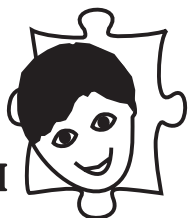


# autism network



ACTION FOR AUTISM



# autism network

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## YOUR CONTRIBUTIONS

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

Cover Illustration

**'Solid Works  
Train Modelling'**

Awayuukt Banerjee, age 13 years, from Noida, NCR

## WISHLIST !

- Computers & Computer Accessories: keyboard, speakers, mouse
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# PAGE ONE

From the time that Action For Autism started over 25 years ago, great strides have been taken, in areas of awareness, in mushrooming services, in policy changes. Of course, in a country of a billion-plus much of it feels like a few drops in the ocean. Regardless the changes are noteworthy. However, despite all the awareness, laws and policies and services, the one constant that remains is that autistic people continue to be viewed through the lens of aggression, lesser beings, psychotic, learning deficient, and in short - people to be fixed. Our perception is so skewed that rarely is it considered worthy to ensure that programs are based on an understanding of the people we are trying to fix.

The goals of most programs are driven largely by the expectations of teachers and aspirations of parents (who are coping with 'shattered dreams'). Where in this does the will of autistic individuals figure? What are their experiences? Do they have any say in how their own lives are lived?

Programs often talk about the 'good life', something that is given to subjective interpretation. One person's idea of a good life can be having a small one bedroom place to stay, enough money to get by, and lots of books to read. For another person, the good life can be having at least one BMW and a Corvette in the garage and be able to take at least three international holidays in a year. Neither is good or bad. These are just personal perspectives.

As practitioners, do we consider the 'good life' from the perspective of the person with autism for whom we are planning that life?

At AFA workshops we often do a session where we first ask participants: what do they want in their life. We then move on to what, as parents and professionals, the participants want for their autistic children. The responses are expectedly always about independence. Adaptive functioning. Academic achievements. Only when we probe further do respondents' realisation sink in, that the ultimate aim is happiness. And emotional well-being.

Which brings us to the consideration of the how much of what we do actually contributes to the well-being of individuals with autism.

We believe that one of the ways to wellbeing for people is to be viewed positively, being spoken of in positive terms and to hear themselves spoken about in words that respect their being. In reality, for most autistic individuals, the lived experience is of being referred to as 'problems'. Right from the diagnostician to parents, to teachers and other professionals, the reference to them is always as 'problems'.

Typically, when the world sees our children stimming, or showing any behaviour that does not fit into the neurotypical mould, they come up and ask:

"Does he have a problem?"

"Why is she doing that?"

And the usual response is one of angst and anger accompanied by:

"Yes."

"She has a problem."

Rarely do carers respond with

"She is different."

"He has autism."

It is the problem that is paramount.

Imagine a life spent being referred to as a problem. As a person who has shattered parents' dreams. How soul destroying is that.

How can we promote happiness and well-being in our children if we view them as problems who have destroyed our lives?

In this issue's lead article 'Happiness In Autism Spectrum Disorders: The Importance Of Assessing Emotional Well-Being' the redoubtable Peter Vermeulen discusses the clinical measures and tools that are used to evaluate success for persons with autism. It is telling that most evaluations of quality of life of people with autism focus on the negatives like stress, anxiety, depression, rather than on positive experiences and how happy people with autism are. Of course, measuring a subjective concept such as happiness would have to rely on self-reports, not a strength for people with autism, even for high functioning individuals. In his article Vermeulen describes some wonderful and concrete ways to assess well-being in autism.

*cont on Pg 17...*

# Happiness in Autism Spectrum Disorders: The Importance of Assessing Emotional Well-being

By Dr Peter Vermeulen

It is remarkable that emotional well being and the pursuit of it, although being highly valued for every human being, have received so little attention in research on autism spectrum disorders. Studies of the effects of certain treatments, for instance, rarely take emotional well being as a desired outcome. The effects of treatments are instead evaluated by measurements and assessment of aspects such as number and degree of autism symptoms, levels of cognitive functioning, measurements of all kind of skills and behaviours, in particular social skills. It is nice to see that certain treatments of autism are evidence based, showing evidence of a significant increase in the children's IQ's and adaptive behavior scores, a decrease in challenging behaviours, less needs of support and more inclusion.

But are these children who are post treatment smarter, more skilled, less challenging, more independent and more included, necessarily, also happier? What is seen in research of treatment effects is also true for follow up or outcome studies, studies that explore the outcome of autism in adulthood. When assessing the outcome of autism in adult life, mostly rather 'objective' criteria are being used. We look at whether adults with autism have a job or not, where they live, what their levels of cognitive and adaptive functioning are, if they have friends and how many, how much support they (still) need. In evaluating the outcome of autism, most studies use labels (very good outcome, good, fair, poor and very poor) based on the original criteria as defined by Rutter et al. (1967). According to these criteria, a very good outcome for example stands for living independently (alone or with a partner), being employed or in higher education and having a (near) normal life, including having friends. A very poor outcome means having no friends, no autonomy, so needing intensive and high level care in all aspects of functioning and is often used for adults with autism who live in institutions or hospitals. So, criteria for success in life exclusively focus on level of independence and adaptive functioning, not on Quality of Life and certainly not on the personal experience of emotional wellbeing. Underneath is the

assumption that success in life and happiness are based on high levels of independence and adaptive functioning. That assumption should be challenged.

To illustrate this, consider the following two cases:

*Andrew is an adult diagnosed with Asperger syndrome. He finished his studies as computer engineer successfully but did not succeed in finding a job in the IT business. He works as packer in a expedition firm, a job he finds very boring. He is ashamed of it. He lives independently in a small flat. He spends all of his free time playing computer games. The other players on those games are his friends. He had some short relationships with women, but they all finished the relationship after their first visit to his flat: he rarely cleans up (the only chair available to sit on, is the one at his computer desk), he only eats junk food, the flat does not smell very nice, and except for the specific soft drink he prefers, he has nothing to offer. He wants to have a romantic relationship and is desperately seeking one through dating sites. He is also worried about what will happen to him after his mother dies: she's the one who reminds him of all kinds of chores and things to do, such as paying the rent. He knows how to do many of those activities, so he's quite independent, but never thinks about initiating them.*

*Michael is an adult with severe learning difficulties and autism. He needs support in almost everything he does: domestic activities, free time, self care etc. He lives in a group home with 5 other adults with a disability. During the day he goes to a day care centre where he helps in the kitchen. He loves food, so he is always very eager to do whatever they ask him to do in the kitchen. Because he has a short attention span, he gets regular breaks during which he can 'play' with his favorite toys and have a cup of coffee, which is his favourite drink. At the group home he joins the free time activities that are being organized by the staff, but only when he likes the activity. He likes especially the trips they organize to the shops, the swimming pool and the animal farm*

nearby. Michael's social network is very limited (his parents and sister, who visit him regularly) but he calls the staff members 'his friends'.

According to the commonly used outcome criteria, Andrew has a very good outcome and Michael a very poor one. But who would be the most happy one?

In their study on quality of life in adults with an autism spectrum disorder, Renty and Roeyers (2006) found no evidence that IQ and autism specific traits (severity of autism) contributed to the prediction of quality of life. On top of that, neither the amount of received formal nor informal support correlated significantly with quality of life, but the perceived informal support did as well as the discrepancy between needed and received formal support. In other words, personal wellbeing does not seem to be related to the degree of disability but to the perception of support, in particular the perceived discrepancy between needed and received support. This finding was recently replicated in the Khanna et al. (2014) study, where greater perceived adequacy of support from family and friends was associated with better (health related) quality of life.

Given the fact that most studies used the traditional more objective outcome criteria, it is not surprising that these studies found a rather poor outcome for the majority of people with autism (for recent reviews, see Levy & Perry, 2011; Henninger & Taylor, 2012; and Magiati, Tay & Howlin, 2014). But is this conclusion valid? Does it really reflect how people with autism themselves would evaluate their own life? Assessing person environment fit and subjective factors such as life satisfaction and emotional wellbeing could possibly give a more complete and accurate picture of the outcome in autism (Henninger & Taylor, 2012).

A Swedish study by the research team around Christopher Gillberg (Billstedt et al., 2011) offers support for this. In 2005 that team did a large longitudinal outcome study with 120 individuals with an autism spectrum disorder (Billstedt et al., 2005). They used the traditional outcome categories based on Rutter et al.'s (1967) and Lotter's (1978) criteria and found that none of the adults had a good outcome. Instead, 21% had a poor outcome and 57% a very poor outcome. In 2011, they reevaluated the same sample, but this time, the researchers included measurements of objective and subjective indicators of quality of life and wellbeing of the adults with ASD, including an assessment of how autism friendly their environment was.

