"autism network"

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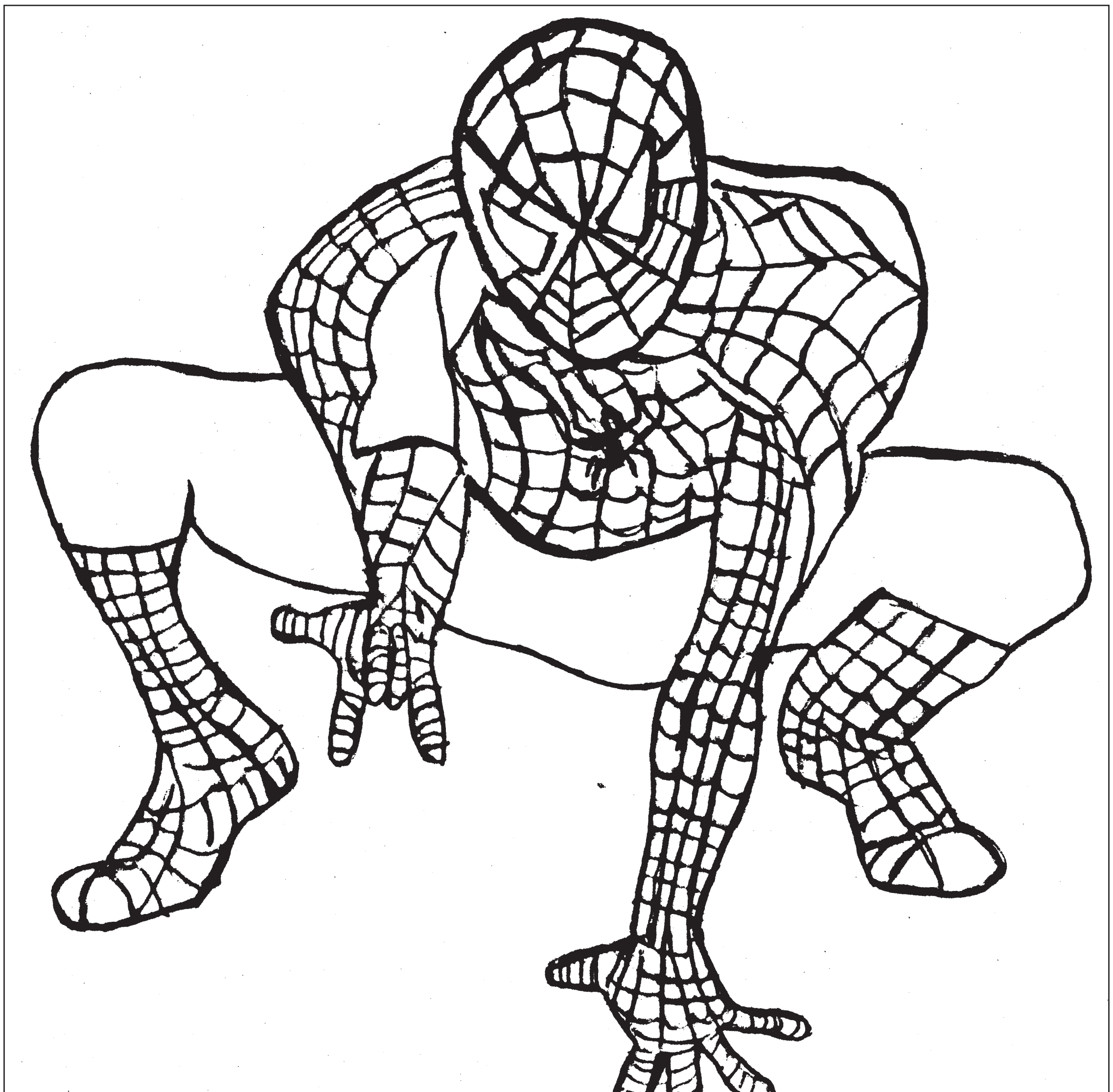

ACTION FOR AUTISM

autism network

AUGUST 2012 **VOL 7 ISSUE 2**

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

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Pocket 7&8, Jasola Vihar, Behind Sai Niketan, Opp. Gate 6
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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

Editor: Merry Barua
Editorial Board: Indrani Basu, Indu Chaswal, Nidhi Singhal, Ann Varavakula,
Design & Production: Bindu Badshah, Sudhir Pillai

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

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

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'Spiderman'
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Springdales School. Dhala Kuan, Delhi

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On 30 June last year the committee chaired by Dr Sudha Kaul to draft a new law to replace the Persons with Disabilities Act submitted the final draft of the Rights of Persons with Disabilities Bill (RPDB) to the Ministry. There is still no information as to when the law will finally be placed before Parliament.

In the meantime, half-way through and the year is turning out to be one of cautious optimism. In March this year came the announcement of a Department of Disability Affairs (DDA) under the Ministry of Social Justice and Empowerment. Within two months a Central Government notification announced the creation of the DDA, under the initiative of the Minister Shri Mukul Wasnik. And a couple of days ago came the announcement of the appointment of Sm Stuti Kackar as Secretary of the division.

The fulfilling of the commitment towards a separate ministry for disability has been long overdue; this quick succession of events is perhaps a sign of better times. We hope this positive development which has come about with the efforts of numerous activist groups in the country working at various levels, will go beyond the superficial and at last give our community a voice and a presence.

With the setting up of the DDA it is time that the disability community try and addresses differences within our ranks, difficult though it may seem at times. Much of these differences are driven by perceptions of disability. These perceptions are often based on a focus of what one experiences personally, and what one is exposed to. This in turn contributes to the mistaken belief in the homogeneity of disability experiences. Much of the discourse on disability, divisive or otherwise, is driven by this unitary view of disability.

The reality is that 'disability' is extremely heterogenous. And perhaps no disability highlights this heterogeneity as sharply as Autism does.

In this issue we carry an article that addresses a critical area, an area in which persons with Autism appear to develop markedly differently from the non-autistic. Professionals, the wider disability sector, and even parents themselves often do not fathom the pervasive nature of Autism. For instance, the general perception is that all persons with Autism are self absorbed and tuned to their own selves. Whereas the reality is that people with Autism have difficulty in reflecting upon their own actions, thoughts and emotions, which directly impact the way they learn, and what they learn. They often have a reduced sense of self, which often impacts on their ability to learn in a group as well as learn from the linear non-experiential manner in which teaching is conducted in our school classrooms. Most 'experts' in the disability sector fail to grasp this, and therefore cannot appreciate that inclusive classrooms often end up being places where persons with Autism are the most excluded. And that children with Autism who are enabled to lead inclusive adult lives often do so due to the special needs education that they receive outside so-called inclusive classrooms.

Even as we go to press, 'experts' in Autism are still locked over the changing definition of Autism. The proposed DSM-V revisions have sparked a debate over the inclusion of all the PDDs under the head of Autism Spectrum Disorders, and the possibility of those on the able end of the spectrum falling through the cracks and losing access to resources and services that they need.

Whether one shares this fear or not, this concern further illustrates the complexity of a condition that is often attempted to be glossed over by a homogenization of the disability paradigm.

Recent Engagements

In April 2012, Merry Barua Director AFA was invited to present on *Autism in India* at the Autism Speaks – GAPH First Annual Conference of the Advocacy Leadership Network in New York. She later spoke on *Education for Persons with Special Needs in International Settings* at the College at Old Westbury, SUNY.

In May 2012, Nidhi Singhal Director Research and Trainings at AFA made a presentation on *Ethical Considerations in Conducting Research in Low Resource Countries* at the International Meeting For Autism Research Conference in Toronto.

In August 2012, Merry Barua was invited to speak on *Empowering Mothers to Increase Reach in Low Resourced Settings* as well as on *Perspectives in Including Children with Autism in Mainstream Classrooms* at the ICare4Autism International Autism Conference in Jerusalem.

The Self in Autism

Rachel Brezis

Historically, researchers and clinicians assumed that since persons with autism are often oblivious to their surroundings, they must be deeply self-absorbed. In fact, when Kanner published his first description of children with autism, he picked the term 'autism' because it is derived from the Greek word 'autos', meaning 'self'. For many decades, researchers focused on these children's difficulties in interpersonal relations, theory of mind, and repetitive behaviors – without questioning the initial assumptions regarding the self in autism. Recent studies, however, are beginning to show that persons with autism in fact have various impairments in their sense of self – and that these in turn can have pervasive consequences in their daily lives. In what way is the self in autism different? How does it affect their ability to remember, to plan, and to empathize? And what can we do to help?

IN this piece, I'll begin by reviewing the different behavioral ways in which the self in autism may manifest differently, continue by looking at some of the different brain structures that would underlie these differences, and conclude with some practical recommendations for helping children and adults with autism develop a stronger and clearer sense of self.

What is the self?

The self has been a central topic of investigation for many centuries, across different cultures and religions – and different definitions of the self abound. On an intuitive level, the self refers to the unitary core we all possess, our essential being – which makes us distinct from others. William James, one of the founders of psychology, made an important distinction between the self that simply acts and experiences (the '*I*') and the self that perceives the acting self (the '*me*'). The '*I*' is the more basic and implicit layer of the self, including an intuitive awareness of our body in space, our self in relation to others. The '*me*' is a more explicit, reflexive layer that emerges later in development, and includes our beliefs about ourselves, and an understanding that our personal identity has continuity over time.

