GOOD INTERVENTION PRACTICES IN AUTISM SPECTRUM DISORDERS – GUIDELINES FOR PARENTS

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Parent reaction, stress and coping

When parents come to know that their child has autism spectrum disorder (ASD), they respond in many different ways. It often comes as shock and they go through a number of different distressing emotions, such as confusion, sadness, disillusionment, disappointment and desperation. Sometimes they may also blame themselves, feel guilty, or may blame their stars for the situation they are facing. They also start worrying about the future of the child and start searching for a cure by one way or the other. These are quite natural reactions and tend to subside with time, especially when parents come to understand and accept the problem and know how to cope with the situation and face the challenges. Sometimes, these feelings might persist and cause a lot of misery and unhappiness, and even disturbed relationships in the family. Seeking appropriate processional help is often useful to learn how to cope well and adapt to situation.

There are a number of web resources that provide accurate, scientific and up-to-date information on ASD. Visiting these sites and learning more about ASD often helps the families to understand and deal with the problems that their child is facing. Following are few such links.

Autism speaks - http://www.autismspeaks.org/
NAC (National Autism Center), Massachusetts - http://www.nationalautismcenter.org/index.php
National Trust, India - http://autismresourcecenter.in/Default.aspx

Minimizing stress and enhancing coping

On the long run, living with and caring for a child with ASD often means a high degree of stress for the families. This can be in the nature of emotional, social, interpersonal, and daily care stress. Family attempts to deal with this in a variety of ways. Some of these may be healthy, while others may not be so for instance, seeking more accurate information, seeking appropriate professional services, accessing available facilities, learning techniques of intervention and practicing them, finding out what works for their child, 'seeing the child behind autism' are healthy ways of coping. There are also many parents and families who have experienced that caring for a child with ASD has had a positive effect on them. On the other hand, cutting on social interactions ("how do I face the society with this child?") or allowing one's life completely dominated by the child and his problem are examples of unhealthy ways of coping.

A few dos and don'ts for parents to cope better and face the challenges

- Get accurate information
- Discuss with other families who have ASD children

- Become member of societies meant for ASD
- Face the challenge with family as a whole
- Organize your and your family's life so that needs of all family members are met
- Do not feel compelled that you have to be attending to the child all the time. It is very important to take time off from the caring for the child for rest, relaxation, entertainment, and pursuing your own hobbies, interests and other activities
- Maintain your social and personal life; do not isolate yourself from your family, relatives and friends
- Be prepared to explain the child's problem to others in simple terms so that they can understand
- It is better to avoid experimenting with expensive and unproven treatments
- There is no need to feel ashamed of the child's problem. It is not your fault.
- Get to know the resources that are available for in your place and approach them for help.
- Do not hesitate to get reasonable help and support from friends and relative
- It is very often helpful and gives a lot of relief when you discuss the worries, problems, and difficulties with somebody whom you trust.
- Do not allow others to be rude with your child; tell them that he is also a human being and needs to treated accordingly and that it is not his fault that he has the problem. You can develop your own appropriate methods to deal with such situations, rather than silently suffering.
- It is not healthy for the child to be engaged in 'therapy' all the time. Both the children and families need rest, relaxation and entertainment like anyone else.
- Learn what works best for your child
- Find out what the child has learnt to do first. Then move on to what s/he needs to be taught.

Areas for teaching /training / intervention and some good relevant practices

General comments

- Children with ASD have impairments in many areas of development from very early childhood
- Recognizing these problems in development at an early age and starting early intervention will help them to slowly overcome these deficits to the extent possible.
- Early intervention is systematic, structured teaching of new skills and competencies to children who are showing signs of ASD, and creating more opportunities for their learning the skills that they are lacking.
- **Simply waiting and expecting that child will become all right with age will lead to accumulation of impairments and deficits that become more difficult to overcome later**
- It is better to start the intervention even when the child is showing only some symptoms and diagnosis is not clear

- It is preferable to avoid excessive exposure to TV and other electronic media, as this will tend to make the child more solitary and lose out on opportunities to learn social and communicative skills
- These children learn faster with home-based intervention in their real-life settings, with parents as trainers or therapists. Therefore, parents can learn the techniques of intervention and practice them at home.
- The training / teaching activities can be incorporated in the child's daily routine
- All members of the family need to participate in training the child – the task of teaching is not mother's alone.
- Developing a good structured daily routine is very helpful.
- Many Individual with ASD have special skills, strengths, talents and abilities – the so-called savant skills. Some examples are exceptional memory (for dates / phone numbers/ events/places), drawing / painting skills, visual skills (recognizing and naming objects), constructional abilities, and academic skills. These have to be recognized when present and can be utilized in the best possible way.
- There are a number of books and manuals that are very helpful in carrying out intervention; here are a few of them. Find out which is most relevant to your child and appeals to you most.