That new approach resulted in a different picture of the overall outcome, one that was, contrary to the first study, 'encouragingly positive' (Billstedt et al., 2011, p. 17). Despite the fact that almost all of the adults were (still) very dependent on parents or other caregivers for support in education, residential and occupational situations, wellbeing and quality of life was estimated by parents and/or carers to be high to very high in 91% of the cases and poor to very poor in only 4% of the adults. Quality of life was found to correlate to having regular and meaningful recreational activities, but not to the level of intelligence, nor to occupational situation and accommodation type. The studies by Billstedt et al., Khanna et al. and Renty and Roeyers support the idea that wellbeing is not necessarily associated with higher IQ, lesser severity of autism and higher levels of independence, shedding a completely different light on the indicators commonly used to evaluate the usefulness and support the evidence base of certain autism treatments. And they illustrate the importance of targeting well-being and quality of life in treatment and education.

Some researchers do focus on emotional wellbeing in autism, but usually from the perspective of a *lack of it*. Illustrative here are the studies assessing the (hypothesised negative) impact of autism on quality of life (for a recent meta analysis of these studies, see van Heijst & Geurts, 2014), showing lower quality of life in people with ASD compared to people without autism and the numerous studies of mental health issues in ASD.

There's more and more evidence for an increased risk for mental health problems in autism with prevalence numbers for depression and anxiety problems that are worrying (Ghaziuddin, 2005; Stewart et al., 2006; White et al., 2009; van Steensel, Bögels & Perrin, 2011; Strang et al., 2012).

These studies have drawn a lot of attention, resulting in a focus on assessing, preventing and treating mental health problems in autism. Although this is undoubtedly a step forward in the development of strategies to improve quality of life, it still reflects a focus on negative feelings. According to Joseph and Wood (2010) clinical psychology and psychiatry have been using a restricted and negative view of wellbeing, defining it as "an absence of distress and dysfunction" (p. 831). Joseph and Wood argue in favour of a more positive approach and call for the adoption of measures of positive functioning and to strive towards what is called

‘flourishing’ in positive psychology (Gable & Haidt, 2005; Keyes, 2002; Seligman, 2011). That means that we should not focus on preventing or treating stress and mental health problems in people with autism, but instead strive for wellbeing and ask ourselves: what makes them happy? Or, in the words of Martin Seligman, it isn’t “enough for us to nullify disabling conditions and get to zero”. Instead, we need to think “How do we get from zero to five?” (Seligman, 1998, cited in Wallis, 2005, p. A1). In other words, instead of trying to prevent people with autism from having negative feelings we should develop strategies that foster and increase positive feelings.

According to Fredrickson and Joiner (2002) a focus on positive emotions triggers an upwards spiral toward emotional well being because positive feelings broaden a person’s attention and cognition resulting in increased flexible and creative thinking. It is that kind of thinking that facilitates coping with stress (Aspinwall, 1998, cited in Fredrickson & Joiner, 2002, p. 172). Positive emotions then seem to increase a person’s resiliency and they make a person less vulnerable to stress. There is valuable clinical evidence that due to the nature of their disorder (social and communication deficits, different cognitive abilities and heightened perceptual sensitivity, people with an autism spectrum disorder are more vulnerable to stress. This is not only evident from self reports, questionnaires and observations (e.g. Gillott & Standen, 2001; Groden et al., 2001; Baron, 2006) but also from studies showing enhanced cortisol responses to stress (e.g. Eurin et al., 2003; Spratt et al., 2012; Corbett & Simon, 2013).

If Fredrickson and Joiner are right about the effects of positive emotions on cognition, then fostering positive emotions in people with autism would not only enable them to cope better with stress, but also to be less ‘autistic’ in their thinking. It is well known that people with autism show a local bias in their cognitive style and that their ‘thinking’ is less flexible (Kleinmans, Akshoomoff & Delis, 2005; Happé & Frith, 2006; Wang et al., 2007). According to Fredrickson & Joiner (2002), experiments have shown that positive emotions produce global biases, broadened attention and flexibility in thought patterns. There is still no evidence for this effect in people with autism, but at least there is reason to assume that positive states and subjective well being could alleviate the autism symptoms.

Although there’s a growing number of studies addressing emotional well being and happiness among

people with (severe) intellectual disabilities (for an overview see Dillon & Carr, 2007), the topic has remained explored in the field of autism spectrum disorders. One of the difficulties implied, apart from the theoretical discussions on the complex concept of well being and the attempts to define happiness (Dodge et al., 2012), is finding valid means of identifying happiness. Good assessment of indices of happiness can not only inform us about the emotional well being of a person but it can also help us to assess the effects of interventions on life quality. When referring to ‘evidence based’ practices in autism, emotional well being and quality of life are out of scope when looking for evidence of positive effects. In their review study of evidence based practices for children, youth and young adults with autism spectrum disorder, Wong et al. (2013) found only 1 study out of 456 evaluating the outcome of an intervention on emotional well being. One of the reasons might be the lack of reliable and valid tools to assess emotional well being. It is quite symptomatic that researchers and practitioners have developed questionnaires on stress, anxiety and depression in people with autism, but no questionnaires for positive feelings, assessing how happy people with autism are.

Since happiness is a subjective concept, it is assessed by default through verbal self reports and questionnaires such as the Oxford Happiness Questionnaire (Hills & Argyle, 2002). This poses a problem in the case of autism. First of all, self reports are useless for assessing well being in non verbal people with autism. With people who cannot express their thoughts and emotions, we have to rely on observations done by caregivers and parents.

Parsons et al. (2012) have described a practitioner oriented process for identifying and validating individualized indices of happiness and unhappiness among three adults with autism who were nonvocal or minimally vocal. But even in more able people with autism who are verbal, the use of self report is not without caution (Hill, Berthoz & Frith, 2004; Lombardo et al., 2007; Mazefsky, Kao & Oswald, 2011). Even high functioning people with autism have difficulties identifying and describing their own thoughts and feelings. Although they might know the meaning of the labels we use for emotions, people with autism still struggle to differentiate between their own emotions (Erbaş et al., 2013). This is largely due to a deficit in their ‘Theory of Own Mind’ (Williams, 2010): people with autism do not only find it difficult to recognize the

mental states of other people, it is equally hard for them to reflect on their own mental states. Besides these difficulties in the area of self awareness, the problem with self report questionnaires on happiness is that the terminology used to describe emotional well being is full of abstract, vague and ambiguous words.

Without concrete examples of concrete contexts, sentences like “I often experience joy and elation” or “I always have a cheerful effect on others” (items taken from the Oxford Happiness Questionnaire) are difficult to rate for people with autism because of their context blindness (Vermeulen, 2012), which makes it difficult to concretise abstract and vague terms (what does a cheerful effect mean concretely, how can you see it? How many times is “often”? Every day? Every week?). On top of their difficulties to make abstract and vague words concrete, people with autism also have a tendency to take things literally. This literal thinking could result in a person with autism strongly disagreeing with the item “I am intensely interested in other people” because he does not feel an intense interest in all people.

Even the concept of happiness itself can be very confusing for some people with autism or difficult to understand in its concrete meaning. A man with autism told he could never answer the question “Are you happy?” because he did not know when one should say “yes” or “no” to that question. If you have a bad day, does that mean you are unhappy then? If you enjoy a certain activity, are you happy then? And how many positive events must there be to make a day a happy day? And how many happy days do you need to conclude you are happy with your life?

Because of their difficulties with self awareness and the difficulties with interpreting the wording used in self reports and questionnaires, we developed some more concrete and autism friendly ways to assess emotional well being and happiness in people with autism. We did a try out with these materials in the activities our centre, Autisme Centraal, offers for adults with an autism spectrum of varying ages and intellectual abilities (but a requirement is that they are verbal and have at least a basic level of functional reading). These activities are cultural (such as visiting exhibitions, museums etc.), recreational (such as sport activities, bowling, table

games) and educational (psycho educational activities on relationships, the meaning of an autism diagnosis, stress management or exploring one’s own sensory profile etc.). In the light of positive psychology approach we changed our educational program on stress management into a “good feeling” program. That program offers the adults with autism the opportunity to explore the sources of their own emotional well being.

Within that program we developed a series of more concrete and autism friendly tools to assess emotional well being in adults with an autism spectrum disorder. The focus is on more concrete communication than the one traditionally used in self reports and questionnaires, contextual clarification of the abstract concepts, visualized communication and a more active engagement of the adults (not only talking, but also doing). The activities and materials described below are not evidence based and are only meant to ‘inspire’ practitioners to be creative and autism friendly in their attempts to monitor emotional well being in their clients or students with an autism spectrum disorder and to find out what makes them happy.

Because of the abstract character of the word “happiness”, we preferred to use the word “good feeling”. Based on the experiences with our psycho education workbooks (Vermeulen & Carette, 2011; Vermeulen, 2013) we found that although people with autism find it difficult to recognize and differentiate their own feelings, in general they can differentiate between a good / positive feeling and a bad / negative feeling (for those instances where they cannot, we have introduced the term “doubt feeling”, meaning they doubt whether it is a positive or a negative feeling). In the beginning of the activity we explain the concepts of good feeling, bad feeling and doubt feeling and with a worksheet we ask the persons with autism to give examples of themselves, to check their understanding of the concepts. We then explain that they are going to find out more about what gives them a good feeling, so they can strive to increase the sources of happiness in their life or ask others to help them with that.

