



## **MENCAFEP**

(Mentally Handicapped Children & Families Education Project)

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## **A Programme For Children & Young People With Special Needs & Intellectually Challenged.**



## **MENTALLY HANDICAPPED CHILDREN & FAMILIES EDUCATIONAL PROJECT - BATTICALOA.**

### **INFORMATION PACK.**

**2005 - 2008.**

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## 1. HOW MENCAFEP - BATTICALOA CAME ABOUT.

The morning of the 26 December 2004, was a bright warm and sunny. The hamlet of Navalady, which is part of Batticaloa Town, facing out into the Bay of Bengal, on the East Coast of Sri Lanka was engaged in the usual Sunday morning activities. As the palm trees swayed in the breeze, Children were playing cricket on the white sand beach, mothers and girls doing the weekly washing and cleaning the compounds of their small dwellings. Most of the men, fishermen, were having the day off, fixing their nets, cleaning their small canoe boats, getting ready for a very early start on Monday morning. Little did they know that Monday morning would never dawn for many of them. At approximately 9:30 on that Sunday morning, 2 hours after a massive earthquake in the India Ocean of the coast of Sumatra, on the other side of the Bay of Bengal, a 20 foot wall of water reared itself out of the ocean, without warning and engulfed the hamlet of Navalady. Another 2 walls of water followed the first. In 15 minutes out of the 460 families that lived in Navalady, 90 were left alive, although out of this 90, family members were missing or dead. It's Pre-school with attached unit for disabled children were washed away.

Just along the beach from Navalady was a Hindu Ashram, where 250 men, women and children were worshipping. After the first wave hit, the Ashram and the 250 people were never seen again.

In Veloor Colony with its Pre-school and disabled children's unit, situated next to a Sri Lankan Army Camp, was ironically to some extent saved by the camp. With the initial waves crashing into camp, allowing water only 5 feet high to wash into the dwellings of Veloor Colony. Although the Pre-school and disabled unit structure was left intact, the school and certain areas of the colony are now surrounded by land mines, washed out from the mine field that encircled the army camp.

The sea front at Kattunkudy, a Moslem Town just to the south of Batticaloa, has been severely damaged; a school for disabled children in this area has been brutally broken; water supplies are polluted.

Many stories like this can be told from all over the Indian Ocean Rim that was hit by the Tsunami's on that fateful day. In Batticaloa's case, the sadness of that day runs even deeper. After 20 years of bloody civil war, 3 years of a cease-fire between Sri Lankan Government Forces and the Liberation Tigers of Tamil Eelam, who control over half of Batticaloa District and communities starting to pick themselves up again. Batticaloa is hit by the worst natural Disaster in living memory, like pouring oil on to a fire.

After MENCAFEP's visit to Batticaloa on the 28 December 2004, where the landscape in some parts of Batticaloa looked as though an Atomic Bomb had been dropped on it. It was obvious that MENCAFEP had to do something, as this community like many other communities is going to take years to rebuild.

Along with encouragement from friends and acquaintances of MENCAFEP from around the world, especially within the UK. Who know and are aware of MENCAFEP's competence's in the field of disability and as part of their efforts towards the Tsunami Disaster, is raising funds for MENCAFEP. Therefore it has been decided that as MENCAFEP's expertise is in disability, especially intellectual disability. That MENCAFEP would set up a project to work with disabled children, their families and orphaned disabled children.

Even in normal times in the Developing World, the disabled are the forgotten, especially the disabled child and her/his family. When a catastrophe hits, such as smashed into Sri Lanka, then the plight of disabled children gets even more desperate.

**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 is the main reason for setting up the MENCAFEP, Batticaloa Project.

In the Batticaloa District, MENCAFEP would like to alleviate some of problems caused by the Tsunami by setting up a Centre. MENCAFEP sees this centre being in place permanently, offering varying degrees of support to disabled children and their families and were appropriate orphans.

The Centre would provide the following:

- Operational Office and Staff Accommodation.
- School and Resource Centre.
- Home Visit and Outreach Support.
- Support and Training for other Organisations.
- Distribution of Disability Aids.
- Assessment and Counselling.

The work will be based on and adapted from MENCAFEP's work in Nuwara Eliya; Day-care school and centre with respite care; Community Based; keeping children with families and supporting these families. MENCAFEP already has a link with Batticaloa, since September 2004 it has been doing 2 week training programmes in Nuwara Eliya, for Carers working with disabled children in Batticaloa.