In what ways can an autistic person's self be different?

Ulrich Neisser, a social psychologist, expanded on James' notion of the '*I*' and the '*me*', and divided the self into five forms of self-awareness. As research on the self in autism is unfolding, it is useful to follow Neisser's categories to better understand where impairments in self-awareness emerge in autism[1].

THE first two categories in Neisser's model are more implicit forms of self-awareness, corresponding to James' '*I*':

a) The ecological self

The ecological self is our ability to perceive of our own body and the effects of its actions in space: 'I' am the person here in this place, engaged in this particular activity. Having an ecological self means recognizing the boundaries of my body – and distinguishing between my body, other bodies, and the environment. At a rudimentary level, newborn babies have the ability to distinguish between their own and others' bodies: if you take a baby's hand and touch it to their cheek, the baby would be less likely to turn and suck than if you touched your own hand to their cheek, as if the baby 'knows' whose hand was touching them.

ANOTHER important aspect of the ecological self is our sense of 'agency', our intuitive ability to distinguish between changes made by the environment, and changes that we ourselves have made. On a broader level, it involves perceiving ourselves as the center of control for our own actions, and recognizing our responsibility for particular changes in the environment. Newborns can learn to suck on a pacifier at a specific rate in order to see or hear a particular sound, such as their mothers' voice – indicating that they can control their behavior to change the environment.

Do persons with autism have an ecological sense of self? It seems that at a basic level, children with autism are

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[1] The following discussion is based on Lind and Bowler (2008) Episodic memory and autonoetic consciousness in autistic spectrum disorders: The roles of self-awareness, representational abilities and temporal cognition. In: D. Bowler and J. Boucher (eds.) *Memory in Autism*. Cambridge: Cambridge University Press. pp. 166-187.

capable of moving their bodies in relation to the physical environment without much difficulty. A recent study of high-functioning adults with autism by Williams and Happe[2] has also demonstrated that persons with autism are capable of identifying which of a number of moving dots on a screen was being moved by their own hand on the computer's mouse – meaning they have an intuitive sense of agency.

HOWEVER, it is unclear whether this ability would extend to persons with low-functioning autism, and whether more subtle impairments in the ecological self would appear. For instance, we know that compared to the non-autistic, persons with autism have many more sensory issues – such as an over-sensitivity or under-sensitivity to sounds, lights, touch and heat. As Temple Grandin recounts:

"My hearing is like having a sound amplifier set on maximum loudness… I have two choices: (1) I turn my ears on and get deluged with sound, or (2) shut my ears off… I can't modulate incoming auditory stimulation." Persons with autism may be highly irritated by the touch of a new garment, but unaffected by painful temperatures or pricks. Furthermore, many persons with autism have difficulties with gait, balance and coordination, suggesting that they have some impairments in negotiating their physical environment. Given these differences in sensory and motor functioning, it is possible that rather than perceiving their bodies as bounded and controllable, they would instead perceive of the relation between their bodies and the world as much more permeable and blurred. Such differences in perceptual experiences may have fundamental consequences for the way in which persons with autism perceive their body in relation to their environment, and their selves in relation to others.

b) The interpersonal self

The interpersonal self is our understanding of ourselves in relation to others in our social environment: 'I am the person who is engaged, here, in this particular human interchange'. In typical development, interpersonal self-awareness is acquired through early social interaction, imitation, turn-taking and so on. For instance, typical infants engage in non-verbal 'conversations' with their caregivers, that involve turn-taking and imitation of vocal, facial and gestural expressions. When the interaction is not responsive and interactive (for instance, if an infant is observing a video-recording of their mother), the infant loses interest and becomes distressed. These behaviors show that typical infants have a clear awareness of themselves in relation to others. By participating in these interactions, and observing the interlocutor's reactions to their expressive actions, they begin to acquire a sense of agency in directing social actions.

IN autism, many of these social behaviors are compromised from early development, and thus children with autism have difficulty acquiring an interpersonal self-awareness. Some children with autism show indifference to other people, treating them as objects rather than as beings with whom they can interact. Even in high-functioning children, conversations tend to be stereotyped and lacking in reciprocity. For example, Therese Joliffe, an adult with high-functioning autism recounts:

"When I was very young I can remember that speech seemed to be of no more significance than any other sound… It was ages before I realized that people speaking might be demanding my attention…"
Without the early ability to engage in social interaction, persons with autism will have a limited sense of interpersonal self; and this, in turn, will make it difficult for them to acquire more sophisticated means of interaction and interpersonal understanding.

THE following 3 categories of the self as described by Neisser appear later in development, and pertain to our more explicit self-awareness (the '*me*'):

c) The private self

The private self emerges when we begin to become aware that some of our experiences are not directly shared with other people: 'I am, in principle, the only person who can feel this unique and particular feeling'. The private self is directly related to theory of mind: between the ages of 3 to 5, typically developing children begin to understand that their desires, intentions and beliefs are different from others', that other people have a different 'mind'. At the same time, they begin to reflect on their own experiences, understanding that some of these are private, and cannot be perceived by others. With time, they become aware not just of *having* an experience, but that *they* are having it.

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[2] Williams and Happe (2009) Pre-Conceptual Aspects of Self-Awareness in Autism Spectrum Disorder: The Case of Action-Monitoring *Journal of Autism and Developmental Disorders*. pp s39:251-259

AS we know, persons with autism have difficulty with theory of mind, and thus, they are also significantly impaired in understanding their own mental states. For instance, persons with autism have difficulty recognizing their own emotions – even when they exhibit an appropriate physiological response to fear or joy, they have difficulty articulating their feeling.[3]

WHAT do persons with autism think about? An interesting glimpse into the inner world of persons with autism was provided by Francesca Happe and Uta Frith, who asked several adults with Asperger's at different points in their days to pause and report on their thoughts. The first indication of a reduced sense of self was provided in that most adults interviewed could not comprehend the task – reporting on their present action (e.g., unscrewing a bottle), rather than the 'mental picture' of their current experience. That said, two of the adults interviewed were capable of reporting their thoughts after several days. The following are examples of their thoughts:

> *Robert was on the train to London and had just seen from the train window a suspicious looking car parked or abandoned on the road near the track. He was trying to memorize where the car was so that he could come back and find it when he got off the train, in order to get its registration number (which he did in fact later succeed in doing). The image of the car Robert was seeing was in accurate color, just behind a low wall, with some garages in the background behind it; the parts of the car obscured by the wall were not seen.*
>
> *Nelson was watching a TV nature documentary about water boatmen [a type of insect] on a pond. He was seeing on the screen how the insects move, from left to right across the screen, and he was also 'picturising' a classroom scene from when he was younger, when he had watched a similar TV programme. In the image, he could see the TV, a group of children sitting in front of it on the floor, and the teacher standing behind the children. The perspective was from the back of the teacher, over her shoulder, past the group of children, towards the TV. The image was in color and movement: he could see the brown of the water and the color of the clothing the teacher and children were wearing.*

WHAT is striking about these examples, beyond the great focus on details and visual imagery, is the fact that they do not report on their emotions and bodily sensations (this is true of other thought samples surveyed as well). Further, Robert's account does not provide any interpersonal reflection on other humans; and while in Nelson's scene, he recalls the memory of his teacher and classmates, those are quickly glossed over in favor of the engrossing image on the TV.

THESE thought samples, as well as more calculated experiments, suggest that the private self of persons with autism may be fundamentally altered from that of typically developing persons. We will return to these experiences later in this article, when examining the possible brain bases underlying the experience of self in autism.

d) The conceptual self

Conceptual self-awareness arises when the self becomes the object, rather than merely the acting subject of thought. In other words, we begin to reflect on our own behaviors, and begin to develop a set of beliefs about ourselves. In typical development, conceptual self-awareness emerges only in the second year of life – and is reflected in the development of self-conscious emotions (such as embarrassment and pride), personal pronoun use, and explicit beliefs about the self.

One of the ways in which psychologists have examined the emergence of conceptual self-awareness is through the Mirror Self-Recognition task. As the child is playing with an adult, the adult covertly smears their face with color, as they are pretending to wipe the child's face. The experimenters then observe the child's reaction to their own reflection. At 18 months, toddlers typically touch the color mark on their face – indicating that they have an emerging self-concept. At 24 months, toddlers also begin to show blushing, shy smiling and gaze aversion – which are indicative of the emergence of self-conscious emotions such as embarrassment.

WHEN children with autism are given the Mirror Self-Recognition task they typically do touch their hand to the mark on their face at the appropriate mental age – indicating that they have a basic self-concept of their

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[3] It is interesting to note that different psychiatric disorders, such as depression, are characterized by an over-rumination on the private self and its experiences.

physical appearance. However, children with autism don't show any of the self-conscious emotions that accompany mirror self-recognition in typical toddlers. More broadly, while persons with autism have a clear experience of basic emotions such as joy, fear, anger and sadness, they have difficulty experiencing and expressing self-conscious emotions such as pride and embarrassment, which require an understanding of how others perceive you.