We created three different ways to help people with autism to assess for themselves their sources of ‘good feeling’:

- The ‘good feeling street’
- The ‘good feeling’ sensory circuit
- The ‘good feeling’ questionnaire

### **Good Feeling Street**

The “good feeling street” is a kind of Post It art project and can be done with an entire school, group home or supported employment centre and can be a good alternative for the traditional art or school project exhibitions on the occasion of an ‘open house day’. However, it can also be used on a smaller scale, for instance in a social skills training where the clients first discover what gives them a good feeling, what other people can do to give them a good feeling, how they can communicate about it and, finally, what they can do to give other people a good feeling.

We did the activity with groups of 6 to 10 adults with an autism spectrum disorder. After a short introduction where everyone presents themselves, the group leader explains the goals of the activity with a visual example (a photo of a Post It wall) and the concept of ‘good feeling’ by naming synonyms and examples (happy, relaxed, positive feeling, proud, etc.). The group leader then introduces 4 categories of sources of a good feeling: sensory stimuli, objects, people and animals, activities. Each category is visually presented with photos of examples, projected on a screen. For instance, in the category sensory stimuli, we show photos of different kinds of light, temperatures, sounds (including silence), and tactile experiences. Having seen these examples, the participants fill in a worksheet with the same items where they can tick the appropriate boxes for those things that apply to them. This way, we can minimize the demands in terms of verbal and writing abilities.

On each worksheet there is an opportunity to add things that were not mentioned in the items, to maximize the individualization of the assessment. The fact that we start with giving examples reduces the demand that is usually done on imagination and cognition with traditional open questions (such as “Tell me, what gives you a good feeling?”) and the examples often help them to name things that are not mentioned on the worksheet.

The same procedure is followed for the other three categories (objects, people and animals, and activities). After completion of the worksheets, the participants copy their answers onto Post Its (support is offered for those participants that have difficulties with writing). In some groups it was possible to have them write their answers immediately on the Post Its, the worksheets then only function as a visual organizer and memory support. However, an advantage of the worksheets is that they can be re-used later for making a stress

management plan or they can be included in a person’s portfolio. All the Post Its are then used to create a display on a window or wall in the building. We used the template of a street, hence the name ‘good feeling street’. We then invited people (relatives, care takers, neighbours, friends of the adults with autism) to come and take a look at the ‘good feeling street’. We offered them little stickers with a symbol that is similar to the ‘Like it’ symbol in Facebook. When they saw something that they recognize or appreciate, they could ‘like’ it. The whole project did not only have the effect that most visitors discovered that people with autism mostly have very common sources of well being (things that give many people a good feeling, like a walk in the nature, a warm bath, preferred music), hence ‘normalizing’ the needs of people with autism, many caretakers afterwards also told us the Post Its made them more aware of the needs of people with autism and it gave them new ideas.

### **Good Feeling Sensory Circuit**

Sensory experiences are not only an important source of stress (Gillott & Standen, 2007; Corbett et al., 2009); they can – as for all people – also provoke positive feelings. When referring to sensory experiences in autism spectrum disorders texts almost exclusively mention the negative sensory experiences (such as sensory overload) and the need to prevent or avoid these. The opposite, strategies to increase positive sensory experiences, are seldom mentioned. When thinking of Quality of Life, positive sensory experiences are pivotal and often they involve changes in the environment that are easy to make.

When a person with autism dislikes taking a shower, the resistance and bad experience will decrease if the water has the right temperature, if shower gel and shampoo have his preferred scent, if the shower nozzle can be adapted to the right pressure of the water flow, if the bath towel has his favourite colour etc.

So, knowing what kind of sensory stimuli give a person a good feeling is helpful if we want to enhance a person’s Quality of Life. Most questionnaires for sensory experiences only focus on sensory responsiveness, such as hyper-en hyposensitivity or sensory integration problems, but not on whether the person finds a particular stimulus pleasant or not.

Focus has been exclusively on sensory difficulties and problems, not on sensory pleasures.



For most people with an autism spectrum disorder, verbal assessment of their sensory pleasures is difficult. Questions like “What kind of scents do you like?” are demanding a lot of imagination and are difficult to answer without direct experience. So therefore, we develop a ‘circuit’ with different ‘stations’ that give a person with autism the opportunity to explore their own sensory preferences. Each station (usually a table) offers different sensory stimuli within a certain modus, for instance different kind of music, different scents, different tactile stimuli (soft, hard, rough...) (*see ‘examples’ of the stations below*) to make it easier for people with autism, who are known to having difficulties choosing between alternatives, we maximize the difference between the stimuli to facilitate discrimination. The person with autism tries different stimuli and then rates them, indicating whether they like the stimulus or not (of course, “I don’t know” is also accepted as an answer). Notes are made on worksheets, in written or pictorial form. This results in a sensory profile that, unlike the well-known ones, does not describe the difficulties of sensory issues but the sensory likes of the person.

### Examples of Stations

- Different shower gels/shampoos with different scents (fruity, flowers, herbs...);
- Different kinds of Music (classical, jazz, hard rock, vocal, instrumental, children’s songs...);
- Different tastes: 5 cups with flavoured water: sour (lemon juice), sweet (sugar), salty (salt), bitter (tonic), umami (ve tsin/dashi);
- Different volumes of a certain (neutral) sound from silent to very noisy;
- Different temperatures (ice cold, cold, tepid, warm, hot);
- Different proprioceptive experiences (pressure);
- Different sounds (nature sounds, trains, murmur of waves, people talking...);
- Different degrees of light (from dark to very bright);
- Different textile textures (cotton, wool, corduroy, satin);
- Different colours;

- Different postures (proprioception);
- Different food textures (crispy, jelly, fluid, creamy...)
- Different drinks (bitter lemon, cola, fruit juices, milk, coffee) and drinks with different colours;
- Different fragrances;
- Different visual scenes (cities, vehicles, nature, animals...)

It is our experience that people with autism do not only love to do this activity, even the more able people with autism, but it offers a lot of useful information to increase the Quality of Life for people with autism. Quality of Life is not only the result of ‘big’ projects, such as having a social network or having a ‘job’ to be proud of, but also of many little things. For people with autism and severe learning difficulties, it makes a big difference if their environment offers them the sensory experiences they prefer: the drinks they like to drink, the clothes they prefer to wear, the amount light they like, objects and clothes in their preferred colours etc.

### Good Feeling Questionnaire

In addition to and as a replacement for all those questionnaires assessing stress, anxiety and depression, we transformed the Stress Questionnaire we had developed for trainings in stress management (Vermeulen, 2005) into a ‘Good Feeling Questionnaire’. This questionnaire assesses emotional well being in different areas that are commonly seen as challenging, but where we ask what gives a good feeling instead of stress: sensory stimuli, social events, communication, changes and transitions, rituals and stereotyped behaviours, people, objects and activities and certain thoughts. For each item, the person can indicate whether it gives him no good feeling, a little bit of good feeling, a good feeling, a very good feeling or “I don’t know”.

In addition to the items, there are open spaces and open questions, giving the opportunity to add things that are not mentioned in the questionnaire. Depending on the age and the cognitive abilities of the individual, the person with autism can fill in the questionnaire independently or with support.

The questionnaire offers no scores and is not meant for an overall assessment of the emotional well-being of a person with autism. Moreover, since the questionnaire is not a standardized tool, it does not allow comparing

individuals. The questionnaire is not meant to be used in a quantitative way, but in a qualitative way. The questionnaire is not meant to be replacing existing Quality of Life Questionnaires and the primary goal is to explore a person's preferences in order to know what to do to increase the emotional well being of the person with autism. The items are more meant to facilitate an interview about the emotional well being of the person. For instance, the item 'being touched' can be an opener for questions such as "By who do you like to be touched?" "Where do you like to be touched?" "How?" "When?" The scores can be used however, for instance to guide decisions in IEP's and individual care plans: all items with a score 3 (gives me a very good feeling) can be gathered on a single sheet, showing the 'good feeling profile' of the person, a valuable source of information for all who have to work with that person (most files on people with autism only mention their difficulties and problems, not their strengths and preferences). The 'I don't know' scores can be used to set up additional informal assessment to help a person with autism to explore his own sources of happiness.

### Conclusion

Emotional well being or happiness has received little attention in the field of autism spectrum disorders. And when the focus is on well being, it is often from a negative perspective, namely the lack of well being and quality of life in autism. Based on the principles of positive psychology, we argue for a change in focus and we suggest that instead of concentrating on the lack of emotional well being in people with autism, we should develop strategies to facilitate their feeling of happiness. Since happiness is a subjective and abstract concept and often is not known what a person's sources of happiness are (not even to the person with autism himself, because of difficulties with self awareness), it is pivotal to develop strategies and tools to assess happiness and emotional well being that are autism friendly. In this article we describe some concrete ways to assess 'good feeling' in autism.