Social development

ASD is primarily impairment of social development from very early childhood. They lack a natural ability of very young children to relate, interact and respond to people around them. However, it is possible to tech them these skills through systematic, step-by-step, repetitive inputs. Basic behaviors that require training are simple social behaviors such as **look, take, give, show, come, go, bring, and point**. These are activities to enhance **joint attention**, i.e., child and mother focusing their attention on an object and then doing things together – for example, both focusing attention on a rattle, then mother shaking the rattle and giving it child, then child shaking the rattle (with or without mother's support) and giving it to mother on request (gesturing and saying 'give"). Other joint attention activities that can come later are mother pointing and child following direction of pointing, child following mother's direction of gaze. With some practice, assistance, encouragement, prompting, and praise these joint attention activities can be taught to the child. This helps the child to become more and more socially alert and aware, and to take greater interest in people and their activities, and responding to them appropriately.

Noticing their responses which are feeble at first, and strengthening these responses by doing this again and again will help them to understand social cues and respond appropriately to these cues, and thereby improve their reciprocal and spontaneous social behaviors.

Another good method is through caregiver – child games. There are plenty of these games in each culture, and child needs to be engaged through these plays and games. Simplest of games are tickling, peek-a-boo, and gentle swinging on the legs with a

lullaby. Initially child may remain indifferent, but with repeated attempts and modifying the approach, which works best with a given child, child slowly starts responding and starts enjoying these activities and games. These mutually enjoyable playful games and activities are often very effective to make the child respond, seek out and interact with people. Once the child enjoys these simple activities one could move and to more elaborate - clap-clap game, run and catch, throw ball and catch, kick ball back and forth, "I am coming…I am coming….I have come!!" game, father pretending to be elephant and giving a savaari(ride) to child with mother being the mahout, train game etc. Similarly, interactive games involving sand, water, play materials, household utensils, are often liked by children. Later, one could introduce turn-taking games (hide and seek, "you first, I next, father last") and rule-based games (you are out!!)

Sometimes child may appear indifferent and not paying attention, but he may be still listening, and comes up with the behavior unexpectedly!

Careful natural observation of the child will help in deciding what the child wants and then one can organize new activities around it. In other word, child's choice for activity is recognized, and given importance. Child can be given many choices, and then depending on the child's preference, one can go ahead with interactive activities. It is also possible to convert child's solitary activities into interactive ones. Suppose child is interested in ball. Parents repeatedly say ball? And give it only when the child gives some indication verbally or by gesture that he wants it.

For older children with good verbal skills, there area number of methods that can be employed to teach them what do and what not to do in different situations. One method is to tell the child clear do's and don'ts, making the child rehearse these and monitoring and role-play the situation and giving them the feedback. This requires a lot of animation on the part of parents, so that messages are clearly conveyed. Another method is to build simple stories around the situation, going over the story and then create mock situations for practice. Later, child's behaviors in real-life situations are observed and appropriately reinforced.

Many of these skills can be taught as a part of interaction in their daily routine, in other words **incidental teaching**.

Self-help skills Training:

From a very a early age, it is very important to encourage, teach and train these children in taking care of themselves in their daily activities, so that they become more and more independent as they grow older. This can start with simple things such as drinking from a cup, and eating by self. Later, toilet indication, undressing, dressing, brushing, toilet training, grooming skills, bathing skills, simple household chores can be the focus of training.

It is a good strategy to select a few targets in different areas at a time that the child is capable of learning and then move further once the child has learnt these.

