



**THE LAND OF THE SINGING FISH
MENCAFEP - BATTICALOA
NEWSLETTER.**

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In all wars and disasters it is the disabled child that is the first to die; it is the disabled child that is the first to get disease and infection; it is the disabled child that is the last to get resources when they are handed out.

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In this news letter about MENCAFEP – Batticaloa, we would like to look at autism, as more children with autism are being identified world – wide; certain reports would suggest that autism is at epidemic proportions. However, children with ‘challenging’ behaviour have always been there and the autism spectrum is vast, as professionals, parents and carers have learned and discovered more about this study of the nervous system.

MENCAFEP – Batticaloa and MENCAFEP as a whole have many children with ‘challenging’ behaviour. As autism has come more and more into the public domain. Here in Sri Lanka where autism, for two years now, has been talked about a great deal in disability circles. Without MENCAFEP – Batticaloa believes without much understanding and success.

MENCAFEP has been asking itself are we teaching autistic kids? Do we need to know more about symptoms as they manifest in class and in the community?

What is Autism?

Autism is a neurological disorder, meaning you are born with it. It affects the way the brain develops.

Autism has a few other names--sometimes called infantile autism or autistic disorder. But regardless of what you call it, autism is something you are born with and something that you will live with for the rest of your life.

Autism is one of five pervasive development disorders (PDDs) that include...

- Autism
- Asperger's syndrome
- Childhood disintegrative disorder
- Rett disorder
- Pervasive development disorder-not otherwise specified (PDD-NOS)



What is autism?

Basically, these are categories that psychologists and therapists will use to try to categorise a child in order to begin a treatment regimen. While a child is born with autism, it is typically not officially diagnosed until the child shows clear outward signs, most times around age 3 or so. But everyone is different and generalities should be viewed cautiously.

With early intervention and appropriate treatment, some autistic patients are able to learn and function productively. There is no cure for the disorder and most patients require lifelong care.

While every person with autism is a unique individual in his or her own way, there are some common traits of autism. These include:

- Poor social skills and difficulties interacting with others.
- Difficulties with communication.
- Restricted or repetitive activities or interests.
- Abnormal response to sensory issues such as touch, sound, light, even smell.
- Some show aggressive or self-injurious behavior such as head banging or biting themselves.



Poor social skills and difficulties interacting with others.

The intelligence level of someone with autism, varies, many have moderate mental retardation while roughly one-third have normal intelligence levels (IQs). In addition, those with autism will have a higher likelihood of developing epilepsy than the general population. Those with Asperger's syndrome (which is often referred to as high-functioning autism) will typically have higher than average IQs and function similarly to those who do not have autism.

Over the past eighteen months, through research, field and teaching experience MENCAFEP – Batticaloa and MENCAFEP overall have been trying to put together a list of signs and symptoms of autism to help us and parents try to confirm we are working with autistic kids. Parents have also benefited from the list of autism symptoms, which have been shared at various levels of parents meetings, support group meetings and home visits.

Autism Symptoms - a checklist:

- Signs of stress: crying, temper tantrums.
- Reclusive and/or depressed.
- Extremely anxious.
- Anxiety driven behaviour (fidgeting, pacing, mumbling, appears to be in flight or fight mode at all times).
- Excessively fearful about being centred out.
- Unusually clingy and insecure.
- Unable to go to their room and carry out a prescribed task as they forgot by the time they got there.
- Take forever to complete a task as everything else in the area caught their attention.
- Moves from toy to toy and does not stay focused for any length of time.
- Asks frequent questions but does not appear to listen to the answers.
- Displays unusual or no response to emotional situations.
- Discipline has no impact on behaviour.
- Unusual ability to hear - heightened ability to hear certain noises, but unable to hear properly in slightly noisy or cavernous rooms, like concert room.
- Dislikes loud noises, prefers a quiet play area.
- Forgetful, loses his belongings and homework.
- Has trouble getting started.
- Awkward pencil/crayon grip - pressure right through the paper.
- Reluctance to try or do puzzles, but may be very good at them when challenged.
- Unusually clumsy - an accident looking for a place to happen.
- Toe walking, hand flapping.
- Needs to learn to take their turn.