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## A Quick Introduction to Dyslexia

By Shabnam Aggarwal

(Cont. from the Aug 2019 Autism Network)

*Myra, a mother of 10-year-old Nilay, a bright child with dyslexia, faced this. In the mainstream class, Nilay was able to cope with the syllabus, but required support and reasonable accommodations – which the school was not providing. He received endless support from his mother – who made notes for him and ensured he went through the chapters that were going to be done in class. Her son, Nilay was forced to make the shift from a mainstream class to another school where he was granted admission but soon told that he would be in the learning centre. This left the parents with no choice. The learning centre pitched their expectations very low and gradually Nilay started losing the motivation to work. Myra started a long, tiring fight for her son to be mainstreamed once more. Met with firm resistance, a determined Myra enrolled Nilay in yet another school. Given the necessary supports, Nilay thrived and scored extremely well in his school leaving exams...going on to do an MBA some years later!*

Myra is one of many mothers who find themselves giving up their careers, creative interests, social lives and devoting all their time towards supporting their child. Many parents spend hours writing notes, reading and re-reading chapters, explaining concepts and teaching their child...trying to ensure that the child stays afloat. Parents too need a lot of support. Becoming a part of a parent support group is one way of ensuring that they find the support and the will to keep going on. They are able to learn from others experience and share theirs, besides sharing resources and strategies.

### The child is at the centre of this

Ironically the child who is at the centre of all this, often remains a blur. Things happen around the child, for the child; but what the child goes through, is often not noticed. They are often teased, bullied and isolated. Children avoid them and refuse to include them into their play and study groups.

This is also a sad reflection of our education system where academic performance and the percentage scored becomes the sole criteria for determining everything- level of confidence, self esteem, whether other children interact with you and include you in

their group during recess and group work. The onus here lies on the teachers to ensure that no child is isolated in class; no child is made to feel a failure because no child is ever a failure! Given all these struggles, many children suffer a blow to their levels of confidence. If this is not recognized and steps are not taken to reverse this early on, the child can become de-motivated, lose self-confidence and become withdrawn.

The first step even before initiating a reading plan with the child, is to constantly reinforce positivity and ensure the child maintains his/her confidence and starts to believe once more in his/ her ability. More important than working on building academic skills and abilities it is important that the child is happy and confident and develops a belief in self.

Equally important it is to ensure that the child finds time in his/her daily schedule to do things he/she is good at or just enjoys doing. Usually what happens is that children are asked to just focus on academics at the cost of other things. Limiting play time/ sport activities/ leisure time activities- means cutting the child off from social groups and friends- leaving the child further isolated and perhaps more frustrated. Every child requires time and space to do things beyond books.

- *Aarya is a good athlete and represents her school in the field and track events. She has won many medals for her school.*
- *Abhay writes scripts, acts and directs short videos. He creates interesting videos with his friends and uploads them on You-Tube. He has managed to create a space for himself in the virtual world.*
- *Adil is a good cricketer and represents his school team in tournaments.*
- *Anay likes to tinker around with mechanical tools. The interest sustained and today, as a student at IIT, he has developed and showcased a robot at an inter IIT competition.*

Care needs to be taken that children are encouraged to explore and pursue areas of their interest. Excelling at them is secondary, what is important is to take the opportunity to find something that gives them happiness and a positive feel about themselves.

All children learn, all children find their path; it is only a question of time. Each child learns at a different pace, has different learning style and has different strengths and challenges. The need is to invest some time to understand the child, her strengths, her needs. Establish

a rapport and devise and implement strategies to ensure full inclusion and participation of all children with and without disabilities within and beyond the classroom. The right support at the right time lays the foundation for a confident learner, with self-esteem intact.

We, as parents, teachers and professionals working in the field need to remember that the child comes first. Listen to the child – whether it is expressed verbally or otherwise. Academic excellence is not the end of the road, there are other strengths and qualities inherent in children. These need to be recognized.

Every child deserves the right to grow up in a supportive environment. Once the basics are in place, learning and academic performance follow. Judging a child solely on the marks scored in tests is a grave injustice to the child. Many children may not perform well on the academic front, initially, but possess abilities, qualities and talents and even excel, given the encouragement and opportunity.

In my years of working with children, I have had the privilege of seeing them transform and evolve from shy, withdrawn children with low self-esteem into confident, young adults. We just need to stop looking and judging children through the same lens or insisting on applying the same measures. The lens needs to become child friendly along with teaching methodologies that are suited to the needs of the child.

Things are changing but way too slowly to make an impact. The system needs to become more enabling and support children through their school years. There are many good practices dotting the landscape across the country. These need to be documented, shared and replicated and this needs to happen as of yesterday.

*All the examples in the article are reflective of true life journeys. The names of the individuals have been changed*

*Shabnam Aggarwal's area of specialization pertains to disability. She has been working in the field for the past 26 years. Her formal training in the areas of Psychology (Masters in Psychology), Learning Disabilities and Counselling, Special Education ( BEd Special Education) and Law (Degree in Law) have enabled her to integrate various dimensions and concerns in my work. As the Founder director Anandini, a disability based organization that focuses on research, training and advocacy, Shabnam works as an independent consultant.*

## व्यावसायिक चिकित्सा (Occupational Therapy) किस प्रकार मेरे बच्चे की मदद कर सकती है ?

डॉ. अंजी जोशी

अनुवाद – पूजा खन्ना

व्यावसायिक चिकित्सा किस प्रकार मेरे बच्चे की मदद कर सकती है ? यह एक ऐसा प्रश्न है जिसका जवाब ऑटिज्म वाले बच्चों के माता-पिता अधिकतर चाहते हैं। ऑटिज्म वाले बच्चे को जीवन के अलग-अलग चरणों में अनेकों प्रोफेशनल्स/पेशेवरों की मदद की जरूरत होती है। माता-पिता अक्सर इस बात से बेखबर रहते हैं कि किसी विशिष्ट हस्तक्षेप (intervention) को कब शुरू करें, रोकें या फिर से शुरू करें, और एक खास हस्तक्षेप (intervention) जिसमें व्यावसायिक चिकित्सा भी शामिल है, में किन मुद्दों के साथ जाये और किन जवाबों को ढूँढें। यह लेख माता-पिता के कुछ सवालों का जवाब ढूँढने में मदद करने की एक कोशिश है।

### केस बिगलेट-

वरुण श्री और श्रीमती खेर का ढाई साल का छोटा सा बच्चा है। उसके माता-पिता वरुण को उसकी बच्चों वाले डॉक्टर की मुलाकात पर मिले ऑटिज्म के निदान (diagnosis) से समझौता नहीं कर पा रहे हैं। उसकी बोलने में अपनी माँ के साथ खेलने और संलग्न होने की असमर्थता के कारण की इतनी गहरी जड़ें होंगी, कुछ ऐसा था जो खेर परिवार कभी कल्पना भी नहीं कर सकता था। ऊपर से वरुण के कुछ ऐसे व्यवहार थे जो उन्हें समझने में बहुत मुश्किल हो रही थी।

वरुण बाल काटने में, दांत साफ करने में और नाखून काटने में चीखता और रोता था। उसका व्यवहार नियंत्रण से बाहर हो जाता है, शादियों, जन्मदिन की पार्टी और दिवाली के उत्सव, जब पड़ोस में बहुत हबड़-दबड़ या पटाखे चल रहे हों। उसकी खाने की और न खाने योग्य चीजों को सूंघने व मुंह में डालने की जरूरत को संभालना बहुत मुश्किल हो रहा था। वरुण की मां कभी-कभी विस्मित होती है कि क्या उसके अन्दर कोई मोटर छिपी हुई है कि वो हमेशा ही गतिशील रहता है। उसे कूदना, झूलना बहुत पसंद है और वो पार्क में बिना चक्कर खाये घंटों झूल सकता है। उसका पसंदीदा खाना चटपटा व कुरकुरें हैं और वो कुछ भी और खाने का विरोध करता है। उसकी मां को उसकी अपनी सुरक्षा की स्पष्ट समझ की कमी की चिन्ता है। उन्हें उस पर लगातार नजर रखनी पड़ती है। बच्चों वाले डॉक्टर की पिछली मुलाकात पर उसनमें ओ.