ANOTHER marker of the conceptual self in typical development is the use of personal pronouns, such as 'I' and 'me'. The unique property of personal pronouns is that their meaning shifts according to who is speaking: e.g., parents addressing their child always say 'you', but typical toddlers learn to call themselves 'me'. Thus, their proper acquisition indicates that the child has a developed self-concept, and that he or she can represent themselves and others as distinct individuals. In autism, pronoun reversal is very common, and even serves as a diagnostic marker for verbal individuals. For instance, rather than saying 'I want ice-cream', Ansh might say 'you want ice-cream' or 'Ansh wants ice-cream'. Ansh's confusion indicates that he has difficulty perceiving of himself in relation to others – his self-concept remains fixed in others' ways of addressing him, rather than becoming a personal 'I' or 'me'.

IMPORTANTLY, the conceptual self continues to develop over time. As we grow, we gradually acquire a set of beliefs about our self, our personal characteristics, features and traits. As children, our self-concept consists mainly of beliefs about physical traits and abilities (e.g., 'I have brown hair'; 'I can skip'). Later, our self-concept extends to psychological and social traits that can be more interpersonal in nature (e.g., 'I'm shy'; 'I have lots of friends').

IN my own research, I asked children and adolescents with autism in Los Angeles how they would describe themselves. Many of the children had difficulty answering the question, saying "I don't know," "I don't understand," or simply changing the topic. Those who did describe themselves, used more physical characteristics than their typically developing peers, such as: "I'm from Mexico", "I'm handsome and charming", "I have a mouth, and nose, and arms and legs." In contrast, typically developing children and adolescents gave more psychological descriptions of themselves, such as: "I try to be friendly," "I'm a good listener," "Sometimes I get mad". As we can see, while typical children and adolescents spontaneously describe their self in emotional and social terms, adolescents & children with autism focus on their physical or external traits.

e) The temporally extended self

The final layer in Neisser's categorization of the self involves our awareness that the self continues to exist through time: 'I am the person who had certain specific experiences, who regularly engages in certain specific and familiar routines.' One simple way of examining this temporal awareness is through the Delayed Self-Recognition task: after the experimenter covertly colors a child's face, the child and the experimenter watch a *video* of the interaction. While typical children automatically reach their hand to their faces, recognizing that the child in the video and themselves are the same, autistic children need to be prompted to recognize this identity. This difficulty in recognizing their self as continuous in time may have fundamental consequences for memory and future planning, as we shall see below.

TO summarize our discussion thus far, persons with autism have impairments at various levels of self-awareness: beginning with the most basic, physical sense of their body, and continuing on to more abstract awareness of their self as a distinct entity with feelings and beliefs that has continuity over time. Not surprisingly, persons with autism have the most difficulty with interpersonal aspects of the self: viewing themselves through others' eyes, and understanding that their own emotions and beliefs are not visible to others.

THUS we see that rather than being self-absorbed and self-focused, as early observers of autism had assumed, we now know that persons with autism have as much difficulty understanding themselves as understanding others.

Why do people with autism have a reduced sense of self?

At the biological level, several brain-imaging (MRI) studies of persons with autism have begun to uncover the possible reasons for a reduced self-awareness. First, persons with autism have reduced connectivity between the limbic regions – which are responsible for emotional response – and the frontal cortex – which is where self-processing occurs. This may explain why persons with autism may have a physical emotional response, but have difficulty articulating their emotion, and remembering the emotional experience later on.

BOTH the frontal cortex and the limbic regions are part of a larger network called the 'default network', which overlaps with self- and other-processing. When typically developing persons and are not given any particular instructions, their brains automatically activate these regions of the 'default network', suggesting that when our minds are left to wander, we typically begin to think about ourselves and others. Individuals with autism, however, did not activate this 'default network' automatically – only when told to do so. This relates to the 'thought samples' provided by Frith and Happe, above: even when told to explicitly reflect on their thoughts, adults with autism focused on visual imagery of objects, rather than persons and emotions. A further manifestation of this phenomenon is that persons with autism apparently do not have as many dreams as typically developing persons (as manifest by Rapid-Eye Movement, or REM, during sleep, and self-report at wake-up). Thus, it seems that persons with autism do not spontaneously reflect about themselves and others when their mind wanders. Since autism is a neurobiological condition that begins at birth, the fact that children with autism do not spontaneously reflect about themselves in relation to others when their mind wanders, may mean that they will lack the experiential 'glue' that gives us our experience of self.

What are the consequences of reduced self-awareness?
Having a sense of self is directly related to three primary human abilities: our ability to remember events in our past, our ability to plan our actions in the future, and our ability to empathize with others.

MULTIPLE studies of memory in autism have shown that while persons with autism have a good memory for semantic facts, such as word lists and train tables, they have difficulty remembering their own events. Why is that? Perhaps it is because children with autism don't have a rich, elaborated sense of self, events in the world that occur to them wouldn't necessarily be worthy of remembering. In one experiment, researchers took a group of autistic and non-autistic children on a walk. When they returned, they asked the kids what they remembered. The typical kids remembered more actions that they had performed (e.g., I petted the horse, I placed a letter in the mailbox), than actions that the other kids had performed. But children with autism remembered just as many actions that they had performed as others had performed. It was as though their self simply wasn't as salient, and events that happened to them didn't get 'tagged' with that special personal connection.

In my own research on memory in autism, I found that high-functioning children and adolescents with autism would often report the facts and physical objects present at events they had experienced, but not the emotional or social aspects of the situation. For example, Jordan, an 11-year-old boy, told me:
"*On my last birthday I went… to a movie. It was nice. Then I went to a restaurant and ate some burgers. They had lettuce and tomato inside.*"

IN contrast, when talking about his favorite fictional character, Meggie, Jordan was capable of giving more elaborate descriptions of his mental states:
"*When Meggie was little he didn't know his mom... He wanted to see his father, but he didn't know where he was.*"

IN a way, it was easier for these children with autism to relate to a fictional character, whose story is pre-fixed, than to construct their own narrative about themselves. Using their ability to relate to fictional characters, we may help high-functioning persons with autism better understand themselves.

REMEMBERING who you are and what you've done in the past, has a direct effect on your ability to plan ahead. We know that persons with autism have significant difficulties in decision-making and future planning. For instance, one high-functioning adult with autism told me that every time his mother would ask him what he wants for dinner, he'd role dice to decide. If he had had a stronger memory of liking dal makhni in the past, or perhaps even an identity that he's a 'saag paneer kind of guy,' it would be easier for him to decide what he wants to eat tonight.

FINALLY, as mentioned above, a reduced sense of self would make it difficult for a person with autism to understand others. If you don't have a good memory for how it felt when you were happy, sad, or in pain, it would be difficult for you to show empathy towards others in the same state. In addition, if you don't have a clear understanding that your emotions are different from others – it would be difficult for you to conceive of someone being sad when at that moment you happen to be happy. Parents of children with autism are often frustrated by their children's lack of empathy – but perhaps their problem is a more fundamental one, a difficulty in self-awareness?

FOR all these reasons, it is important to work with persons with autism to increase their self-awareness. This will help them develop a stronger identity and memory for themselves, help them make their own decisions, and ultimately, help them better understand others.

How to increase a person with autism's sense of self?
Going back to Neisser's layers of self-awareness, we can see that an autistic child's self-awareness may be improved upon on several levels. Arnold Miller, a therapist who works with children with autism, suggests several techniques.

FIRST, on the physical, ecological, level – it is important to increase children's awareness of their own bodies, their sense of propriception. Some techniques include: rough and tumble play, tickling, face touching, elevation (activities on raised platforms), and pressure or weight related activities (pushing, pulling, weight-bearing). All of these activities help children 'feel' their bodies, and gain more awareness of what they are 'doing', and how that affects the world. Since children with autism may not seek physical activity on their own, it is important to expose them to a variety of novel activities. The more physical experiences a child encounters, the easier it will be for them to develop a generalization of themselves as 'doers', and they can begin to form a sense of self as someone who can do many different, specific things.

AS children become more aware of their bodies and what they can do, it becomes easier to teach them about what other persons are doing. This can be taught through social games such as hide and seek, tag, musical chairs and jump rope, that highlight for the child how his actions *relate* to others. This will increase the child's awareness of themselves in the context of other persons (the interpersonal self), and may also lead to stronger emotional experiences (the private self) and more communication.

IN order to increase a child's conceptual self-awareness, and their sense of self-continuity over time, we can help them by highlighting the traits that make them special. Since persons with autism may not be able to do so on their own, it is important to teach them to express who they are – what they want, need, and feel – in whatever way they can. Some strategies include: covering their walls with pictures of themselves doing a variety of activities with a variety of people; writing a list of traits, reading and acting them out; giving them chores you rely on them doing; and pointing out emotions as they are experienced, till the individual can express the emotions themselves. High-functioning children may be taught to reflect on their own thoughts emotions by harnessing their special interest in a fictional character – first teaching them to recognize the emotions in the story they read or see, and then relating those emotions to real-life experiences as they occur.

IT is also important to encourage individuals with autism to make their choices – in how they'd like to decorate their environment, what they'd like to wear, and what they'd like to do. This will enhance their sense of agency, and make them more attuned to the physical and social consequences of their behaviors. With time, children's identities will become stronger, their thoughts and feelings will be clearer and more intense, and they may be able to better recall the past and project into the future.

