to register yourself as a trust or a society. The procedure to follow differs from state to state. So I suggest that you buy a book on the subject which would be available from any legal bookstore. The book will give you all the information in detail: on how to form a body and go about registering it.

However, first in order to start a school you will need people who are experts in the field. You will also have to recruit trained staff. The number of staff you will need will be based on what size of school you wish to start with, and to what size you plan to expand to.

So as you can see, much will depend on your short and long term plans.

You will also need to have a place i.e. location to run the school from, a starting capital, and plans on how to be self sufficient.

Finally, there is no quick way of going about this. There are no shortcuts. If you want to do this, and to do it well, then you have to be prepared for the long haul.

Q I am a social work student at Coker college in South Carolina. I am doing a research project on autism insurance coverage. I am comparing and contrasting coverage and legal issues of autism here in America with

issues in India. Could you please give me information on autism policy in India, and mail me any documents that I could use.

A In India issues related to Autism are being addressed steadily and the process has started only in the recent years. The Government of India has a number of policies addressing different needs in the field of disability but as of now not all are applicable to Autism. However there are schemes, policies, acts through which several benefits can be availed but at present the challenge before persons with Autism is that of getting a disability certificate that defines the percentage of disability in the person. The work on developing an autism specific test for assessment of the extent of disability in a person with ASD is still on.

Some of the Important Acts and Government bodies working for the rights and welfare of the disabled are-

1. The Rehabilitation Council of India A statutory body under the Ministry of Social Justice and Empowerment. It monitors and supports the rehabilitation services in the country. You can find out more on their website <www.rehabcouncil.nic.in>

2. The National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation, and

Multiple Disabilities also under the Ministry of Social Justice and Empowerment. The main focus is to look into matters related to legal guardianship and rehabilitation of persons with these disabilities in the case of the death of the parents. The execution of the Trusts mandate is carried out by the National Trust office located in New Delhi and the Local level Committees that are appointed and established by the trust in different districts in the country. For more information you can visit their website: www.nationaltrust.org.in

3. The Persons with Disabilities Equal Opportunities, Protection of Rights and Full Participation Act. For details check out <<http://socialjustice.nic.in/disabled/welcome.htm>>

4. Sarva Shiksha Abhiyan is a Government initiative working towards the realization of Universal Elementary Education For All. Their website is www.ssa.nic.in

Other benefits for people with autism include an Income Tax rebate for individuals and also for the parents in case the individual is dependent. There is an exemption of tax on income up to Rs 75,000 in case the percentage disability is 80% and more and on income up to Rs 50,000/- in case the percentage of disability is below 80%.

ANNOUNCEMENT

Workshop for Teachers in Mainstream Classrooms **Understanding & Including Children with ASD** **and Communication Handicaps**

DATE: Saturday 8 - Sunday 9 November 2008 TIME: 9.00 - 4.00 pm

VENUE: The National Centre for Autism, New Delhi

Children with autism and other social-communication disorders often face difficulties in coping with the demands of the mainstream classroom, in spite of supportive teachers and intellectual and cognitive capability. As a result children on the spectrum fall behind, and are perceived as lazy and combative. Their different social understanding make them appear to be disruptive and provocative, and they often end up being punished repeatedly, leading to spiraling behaviours and what are perceived as 'disciplinary issues'.

The two-day workshop is designed to assist teachers develop approaches based on an understanding of

different abilities. The sessions will focus on planning and executing flexible and effective curriculum and learning environments. Participants will understand how to implement curriculum for the ASD students that can improve their quality of life.

This workshop will lay the foundation for a second workshop that will address advanced Remedial Teaching to develop understanding of concepts in the students leading to successful learning.

For information contact:

Shikha Bharadwaj: 91 11 40540991, 40540992 Email : shikha.afa@gmail.com

Asperger's Syndrome: Deficiencies or Selective Advantages?