टी.एस.टी. जैसे शब्द लिखे और उन व्याकुल हुए दम्पति को ऑटिज्म पर कुछ साहित्य थमा दिया। उस लेख में मैंने वरुण और उसके माता-पिता की उसके व्यावसायिक चिकित्सक के साथ की यात्रा को लिखा है।

वरुण की ऊपर लिखी चुनौतियां बहुत से छोटे ऑटिज्म वाले बच्चों में दिखने वाली चुनौतियों के समान हैं। उस समय उसको और उसके माता-पिता को जो मदद चाहिए थी वो थी जानना कि उसके खेल के कौशल पर कैसे काम करें और उसकी संवेदी (Sensory) चुनौतियों का सामना कैसे करें जो कि पहले बताये गये व्यवहारों का कारण थे।

### खेल : एक हस्तक्षेप (Intervention) का साधन ऑटिज्म वाले बच्चों के लिए

खेल बचपन में एक प्राथमिक उपजीविका है। खेल के द्वारा, बच्चे बहुत से मील के पत्थर (milestones) प्राप्त करते हैं और कौशल सीखते हैं जो वातावरण से परस्पर क्रिया के लिए जरूरी है। खेल में व्यस्तता एक बच्चे के विकास का अभिन्न हिस्सा है, और शोधकर्ताओं से स्पेशल जरूरत वाले बच्चों के विकास में देशी में खेल की भूमिका पर प्रकाश डाला है। वरुण का दूसरों को ध्यान से देखने के प्रति उदासीनता अथवा अपने माता-पिता की उसके साथ खेलने की कोशिश पर जवाब न देना, यह सब उसका ऑटिज्म से प्रभावित कर रहा था।

### खेल की परिभाषा-

खेल एक आनन्ददायक शारीरिक गतिविधि में उत्सुक संलग्न अथवा मानसिक कोशिश द्वारा भावनात्मक संतुष्टि को प्राप्त करना है।

### खेल की विशेषतायें-

किसी भी कार्य या गतिविधि के लिए एक बच्चा संलग्न होता है जिसे खेलने के रूप में बुलाया जाता है। इसे सहज, रचनात्मक और स्वयं शुरू करने की आवश्यकता होती है।

### खेल का विकास-

एक बच्चा पैदा होते ही खेल में संलग्न हो जाता है। शुरुआत में

वो अपनी मां से खेलता है, अपने हाथ पांव से और फिर खिलौनों से और बाद में दोस्ती से। खेल पहले एक साधारण गतिविधि जैसे ब्लॉक्स (blocks) पकड़ना या झुनझना हिलाना, से परिपक्व होकर धीरे से रचनात्मक और बनावटी खेल में विकसित होकर और जटिल खेल जैसे क्रिकेट व फुटबाल की ओर बढ़ता है।

वरुण जैसे बच्चे की खेल में संगठन में चुनौतियों का सामना-वरुण की उसके चारों ओर के लोगों एवं वस्तुओं को ध्यान में रखने की असमर्थता, उसका सीमित ज्ञान सम्बन्धी कोश, उसकी खिलौनों को खोजने व सही तरीके से चलाने में असमर्थता और उसकी छूने, आवाजों व लोगों के प्रति सहनशीलता की कमी उसके खेल कौशल के विकास के आड़े आ रहे थे। उसके ऑटिज्म की वजह से, उसका लोगों से जुड़ने के अवसर, साथ ही साथ सामाजिक संपर्क को शुरू करने या कायम करने के कौशल उसकी खेल को सीखने की क्षमता को सीमित कर रहे थे।

वरुण के माता-पिता ने उसके खेल को सुविधाजनक कैसे बनाया-वरुण के माता-पिता को पता था कि केवल खेलना और उसके साथ मस्ती करना ही उसके लिए सबसे प्रभावी मजे/मस्ती पर आधारित चिकित्सा होनी थी।

### यहां पर कुछ रणनीतियां हैं जो उन्होंने उसके साथ इस्तेमाल करना शुरू किया।

शारीरिक मदद का इस्तेमाल, जैसे बच्चे के हाथ पर हाथ रखकर मदद करते थे।

उसके चिकित्सक (therapist) ने उसके माता-पिता को यह दर्शाया कि किस प्रकार वह कम से कम दिशा के स्तर अथवा मदद (prompts) से शुरू करे और फिर किस तरह उस मदद (prompts) करे धीरे-धीरे कम करे। इस तरह वरुण की चीजों में लगे रहने में मदद हुई।

वरुण की बड़ी बहन और उसके चचेरे भाई-बहन (cousins) उसके प्रेरणा स्रोत बने। उन्होंने उसे किस प्रकार साधारण घर के सामान से खेलना है करके दिखाया और उसे दिखावे वाले खेल (Pretend Play) को शुरू करने के अवसर प्रदान किये।

वरुण साधारण सुदृढीकरण (reinforcements) जैसे गले लगाना, तारीफ करना, चूमना अथवा उसको उसके पसंदीदा खिलौने के साथ खेलने का मौका देना पर प्रतिक्रिया दिखाने लगा और धीरे-धीरे उसका अपने माता-पिता व भाई बहन के साथ लेख में लगे रहने का समय बढ़ने लगा।

इस प्रक्रिया में वरुण के माता-पिता ने संचार के छोटे संकेतों को जो वो दिखाता था जैसे आंखों के कोने से देखना, अस्थिर आंख द्वारा संपर्क, इशारा करना या मुस्कुराना को पकड़ना सीखा। उन्होंने इन संकेतों पर निर्माण करना सीखा, उसने न सिर्फ

खेल को सुविधाजनक बनाया बल्कि उसके संचार को भी बढ़ाया। इस खेल में उन्हें उच्च स्तर के संचार को करके दिखाने के अवसर दिये।

उनका खेल का समय उसका वरुण के साथ थरेपी समय है। उन्होंने उसका साधारण परन्तु रंग-विरंगे और सुरक्षित खिलौनों से परिचय कराया। उसके चिकित्सक (therapist) ने उनके साथ ऐसी रणनीतियों की चर्चा की थी जैसे खिलौनों को पारदर्शी डिब्बे में रखना, उन्हें ऊंची स्तर के शैल्प में रखना जो संचार के अवसरों को बनाये।

संवेदी एकीकरण (Sensory Integration) से परिचय :

संवेदी एकीकरण एक व्यावसायिक चिकित्सक डॉ. ए. जीन एयरस (Dr. A. Jean Ayres) की कल्पना व उनके द्वारा विकसित किया सिद्धान्त है। यह सिद्धान्त न केवल दिमाग व व्यवहार के बीच के सम्बन्ध को समझाता है, साथ में यह भी बताता है कि किस प्रकार दोनों में बदलाव लाये जा सकते हैं।

हम सब अपने चारों ओर की दुनिया के बारे में अपने संवेदी अनुभवों से सीखते व पता लगाते हैं। संवेदी सूचना (sensory information) अपनी पांच इन्द्रियों (senses) जो कि छूना (tactile) देखना (vision) , आवाज (auditory) , सूंघना (olfactory) और स्वाद (gustatory) है और तीन अन्य इन्द्रियां भी हैं जो हम किस प्रकार अपने वातावरण के अनुकूल होते हैं उसमें एक अहम भूमिका निभाती हैं, वह ये हैं :-

1. रिसेस्पर्ट/ग्राही जो मांसपेशियों के सकुचन और खिचाव और जोड़ों के मोड़ने और सीधा करने के कारण संवेदी सूचना भेजते हैं (प्रोप्रियोसेप्शन/प्रगाही)।
2. रिसेस्पर्ट/ग्राही जो गति एवं संतुलन के उत्तरदायी हैं (वेसटीब्यूलर/कर्ण-कोटर)।
3. हमारे शरीर के अन्दर के रिसेस्पर्ट जो हमें अपने बुनियादी कार्यों को समझने में मदद करते हैं जैसे कि भूख, प्यास, मल त्यागने की जरूरत अथवा यूरिन पास करना (इन्ट्रोसेप्टर/अंतर्ग्राहक) दिमाग की इन सारी सूचनाओं को आयोजित करने और उनकी व्याख्या करने की प्रक्रिया को संवेदी एकीकरण (Sensory Integration) कहते हैं।

हम सब जिसमें बच्चे भी शामिल हैं कैसे सीखते हैं काफी हद तक इस बात पर निर्भर है कि हम किस प्रकार अपनी संवेदी सूचनाओं की प्रक्रिया और उनका एकीकरण करते हैं। अधिकतर बच्चों में संवेदी एकीकरण उनके स्वाभाविक रूप से बढ़ने की प्रक्रिया का

हिस्सा होता है। बच्चे, यहां तक की जब बहुत छोटे होते हैं हर चैनल से सूचना और बहुत से कौशल का खुद व खुद ही प्रदर्शन कर लेते हैं। यह प्रक्रिया कुछ बच्चों में धीमी अथवा तेज हो सकती है। हम में से कोई भी संवेदी सूचनाओं को पूरी तरह से व्यवस्थित नहीं कर सकता है। कुछ लोगों को संवेदी एकीकरण बहुत अच्छा होता है, कुछ का केवल औसत और फिर भी कुछ का खराब। शान्त निर्मल गति, भाषा, भावनात्मक परिपक्वता सामाजिक परस्पर क्रिया और शैक्षणिक कार्यों में प्रभुत्व/कौशल संवेदी एकीकरण के प्राकृतिक परिणाम हैं।

वरुण जैसे बच्चे, संवेदी एकीकरण रोग है उसकी संवेदी प्रणाली या तो हाइपो (कम) अथवा हाइपर (अधिक) होती है। उदाहरण जैसे कि कुछ बच्चों में मुलायम ऊन का स्पर्श एक कीलों के बिस्तर के समान महसूस होता है। (हाइपर) या कुछ को बहुत ऊंचाई से गिरने के बावजूद दर्द महसूस नहीं होता (हाइपो)। वरुण की संवेदी प्रौद्योगिकी चुनौतियों के कारण, वरुण रोज की साधारण गतिविधियां जैसे नाखून अथवा बाल काटने में संघर्ष करता था।