Summary and Conclusions
While early research on autism assumed that persons with autism are self-absorbed and therefore have a rich sense of self, more recent work is revealing that persons with autism have a reduced sense of self. In fact, the ability to understand self and others co-develops: such that without a rudimentary physical and interpersonal sense of self, persons with autism find it difficult to engage with their surroundings. And their difficulty engaging in interpersonal exchanges in turn makes it difficult for them to develop a rich sense of self.

IMPAIRMENTS in self-understanding in autism can be manifest at different levels: from a sensory difficulty understanding the boundaries of one's physical body in space, to more complex abilities to understand that certain aspects of the self (such as thoughts and emotions) are private, and that the self is an entity that continues through time. While typically developing persons turn spontaneously to self- and other-reflection when their mind 'wanders', persons with autism will only do so with explicit instruction – and even then, their thoughts are likely to focus on visual details, rather than emotional and social perceptions. This pervasive difficulty from birth has important consequences – affecting a person with autism's ability to remember personal events, imagine a future activity, and empathize with another person's emotions. In order to help persons with autism gain a better self-understanding, we can begin with simple sensory techniques to enhance their physical sense of self, and gradually add activities that enhance their interpersonal and conceptual sense of self. Ultimately, these activities will serve to strengthen their personal identity, and empower them to assert their agency in the world.

Rachel Brezis, PhD holds a postdoctoral fellowship from the Foundation for Psychocultural Research at the University of California, Los Angeles (UCLA). She is currently coordinating the research collaboration between UCLA and Action For Autism (AFA), and is working with AFA to conduct an evaluation of the Parent-Child Training Program, and a study on adults with autism in India.

Token Economy

Sudhanshu Grover

Very early in its history, human kind had developed the barter system. You had grains that I needed to satisfy my hunger. I had animal skins which you needed to wrap around you to ward off the elements. I exchanged some of my grain for some of your animal skins. We both got what we desired. But soon people realised that barters could be problematic. I had a lot of skins which no one needed, so I used them up for various things. Now I need your grain but have no skins to give away. That is how neutral 'tokens' came into being. The term 'token' suggests something that is a *sign* or a *symbol* for something else. These tokens were something that could be bartered for anything.

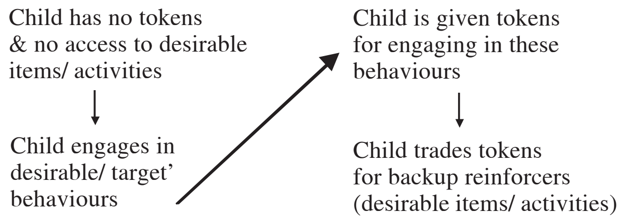
THE earliest use of 'tokens' can be traced to clay coins that first appeared in human history in the shift from nomadic hunter-gather societies to agricultural societies, and with the progress from simple barter to more complex economies. At different times and in different climes, this neutral 'token' took the form of cowrie shells, bits of engraved stone, and bits of metal, and paper, which we now know as money. This neutral item had no intrinsic value of its own; the value was derived from the power of exchange, the power to access things that one desired. After all, there is nothing particularly motivating about bits of paper. However, because we can exchange these bits of paper to buy food, housing, entertainment, etc, these bits of paper we call money is extremely reinforcing, and we are willing to do a lot of work to obtain them.

THIS use of money is what is also known as 'token economy', and is probably the token economy system that is the most well known. However, an area where another variation of the token economy system is widely used is in teaching children, and especially children with developmental disabilities.

How does a Token Economy work?
Based on the principle of providing support for positive behavior, it works in much the same way that money works, except at a very simplified level. So the shop assistant works hard the whole month and knows that for every day he works he is accumulating bits of paper (which is the token called money) and every day he does not work he does not accumulate any. Then at the end of the month he collects all his earned pay (all the bits of paper called money) which he can how exchange for whatever he desires. Likewise a kid does the work which we want from him, and in exchange he earns tokens. When he has accumulated a predetermined number of tokens he can then exchange them for items or activities he desires.

SO, a token economy is a system in which an individual earns tokens for doing the work we want from him, or in other words for engaging in or displaying desired behaviours or 'targeted behaviours'. Once he has collected a predetermined number of tokens he can trade them for an item or activity that he desires, which is the 'backup reinforcer'. Token economies are a type of secondary or conditioned reinforcement since, as already mentioned, tokens begin as essentially neutral, of little significance in and of themselves. However, as the tokens become increasingly associated with the reinforcers for which they are exchanged, the tokens themselves can become reinforcing, making the learning more motivating. Just like our money!

Fig. 1: The basic chain of Token Economy



What can be used as tokens?
When we want to use a 'token economy' in helping children learn, in teaching and/or strengthening behaviours, we can use a range of items as tokens. However these must be things that are portable, and easy to dispense when the target behaviour occurs. Tokens can be objects such as buttons, printed cards with smiley faces, fake money or marbles. They can even be a 'non-object' such as a tick on a sheet of paper, a hole punched in a card, or a picture or design stamped onto a card (Foxx, 1998).

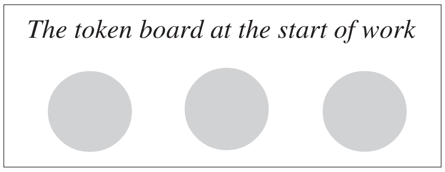
TOKENS can also be iconic, using images of the targeted behavior. For example, if a child were working on being quiet, one might use a token system where he earned pictures of a student with his finger on his lips. These tokens are then exchanged for a backup reinforcer.

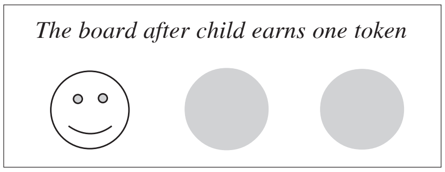
TOKENS could also be representative of the backup reinforcer, for instance using pictures of what would be delivered after the occurrence of the target behavior. ‘Reinforcement puzzles’ would be an example of these and are a creative way to implement a token economy system. So say, the child in question enjoys working on the computer, and that is his back up reinforcer, one could use a photograph/picture of the computer. Initially, the photograph/picture is cut up into a two-piece ‘puzzle’. The child learns that he has to earn each piece of this ‘puzzle’ individually and complete the ‘puzzle’ of the computer in order to receive the favoured reinforcement, which in this case is time on the computer. The completed picture of the computer serves as a visual cue to the individual of his success. As the child gets more proficient with the use of the token economy, and is able to work for longer periods, the number of pieces that make up the ‘reinforcement puzzle’ can be increased by simply cutting the photograph/picture up into more pieces.

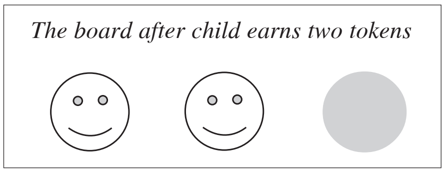
For a token system to work effectively, it should provide clear visual representation of how much the child has already accomplished, and how much more he needs to accomplish, before he can get access to the reinforcement. One of the ways to do this is by using a strip of board with defined spots on which the child affixes the tokens that he earns. The number of discrete spots would be predetermined depending on the number of tokens that the child needs to earn before he can exchange them for the backup reinforcer. The discrete spots on the token board provides a visual cue that helps the child predict exactly how much work he needs to do before he gets the reinforcement.

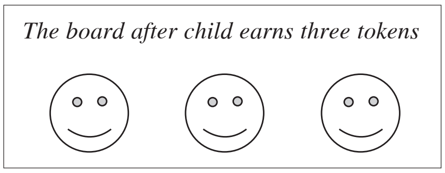
IN Fig 2, given below, it has been determined that the child has to earn three ‘smileys’ which are his tokens. His token board has three distinct spots where he has to affix the tokens that he earns. As the child earns each token, he can fix it on one of the blank spots. When he fixes one smiley the token board shows him that he has to still earn two more. When he earns a second smiley he places it on the next blank spot and can see that he needs to earn one more token. When he places the third smiley token on the token board, the child knows that he can now get his backup reinforcer.

Fig 2: The Token Board









The target behaviour

A token economy can be used to address any target behaviour that is socially significant or meaningful for the individual. This could be a new skill that one is targeting for the child such as when Rocky is learning the new skill of identifying the colour ‘red’. When asked to “Touch red”, after being presented with red, blue, yellow colour cards, Rocky could earn a token every time he touches the red colour card independently. A token economy can also be used to maintain or strengthen a skill/behaviour that the child already has. For instance, Reena can thread 10 beads independently. To maintain the behaviour of her threading 10 beads, Reena can be given a token for threading ten beads.

ADDITIONALLY, to increase the number of beads that Reena can thread independently, she can be given tokens for threading additional beads.

A target behaviour can include social skills, self help skills, academic skills, vocational skills and so on.

THE token economy can also be used to encourage positive behaviours and thereby reduce challenging behaviours. For instance, Shil vocalises very loudly in class and this disturbs all his classmates. The ‘challenging behaviour’ in this case is the loud vocalising, and the target behaviour for Shil would be ‘not vocalising’. So, if one were to use a token economy here, one would first determine Shil’s motivator which would be his backup reinforcer. His teacher would then determine how many tokens Shil would have to earn in order to have access to his back up reinforcer. Having thus set up the token economy, Shil would then earn tokens at the times at which he is not vocalising; or in other words he earns tokens when not engaging in the challenging behaviour. Delivering tokens when the individual is not engaging in the 'challenging behaviour' strengthens the occurrence of the alternative behaviour that we would want to encourage. In Shil's case the alternative behaviour is that of his keeping quiet in class.

