



**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.

THIS NEWSLETTER IS DEDICATED TO PAVITHRAN AND HIS FAMILY. PAVITHRAN DIED ON 15 OCTOBER 2009 (DURING THE PUTTING TOGETHER OF THIS NEWSLETTER), HE WAS 6 YEARS OF AGE AND A FOUNDER CHILD OF MENCAFEP - BATTICALOA.

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Humankind in the twentieth century and now as we nearly complete the first decade of the twenty first century has taken up many awesome challenges, ranging from space travel and plumbing the origins of the Universe to unlocking the secrets of life in the DNA double helix; from polar exploration to design of computers which perform more calculations in an hour than the entire human race has performed since its beginnings. The technical virtuosity employed would have been unbelievable to the savants of previous centuries; indeed, it is amazing even to its practitioners in the first decade of this century.

One area of life still challenges mankind in a way that would be understood without difficulty in most times and places of human history; a challenge to which the response by 20th and 21st century humans is little further advanced than that of human ancestors and has indeed at times regressed to barbaric depths. **It is the challenge of profound mental disabilities**, in which the normal assumptions of human growth and developing individual autonomy do not hold good, even allowing for extra time and effort.

The exponential increase of knowledge and the pinnacles of technological achievement in this century and the previous one have tended to accentuate the **'differences'** of those whose intellectual capacity is weak or virtually absent. The modern 'virtues' of growth, speed, efficiency, productivity, profitability and high profile image marketing seem to leave little enough room for the ordinary person let alone the person with any disability. In the laser - sharp communications age the profoundly handicapped person, especially the profoundly disabled child, is an anomaly, seeming to defy and negate the popular image of 'progress'. Yet the existence of such persons, whose participation in creating the future appears to be marginal, poses profound questions about the very nature of 'progress' and the sort of social systems towards which each nation is evolving.

Theoretically, the availability of advanced autonomous electronic apparatus opens up many possibilities for persons with profound mental handicap. Will such apparatus be developed to enable profoundly disabled persons, for example, to choose, cook, and consume their own food without lifting more than one finger? Or will priority be given to the use of such apparatus for the precision bombing of 'enemy' targets at 20,000 kilometre distance?

What understanding and response is to be given by the individual, the local community and society at large, to persons with profound disabilities. What can be done? What should be done? What can be recommended to such countries as Sri Lanka that are seen as a developing country?



Caring for the profoundly disabled children at MENCAFEP – Batticaloa.

MENCAFEP does not have all the answers to the above questions, but since its inception MENCAFEP has been the only organisation in Sri Lanka and some say in South Asia to work with profoundly disabled children and young people in the community with their families. Families with children with profoundly disabled children have moved their homes to be near a MENCAFEP centre so that their children can attend a school!

Since MENCAFEP moved into Batticaloa after the December 2004 Tsunami, MENCAFEP has carried on this proud tradition of being the only organisation in Sri Lanka and South Asia doing such work. In Batticaloa, at times, MENCAFEP has been overwhelmed by the amount of profoundly disabled children and young people have presented themselves for MENCAFEP to work with.

Working with the profoundly/ multiple disabled child/young person has been called the 'ultimate challenge' for professionals, parents, family and the community at large.

What is profound disability? This is a multiple handicap in one individual, a person with severe brain damage, causing non/partial sight, hearing impairment, incontinence, no mobility, no speech severe learning difficulties and understanding of their environment. An individual can have all the above disabilities or a combination of them to be seen as profoundly disabled. Through

the phase ‘profoundly disabled’’, there are classifications from moderate to high through too severe.

However, MENCAFEP has a philosophy of working with the severely handicapped child. MENCAFEP believes the purpose of the profoundly disabled is to be joyful. That is what they are there for, to bring joy, to give joy.

In all its work with the handicapped, MENCAFEP practices, that human worth and dignity of the individual, however disabled is the most important aspect of its work.

MENCAFEP has developed over the years many ways of working with the profoundly disabled child and her/his family, the first of these is:

a. Advocacy and self-advocacy.

Children and young people with severe disability must have a say in everything that concerns their life. But they must also be able to understand it! They often do not understand difficult things. For them, self-advocacy might mean to decide about simple things:

- * What to eat and drink.
- * What music they like.
- * Going out.

But these things are the most important. For difficult things they need other people to speak for them. This can be parents, self-advocates or supporters. In MENCAFEP’s case, it is the parents that speak for children with severe disability.

Parents and MENCAFEP have taught each other to let disabled children and young people take as many decisions as possible themselves. Parents and MENCAFEP have learnt how to speak for people with severe disability. MENCAFEP and parents have learnt about the needs of profoundly disabled children. And children and young people with severe disability are very much part of the MENCAFEP movement.



Children with profound disabilities should have a voice, if they can.



MENCAFEP - Batticaloa mobile clinic in Batticaloa District, severely disabled child and mother waiting for advice.

The second of MENCAFEP's developments and possibly the most important is the following:

b. Towards better inclusion!

MENCAFEP's does and encourages its projects to include children and young people with severe disabilities in its activities. First, MENCAFEP makes sure that these children and families feel comfortable. It can be really difficult to talk with children with severe disability, but not to communicate!