### संवेदी एकीकरण के पीछे (S.I. Therapy) क्या सिद्धान्त है ?

इस चिकित्सा/थेरेपी का केन्द्रीय विचार संवेदी इनपुट्स को इस प्रकार देना और नियंत्रण करना है, खासकर स्पर्श, कर्ण कोटर (vesicular) दृश्य (visual) सुनने, और प्रगाही (appropriative) समझ से कि बच्चा स्वाभाविक तरीके से एक अनुकूल प्रतिक्रिया दे। संवेदी एकीकरण हस्ताक्षेप का केन्द्रीय सिद्धान्त यह है कि यह चिकित्सा सबसे अधिक प्रभावी तब होती है जब बच्चा शरीर की जरूरत के हिसाब से संवेदी इनपुट का चयन करता है और चिकित्सक सिर्फ एक सहायक का कार्य करता है। एक प्रशिक्षित चिकित्सक खेल के उपकरण जैसे झूले, ट्रैमपोलीन, थेरेपी गेंद का इस्तेमाल बढ़े हुए संवेदी इनपुट्स को सुअवसर देने के लिए करता है साथ ही साथ बच्चे के उत्तर व व्यवहार की निगरानी भी करता है। यह एक वैज्ञानिक तरीका है जो एक विस्तृत शोध पर आधारित है और इसलिए इसकी बदली नित्य के खेल से नहीं की जा सकती है।

### संवेदी एकीकरण शिथिलता के लक्षण—

निम्नलिखित विशेषताएं जो वरुण के पास है उनके अतिरिक्त संवेदी एकीकरण शिथिलता के सूचक है।

1. तालमेल में कमी या बेडौलता बारीक क्रियाओं के साथ।
2. शारीरिक गतिविधियों को करने की अनिच्छा।
3. बोली और भाषा के विकास में देरी और उचित सामाजिक कौशल को विकसित करने की अयोग्यता।
4. अनुचित भावनात्मक प्रतिक्रिया जैसे बेकाबू होकर हंसना या रोना।

5. आंखों का संपर्क बनाये रखने में मुश्किल और बोलने में देरी।
6. अस्थिरचित्तता एवं खराब ध्यान अवधि।
7. कुछ स्पर्श, आवाज इत्यादि को सहने में असमर्थता।

वरुण के चिकित्सक ने उसके माता-पिता से यह चर्चा की थी कि किस प्रकार व्यावसायिक चिकित्सा उसके कुछ चुनौतियों का सामना करने में मदद कर सकती है, परंतु उसके ऑटिज्म को ठीक नहीं कर सकती है। संवेदी एकीकरण अन्य हस्तक्षेप का विकल्प नहीं है, इसलिए वरुण को स्पीच थेरेपी भी मिल रही है और वो एक नर्सरी स्कूल भी जा रहा है। वरुण ने अपने व्यावसायिक चिकित्सक से संवेदी एकीकरण थेरेपी हफ्ते में दो बार लेनी शुरू की और उसने उसके माता-पिता को भी बहुत से खेल और गतिविधियां सिखायीं। इन गतिविधियों ने वरुण को शान्त किया और वरुण धीरे-धीरे बहुत से नये कौशल सीखने लगा। संवेदी प्रणाली की शिथिलता समझने से उसके माता-पिता को वरुण की चुनौतियों को निपटाने में मदद मिली।

### स्पर्शनीय (स्पर्श) प्रणाली—

यह हमारी एक बहुत ही महत्वपूर्ण इन्द्रि है। इसका विकास तभी होने लगता है जब बच्चा गर्भ में होता है। बच्चा जिसमें संवेदी एकीकरण शिथिलता है, उसकी स्पर्शनीय प्रणाली हाइपो या हाईपर उत्तरदायी होती है। मतलब प्रतिक्रिया कम या ज्यादा होती है। एक उदाहरण हाइपो का है जब माता-पिता बताते हैं कि उनका बच्चा ऊंचाई से गिरने के बावजूद रोता नहीं है, और हाइपर होना जब वो नाखून व बाल काटने का विरोध करता है। बाद वाले में देखे गये व्यवहार चीखना, रोना, आक्रामक विस्फोट अथवा बड़ी जल्दी मूड बदलना (बच्चा बहुत अधिक बिना कारण रोता या हस्ता है) हो सकते हैं। कुछ बच्चे कुछ व्यवहार जैसे सक्रियता (hyperactivity) आलस, खराब सामाजिक कौशल/अखाद्य पदार्थों को बहुत ज्यादा मुंह में रखना। अन्य व्यवहार जैसे चीजों/लोगों को छूने का जुनून, कुछ खास बनावटों (textures) के प्रति संवेदनशील होना था। स्वाद से घृणा अथवा बारीकियां संबंधी मोटर कुशलता सीखने में परेशानी यह सब भी स्पर्शीय सूचना को बनाने के काम में मुश्किल की वजह से आ सकती है।

### हस्ताक्षेप—

एक बच्चा जो स्पर्श संबंधी जानकारी को तैयार करने में मुश्किलें दिखाता है को खेल जैसे रस्साकशी, बालू व पानी का खेल और यहां तक कि उसकी रोज के कार्यों में भागीदारी जैसे फर्नीचर खिसकाना, छोटे शापिंग बैग उठाना इत्यादि लाभ देते हैं परन्तु रणनीतियां जैसे वजन वाले कफ (cuff)/वजन वाली जैकट के इस्तेमाल पर नजर रखने की जरूरत होती है और उसे पेशवर पर्यवेक्षक की निगरानी में ही इस्तेमाल करना चाहिए।

वरुण के माता-पिता ने देखा है कि उसे किसी का उसके चेहरे पर छूना अथवा गुदगुदी करना बिल्कुल नापसन्द है और वो इस बात का ध्यान रखते हैं कि यह सब उससे खेलते समय करने से बचे उनके थेरेपिस्ट ने उन्हें यह करके दिखाया है कि उसे किस प्रकार शीतलता से पकड़ कर गोदी में बिठाकर, गुनगुनाकर अथवा मन्द स्वर में गाना चलाकर शान्त कर सकते हैं। उसकी मां उसके बाल व नाखून काटने के विरोध को उसके खोपड़ी व नाखून के टिप्स को काटने से पहले मसाज कर उनको संबोधित करती है। थेरेपिस्ट ने उसके माता-पिता को कुछ गतिविधियां व खेल स्पर्श से संबंधित मुद्दों को संबोधित करने के लिए बताया है -

1. सूखी, राजमा या चावल में चीजों को छुपाकर लुक्का छुपी खेलना।
2. टेक्चर्ड सामग्री जैसे बालू, साबुन का फोम प्ले-डो (Play-dough), टैलकम पाउडर, आटा आदि में चित्रकारी या लिखना।

### कर्ण-कोटर प्रणाली (Vestibular System)

यह सबसे बुनियादी परन्तु समझने में सबसे कठिन संवेदी प्रणाली है। कर्ण-कोटर प्रणाली गर्भधारण के कुछ सप्ताह बाद ही विकसित होना शुरू हो जाती है और यह बच्चे के आरंभ में विकास में एक महत्वपूर्ण भूमिका निभाती है। कर्ण कोटर प्रणाली की संरचनायें दिमाग को गति गुरुत्वाकर्षण और सर की स्थिति की सूचना के लिए जिम्मेदार होती है। इस सूचना को बनाना/निर्माण करना मांसपेशी स्वास्थ्य और मुद्रा के लिए बहुत जरूरी होता है। इस प्रणाली में मुश्किल आने वाले बच्चों को रोजमर्रा की गतिविधियों में भी परेशानी होती है जैसे कि-

1. आपसी तालमेल की कमी या सूक्ष्म मोटर (fine motor) गतिविधियों में बेडौलता।
2. शारीरिक गतिविधियां करने में अनिच्छा। बच्चा अधिकतर आलस या लेटना पसन्द करता है।
3. भाषा व बोली के विकास में देरी।
4. अनुचित प्रतिक्रियाओं जैसे अनियंत्रित हंसना या रोना इनको शान्त करने में परेशानी जैसे कि बाकी संवेदी प्रणालियों में, कर्ण-कोट-2 प्रसंस्करण कठिनाइयों में भी बच्चे हाइपो या हाइपर अनुक्रियता दिखाते हैं। वरुण का हर समय गतितमय होना या उसकी झूले व अन्य गति आधारित बगीचे के यंत्र के लिए तृष्णा उसके हाइपो उत्तरदायी कर्ण-कोटर प्रणाली का परिणाम है। वहीं कुछ बच्चों में उनके हाइपर-उत्तरदायी कर्ण कोटर प्रणाली के कारन इसका बिल्कुल उल्टा व्यवहार दिखायी देता है।

### हस्तक्षेप-

क्योंकि गति आधारित गतिविधियां बच्चे के कर्ण-कोटर प्रणाली के विकास के लिए अत्यन्त जरूरी है, वरुण के माता-पिता