- Doesn't concentrate on work: unfocused, disorganised, uses time poorly.
- Prefers to be read to as opposed to trying to read.
- May be able to read at a very advanced level but still have a lower level of comprehension.
- Work has many reversals and is impossible to read.
- Chews on the front of shirt.
- Has very advanced verbal abilities and poor writing skills.
- Hyper focus or preoccupation.
- Unusually repetitive motor movements (hand flapping, finger twisting, whole body movement) .
- Tics (may include odd ones like the need to touch genitals).
- Inability to take social and/or emotional ownership of behaviours - they don't get it!
- Has poor social skills and few friends, but is desperate for friends and lacks abilities to make friends.
- Very inflexible, has great difficulties with transitions.
- Unable to handle the unstructured times of the day such as play, lunch, playground, etc.
- Have problems with abstract concepts and metaphors.
- Has little or no awareness of body in space, personal auras.
- Overly sensitive sense of smell.
- Abilities in music, art, drawing.
- Strong interest in technology, computers, etc.
- Extremely tactile, likes the feel of certain things.
- Does not like to be touched.



Has little or no awareness of body in space, personal auras.

Although the above autism symptoms can help identify a potential autistic child in MENCAFEP schools and centres. However, we need to be careful with this list of symptoms as children can be wrongly diagnosed, points on the list should not be used in isolation! A firm confirmation is needed, with the help of other professionals. If a probable autistic child were identified in the industrial /developed world the following would happen:

- Confirm that the child has had a complete medical to ensure that there are no physiological problems. Ensure the child is seen by a medical professional who has in-depth knowledge of autism spectrum disorders (including Aspergers Syndrome).
- Confirm or arrange a vision test.
- Confirm or arrange a hearing test for the child. Make sure it includes an auditory processing test which will tell you if the child understands what they hear. Make sure the child is checked for sound sensitivity as well.
- Confirm or arrange an assessment from a psychologist that is well versed with autism and especially Aspergers Syndrome.



MENCAFEP children and the majority of autistic children in Sri Lanka do not have access to psychologists or psychiatrists, due to them being very few and far between in Sri Lanka.

MENCAFEP is able to arrange basic vision tests and hearing tests and although we don't have the psychologists or psychiatrists we have 23 years of experience working with disabled children, with many of those disabled children being on the autistic spectrum. MENCAFEP over the years has understood that to diagnose autism many of the psychological tests are auditory- based, therefore the results of the auditory processing are important, although due to poor

professional expertise in Sri Lanka, this at times is very difficult. Also many children can be overlooked if they have high intelligence.

As with all MENCAFEP children the development of an individual education plan (IEP) for autistic children is also very important.

At present MENCAFEP is working on a Childhood Autism Spectrum Test (CAST), that will hopefully help parents, care givers and the professionals that MENCAFEP works with in Batticaloa and Nuwara Eliya Hospitals, help guide them through a mine field that can be the autistic spectrum in a society that many people are talking about, but very few people know that much about!

When teaching autistic children, again, as with all children at MENCAFEP and in developing countries, like Sri Lanka, MENCAFEP is aware that to prepare a list of the child's strengths and needs is significant. As with the above, talking to the parents and the MENCAFEP team are central. They may have ideas for both the teacher/ CBR worker and parent.



Individual Education Plan.

MENCAFEP again and especially in Batticaloa, where children with very 'challenging' behaviour are being referred, MENCAFEP is understanding that once all the information is gathered, the parent and teacher / CBR worker should meet with the MENCAFEP team. We believe that this process legalises the child's right to have their needs met with appropriate education.

It is interesting to know at this point that the Sri Lankan Human Rights Commission has determined that education is a service and therefore the child

must receive the appropriate interventions. This is in law and on paper, but in Sri Lanka this has never happened! So much for a middle income country!

MENCAFEP has to keep remembering that the above activities, for all children in the MENCAFEP programme, especially those with autism is not a one-shot deal. Each year will bring new challenges. MENCAFEP staffs need to be aware of the child's stress and look for ways to help. Over the past two decades MENCAFEP has understood more than anything else that early intervention is the most positive way to help a child experience success. It's also the best thing staff and parents can do to help in teaching autistic children.

What MENCAFEP has also discovered, is that another wise thing to do as soon as identification of a child with autism symptoms has been done, is to create a mechanism to and track appropriate goals, and also a way to communicate effectively with parents. A parent - teacher communication book gives an easy way to track information. (This communication book was designed especially to meet the needs of special needs kids.)



Awareness.

With more awareness about autism in the public domain, both in the developed and developing world. With as seems to be happening, more children becoming identified with autism (children may have already been identified with 'challenging behaviour' and/or 'mental disability, but not with autism), with many thanks to Terre des hommes - Netherlands, MENCAFEP - Batticaloa,

along with MENCAFEP in general are preparing to meet this new challenge, by being prepared and making themselves aware of what the challenges are.

Ranji and Chris Stubbs.
October 2010.