How to make children respond to our efforts to teach and train? Parents often get disappointed when there is child does not seem to care when they tell the child to do something. Behavior modification methods to build new skills c are very useful when this happens. These are **modeling or imitation** (showing how), **physical prompting** with fading (holding the child's hand and doing the required task – hand on hand technique - and later gradually reducing the support), **shaping** (simplifying the task and then gradually making it more and more identical to the goal), **backward chaining** (when the activity is complex, breaking it into many small steps and teaching them one by one, beginning with the last step first; example for drinking from a cup, give the cup to hand, then picking cup from table, and so on). Noticing the child's efforts to learn, however small and feeble they are, and praising immediately in a manner that child understands, will help the child to remember and learn faster (**rewarding or reinforcing**).

Communication and language

- Communication and language is one of the core problems that these children face – but can be improved with appropriate training/therapy/intervention
- Communication means exchange of messages, intentions, thoughts, information etc between people – a two-way process – shared understanding
- **Non-verbal** (gestures, vocalizations, and body language) and **verbal** (language and speech, written)
- Non-verbal – involves understanding others' gestures and body language, and expressing through gestures and body language
- Verbal – involves understanding others' speech, reading, and expressing through words, phrases and sentences, and writing
- Reception first, expression later
- Start early; focus on gestures accompanied by simple words
- Talk and play while feeding, dressing, bathing, etc. Give running commentary. Keep it simple and relevant to activities
- Let the child watch the way you speak by getting attention and look at face
- Make it two-way: Listen to noises and sounds, take interest and imitate his/her sounds – parallel vocalization
- Use gestures, body language and facial expressions to help clarify the meaning
- Name the objects that are in the child's focus of attention repeatedly
- Rhymes, lullabies, songs are useful media
- Using mirror to promote imitation
- Do not unduly pressurize or force
- Notice and take pleasure in utterances, vocalizations, and words
- Try to figure out the meaning of child's utterances and rephrase
- Recording and playing may help some children
- Using pictures to communicate
- Recognizing, naming, describing, relating experiences
- Mini-conversations around ongoing activities

- Question with answer in end in different tone
- Written language

Cognitive skills

Cognition means to know, and children with ASD need inputs to understand their surrounding so that they can learn to deal effectively with their environment. Simplest examples of cognitive skills are physical concepts such as size, shape, consistency, temperature (hot/cold), color, quantity (more/less), etc. Sorting, arranging, classifying activities enhance concept formation. Other concepts child has to master are directions (up/down, right /left,) relationships between objects (inside/outside, under/above) time (now/later, night/day, yesterday/tomorrow, day, date etc), distance (near/far). Later they need to learn readiness or pre-academic skills such as scribbling, drawing, coloring, copying. This is followed by scholastic skills of reading, writing, spelling and arithmetic. It is preferable not to force the child into any activity; alternatively; one can try different methods and find out which approach suits the child best **(individualization of approaches).** Some children may do better with computer-based learning.

Education

- Few hours of play home, baby nursery, or Anganwadi center, when they are very young is useful.
- Can and should go to school once they are ready
- There are laws that ensure that no child is excluded from schooling – this is called inclusion education
- Type of school, hours of schooling, teaching methodology are some of
- Having a dialogue with the school before putting the child to school and later to follow-up how are things going in school is necessary.
- Expectations about what child learns can be worked out.
- It is possible to develop peer support with some effort by the school
- Open schooling (nios.org) is another alternative that might suit some of them.

Problem behaviors

Sometimes individuals with ASD develop problem behaviors. Some common examples are aggression, self-injury, hyperactivity, and sexually inappropriate behaviors. Studying the patterns – how it started, where, when and with whom it occurs, and when it is not present, what happens after the behavior- otherwise called as functional analysis – will help in understanding the roots of problem and how to help the individual overcome the problem. Sometimes these behaviors serve some purpose – for example, trying to communicate something, getting frustrated because s/he can’t make others understand, and developing his/her own methods of doing so.

Behavior Modification techniques are often very useful in minimizing these problems. Some examples are as follows:

- Time structuring and Activity scheduling (predictable and organized sequence of activities in a day at appropriate times; care must be taken that the schedule is realistic and fulfills all the needs of the individual. Whenever possible, individual should have a say in the preparation of the schedule)
- Attention-enhancing tasks
- Disregarding (attend to the child, but completely ignore the behavior),
- Ignoring (ignore the behavior and child),
- Differential reinforcement ('catch' the child when s/he is showing appropriate behavior and attend/praise/reward),
- Antecedent management (taking pre-emptive steps to prevent the behavior from occurring),
- Limit setting (clear instructions about what is allowed what is not allowed and following it through),
- Graded exposure / desensitization (gradual exposure to the situations that the child is scared of, so that the child slowly overcomes the fear),
- Time-out (putting the child in a boring place without attention till s/he cools down).