In the case of disabled orphans, extended family will be traced and if possible the child placed with family. If not, then MENCAFEP has a Family Group Home system that it can feed these children into and/or use other agencies.

With the above in place, the MENCAFEP Centre can contribute quite significantly to the re-building of Batticaloa. By giving disability a presence that is not 'swept under the carpet', providing opportunities to disabled children not normally available to them. And most of all giving disabled children and their families dignity within their community.

MENCAFEP will be making regular assessment visits, meeting with and talking with potential partners. As well as getting a clear picture of the ground situation and what other needs maybe needed as the post-Tsunami period unfolds.

## **2. WHAT IS THE PROBLEM?**

On the morning of 26 December 2004 Tsunami's hit the Eastern and Southern coasts of Sri Lanka, as well as parts of the Western coast. These Tsunami's swept people away, caused flooding and destruction on a monumental scale, never seen in Sri Lanka's history. The worst affected areas are Jaffna, Mullaitivu, Trincomalee, Batticaloa, Ampara, Hambantota and Galle.

Over 40,000 people lost their lives and around 800,000 people that are displaced. The full extent of damage and casualties and the impact of these tidal waves on children will take years to be assessed.

On the 9 January 2005 according to official statistics in Batticaloa District over 63,000 people have been affected by the disaster. There are 68 camps housing over 19,000 people; 9,500 people are being housed with relatives or friends; over 34,000 have returned to their homes; 3,000 are dead and over a 1,000 people are missing. In Batticaloa Municipal Limits there are 14 camps housing nearly 7,150 people, with 3,000 people living with friends and relations; over 3,000 have returned to their homes 1,500 are reported dead and 630 are missing.

The Government, INGO and NGO community after a confused, shaky completely unorganised start got its 'act together' and the situation in the majority of the District is under control. The camps that were in existence and the few that are still being occupied were and are getting water; food, shelter and medical facilities. However a dependency pattern has developed among the people that survived the Tsunami.

The devastation at the four Batticaloa sites that bore the brunt of the Tsunami was on a Biblical scale, bodies in the street and in collapsed buildings, along with the bodies of animals. Water supplies in the four areas were completely polluted with no major clean up happening until many months later.

After 20 years of Civil War in Batticaloa District and nearly 3 years of an uneasy ceasefire any statistics on the District are very difficult to come by. The last census done in Batticaloa District was in 1981, however some facts about the District are available.

Batticaloa District occupies the central part of the Eastern province. The total land area of the District is approximately 2633 sq. Km., including inland water bodies to an extent of 168 sq. Km. The District is bounded by Trincomalee District in the North, by Polonaruwa District in the North-West, by Ampara District in the South and by the Bay of Bengal in the East.

The Batticaloa lagoon, which forms the water body, extends to about 74 km. to Verugal in the North and 33 km. up to Thuraineelavanai in the South from Batticaloa Town. The lagoon divides the District into two areas. The Eastern Sea Board which is mainly residential and hence the devastation and loss of life on 26 December 2004. The Western area is where the bulk of the paddy lands are located. The District accounts for 3.8% of Sri Lanka's total area and 2.2% of the Country's population.<sup>1</sup>

Batticaloa had a population of approximately 487,000<sup>2</sup>, the majority of the population being Sri Lankan Tamil, with a significant minority being Muslim.

Since 1983 the District has suffered immensely from the Sri Lankan Civil War, with LTTE controlling more than half the District. Although as mentioned, there has been a cease-fire for nearly three years, it is an uneasy truce. The infrastructure of the District that was all but destroyed in the LTTE controlled areas is very slow in being repaired, due to disagreements between the LTTE and the Sri Lankan Government.

Infant mortality in the District is 39 deaths per 1000 births<sup>3</sup> (in 1982 19 deaths per 1000 births), compared with a Sri Lankan average of 12.2 deaths per 1000 births<sup>4</sup>, with maternal death 1.15 per 1000 live births<sup>5</sup>. Under nourishment in pre-school children is a problem in the District, where in some areas over 50% of children have been found to be under nourished.<sup>6</sup> These figures are no doubt in part to the Conflict in the North and East of the Country.