ONCE a target behaviour has been identified, it is important to define the behaviour in specific and observable terms so that it is clear to both the teacher and the child what exactly is expected of him. For example, the target behaviour for Gyan could be that in a period of ten minutes he will do at least four out of a given five addition sums correctly. On the other hand, the target behaviour for Nitin could be that whenever presented with soap during 'hand wash' time, Nitin will be able to wash his hands independently.

The Backup Reinforcer

The backup reinforcer is the item or activity that the individual trades or exchanges his tokens for; and this defines the effectiveness of a token economy. Therefore it is important that the backup reinforcers are chosen specifically, keeping the individual's preferences in mind. A backup reinforcer can be an activity, item or privilege that the individual likes and enjoys. They may be consumables, toys, games, a magazine, painting activities, TV time, free time, listening to music, an outing and so on. When working with a simple token system the individual can choose from an array of available reinforcers the item or activity that he would like to be working towards. With more complex token systems one may have a 'menu' of reinforcements posted along with the 'prices' of various items for example, bubbles might cost five tokens; a video cost 16 tokens; a trip to McDonald's 50 tokens.

Following the steps

Whilst using a token economy, the first steps would be to decide upon: 1) the target behaviour viz the desirable behaviour to be taught or the behaviour to be strengthened; 2) the backup reinforcer viz the activity or item as well as the quantity that will be delivered in exchange for the tokens; 3) the type of tokens that will be used.

THE next step would be to establish a schedule of reinforcement ie to determine the number of tokens that would need to be exchanged for access to the backup reinforcer. Initially the child may have to earn just one token to get access to his backup reinforcer. This would mean that each time the child achieves the target behavior; he earns a token which he can then immediately exchange for the backup reinforcer. Once the individual makes the connection between the delivery of token and the consequent earning of the reinforcer and we see the target behavior beginning to occur with more regularity, the number of tokens that the child needs to earn in order to get his backup reinforcer can slowly be increased.

IN this manner one can move from a situation of immediate delivery of the backup reinforcer, to a point where the delivery of the backup reinforcer is progressively delayed, such that tokens are earned and exchanged for the desired reinforcement after an extended period of time.

LET'S say that the behaviour that is being targeted for Anoop is making eye contact with the teacher for at least three seconds, and his backup reinforcer is tickles from the teacher. In the initial stages of implementing the token economy, Anoop would receive one token every single time he made eye contact for three seconds; or in other words engaged in the target behaviour. This token would immediately be traded for tickles, ie the backup reinforcer, from the teacher. Later, as Anoop's behaviour of looking for three seconds at the teacher happened with greater frequency, he learnt to wait longer and longer before receiving his backup reinforcer of tickles. He had to accumulate a total of ten tokens before he could get access to the backup reinforcer.

ONCE a child is comfortable with the delay in reinforcement, one can design token systems that may encompass an entire day or week instead of just one particular work session. For example, in a classroom, individual students and often the class as a whole are awarded tokens for 'being good'. When the student or the whole class accumulates a certain number of tokens, they then receive a 'prize' or get to do a special activity which is their motivator. As token systems become complex and sophisticated, there is often a 'menu' of reinforcements that are posted, along with the 'prices' in tokens, and a specified time place for exchanging the tokens for backup reinforcers.

IT is vital to remember to always pair verbal praise with the presentation of the token. Giving a "Good sitting!" or "Great reading!" will remind the child why he is getting the token. Also when tokens have been established as secondary reinforcers, they can in turn help establish social praise as a reinforcer. When that happens it is then easier to fade the tokens over time and ultimately the person will be naturally reinforced through the social interaction with the adult.

Advantages of a Token Economy

The use of tokens as a means of delivering reinforcement through the individual exchanging them for back-up reinforcers has a number of advantages.

1 Token economies establish a visual routine. Given the fact that most individuals with autism are visual learners, they understand the process of how the token economy works really well.
2 A token system is a great way to build an individual's ability to delay gratification as they learn to wait for reinforcing items or activities for gradually lengthening periods of time. They help the individual understand that he can get to do something really enjoyable and fun, and exactly how much work he has to do before he gets to do so. Token systems can help individuals who have little sense of time become more aware of how long they have been at a task and how much longer they will have to remain at that task.
3 By delaying the reinforcement and providing a variety of backup reinforcers, token economies can ensure that the individual's desire for the reinforcer remains high and results in lowering the rate at which the individual becomes satiated with a particular form of reinforcement. Thereby the item or activity continues to have value as reinforcement.
4 Whilst working with a student if one has to deliver the reinforcement after every response, then even relatively brief reinforcement can greatly interrupt the interaction and slow down the rate of instruction. Reinforcing a response with a token is quick, and allows for speedy, interruption-free instruction, thereby ensuring that the student's attention is maintained.

When the reinforcement is delivered after several responses instead of after each response, items or activities that are longer-lasting can be chosen for reinforcement. As an example, where a video is a backup reinforcer, it is probably not effective to use it as the reinforcer when it has to be delivered for each correct response. Even a few seconds of a video after each response can slow down the rate of interaction and possibly result in the loss of attention. However, if the video is especially rewarding for a child, he may be willing to work for and earn several tokens in order to get a chance to watch it.

5 In most school settings, it is not common to see teachers walking around handing out crazy balls or blowing bubbles after every correct answer. Using tokens can be less obtrusive in the classroom. They also provide the same reinforcement for individuals who have unique preferences in back-up reinforcers. So in a classroom, irrespective of what each child likes, each child essentially gets the same token. Therefore tokens are easy for the teacher to dispense and easy for children to accumulate. For this reason a token economy is particularly successful in inclusive classrooms.
6 Token systems are a very good opportunity to introduce some real-world math skills to the child. Asking questions like, “How many stickers do you have?” “How many more do you need to get the bubbles?” “Does Sunny have more stickers than you?” “How many more?” can get children thinking about numbers in a new setting.
7 Finally, use of token economies can also help to develop an individual's planning skills as different quantities of tokens need to be earned for different types of backup reinforcers, and further the tokens must be gradually accumulated until enough have been earned.

Disadvantages of a Token Economy

As with any system, token economies too have some disadvantages:
1 Teachers have to be vigilant in pairing social praise with tokens. As with any tangible reinforcement, it is important to wean the individual off the tokens and therefore it is absolutely necessary to pair social praise with the tokens so that the social praise in itself can work as the reinforcement at a later stage.
2 When a token economy is used for a large number of students or an entire class, it requires some extra effort in organising and conducting the program,
3 When used inappropriately and without understanding the principles behind it, token economies can end up being counterproductive.

IN conclusion, it is important to note that token economy is not ‘special education’. Tokens in the form of stickers and stars have always been used in regular classrooms. In fact, they work in the ‘real’ world with adults as well. Most adults participate in some form of token economy, whether it be a card point system of a department store like ‘Shoppers Stop’ or the frequent flyer miles by ‘Jet Airways’.

IF used appropriately, with a clear understanding of the principles guiding it, token economy can be a very effective system of helping children learn. Token economy systems build confidence, patience, and demonstrate the meaning of the phrase, ‘Good things come to those who wait.’

ऑटिज्म के लिए वैकल्पिक चिकित्सा (स्वलीनता)

मैथ्यू के बलमोन्टे

मानव विकास विभाग, कार्नेल विश्वविद्यालय

(...cont from April 2012 issue of Autism Network)

भाग–3

चिकित्सा–कम सबूत के साथ और कुछ बिल्कुल बिना सबूत के।

टीके से आटिज्म नहीं हो सकता

आटिज्म के बारे में कुछ अनकही बातें अमेरिका और ब्रिटेन से आई हैं। बिना किसी शक के, इसमें से सबसे खतरनाक लेकिन पूर्ण रूप से झूठा दावा है कि टीकों से आटिज्म हो सकता है। यह दावा दो शर्मनाम बातों पर आधारित है। इसमें से पहला दावा ऐनड्रीयू फेकफील्ड और उनके सहयोगियों द्वारा सन् 1998 की एक रिपोर्ट में कहा गया जिसके अनुसार उन्होंने जीवित खसरा के कीटाणु उन आटिस्टिक बच्चों के अमाशय में पाये जिन्हें गैस्ट्रोइंटेस्टाइनल समस्या थी। यह रिपोर्ट प्रतिभागियों के नियंत्रित चयन और नियंत्रित प्रयोगशाला परीक्षण के अभाव में उसी किताब से वापिस ले ली गई जिसमें यह प्रकाशित हुई थी। लेकिन इस सबसे टीकों का विरोध करने वाले लोग जो दावा करते हैं कि डी.पी.टी. टीके से आटिज्म हो जाता है, चुप नहीं हुे। हलांकि यह सच है कि प्रतिरक्षा असामान्यताओं और आटिज्म के बीच गहरा रिश्ता है, फिर भी यह बिल्कुल सच नहीं कि आटिज्म का कारण टीके होते हैं। यह हम इसलिए जानते हैं क्योंकि बहुत बड़ी खोजों ने टीके वाले बच्चों की तुलना करी और आटिज्म के होने या न होने में कोई फर्क नहीं पाया। दूसरी शर्मनाक बात जो टीके और आटिज्म को लेकर कही गई वो एक अनुमान है कि थामोमरसल जो कुछ टीकों में पाया जाता है और पारा युक्त होता है, कुछ लोगों में आटिज्म का कारण हो सकता है क्योंकि वह लोग पारे जैसे विषाक्त धातुओं को जल्दी शरीर से नहीं निकाल पाते। हलांकि कुछ रिपोर्ट बताती हैं कि थायोमरसल मस्तिष्क पर विषाक्त तरीके से असर कर सकता है और इसको बचपन में लगने वाले टीकों से निकाल लेने में ही समझदारी है, लेकिन सन् 2003 में ऐनड्रिस हेविड और उनके सहयोगियों ने पाया कि पारे को टीके में से निकाल देने के बाद भी आटिज्म के होने या ना होने पर कोई असर नहीं पड़ा। टीकों और आटिज्म के बीच इस झूठे दावे की वजह से आयरलैंड और ब्रिटेन और काफी हद तक अमेरिका में लोगों ने टीके लगवाना बंद कर दिया। इसका सीधा नतीजा वह हुआ कि कई हजारों बच्चों को खसरा हो गया और कुछ की मृत्यु हो गई जबकि उनकी जान बचाई जा सकती थी। इसलिए बच्चों को टीका लगवायें।