MENCAFEP has learnt that it needs help to understand what these children and young people want. Parents and MENCAFEP again have taught each how this communication can take place. MENCAFEP, its parents and community can communicate through movements or by watching the person's breathing. MENCAFEP can communicate with symbols and pictograms. Please see the MENCAFEP - Batticaloa Newsletter Number 8 – Total Communication.

MENCAFEP's children and young people with severe disability are also included in all everyday activities. They have a meal with all the rest of the children, they play with the rest of the MENCAFEP children. They also paint, dance and make music.

MENCAFEP is very aware that profoundly disabled children need more time than other disabled children. But MENCAFEP is also aware that these children must be included in the life of society!

Pavithran's Story.

I am Mallika and mother of a profoundly handicapped son, called Pavithran. My son is severely brain damaged with hydrocephaly, he cannot walk, talk, feed herself, go to the toilet and his eyesight is very poor. But he has a beautiful smile and when content with life smiles and smiles to his-self. When not content with life, tears weep out of his eyes and roll down his cheeks and he sobs to himself. My Pavithran is a sensitive child and feels what we feel.

At present I and my son are part of a family that includes my husband a carpenter and my eldest son Sindujan. With them and my innocent Pavithran, along with MENCAFEP their caring, loving staff hope has been given to us as a family.

Pavithran was only three years when MENCAFEP staff came to see me. I remember the first day our Chris, an outsider, a white person in our town and his lovely wife Ranji and their beautiful daughter Enya came to see us. Nobody

ever touched or talked to Pavithran, apart from us his family. They cuddled him, touched him and talked with him, especially their daughter Enya, who was so natural with Pavithran. They said they were starting a school and centre and would I like to send my son? The feeling that went through my body, when they said that will be with me until I die. I was so proud that my son was going to school. I felt so happy that I could have shouted for the whole world to hear.



Pavithran and Mother.

Pavithran is now 6 years of age he now not only has his family to care and think about him, he now has the staff at MENCAFEP and the MENCAFEP families.

Until MENCAFEP came into Pavithran and my life, I believed through my life, my sons life and our family life experience would be one of sorrow. MENCAFEP has given me a shoulder to cry on and some hope for the future, they have given hope to my darling Pavithran.

During the putting together of this newsletter, Pavithran passed away, he was 6 years of age and a founder child of MENCAFEP - Batticaloa. Pavithran - thanks for the memories.



Pavithran - 2003 - 2009.

Children and young people with profound disabilities are easily overlooked or even forgotten. In many developing countries, they may not live very long, because of the absence of medical technology which will keep babies alive in Western Countries. Even abler children with Down's Syndrome are rarely found in many African and Asian countries, if they do survive, they are often hidden from view by their families or by society; very few of them are likely to receive help, to attend any form of school or to find any form of work or training in adulthood. Their families rarely receive any support or assistance in helping their relative to be accepted by the local community.

As MENCAFEP - Batticaloa stated above it does not have all the answers, but with many thanks to Terre des hommes - Netherlands and her supporters, MENCAFEP - Batticaloa has been supported to take on the 'ultimate challenge'. Although MENCAFEP - Batticaloa works and helps all disabled children, young people and their families, the most vulnerable of the vulnerable is the profoundly disabled child.

With the support of Terre des hommes - Netherlands, MENCAFEP, both Batticaloa and Nuwara Eliya, the organisation working in a developing country, is becoming an invaluable resource for working with the profoundly disabled child and their families in the community. Not only is MENCAFEP trying to give dignity to these children and their families, help, support, assistance and some form of schooling. But MENCAFEP, with the support of Terre des hommes - Netherlands, has a very strong belief the profoundly disabled child has the right to fulfil her/his potential. In the case of the profoundly disabled child's case

what is fulfil his/her potential? Is it reading and writing? Is it getting a job after so many years of schooling? For the profoundly disabled child and young person, what is written above is not possible! MENCAFEP is trying to develop a guide for children and young people with profound and multiple disabilities. This guide proposes a strategy for the development of opportunities, from aromatherapy and sense gardens to water play and movement. It is hoped that this information will be accompanied by diagrams and illustrations, as well as by a DVD.

The guide will be based on the MENCAFEP – Batticaloa philosophy for the multiple disabled child and young person. ¹**“It is better to have some motion than lie still, it is better to sit than to lie, it is better to stand than to sit, it is better to walk than stand and it is better to run than to walk.”** Profoundly disabled children and young people fulfilling their potential

However, let us be honest, MENCAFEP’s work with profoundly disabled children is a ‘small voice in the dark!’ There can be little doubt that without a good measure of Government and INGO/NGO financing, the distribution of knowledge, equipment, techniques and strategies will remain confined to a few isolated spots (like MENCAFEP – Batticaloa – Nuwara Eliya) with a handful of beneficiaries. To have any realistic chance of ‘getting anything done’ for the profoundly and multiple disabled child and their families, together with interested professionals in Sri Lanka, need to plan a campaign over a five or ten year period, having clearly defined objectives and a hard boiled plan for reaching such children and families. ‘Society’, ‘Government’, ‘INGO/NGO’, ‘Financing’, are in most cases large, profoundly amorphous blobs which can absorb random impacts without any visible or practical effect. But they can be shifted and reshaped a little by a carefully organised and well-timed input.

¹ MENCAFEP Respite Care for profoundly disabled children – Chris Stubbs 2001.



The 'Ultimate Challenge' for any society!

Ranji and Chris Stubbs - October 2009.