Nidhi Singhal, PhD, Clinical Psychologist

In 2002, Vernon Smith received the Nobel Prize for inventing the field of experimental economics, which uses laboratory methods to test economic theories. He says his capacity for deep concentration contributed to his ability to win the Nobel Prize. Prof Vernon Smith has Asperger's Syndrome. This is no lonely feat. Geniuses throughout history, including Albert Einstein, Andy Warhol and Emily Dickinson, have all been thought to have had Asperger's Syndrome. It is a common belief that a number of highly influential executives may also have Asperger's or are on the autism spectrum.

THE term autism, when attached to a child, is bound to come as a profound shock at first - but if you look closer, you may find several positive aspects. As Donata Vivanti, president of Autism-Europe and Autismo Italia, points out, *"When you get to know them, you realise that people with autism cannot lie, do not understand the concept of hypocrisy, and, even if their behaviour can seem bizarre and inappropriate, they never harbour ugly intentions."* Many individuals with autism have a great gift for focusing on detail and as they focus on their narrow fields of interest, with appropriate help some may be able to constructively pursue those interests with great intensity. Prof Smith elaborates that when he is involved in a certain activity, for instance, if he is writing something, nothing else exists for him. He says, *"I can switch out and go into a concentrated mode and the world is completely shut out."*

FURTHER, for him impairments in social interactions and inter-relatedness translate professionally into *"a lack of social pressures to do things the way other people are doing them"*. Prof Smith says, *"I don't have any trouble thinking outside the box, and so I have been more open to different ways of looking at a lot of the problems in economics."* Though social situations are not his 'favourite pastime', Prof Smith finds that teaching has forced him into being more social. He shares that social situations that last for a couple of hours are a tremendous strain where people often describe him as 'not there' and he much prefers going to bed and reading instead. In contrast, Prof Smith portrays teaching as a comfortable dimension where he is able to talk about things that he has a lot of experience with, and relate to students very

easily in that mode. According to Prof Smith, *"They're in my world. And there are maybe worlds out there that I don't understand, so I don't go there."*

HIS wife, Candace Smith says it is hard at times to understand why her husband can't be part of her emotional world. She shares, *"He might not always know what he feels. In fact, many times he doesn't. If you ask him what are you feeling right now, he'll say, 'I don't know. What do you mean what am I feeling?' Ask him what are you thinking and he says, 'I don't know that either. I can't tell you those things. I don't know those things. Ask me something interesting.' But if you ask him, what are you doing, he will say, 'Oh, I am doing this' and he will show me."* Candace Smith says she's found comfort in the Asperger's label because it has helped put some of her husband's actions into perspective. *"If you didn't have these words like autism or Asperger's as entry words into your own experience and understanding then you could categorize a child or adult as unemotional, cold, and insensitive. Many people don't understand Vernon and they conclude wrongly about him," she says.*

FOR Prof Smith, finding out that he had Asperger's meant that there were other people he could relate to in terms of particular characteristics that 'always tended to seem strange in the eyes of other people'. Living with autism, Prof Smith is of the opinion that society has many different kinds of minds, and it is important to recognize that certain mental deficiencies may actually have some selective advantages in terms of activities. He believes that *"We've lost a lot of the barriers that have to do with skin colour and with various other characteristics. But there's still not sufficient recognition of mental diversities. And we don't all have to think alike to be communal and to live in a productive and satisfying world."*

A diagnosis of autism can open doors - it is essential if you want to open doors. The vast majority of individuals with Asperger's Syndrome need help to overcome a great deal of difficulty, to maximize their potential and to get the things in life they deserve. Prof. Smith's success is not typical of people with autism but he does exemplify the potential of people on the spectrum by being able to use his strengths to get around his difficulties.

Understanding & Teaching Children with ASD An RCI CRE Programme

DATE: *Wednesday 1 - Sunday 5 October 2008* VENUE: *National Centre for Autism, New Delhi*

AFA's annual workshops are an eagerly awaited event each year. The workshops build on an understanding of ASD and work through teaching various cognitive, communication, and daily living skills. They are free of jargon, and illustrated with practical examples based on AFA's hands-on experience and exposure to children with autism of varying ages and across the spectrum and follow a format of lectures, a demonstration class, video clips, question and answer sessions and discussions.