चिलेशन मदद नहीं कर सकता, बच्चों को नुकसान या मार सकता है

अमेरिका में पारे से होने वाले विषाकता विचार का समर्थन करने वालों ने एक प्रक्रिया जिसे चिलेशन कहते हैं, को आगे बढ़ाना शुरू किया। चिलेशन से पारा विषाक्तता के गंभीर मामलों का उपचार किया जाता है। उनकी सोच है कि पारा जिससे आटिज्म होता है, अगर शरीर से पारे को निकाल दिया जाये तो आटिज्म कम हो सकता है। अगर यह दावा सही भी था तो बचपन या किशोरावस्था के दौरान ये सब करने को कोई ज्यादा फायदा नहीं होगा, जबकि नुकसान तो काफी साल पहले बचपन में ही हो चुका होगा। इसके अलावा, चिलेशन एक पूरी तरह से सुरक्षित प्रक्रिया नहीं है, अगर गलत तरीके से लागू हो जाये तो यह शरीर से लाभकारी धातुओं को हटाकर नुकसान कर सकता है। सन् 2005 में एक पांच वर्षीय आटिस्टिक बच्चे अबूबरवर नाडामा की मृत्यु चिलेशन 'चिकित्सा' की वजह से हो गई। चिलेशन को कोशिश मत करना।

लुपरौन चिकित्सा मदद नहीं कर सकती और बच्चों के यौन विकास को नुकसान न पहुंचा सकती है

समय–समय हम देखते हैं कि खराब योग्य लोग वैज्ञानिक परिणामों को गलत तरीके से पेश करते हैं और उपयोग करते हैं (और आटिज्म के सिद्धान्तों) और फर्जी उपचार का समर्थन करते हैं। टीकाकरण विरोधी आंदोलन ने साबित किये हुए प्रतिरक्षा विज्ञानी जुड़ावों का उपयोग इस झूठे दावे के समर्थन के लिए करा कि टीकों से आटिज्म होता है। चिलेशन का प्रयोग करने वाले लोगों ने इस झूठे दावे को कि आटिल्म के लक्षण पारे की वजह से होते हैं, को साबित करने के लिए इस तथ्य का सहारा लिया कि पारा तंत्रिका पर असर करने वाला बिश होता है। अमेरिकन चिकित्सक मार्कगियर द्वारा प्रस्तावित चिकित्सा शायद सबसे ज्यादा बेतुकी और खतरनाक है। गियर ने शुरूआत करी अंग्रेजी मनोवैज्ञानिक साइमन बेरोन कोहेने के दावे के साथ की सेक्स होर्मोन्स टेस्टोस्टिरोन का जन्म से पूर्व का उच्च स्तर आटिज्म का खतरा बढ़ा सकता है। हलांकि जन्म के पूर्व टेस्टोस्टिरोन होर्मोन्स की बात सच है लेकिन गियर ने इसका समर्थन आटिस्टिक बच्चों को लियोप्रोलाइड (लूपरौन) देने के लिए करा लियोप्रोलाइड जो कि अकालिक यौवन और प्रोस्टेट कैंसर के लिए एक चिकित्सा है, रासायनिक बधिया के रूप में काम करता है। यह आक्रामक व्यवहार को वैसे ही कम करता है जैसे बधिया करता है। लपरौन का उपयोग न करें।

ज्यादातर 'संवेदी एकीकरण चिकित्सा वास्तव में संवेदी एकीकरण के लिए नहीं होती

टोमेटिस चिकित्सा और उससे संबधित श्रवण एकीकरण चिकित्सा के बारे में बहुत कुछ कहा गया है कि यह कान के प्रशिक्षण का तरीका है जिससे आटिस्टिक लोगों के इलेक्ट्रानिक संसाधित आवाज और/या संगीत के द्वारा कुछ ध्वनियों के अनुकूल बनाया गया। इनमें से किसी भी तरीके को नियंत्रित अध्ययन से साबित नहीं किया जा सकता है। फिर भी चिकित्सक अक्सर टोमेटिस या श्रवण एकीकरण चिकित्सा के लिए बड़े शुल्क ले लेते हैं। हलांकि यह सच है कि बहुत सारे आटिस्टिक लोगों को अलग–अलग संवेदी तरीकों को एकीकरण करने में परेशानी होती है–जैसे कि एक ही समय में देखने और सुनने में परेशानी होना या दो अलग–अलग स्थानों पर चीजों की तरफ ध्यान देने में परेशानी होना। इनमें से कोई भी संवेदी एकीकरण समस्याओं को टोमेटिस या श्रवण एकीकरण चिकित्सा द्वारा संबोधित नहीं किया गया। सन् 2007 में कैलिर्फोनिया विश्वविद्यालय के ब्लीथ ने इस बात को ध्यान में रखते हुए की माता पिता टोमेटिस चिकित्सा पर बहुत ज्यादा पैसे खर्च कर रहे थे, दोहरे अंधे अध्ययन से आटिस्टिक बच्चों के भाषा कौशल पर टोमेटिस चिकित्सा के प्रभाव को जानने की कोशिश करी। उन्होंने पाया की नियंत्रित समूह ने असली में अपने कौशल को उपचार समूह की तुलना में ज्यादा सुधारा था। हलांकि इन उपचार दावों से कोई गंभीर नुकसान नहीं हो सकता, लेकिन उन पर पेसे खर्च होते हैं और वह मदद भी नहीं करते।

लस मुक्त और/या कैसीन (दूध का प्रोटीन) मुक्त आहार मदद करने के लिए सूचित किया गया है, लेकिन साबित नहीं किया गया

कई वर्षों से लस मुक्त आहार (गेहूं उत्पाद) और/या कैसीन (दूध उत्पाद) आटिज्म में मदद के लिए जाने जाते हैं, लेकिन शायद हो कभी उनकी वैज्ञानिक जांच की गई होगी। उदाहरण के लिए आटिस्टिक लोगों की दर्द के प्रति असंवेदनशीलता के लिए या धारण है कि लस और कैसीन के आशिक पाचन से मुक्त हुए प्रोटीन के टुकड़े शायद रिसावदान आंतों की दीवार मे से पारित होकर खून के संचलन में मिल जाते हैं और नशीले पदार्थों के प्रभावों की वजह से शुरू हुए दर्द का भ्रम देते हैं। एक संबंधित परिकल्पना है कि आंशिक रूप से पचा हुआ प्रोटीन प्रतिरक्षा प्रतिक्रिया शुरू कर सकता है। बहुत कम या कोई भी सीधे प्रमाण इन परिकल्पनाओं को साबित नहीं करते, लेकिन फिर भी माता–पिता लस मुक्त और कैसीन मुक्त आधार के कथित प्रभाव की सकारात्मक रिपोर्ट दे रहे हे।। शायद क्योंकि आटिस्टिक बच्चों के भोजन के सेवन को नियंत्रित करने की कठिनाई माता–पिता के लिए एक जाना माना विषय है। इस आधार के लिए सिर्फ एक दोहरा अंध अध्ययन लागू करा गया है। वर्ष 2006 में, जैनिफर ऐलडर और उनके सहयोगियों ने फ्लोरिडा विश्वविद्यालय में लेख प्रकाशित किया जिसके अनुसार उन्होंने बच्चों के व्यवहार का अंध मात्रात्मक मूल्यांकन किया और आहार का व्यवहार पर कोई प्रभाव नहीं पाया। फिर भी कुछ माता पिता ने दावा किया कि जब उनके बच्चे उस आहार पर थे तब उन्होंने अपने बच्चे