Literacy in Batticaloa District stands at 68.3%, with males at 74.4% and females at 61.9%; this is the lowest in the country. The Sri Lankan average for literacy is 87.2, males at 91.1 and females at 83.2.<sup>7</sup>

The Ministry of Social Services conducted a study into the number of children with disabilities of school going age and found that out of 6010 children in 76 Divisional Secretary Divisions over half (3015 children, 50.1% of the whole) do not go to school. The figures are even higher among pre-school children. Out of 1425 children with disabilities of pre-school age, 909 (63.7%) do not attend a pre-school. This could be due to poor attitudes of teachers and other pupils, poor access to, and a lack of transport to and from schools. Most specially trained teachers do not go on to work in the special units of schools. In the Batticaloa District there is no special units in Government schools.

Information gathered by Dr. Padmani Mendis on the prevalence of the different types of disabilities among children (looking at 193 children) has come up with the figures shown below. As with MENCAFEP, Dr. Mendis found that no official data is available for the prevalence among the whole population these results can be generalized to give an estimate.

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<sup>1</sup> Annual Health Plan Batticaloa District 1999.

<sup>2</sup> Department of Census and Statistics 2001.

<sup>3</sup> Annual Health Development Plan Batticaloa District 1999.

<sup>4</sup> Department of Census and Statistics 2001.

<sup>5</sup> Annual Health Development Plan Batticaloa District 1999.

<sup>6</sup> Annual Health Development Plan Batticaloa District 1999.

<sup>7</sup> Department of Census and Statistics 2001.

Type of Disability	No. of children	As % of group
Mobility	26	13.5
Hearing	26	13.5
Sight	9	4.7
Speech	15	7.8
Learning	13	6.7
Fits	9	4.7
Different Behaviour	14	7.2
Other Disabilities	24	12.4
2 disabilities	40	21.0
3 disabilities	9	4.7
More than 3 disabilities	8	4.1
Total	193	100%

If we take the WHO's statistics and MENCAFEP's own research we have the following figures for a total population in 'normal' circumstances:

Below average intellectual ability present from birth or early childhood, manifested by abnormal development and associated with difficulties in learning and social adaptation, is about 3% of the total population. This is reported to be mentally underdeveloped (having an IQ of below 70), but only about 1 to 1.5% is actually identified as underdeveloped.

Two distinct levels of mental underdevelopment have been defined. These are educationally subnormal (mild) with an IQ range of 50-70 and educationally subnormal (severe) with IQ's less than 50. It is not possible to measure reliably IQ's under 30.

Mildly affected individuals comprise about 75% of the mentally underdeveloped population and often cannot be distinguished from fully mentally developed children, until they attend school. The mildly underdeveloped can generally learn certain academic skills, although at a slower pace than other children.

As adults they can usually support themselves if helped during times of social or economic stress.

In most cases no obvious physical symptoms are present, although there may be a higher than normal incidence of epilepsy. About 20% of underdeveloped individuals usually develop only minimal speech and communication skills. The profoundly underdeveloped have little capacity to move about or communicate. The former group must be under supervision, but may be able to take care of themselves, whereas those who are profoundly underdeveloped require nursing care. Several factors have been identified as causes of mental underdevelopment/learning disability. These include genetic factors, infection before birth (e.g. Rubella), brain injury at birth, brain infections or brain damage after birth (e.g. meningitis). Examples include Downs Syndrome, Fragile X Syndrome, and Cerebral Palsy. In nearly one-half of children affected, the cause of disability remains unknown.

MENCAFEP - Batticaloa is and will be working with a whole gamut of disabilities, listed below are the disabilities worked with in the project.

1. Brain Damage.
2. Attention Deficit Disorder/Hyperactivity.
3. Down's Syndrome.
4. Fragile X Syndrome.
5. Cerebral Palsy.
6. Deafness and Hearing Impairment.
7. Sight Impairment.
8. Autism.
9. Muscular Dystrophy.

10. Epilepsy.
11. Microcephaly.
12. Hydrocephaly.
13. Poland's Syndrome.
14. Spina Bifida.

Data on disability in Batticaloa District is very difficult find, in fact there is none. However, there is some information that might suggest the extent of disability. Five major health problems keep surfacing in literature about Batticaloa. These are Foetal Malnutrition, Prenatal Conditions, Neo Natal Malnutrition and Infection<sup>8</sup> all of which can cause many different forms of disability as well as death.

If WHO's guidelines are taken that 10% of any given population will be disabled in one way or another. Then we add to that the war situation that Batticaloa has been through over the last twenty years. Plus the major health problems that are being faced by the District, which can be causes of disability. In which case in Batticaloa District perhaps 15% of the overall population are disabled, then we can estimate that over 73,000 people are disabled in Batticaloa District. Predictably a lot of those people will be children, due mainly to the major health problems being faced in the District. However, due to children facing health problems and becoming disabled how long do they survive? Also after 20 years of Civil War and now the Tsunami Disaster how many have survived? The disabled child, especially the Mentally Disabled Child is the first to die in war and disasters, the first to get infection and the last to get resources when they are handed out!