निम्नलिखित गतिविधियां व खेल उसके साथ खेलते हैं।

• उसकी मां बहुत बार उसको पार्क में ले जाती है जहां वो झूले पर जाता है, दौड़ता है सिलपट्टी पर खेलता है और मेरी गो राउंड झूले पर गोल-गोल घूमता है। थेरिपी पर जाते हुए बस की यात्रा वह समय है जब उसकी मां उसे चित्रों वाली किताब दिखाती है या कहानी सुनाती है क्योंकि उन्होंने देखा है कि ऐसे समय पर वरुण बहुत शान्त रहता है।

### प्रोप्रियोसेप्शन या शरीर की स्थिति की जागरूकता-

प्रगाही इन्द्री एक खास छिपी हुई इन्द्री है। प्रगाही अनुभूति के कारण, दिमाग हमारे मांसपेशी और अंगों के जोड़ों द्वारा हमारे शरीर की स्थिति की सूचना लेता है। यह सूचना हमें अपनी गति/चाल की योजना में मदद करती है। उदाहरण स्वरूप एक कुशल प्रगाही चेतना हमें यह पता करने में मदद करती है कि आईक्रीम कोन को कितनी नाजुकता से पकड़ना है या लिखते समय कितना जोर लगाना है और किस प्रकार लोगों से दूर खड़े होना है। वरुण की हस्त कौशल के प्रदर्शन जैसे बोटल का ढक्कन खोलना या छोटे ब्लाक से खेलना में मुश्किलें उसके प्रगाही प्रणाली के बहुत अच्छे से संगठित न होने के कारण है।

### हस्ताक्षेप-

खेल के मैदान की बहुत सारी साधारण गतिविधियां इस प्रणाली को आसान करने का अति उत्कृष्ट क्षेत्र दे सकती है। वरुण को खींचने/धक्का देने की गतिविधियों जैसे रस्साकशी, कूदना, जिस्मानी बेदंगी तमाशा या कुश्ती से बहुत प्यार है और यह उसकी प्रगाही प्रणाली को सक्रिय करते हैं। उसके पिता उसे रोजमर्रा की साधारण गतिविधियां जैसे तकियों का ढेर उठाना, कुर्सी या फर्नीचर को खिसकाना, एक छोटा कन्धे वाला बस्ता लटकाना इत्यादि में शामिल करते हैं। वरुण को संवेदी एकीकरण आधारित व्यवसायिक चिकित्सा पिछले डेढ़ साल से प्राप्त हो रही है। उसकी कुछ चुनौतियां काफी कम हो गयी हैं। अब क्योंकि उसके माता-पिता कारणों को पहचान लेते हैं वो उनका खेल आधारित मनोरंजक गतिविधियों द्वारा सामना करने में अब बेहतर स्थिति में रहते हैं। वरुण अब करीब चार साल का है और खैर दम्पति उसके लिए स्कूल तलाश रहे हैं। उसकी सीमित बोली और एक वयस्क पर रोजमर्रा की गतिविधियों के लिए निर्भरता यह दो चीजें उसकी सबसे बड़ी बाधा है। उसकी मां का संघर्ष उसको उठाने से शुरू होता है, उसको नहलाना और उसको खुद से खाना खाना सिखाना। अधिकतर स्कूल उसके हाइपर हटाने पर जोर देते हैं और उसके माता-पिता इसको प्राप्त करने की पूरी कोशिश कर रहे हैं।

(To be cont. in the April 2020 issue of the Network...)

# The Privileges and Hegemony of Mental Health Professionals

By Itisha Nagar

My journey with autism began at Action for Autism, New Delhi. I volunteered for a summer to interact with and learn from the AFA family. Subsequently, I went on to do my PhD thesis on the topic. Currently, I'm an assistant professor of Psychology at University of Delhi. By virtue of the position I hold, I'm often expected to have an in depth understanding of the world of autism. I've always found that expectation somewhat disconcerting. The expectation that I or any other mental health professional would know autism more intimately in my few years of research than those who have lived with autism is flawed.

Years of research and education have made me adept with the use and understanding of scientific language, theories, and jargon. Whenever someone asks me about my PhD work, I reply 'Examining Executive Functioning and Theory of Mind in High Functioning Individuals with Autism' with the same fluency as Dr. Bhaskar's 'Lymphosarcoma of the Intestine' in the classic movie Anand. The impact on the audience is the same in both cases, that something important has been said but nobody is quite sure what. Scientific language serves many functions; an important one is that it binds a community of scientists through a common language. However, an overemphasis on jargons by researchers especially in the field of social sciences can alienate the common person.

Mental health professionals like me are often faced with this challenge, how do we communicate to the general public without alienating them with our armory of scientific terminology? Conversely and perhaps more importantly, how do we prevent ourselves from being alienated from the community we work for? How do we prevent ourselves from being reduced to echo-chambers of our own language, voice, and jargons?

My conversations with parents who received the diagnosis of autism for their child in 90s made me understand how inadequate the scientific understanding of autism was. In words of a parent, "there were no good books available for parents back then. Desperate parents like me who ended up ordering these books from the US were disappointed with what was written.

Autism was all about deficiencies and impairments in the natural order of things. There was little hope and we were not any step closer to understanding my child after reading the book. If anything, I wished I didn't read them at all." Given the history of psychology with autism, I don't blame her.

Take the example of one of the earliest theories of autism; 'the refrigerator mother theory' believed that autism was a result of lack of maternal warmth (Langan, 2001). The theory blamed mothers for autism and painted them as neglectful and cold. Or the now widely discredited paper on the role of vaccines in the causality of autism. In spite of repeatedly establishing that the initial link between vaccination and autism was fraudulent (Rao & Andrade, 2011), many parents today continue to hold an anti-vaccination stand. Closer home, in India in 1990s few professionals could distinguish autism from intellectual impairment (Daley, 2004).

To clarify, the objective of this article is neither to belittle the contributions of professionals in understanding of autism nor to unduly challenge the validity or reliability of present day scientific theories of autism. Instead, my objectives are three fold. First, medical professionals to check the privileges bestowed on them where conversations on autism are concerned. Second, challenging the hegemony of professionals in determining the limits and boundaries of what autism is or isn't. Finally, an attempt is made to emphasize on empowerment of people with autism through their active participation in the scientific discourse on autism.

First, addressing the issue of privilege. Mental health professionals are in privileged positions to 'create reality'. According to psychologist Thomas Leahey (1987) "unlike Physics or Chemistry, psychology can invent its own reality and mistake it for universal truth". Leahey reminds us that what psychologists say is human nature may create socio-cultural scripts that that ordinary people unwittingly enact. Simply put, people may reproduce what a psychologist thinks is real, thereby seeming to confirm the proposed 'scientific fact.' For instance, guided by traditional research that believed autism to be a predominantly a male condition,



the diagnostic criteria of autism has focused on male presentation of symptoms. Consequently, autism symptoms in girls/women may be frequently missed or misdiagnosed. In essence, professionals can be blindsided by their own theories. This is not to say that psychological theories serve no purpose or are lesser than theories in other scientific disciplines. It means that as a result of the subject matter of our discipline, there is a strong need to acknowledge our privileges lest we end up inadvertently abusing them.

Second, the hegemony of professionals in discourse of autism needs to be checked. Scientists have long claimed authority over others because they believe that the objectivity they bring is superior to the subjective experiences of individuals. Exclusion of voices on the spectrum lied in the belief that one must not get 'too close to the subject matter of investigation'. However, some thinkers have challenged the concept of objectivity in itself; "objectivity is unexamined subjectivity." For instance, sensory processing difficulty was identified as one of the diagnostic criterion for autism only recently. However, people on the spectrum have long articulated sensory processing issues, "to me the outside world is a confusing mass of sights and sounds. It is totally baffling and incomprehensible. Try watching a soap opera on TV with no volume..." From the perspective of an objective and empirical professional, sensory overload was likely to be labeled as a 'behavioural difficulty' to be modified through rewards or punishment. If only we were less rigid about objective observations and more open to subjective experiences in construct of scientific theories, perhaps we would have understood sooner that a child with autism is not misbehaving, s/he's being misunderstood. While science is evolving to understand and deal with qualitative phenomena such as narratives and interviews of people with autism, it is safe to say that autism discourse cannot be hegemonized by the voices of professionals.

Finally, empowerment of people on the spectrum not only includes their ability to make decisions in their lives, but their ability to play a role in determining what the professionals say autism is or isn't. Fortunately, in the recent past, there has been change in the traditional power dynamics between professionals (outsiders) and people on the spectrum (insiders). People like Temple Grandin have defied the medical scripts of deficiencies by telling the world "I'm different, not less". Parents who could not find sense or satisfaction in what professionals had to say about their children formed their own support groups and centres. These centres are

dedicated to not just working with their children to adjust to the world, but also for the world adjust for their children. The centres assisted by professionals, are also leading researches in the field. The professionals associated with these centres understand the significance of inclusion of voices of people on the spectrum to improve the reliability and validity of psychological theories of autism. A new way of doing research sees individuals with autism as not 'subjects' for their researches, but as collaborators on a journey to unravel the enigma of autism. Invitation to people on the spectrum for academic conferences, workshops, and training sessions is also an important component of active inclusion of autism voices in the scientific discourse. People like Eloise Stark, a person on the spectrum and scientist at Oxford University is a noted example of what empowerment of people on the spectrum looks like. Her work on examining the differences in experiences of autism for men and women arising from her own experiences of misdiagnosis has initiated a new era in autism research. To have a person on spectrum as researcher, psychologist, and mental health professional is not an anomaly anymore. Scientists and community alike are beginning to understand that scientific knowledge that does not include subjectivities of the people on the spectrum or their families is sterile.