में पहचानने योग्य सुधार देखे। अगर वास्तव में लस मुक्त आहार का सकारात्मक प्रभाव पड़ता है तो इस तरह का प्रभाव केवल भोजन के सीमित सेवन का परिणाम हो सकता है–मुख्य रूप से आटिस्टिक बच्चों के उपसमूह में जिन्हें गैस्ट्रोइंटेस्टाइनल समस्याएं हैं। लस युक्त खाना जैसे रोटी और पास्ता कार्बोहाइड्रेट के मुख्य स्रोत हैं और इसलिए लस नष्ट कम करने से पूरी कैलोरी का सेवन कम हो सकता है और तब शायद उससे जुड़े गैस्ट्रोइंटेस्टाइनल संकट को कम करने की उम्मीद करी जा सकती है।

किसी मदद से करा हुआ संचार एक त्रृटिपूर्ण विधि है लेकिन अगर हालात देखें तो कम से कम हानिकारक नहीं है।

1970 के दशक में आस्ट्रेलियाई शिक्षक रोज़मैरी क्रासले ने गंभीर मस्तिष्क पक्षाघात से पीड़ित बच्चों के हाथ, हथेली और कलाई का समर्थन शुरू कर दिया क्योंकि वह बुद्धिमानी से संवाद करने और बोलने में असमर्थ होने के बावजूद भी लंबी बौद्धिक गहरी संवाद कुंजीपटल या अक्षर पटल पर टाईप करके कर पा रहे थे। इस तकनीक का कभी भी बड़े पैमाने पर नियंत्रित अध्ययन के रूप में मूल्यांकन नहीं करा गया लेकिन फिर भी बाद में इसे उन आटिस्टिक लोगों के लिए उपयोग करा गया जो बोल नहीं सकते थे या जो भाषा का ठीक से उपयोग नहीं कर सकते थे। वर्ष 1989 में यह विधि सिरैक्यूज विश्वविद्यालय के डौग किलेन द्वारा अमेरिका में आयातित करी गई। बाद में इस विधि के संदर्भ में झ़ूठे आरोपों की एक श्रृंखला आई जिसमें कहा गया कि बहुत सारे चिकित्सक अन्जाने में अपने ग्राहकों को कुछ विशेष अक्षर सिखा रहे हैं। इस प्रकार यह तकनीक एक दोषपूर्ण तकनी है जो सामान्य रूप में विश्वसनीय संचार उत्पादन नहीं कर सकती। इस तकनीक के लगभग हर नियंत्रित अध्ययन में पाया गया कि ग्राहक उन प्रश्नों के उत्तर देने में असमर्थ थे जिनके जवाब एफ.सी. चिकित्सक को ही नहीं पता थे। फिर भी बहुत सारे लोग जिन्हें आटिज्म है उन्होंने एफ.सी. की शुरूआत चिकित्सक का हाथ पकड़ कर करी और अंततः बिना किसी की मदद के सफल हो गये। शायद इन मामलों में से सबसे प्रसिद्ध मामला सुई रूबिन का है जिसने एफ.सी. का उपयोग करके स्वतंत्र रूप से टाइपिंग करके विश्वविद्यालय की डिग्री हासिल करी। जैव तंत्रिका विज्ञान ने माना है कि आटिस्टिक लोग भाषा और बातचीत जैसे तेज माध्यम की तुलना में धीमी गति से टाइपिंग करके अधिक संचार करने में सक्षम हो सकते हैं। (मेरे विद्यार्थी ग्रेस चेन और कीथ थोडर ने इस विषय की तैयारी से संबंधित एक लेख लिखा है) बहुत सारे अभिभावकों ने माना है कि उनके बच्चे जो एफ.सी. का आयोग करते हैं, कम हताश होते हैं जब वह टाईप कर पाते हैं। हलांकि इस तरह से वास्तविक संचार नहीं हो पाता हो फिर भी कुछ मामलों में भावनात्मक लाभ जैसे कि बच्चे के सम्मान और उससे जुड़े रहने के लिए कोशिश करी जा सकती है। यह बच्चों की क्षमताओं की बुद्धि में विश्वास दिलाने के लिए भी बहुत जरूरी है। और कुछ मामलों में एफ.सी. से अंततः बिना किसी की मदद के वास्तविक संचार कर सकते हैं। फिर भी एफ.सी. एक संदिग्ध और त्रृटिपूर्ण तकनीक है क्योंकि एफ.सी. चिकित्सक की मदद और बिना मदद के भी टाईप करे हुए संदेश स्पष्ट रूप से सही नहीं मानने चाहिए और माता पिता को बुहुत सावधान रहना चाहिए। अगर उन्हें एफ.सी. उपचार के लिए ज्यादा धन देने के लिए कहा जाता है।

तेज तरक्की वाली विधि आर.पी.एम./जानकारीपूर्ण इशारा करती हुई विधि आई.पी.एम.

आटिस्टिक कवि टिटो मुखोपाध्याय की माँ सोना मुखोपाध्याय ने शिक्षा का एक तरीका विकसित करा जो आर.पी.एम. के नाम से लोकप्रिय हो गया। सहज ज्ञान पर आधारित इस विधि को इसका नाम पोर्टियां यावरसन ने दिया था जो डोव शेसटेक की माँ और क्योर आटिज्म बाओ की सह–संस्थापक हैं। सुश्री यावरसन ने बाद में इस तकनीक के और तत्व 'आई.पी.एम.' नाम के नीचे विकसित करे। इस तकनीक को शुरूआत उपभोक्ताओं को बहुत आसान प्रश्न के दो वैकल्पिक प्रतिक्रियाओं में से एक को चयन करने का प्रशिक्षण देकर करी गई जैसे की आसमान लाल या नीले रंग का है ? या "एक जमा एक क्या होता है ? जब एक बार उपभोक्ता दो विकल्पों में से एक चुनने में आरामदायक हो जाता है, तब जटिलता धीरे–धीरे बढ़ाई जाती है जब तक बच्चा रोमन लिपि के छब्बीस अक्षरों में से विकल्प चुन पाता है। महत्वपूर्ण बात है कि उपभोक्ता को चिकित्सक से कोई भौतिक सहयोग या मार्गदर्शन नहीं मिलता (इस प्रकार यह तकनीक एफ.सी. से

अलग है)। केवल थोड़े से गैर विशिष्ट संकेत दिये जाते हैं जो अस्थिर ध्यान के दुबारा ठीक करते हैं। उदाहरण के लिए उपभोक्ता के आंखें को सामने अक्षर बोर्ड को हिलाना, आदेश देना या दृढ़ता से बच्चे का उकसाना। आर.पी.एम./आई.पी.एम. का नियंत्रित अध्ययन नहीं करा गया और जब तक नियंत्रित अध्ययन नहीं हो जाता, तब तक आर.पी.एम./आई.पी.एम. आधारित संचार संचार की सच्चाई संदेह में रहेगी। इस कारण से माता पिता को सावधान रहना होगा। अगर उन्हें आर.पी.एम. चिकित्सा के लिए बहुत ज्यादा पैसे चुकाने के लिए कहा जाता है। जैसा कि एफ.सी. के मामले में है, आर.पी.एम./आई.पी.एम. से कुछ उपभोक्ता स्वतंत्र रूप से बातचीत करना सीख गये हैं। इन सब में सबसे उल्लेखनीय हैं टिटो मुखोपाध्याय, जिन्होंने पूरी किताबें लिखी हैं। मेरा अनुसंधान समूह आर.पी.एम./आई.पी.एम. द्वारा उत्पादित संचार की प्रमाणिकता साबित करने के लिए नियंत्रित अध्ययन का आयोजन करने के लिए परीक्षण कर रहे हैं।

निश्कर्ष– यदि यह आपके बच्चे के लिए काम करता है, कोई नुकसान नहीं कर सकता और खर्च नहीं कराता तो उसके साथ रहो।

वैकल्पिक चिकित्सा के बारे में बिना प्रमाण के दावे बहुत तेजी से बढ़ रहे हैं कि उनका इस लेख में गणना करना मुश्किल है। मुझे आशा है कि मैं आपको इस सबके बारे में थोड़ा बहुत समझा पाया हूं और भव्य दावे जो आपको बताये जाते हैं, उसका मूल्यांकन कैसे करेंगे, ये भी समझा पाया हूं। अपने आपसे यह सवाल पूछो :

– क्या यह काम करता है ? क्या चिकित्सा का नियंत्रित अध्ययन किया गया है ? यदि हाँ तो अध्ययन का अंधा स्तर क्या था ? क्या परिणाम माप निष्पक्ष, मात्रात्मक और चिकित्सा के उद्देश्यों का वर्णन करते हैं ?
– यह कैसे काम करता है ? क्या वहां कम से कम एक विश्वनीय तंत्र है जिसके द्वारा चिकित्सा का प्रभाव हो सकता है ?
– यह किसके लिए काम करता है ? कितने प्रतिभागियों ने अध्ययन में भाग लिया था और क्या सबने चिकित्सा में एक जैसा व्यवहार करा था? अगर नहीं तो जवाब देने वालों में क्या विशिरूट लक्षण थे जो जवाब देने वालों में नहीं थे ?