How many mentally disabled children are in Batticaloa District, it is difficult to say. If we take MENCAFEP's own research and WHO's guidelines that 3% of any given population could be in some way or another mentally disabled. If another 1% is added due to Batticaloa Districts other factors, making it 4%, then estimated, Batticaloa could have up to 20,000 mentally disabled people and if they have survived many could be children.

There are approximately 10 small residential and Day-care units dotted around the District working with mentally and physically disabled children. The majority are near to Batticaloa Town; they are under resourced and under used. Staffs have not been trained in many aspects of working with mentally disabled children. Although since September 2004, MENCAFEP has been doing training programmes for staff in the Batticaloa District working with disabled children.

The Sri Lankan Government has signed and enshrined into it's own law the Convention on the Rights of the Child. These rights are universal and take into consideration all children, that is to say, able and disabled children.

The Social Services Department has guidelines to be endorsed on behalf of the disabled child as well as what services the Social Services should provide.

Social Service Guidelines:

- Early identification of the disabled child and her/his rehabilitation.
- To protect the disabled child and give her/him all his/her rights.
- The disabled child to be integrated into her/his family and the community.
- Development of the disabled child to be worked at.
- The disabled child should attend school.
- The disabled child once adult should have an independent life.
- The disabled child/adult should have social skills training.
- The disabled person should have an income.

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<sup>8</sup> Annual Health Development Plan Batticaloa District 2001.

## Services Provided by the Social Services:

- Mobility aids.
- Vocational training.
- Finding jobs.
- Income generation/Self help/Self employment.
- The development of pre- schools for hearing impaired children.
- Help with housing needs.
- Rehabilitation centres.
- Hearing aids.
- Spectacles.

All the above is on paper, however MENCAFEP has little or no evidence that this is being put into practice. Examples of this would be; a child attending any of the small centres in Batticaloa does not get free school uniforms or books, like a child attending a State school. In MENCAFEP's experience Schools actively discriminate and discourage families of disabled children from joining a State school. An able child in a residential institution receives a small per-diem of Rs. 300.00 while in care. A disabled child in a similar situation receives Rs. 50.00!

At this point it is interesting to note that in Sri Lanka Law, the able child comes under the Probation and Child Care Department, whereas, the disabled child comes under the Social Services Department<sup>9</sup>. Two Government Agencies to work with and act for children. Therefore if the child is classed as disabled then she/he will come under the auspices of the Social Services Department. If the child is able and the welfare of the child needs to be looked into, then she/he will be seen through the Probation and Child-Care Department.

With the above being law and certainly practiced, MENCAFEP has to ask, is this implementation discriminatory? MENCAFEP not only believes that it is discriminatory, but that it is one of the most important factors leading to the degradation and social isolation of disabled children and their families in Sri Lanka Society.

Within the Social Services Department there is also a division on how a physically disabled child and a mentally disabled child are perceived. It has been MENCAFEP's experience that the Social Services would rather deal with a child with a physical disability than a child with a mental disability. Feedback on this has been interesting and perhaps puts into a nutshell Sri Lankan (Worldwide?) societies attitude to disabled children... "A physically disabled child who looks normal (apart from her/his physical disability) and can communicate, is less frightening than the mentally disabled child who looks wild and mad."

In general Sri Lanka societies attitude to the disabled child is as above plus that other common attitude that is worldwide... "Out of sight, out of mind." To the majority of severely physically disabled children and mentally disabled children in Sri Lanka this phrase is very apt. Some children are hidden away in family dwellings, sometimes in appalling conditions, that not even animals would be kept in. MENCAFEP is aware of cases that involve the death of severely disabled babies, soon after birth, being killed or abandoned and left to die.

Within Sri Lankan culture families of disabled children, especially the mother and the child are seen to have done something wrong in a previous life. This 'wrong doing' is the cause of the disability; therefore in the traditional way of life, sympathy and understanding are at times rare commodities within the Sri Lankan social order. In some cases families of disabled children can be ostracised from their communities. This is very much the case in Batticaloa, which is steeped in traditional beliefs.