Overall, acknowledging of one's privilege, hegemony and inclusion of the voices on the spectrum is not as complicated as it may appear. For instance, at the cost of oversimplification, I believe that democratizing of conversations on autism begins with the simple process of listening with an open mind. Ironically, sometimes we are so focused on making a child with autism talk that we forget to listen to what the child may have to say. Mental health professionals need a reminder that a major part of our job is to listen without the aggressive attempt to capture and label autistic experiences in the nets of our stifling jargons.

Personally, whatever I consider meaningful in my understanding of autism has come from parents and individuals with autism themselves. Textbooks have helped for sure, but they cannot replace the rich experiences of one on one conversation.

To illustrate, I would like to share an interesting flight experience I recently had. I was seated next to a cardiologist in a reputed hospital who started discussing about psychology in general. He seemed to be very intrigued when I informed him of my PhD work in the

area of High Functioning Autism. His eyes lit up as we talked about it for some time. Sometime later he shared that his son has autism and he thought that he is on the spectrum too. Apparently his grandfather had it too. I was a little taken aback by the serendipity of the moment. He said he developed a hunch long back, given his experiences as a medical professional. He told me about his son who although lacking in socialization and communication was a bright and happy-go-lucky chap. Further, he went on to describe his own eidetic memory (photographic memory) that he considers to be one of the reasons for his success in his profession. He believed that he got better with age and so will his son. I couldn't help but wonder that perhaps he learned to socialize and communicate better with age, but in essence he was and is different and so is his son; different not lesser, as Grandin would say. When I asked him if he has shared this information with anyone, he replied in negative. "Not even your wife?" I asked. He shrugged. I enquired if it was burdensome to carry this information to which he just smiled. A part of me wanted to communicate barrage of unsolicited advice, something around the lines of "reconciliation of identities", "intellectual compensation of social deficits" and some other jargon, but I checked my privilege and smiled back at him. In a nutshell, I as a mental health professional do not get to dictate what is the best way to be for a person with autism to be.

Scientific discourse of autism cannot be constructed by isolating voices of people with autism and their families; scientists are allies in the process, not the owners of the autism narrative.

It is my belief that active inclusion of people on the spectrum as professionals is likely to prevent us from facing embarrassing news headlines like we did in past: "Young woman with autism proves every expert wrong, graduates from college!"

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#### Excerpt from...

*The balance between helping autistic people and doing it for them (and how to get it right)*

by Chris Bonello

Full article in the April 2020 Network

...

#### "2. People are 'lazy'.

One quote from my mathematics professor has stuck with me to this day:

*"I encourage you to be lazy. If you are lazy in a clever way, people will think you're efficient."*  
Prof. Anvar Shukurov, 2007.

I could go into several reasons why people like to be lazy. And actually, not all those reasons are negative. There's even an evolutionary case for being lazy: in a contest between those who can fulfil their physiological needs without spending energy, and those who need to spend *lots* of energy, who has better survival chances?

Honestly – and I mean this in no negative way whatsoever – people prefer to be lazy if they possibly can. This means if we get the chance for someone else do something for us, we'll usually let them. Let's face it, if someone offers to fetch us a snack from the fridge, we're more likely to say 'yes please' than 'no it's okay, I'll walk over there and get it myself'.

(This, of course, leaves aside the issue that autistic people can often have the appearance of being lazy when it's actually the impact of executive functioning/anxiety issues. That's a topic for another time.)

So how does this apply to supporting autistic people?

Well, the main thing I'm thinking is this:

**When offering support to an autistic person, it's better if the support is *needed* by them, rather than just *convenient* for them.**

If your support is for anxiety relief or as a learning tool, that's great. If it's simply one thing less for them to do, that's not so great...."

< *UPCOMING WORKSHOPS* >*At A Glance***January 2020****B Ed Spl Ed ASD 2020-22**

Applications open at Guru Gobind Singh Indraprastha University for their Common Entrance Test for admission to the two-year Rehabilitation Council of India certified training *Bachelor of Education Special Education - Autism Spectrum Disorders* academic session 2020-22. The training is conducted at AFA. For more details, visit ipu.ac.in.

**29 - 31 January 2020****Maximising Potential - A training for Parents & Professionals**

An ideal workshop for those starting out in the field of autism, focusing on skills to empower parents and professionals with an understanding about autism and will helping them relate to, interact with, and teach children with autism more effectively.

**March 2020****D Ed Spl Ed ASD 2020-22**

Recognized by the Rehabilitation Council of India, the Diploma in Education in Special Education - Autism Spectrum Disorders [D Ed Spl Ed-ASD] is a two-year intensive training programme for those interested in developing a career in special needs, with a particular focus on autism. Applications for admission is through the All India Online Aptitude Test (AIOAT) conducted by Rehabilitation Council of India, opening in March 2020. For more details, visit rehabcouncil.nic.in.

**8 - 10 July 2020****Empowering the Child with Autism**

A workshop for parents & professionals who wish to appreciate autism beyond theoretical explanations. This is an opportunity to understand autism and our children better, and facilitate more effective teaching.

**29 September – 1 October 2020  
AFA's Annual Training Workshop**

For over 15 years now, AFA's annual training workshop has become one of the most awaited workshops.

Attended by participants across India and overseas, this workshop moves away from trying to fix a person with autism and instead focus on trying to understand him or her and help them learn and grow with dignity.

**17-20 December 2020****Training by Peter Vermeulen**

Peter Vermeulen, MSc and PhD in Psychology and Educational Sciences, has worked with people with ASD and their families for more than 30 years. He is a Senior lecturer at *Autisme Central*, a training and education centre for autism spectrum disorders. An internationally respected lecturer/trainer Peter presents all over Europe and other countries. Peter has written more than 15 books and several articles on autism. His books include:

- "On Autistic Thinking" (2001)
- "I am Special: Handbook for Psycho-education" (2000, revised edition 2013)
- "Autism as Context Blindness" (2012), a book that won several awards in the USA

*This is a tentative events calendar and the dates and events are subject to change.*

*Please stay in touch with us to get regular updates and let us know if you wish to be added to our mailing list to get updated information about AFA and our events.*

*For more information contact our Coordinator:*

*Tel: 011-40540991/92*

*email <anvay.trainings@gmail.com>*

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*...cont from Pg 1*

*In this last closing issue of the decade there is more fabulous reading. We bring you the final part of Shabnam Aggarwal's piece that gives us a much needed insight into dyslexia. And I cannot but conclude with a statement from Isha Nagar's piece: I as a mental health professional do not get to dictate what is the best way to be for a person with autism to be.*

*Good reading and good wishes for the festive season and for the start of the new year.*

## AFA MEMBERSHIP FORM

Action For Autism(AFA) is a parent organization that strives to create an environment where individuals with autism and their families can live as fully participating members of the community.

To support AFA to further its mission, please complete the form below and return to: Action For Autism, The National Centre for Autism, Sector 7 & 8 Jasola Vihar, New Delhi 110025.

**Please complete in BLOCK letters and mail to Action For Autism**

Name \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_

Country \_\_\_\_\_ Pin/Zip \_\_\_\_\_

Phone \_\_\_\_\_ Email \_\_\_\_\_

I am a: (Check all that apply)

Mother  Father  Other (please specify) \_\_\_\_\_

Professional: Name of Organisation \_\_\_\_\_

**For Parent of a person with autism ONLY:**

Child's Name \_\_\_\_\_

Gender:  Female  Male Date of Birth \_\_\_\_\_  
 dd mm yr

Diagnosis \_\_\_\_\_

Diagnosis received from \_\_\_\_\_

I wish to become a member of AFA. Enclosed is a contribution (Check as applicable)

Via:  Cash  Online  Demand Draft  
 (in favour of Action for Autism, payable at New Delhi)

Online Transaction/Draft No \_\_\_\_\_ Dated \_\_\_\_\_

Drawn on \_\_\_\_\_

Amount in Words \_\_\_\_\_

**Annual Membership Charges:**

Parent: Rs. 500 Professionals: Rs. 1000 Institutional: Rs. 3000

Online bank transfer may be made to:

*Beneficiary: Action For Autism*

*Bank: Vijaya Bank, Defence Colony, New Delhi, India*

*SWIFT No: VIJBINBBDCD*

*IFSC Code: VIJB0006005*

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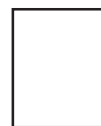
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