Many times these problem behaviors result from faulty parent-child interaction patterns. These can be identified and changed, so that behavior decreases.
Improving the skills of the child also helps the child to give up problem behaviors
Please see below for the role of medications in the management of problems behaviors

Medical problems

Epilepsy is the commonest problem and is discussed below. These individuals may also occasionally have disturbances in vision and hearing, which needs appropriate medical evaluation and treatment. Like others, these children also may develop other medical problems such as infections, allergies, wheezing, etc. These need to be recognized and treated.

Medication

ASD is a neurodevelopmental disorder. In other words, it is a condition in which certain brain networks or circuits are not properly developed, and this results in impairments in development of functions in many areas. A lot of research is being conducted all over the world to understand the causes and how they interfere with development. It is possible that there may be some major advances in the treatment of ASD in the coming years. Till now there has been no medical treatment that has been found to correct these underlying abnormalities. In other words, as of now, there is no "medical cure" for ASD.

However, there are some associated conditions that require medical treatment. Some examples are as follows:

1. Epilepsy or seizure disorder: about 25% of individuals with ASD develop epileptic attacks in their lifetime, most commonly in childhood & adolescence. Different types of seizures can occur, for example in the form of convulsions, or attacks of staring with impaired consciousness. These attacks can be controlled with appropriate anti-epileptic medication. Doctors decide on type of medication, dose, timing of medication and duration of treatment. Like other drugs, these medications also have side effects. Families need to discuss the benefits and side effects of medication with their Doctor so that proper course of action can be found that suits their child the best.
2. Associated or co-occurring (comorbid) psychiatric disorders: individuals with ASD sometimes have symptoms of another psychiatric disorder over and above the features of ASD. Common examples are attention deficit hyperactivity disorder (ADHD) characterized by persistent hyperactivity in many situations, easy distractibility, inability to concentrate on most activities, and impulsivity. Other common conditions are anxiety disorders (excessive, unwanted fearfulness) and obsessive compulsive disorder (repetitive or ritualistic behaviors, such as arranging, cleaning, checking, washing, excessive insistence on sameness; child typically resists any attempt to change these behaviors), and tic disorder (sudden, jerky, brief-lasting, repetitive movements of face (blinking, grimacing, pursing of lips), neck, shoulder, trunk, and repetitive sounds). In some children, troublesome and persistent disturabces of sleep such as inability to fall asleep, repeated awakening, or sleep rhythm disturbances (for example sleeping in daytime and awake in night) can occur. These conditions require careful evaluation by a Doctor experienced in treating ASD such as pediatrician or psychiatrist. When the symptoms are very persistent, severe and interfere with the activities of the child, appropriate medication may be required to manage these co-occuring disorders. As mentioned before, drugs used to treat this condition also have side effects. Parents need to freely discuss the benefits and side effects of medication before a decision is taken to start the medication. When medicines are started, it is important to note and monitor the improvements as well as side effects so that the child gets the benefits and is not harmed.
3. Sometimes, problem behaviors such as self-injurious behavior, aggression and excessive stereotypies become very severe and do not respond adequately to psychosocial or behavioral intervention. Judicious and careful use of medication can be considered in such children and youngsters under close monitoring and supervision.

Life cycle issues

As they grow up, children with ASD and their families face different situations, and challenges at different ages.

Early childhood: medical issues, investigations, confirmation of diagnosis, coming to grips with the condition, accessing early intervention services, learning how to do home-based training and teaching

School age: finding the appropriate educational set-up, facing challenges in school, co-coordinating with school, expectations about academic learning, class-room behaviors, behavioral difficulties at home

Adolescence: challenging behaviors, sexuality issues, co-occurring psychiatric problems, interpersonal difficulties,, transition to vocational training

Adulthood: vocation, productive and meaningful daily routine, issues concerning future and social security