The other "out of sight, out of mind" technique used in Sri Lanka and again with communities worldwide is the large residential institution for the disabled child/adult. Where in the majority of cases the conditions and the lack of rights of

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<sup>9</sup> Both Departments come under the Ministry of Social Services. It would seem that historically that this has always been the case, although if a disabled child and their family comes into a Probation and Child Care Office they should be seen, due to it being a child. However, what happens is that the child and the family are told to go to the Social Services Department, as they are the Department that deal with disability.

the child/adult have to be seriously questioned. In Batticaloa District there is no big residential institution as such, as mentioned small ones exist. However, some severely handicapped children have been handed over to the Social Services Department in Batticaloa. Then moved to a large residential home in the west of Sri Lanka, where most of these homes are located.

However, it is not all negative, but it is very sad how Sri Lankan people have to confront and come to terms with some disabilities. As has been mentioned a civil war that has cost thousand of lives has also left thousands of casualties. Children, women and mainly young men with limbs missing, sight and hearing destroyed and mentally disabled through psychological trauma. Slowly, very slowly Sri Lankan society is beginning to acknowledge that disability and especially the disabled child are part of their fabric. With post Tsunami now beginning to settle on Sri Lanka the above sentences is even truer.

For the mother with the disabled child, especially the mentally disabled child, the situation is very poor in Batticaloa District.

Apart from the emotional shock and strain, of a mother giving birth to a disabled child. The underlying factors of embarrassment, shame and guilt are very heavy burdens on the mother and child. These factors very much hinder the development of the mother, family and especially the child.

To work with the mother, family and child on the above, is the key to community-based rehabilitation (CBR). This allows the child and mother to care for each other in their home environment. This concept allows the child to be with their extended families, and for the child and mother to gain acceptance and dignity within their own communities.

In the case of the abandoned or at-risk disabled child, the Government institution with its concepts of the old Victorian workhouse looms very large. If a disabled child / young person, particularly those that are intellectually challenged, enter such an establishment, their life expectancy drops significantly.

In Sri Lanka, like most developing countries, the disabled and especially the intellectually challenged are a very disadvantaged group. With very little access to education, health care, training and the job market.

The relationship between the different problems faced by special needs children and young people is, the basic acceptance into the human race and the dignity that goes along with that acceptance.

In MENCAFEP's experience the main factors for mental underdevelopment of children in a developing country like Sri Lanka is poverty, not enough nutrition given to the mother during and after pregnancy - not enough nutrition given to the child after birth. Along with this we also come across general neglect of the child due to ignorance, with lack of knowledge about some family relationships/marriages causing genetic and chromosomal abnormalities.

As mentioned above, that disability and poverty are closely interlinked is well documented, this has many consequences. Families struggling with disability are more likely to be trapped in poverty due to range of challenges, as again mentioned in some detail, this includes negative attitudes, problems with mobility, earning power, child-care problems etc. As can be seen in this section children and families struggling with disability are systematically excluded from the mainstream, and the poorer they are the greater that exclusion is likely to be. In these situations poor children who have disability are less likely to receive early intervention and support and get an education, and more likely to suffer lasting consequences.

The degree of which disability and poverty are combined increases the degree of social exclusion. Looking at a global perspective, while 83% of individuals who have disability have access to radio and 67% to television, only 32% have access to newspapers. As little as 6% have the opportunity of deriving enjoyment from musical shows, concerts, cinema and other forms of entertainment. Over 33% never go out with the rest of family and the same proportion has never been to wedding, nor have they taken part in community activities and festivals. Only 21% take part in religious activities. While only 14% had taken part in any kind of sports, and this had been almost wholly at school and village level. It is very difficult to measure these social costs of disability.

The general situation in Batticaloa District is that many of the rural households, show high indices of poverty. Along with other welfare indices like literacy rate, school attendance, health services, infant mortality rate, civil war and now the Tsunami Disaster show that Batticaloa District is in very poor shape and is going to need help for sometime to come to get back on it's feet.

Taking all the above into context, the plight of the disabled child in Batticaloa District is real and very serious. Through this proposed project, MENCAFEP will be trying to reverse some of the damage that continues to be inflicted on the disabled child and their families.

### **3. WHAT MENCAFEP IS DOING ABOUT THE PROBLEMS.**

A primary goal in the treatment and management of the mentally underdevelopment child is optimal development of the child's strengths. Taking into account individual interests, personal experiences, and available resources.