Individual consultation available at no extra charge on the last day of the workshop to those who book in advance .

Reading material: Books & handouts on understanding autism, interventions, and personal accounts on sale.

Childcare will be available during workshop hours for families who find it difficult to leave their children at home. **Please register in advance.** The *Child Care Registration Form* must be filled in and submitted ahead of the workshop so that adequate arrangements can be made.

Do register in advance. *Last date to register is 14th September. Childcare will not be available to on-the-spot registrants.*

Registration Costs

- *Parents*

~ Rs 2000/- per parent attendee (Rs 1650/- for life members & full annual members)

~ Rs 3500/- per parent couple (Rs 2500/- for life members & full annual members)

- *Non-parents*

~ Rs 3000/- per non-parent attendee (Rs 2500/- for life members & full annual members)

~ Rs 2700/- for each attendee from an organization that has taken membership if more than one person attends

- *Registrations received after 14 September 2008*

~ Parent 3000/- , Non-Parent Rs 3500/-

20% of total payment deducted as handling charges on cancellation received by noon of 15 September 2008.

No cancellations after noon of 15 September 2008.

Daycare charges

- Rs 200/- per child, per day

Accommodation

Limited number of shared accommodation on first come first served basis, from noon of 30 September to noon of 5 October at Rs 1000/- per person for a five-night stay without food. *Last date for booking accommodation: 21 September 2008.*

----- CUT HERE -----

PRE-REGISTRATION FORM UTCA 08

Do fill this form in **BLOCK LETTERS** and mail, with a self-addressed stamped envelope to:

Action For Autism, Pocket 7&8 Jasola Vihar, New Delhi 110025

Name _____ (Tick relevant box) Parent Professional

Address _____

Tel. _____ Email: _____

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

Please find enclosed a Demand Draft No _____

dated _____ drawn on _____ Bank _____

Do you require accommodation YES/ NO _____ Do you require childcare YES/ NO _____

(cont from page 1...)

will need to learn that other people too may not want their private parts touched without consent.

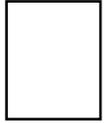
ANOTHER important focus that needs to become a part of the daily routine is good hygiene practices. Personal hygiene can be a concern for parents when their child is going through puberty. Pubertal development with extra hair and newly active sweat glands can lead to offensive odours, which the individual with autism spectrum disorder may not recognise are a cause for concern. The person may not recognise how they are perceived by others, understand what is socially acceptable, or might be avoidant of self-care tasks because of the sensory issues with brushing teeth, and brushing or washing hair.

WE have to use the same teaching strategies that are used to teach children other skills. Given the strength in visual skills for individuals with autism spectrum disorder, in order to teach the individual about puberty and sexuality it might be useful to use modelling, photos, line drawings, and even 'how to' videos, and reducing language prompts as far as possible. Some other strategies may include visual schedules or check off lists, videos, facts in books, pictures of what is happening to their bodies, separate social stories personalised to the individual adolescent to clearly state the facts. These will help prepare the individual as well as tell them what they may do.

NONE of us has a crystal ball to predict how an individual will respond to the challenges of puberty. An individual may require assistance with all or none of the issues outlined in this article. Being informed in advance may just mean as a parent or carer there is not the element of surprise and uncertainty as to how to approach such challenges as and when they do arise.

WHEN faced with a situation, most carers will have to deal using strategies on a 'trial and error' basis. There are no magic answers. Teens and adults with autism present us all, whether we are a parent or a professional, with huge life-long challenges. They also offer us, as individuals, opportunities to develop empathy and unconditional acceptance. We cannot be exposed to a son, daughter, child or adult with this disorder without being affected. Whether our experience of this challenge is positive, and promotes personal growth, lies entirely in the open-minded manner by which we approach the individual and the issue. We have to think of puberty as just another stage of development: Embrace this time and move forward.

BOOK POST



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