आप जो भी सुनते हैं, सब पर विश्वास ना करें। आटिज्म के लिए हर दावे वाली चिकित्सा के लिए कहानी होती है कि इसमें मेरे बच्चे के लिए काम किया है। मनुष्य के रूप में हम अक्सर वैज्ञानिक नियंत्रित प्रयोगों में इस्तेमाल होने वाले निराकार और अलग भावों के बारे में नहीं सोच पाते। इसकी जगह हम ठोस और व्यक्तिगत कहानियों से ज्यादा प्रेरित होते हैं। जब हम देखते हैं कि चिकित्सा से व्यक्ति सुधर रहा है तब हम दो और दो एक करने लगते हैं और गलती से कारण और प्रभाव के बीच का रिश्ता ढूंढने लग जाते हैं। लेकिन अगर यही व्यक्ति बिना चिकित्सा के ही ठीक हो गया हो ? अगर बहुत सारे लोग उपचार अपनाते हैं, हमें पूरा यकीन है कि उनमें से एक जरूर सुधर जायेगा। और उस व्यक्ति के माता पिता भी होंगे जो उपचार का जोर शोर और नियमित रूप से बचाव करते होंगे। ऐसे बचाव करने वाले लोगों पर गलत चिकित्सा का दोश लगाना मुश्किल है क्योंकि उन्हें पूरा विश्वास है कि उनकी चिकित्सा काम करती है और वह चाहते हैं कि दूसरे लोग भी उससे फायदा उठायें।

इसलिए मैं माता पिता से कहता हूं कि अगर चिकित्सा उनके बच्चे के लिए काम करती हुई लगती है और कोई नुकसान नहीं कर सकती और उस पर ज्यादा पैसे भी खर्च नहीं होते तब उसको करते रहो। इसी में इसका मान–सम्मान है, भले ही यह विश्वास की रस्म हो।

उपचार जो काम करते हैं और जो काम नहीं करते, के बारे में ज्यादा जानकारी हमारी वेबसाईट : http:/www.asatonline.org पर प्राप्त की जा सकती है।

मैथ्यू बैलमोन्टे कार्नेल विश्वविद्यालय में सहायक प्रोफेसर हैं और दो आटिस्टिक लोगों के भाई और चाचा हैं।
उनकी वेबसाईर्ट का पता इस प्रकार से ख्यातिलब्ध है :
http:/www.mit.edu.

।। इति सिद्धम् ।।

HELPLINE

ACTION FOR AUTISM

Q I'm from Alexandria, Egypt. My son is 23 months old, and his paediatrician suspected that he has some autistic symptoms. I have read up quite a lot about autism online, however I cannot judge if my son is really autistic or not.

I'd like to describe a few of the main symptoms that my son has. He tends to flap his hands frequently. He does not point to things, nor does he use gestures like 'bye bye' etc. On some instances , I have observed him walking on his toes: a few steps every 2-3 weeks. He has very good eye contact even with strangers, but when I sing to him, he looks only at my mouth.

There is a delay in speech and at present he only babbles with sounds. He started babbling at 9 months and then stopped at about 18 months. Then, about two months ago, when we completely stopped watching TV, which he used to spend extended hours in front of, he started babbling again.He doesn't go to a nursery, so I cannot describe what his interactions with peers might be like. However, with his cousins he tends to play for some time and then stops and so on.

I have gone to a few centres dealing with autism in my city. One of these centres diagnosed my son as having 'severe autism'. Another organisation I visited said that my son has only some symptoms of autism.

I have also consulted a professor in pathology, and he said that all the symptoms my son has are only due to the delay in speech. He said that this was due to the extended periods that he would spend in front of the TV and that we were not talking enough to him and not interacting enough with him. The professor also administered a test on my son, and told us his abilities are of 16 months old toddler.

I am really confused. Sometimes my son seems perfectly well, and other times he seems typically autistic. Can you give me any opinion in view of above information? Also if you know of a center/doctor in my city, can you please give me contact details of the same?

A I can well imagine the amount of confusion that must be surrounding you at the moment. In India, we are faced with a very similar situation - limited awareness and services available for children with autism. Very often children are at least 3 years old before a diagnosis of autism is suspected even though we know that autism can be identified as early as 18 months of age. It is truly terrific that you are seeking answers when your child is only 23 months of age.

In India as in many parts of the world, at this age, we are able to screen a child for autism and say if s/he is 'at risk' for autism. Other words that are used to describe this are 'symptoms of autism'; 'mild autism' or PDD. Regardless of the term used, we strongly recommend that children who is 'at risk' of a later diagnosis of autism are put on an early intervention programme as soon as possible using autism specific techniques. A follow-up visit for a diagnostic assessment in 9 -12 months is then recommended. This ensures that we have effectively utilised the child's early years that has been proven to be so very important to development.

Some of the behaviours that you describe in your email closely resemble autism. However, a diagnosis can be given only after meeting with the child. However, in the meantime you could also answer a few questions at home through the attached questionnaire the M-CHAT. This is a screening tool that is well known and used internationally and can be a reliable indicator to check if your son is at risk for autism. You can also read about the M-CHAT on the internet.

Here are some organisations that we are aware of in Egypt. Please note that this is just a simple list of places we know of and not a recommendation. There are probably many more organisations that are not on this list.

Organisations in Egypt

The Egyptian Autistic Society, 7 Naguib Mahfouz St.
New Nirco, Maadi, Cairo

The ADVANCE Society (The Egyptian Society for Developing Skills of Children with Special Needs)
34 Al-Nadi Al-Gadeed St., New Maadi, Cairo 11435
Tel: 2025193721/ 5193723
Fax: 2025203110
Email: helali@lrcegypt.com
Website: http://www.advance-society.org

The ADVANCE Center [run by Learning Resource Center], 34 Al-Nadi Al-Gadeed St., New Maadi, Opp. the New Maadi Telephones Central Office, Cairo 11434

Tel: 202519-3721, 202519-3723
Website: http://www.lrcegypt.com/autism.html

Q Our 15-year old son has autism. I have noticed a difficulty in his speech right from the time he started uttering sounds. He has a difficulty in uttering the sounds of 'k',' kh',' g' and 'gh'. Now when he recites lines of poetry from memory, we see that he has a hesitation in doing so, and feel that perhaps this is because of the presence of the 'k',' kh',' g' and 'gh' sounds there. He recites haltingly, but he does not say he has any pain or such other thing. His speaking otherwise is normal as far as his condition allows. His eating habits and patterns are absolutely normal. Is the problem mentioned likely to be very serious concerning his vocal chords — something to worry about and worth examining by a specialist? Ours is a small place without such specialists. Please advise what we may do now.

A Speech difficulties are common in verbal individuals with autism, this may be partly due to reduced ability to 'tune in', listen and process sounds in the environment. In addition to this, people with autism sometimes feel less social pressure to have their speech match the speech of others. Is your son aware of his speech difficulties?

The four sounds that you mention are made in the same place in the mouth and using the same process. This means that your son's speech difficulties are unlikely to be due to a serious medical issue. It is more likely that when you son was younger he did not tune into these sounds and has now developed a habit of producing these sounds in an atypical way. He has articulation difficulties.

How does your son produce these sounds? Often individuals make these sounds at the front of the mouth rather than the back of the mouth so the sounds are replaced with 't' and 'd'.

Since, presumably, you do not have access to a speech and language therapist locally, perhaps you could check out this website. http://speech-language-therapy.com/index.php?option=com_content&view=article&id=11&Itemid=117. In particular you may find the Resources and Word List section helpful. I am unsure about your son's language level so not all activities may be appropriate.

(The responder is Maeve Mc Cutcheon, Speech and Language Therapist at Action for Autism)

Upcoming Workshop at a Glance

AFA's much-awaited Annual Training Workshop: ***Know Me Teach Me*** has been scheduled from **4 - 7 October 2012.** Through a series of lectures, videos, practical demonstrations and interactive exercises, the workshop will focus on an understanding of autism and specific teaching strategies that take into account the unique learning styles of people with autism.

Based on techniques, internationally recognised as 'Best Practises' for teaching people with autism, modified to take into account our own cultural needs, the participants will learn creative and resourceful methods to teach communication, social skills, activities of daily living, cognitive skills, as well as address challenging behaviours - a priority both in classroom situations and at home.

The workshop is designed to move away from providing 'solutions' or 'recipes' in one particular area of difficulty, but instead focuses on helping participants understand autism and approach teaching from that paradigm of understanding. This leads to participants being able to apply and generalise their learning to teach children holistically and deal with challenges faced in varied situations and environments.

The workshop is for both the newbie as well as a refresher for experienced hands and can be attended by all those who work closely with children with autism on a daily basis: professionals of every discipline related to ASD, as well as parents interested in learning how to teach their children life skills.

Registration forms for the workshop are available on our website www.autism-india.org.

For more information, please email us at:

<anvay.trainings@gmail.com> mentioning the word: **AT WORKSHOP** in the subject line.

MEMBERSHIP TO AFA

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

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Parents: *Associate Member* – Annual: Rs 150/- *Full Member* – Annual: Rs 500/- *Overseas Member* : $ 30

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Associate Members receive copies of Autism Network and information on all upcoming events and activities. Full Members, Life Members, Overseas Members and Institutional Members are in addition, entitled to concessionary rates for AFA events and workshops.

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Phone _______ Email _______

I am a: (tick all that apply)

☐ Parent ☐ Relative _______________

☐ Professional: Name of Org. _______________

____

☐ Other _______________

If you are a parent of a person with autism, please answer:

Child's name _______________ Sex _______

Date of birth _____ dd _____ mm _____ yr _____

Diagnosis (if known) _______________

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