Another major goal is the development of social adaptive skills to help the child function as normally as possible. It is particularly important that mentally less developed children receive special education and training, ideally beginning in infancy. Such education has been enormously beneficial and has been extended with positive effects including to those suffering profound underdevelopment.

The prognosis for mentally underdeveloped children is related more to the timing and aggressiveness of treatment, personal motivation, training opportunities, and associated medical and environmental conditions, than to the mental underdevelopment itself. With early intervention and good support systems, many mentally underdeveloped children can and have become productive members of the society.

Successful management leads to independent functioning for some and a sheltered environment for others. Even those whose disabilities require total care benefit from appropriate stimulation and training.

Therefore with the above in mind and taking into account how MENCAFEP has worked in the past, present and will work in the future, MENCAFEP Batticaloa Objectives will be as follows:

- Pressure eased on families caring for disabled children & young people; facilitation given to child, young person & families for their development through MENCAFEP school, centre, training and support.
  - Disabled children/young people and their families have been exposed, to stimuli and experiences not normally provided for them. This has included music, exercise, constructive play, total communication, speech training, physiotherapy, social skills, vocational training, job experience and employment.
  - Disabled children/young people and their families have been prepared for adulthood, through social programmes.
- Education given to families and communities through the home visit programme.
  - Families and communities have been made aware, of all they have to offer disabled children, and what disabled children/young people can offer their families and communities.
  - Families and communities of disabled children helped to understand that; embarrassment, shame, and guilt are unnecessary burdens that hinder the child's, families and communities development.
  - Family support groups established were families help each other and meet the challenges of caring for a disabled child.
- MENCAFEP Batticaloa is a resource centre for training and for supporting, other groups interested in community based rehabilitation of disabled children.
  - MENCAFEP and outside resources providing on going training and learning experiences for partner staff members. Who in addition to being teachers also serve as social workers, health care providers and friends of the child, family and community.
  - Distribution of Disability Aids.
  - Rebuilding and equipping disabled school and centres.
  - Operational Office and logistical base in place.

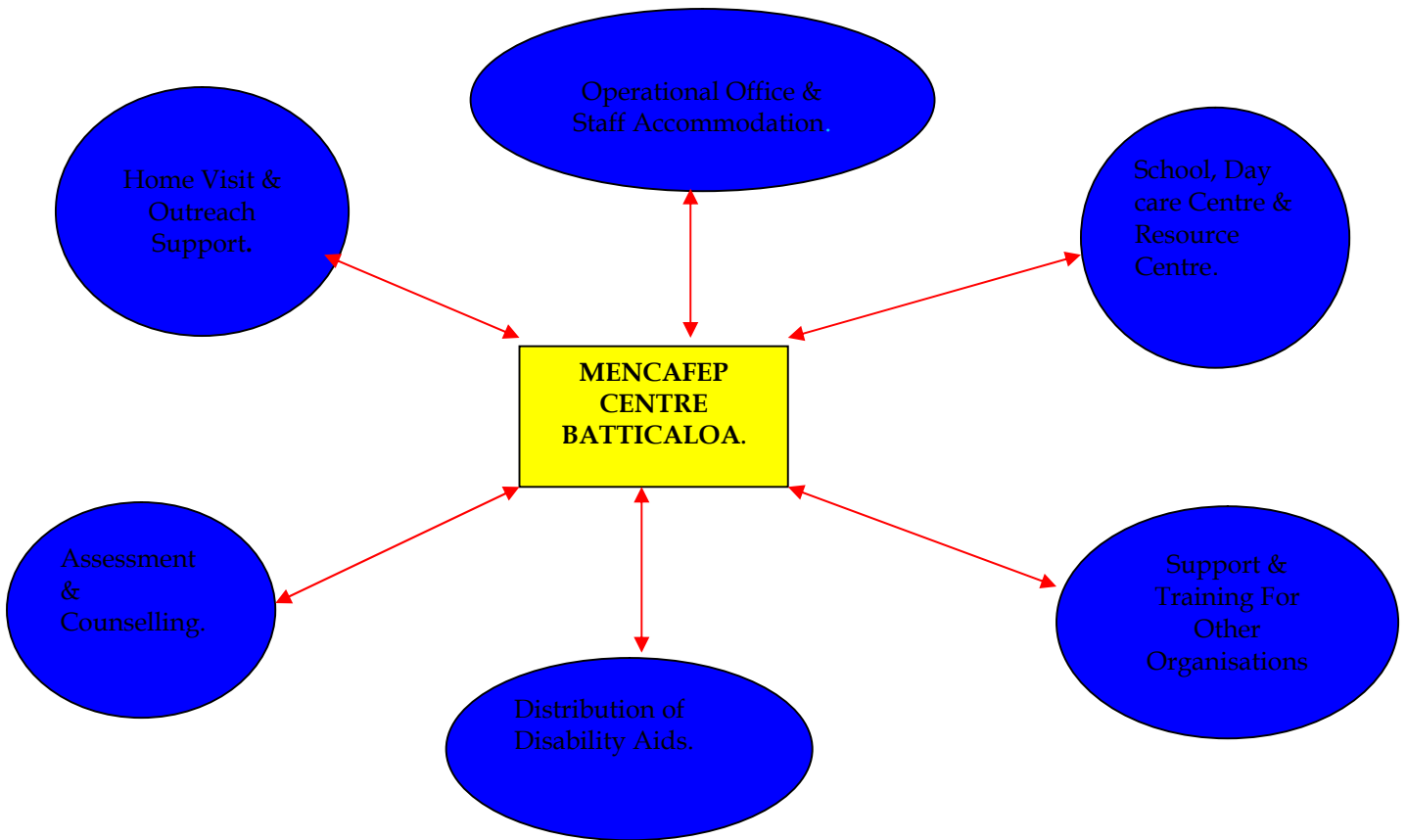
Looking at the objectives it is necessary to examine whether they meet the overall goal, by examining the means-end relationship. What means are MENCAFEP going to use to meet the end-the goal? The goal of the MENCAFEP project is as follows:

**GOAL**

**This programme will make available opportunities to disabled children / young people and their families, that will enable them to have the right, to live in and be part of their own communities with dignity.**

In MENCAFEP’s Batticaloa case it will be working in various Community Based Rehabilitation aspects to meet the goal it has set itself. This will be mainly done through it’s school, centre and community work within it’s client group neighbourhoods and communities; support and training to various other organisations; with some centre based work on assessment and counselling; with the MENCAFEP Batticaloa School and Centre becoming a Resource Centre.

**MENCAFEP PLAN FOR WORK IN BATTICALOA.**



#### **4. HOW MENCAFEP - BATTICALOA WORKS.**

##### **A. Operational Office Unit.**

###### **Staff:**

**Project Coordinator.**

**Project Manager.**

**Administration Officer.**

**Security Guard.**

Accounts, reports, recording and planning are initiated in this unit, along with decision making, on a consultative basis as much as possible. The 'buck also stops' with this unit, bad practices such as wrong accounting, major reports and recordings not done are the responsibility of the Senior Management in this unit, along with bad planning, supervision, training and advice to staff. This is also where all the files and information pertaining to the whole project are kept either in Intermediate Technology terms or/and on paper. The tools of this Unit include computers (with E-mail and Internet connection), telephone, facsimile and the general materials needed for administration. The hub of MENCAFEP Batticaloa - without the hub the wheel cannot turn, such is the case with this Unit.

##### **B. . Staff Accommodation Unit.**

###### **Staff:**

**Housekeeper.**

Alongside the Operational Office will be Staff Accommodation catering for the needs of specialised staff coming from MENCAFEP-Nuwara Eliya on a regular basis.

##### **C. School and Centre with Resource Unit.**

###### **Staff:**

**All Staff connected with MENCAFEP-Nuwara Eliya and Batticaloa.**

The school and centre is very strongly based and adapted from the MENCAFEP - Nuwara Eliya model. Please information pack MENCAFEP - Nuwara Eliya 2005 - 2008.

The Disability Resource Unit aims to provide advice, information and support to:

- Disabled children and their families.
- Carers, Teachers, Workers and Practitioners working with the disabled children.
- People interested or thinking of working with disabled children and their families.

The Disability Resource Unit aims to provide advice, information and support to Carers, Teachers, Workers and Practitioners working with the disabled children on:

- The Sri Lankan Social Services Disability Provision.
- Facilities and support for disabled children, their families and Carers.
- Physical access issues.
- Teaching and learning.
- Training opportunities.
- General support in dealing with disability issues.

##### **D. Training and Support Unit.**

###### **Staff:**

**Senior Trainer and Support Staff.**

**Trainer and Support Staff.**

**Prospective Trainees = 30+ working with a 100+ children.**

Through MENCAFEP-Nuwara Eliya this unit has developed over the years. It was primarily set up to deal with MENCAFEP's staff training needs. As the programme and staff have developed, and with word spreading of the unique work that was taking place. It was decided to open up the project as a training resource.

Trainees have come from all over Sri Lanka, South Asia and Europe, from 1 weeks training to 3 months training. The training technique used is **'learning by doing'**. It is very much a practical/hands on training course. With the trainee becoming part of the MENCAFEP family, with theory input taking place in the evenings.

The emphasis will be much the same with MENCAFEP-Batticaloa, trainees coming to MENCAFEP-Nuwara Eliya for training. However, there will now also be more practical help and support for trainees in their own work places. With MENCAFEP staff coming into their special units and working alongside them for certain periods of time, within their set timetable.

Networking in and around Batticaloa is going to be a very important aspect, with the many resources that are Batticaloa being utilised for the benefit of this whole project.

#### **E. Disabled Aids Unit.**

With the help of Motivation UK and MENCAFEP's own expertise in building disability aids for disabled children. This unit will assess both within the home visit and outreach unit and the assessment and counselling unit what disabled aids children and their families need to make their lives easier, comfortable and accessible.

#### **F. Assessment and Counselling Unit.**

**Staff:**

**Assessment and Counselling Worker.**

#### **Children and Families = 30.**

This unit provides a community based service. Children and families with severe and enduring disability problems can access holistic support. Support Groups within the community are aimed at helping people cope with their problems in a variety of ways. These include symptom management, recreational activity, art, social and educational groups.

#### **G. Home visit and Outreach Unit.**

**Staff:**

**Home Visit and Outreach Worker.**

**Driver.**

#### **Children and Families = 25.**

This unit is being designed primarily, to meet the needs of child's family and the disabled child within that family. And secondary to help and assist the family to inter-change with the community. Therefore supporting the child and family in the community. Allowing the child and family to live in and be part off their community with dignity.

The whole idea behind the MENCAFEP organisation is the empowerment of the people that the programme belongs to, the families, children, staff of MENCAFEP and the community at large.

This philosophy is well known to Tdh-Netherlands and will not change within the MENCAFEP-Batticaloa set-up. Obviously, adaptations are going to have to be made in Batticaloa, but MENCAFEP-Batticaloa will very much be part of MENCAFEP Nuwara Eliya. With the very close links that MENCAFEP-Nuwara Eliya and Batticaloa will have, inputs from Batticaloa will have no problem making themselves known to the overall structure in Nuwara Eliya and vice-versa.

MENCAFEP has several structures in place to allow it to function. The Co-ordinator and the staff undertake the day-to-day running of the project. The Co-ordinator and staff meet once a week or more if needed, to plan for the coming week. Daily planning and lesson plans are done in consultation with each other, the Coordinator and the Community Development Coordinator.

An Executive Committee made up of parents and staff representatives. Meet every 6 - 8 weeks, with elections for the Executive Committee, from the full parent and staff group, taking place every year. There are 10 members, the Chairperson and Secretary are parents, and the Co-ordinator and a parent are Joint Treasurers. Of the other 6 members, 3 are parents and 3 staff. MENCAFEP- Batticaloa is represented by the Community Development Coordinator and the Project Coordinator.

**Election of MENCAFEP Executive Committee: -**

**Chairperson - elected from the parents annually at the yearly parents meeting.**

**Secretary - elected from the parents annually at the yearly parents meeting.**

**Treasurer - Mencafep Project Coordinator and an elected parent.**

**Three committee members elected from the parents annually at the yearly parents meeting.**

**Three staff members elected from the staff group annually.**

**Advisor to the committee Community Development Coordinator.**

**MENCAFEP-Batticaloa representation Community Development Coordinator and Project Coordinator.**



**Children/young people's representatives feed into this Executive Committee on a regular basis.**

(Please see organ-a-gram below).

The Executive Committee's main tasks are to look at community involvement, through meeting and talking with local dignitaries and the community at large, helping with MENCAFEP family support groups and looking at the overall development of the organisation. With suggestions for further development, fund raising ideas, training and events that are taking place in and without MENCAFEP.

The full parents group meets once a term, with the full staff. At this meeting they discuss their children's progress, and the overall progress of MENCAFEP.

MENCAFEP-Batticaloa will bring its change agents, partners and representatives from its community, together every two months to talk about the work in the field and centre. Plus feeding into the MENCAFEP Executive Committee and feedback from the same Committee.

At the present moment in time MENCAFEP has a total of 24 staff, 19 being female and 5 being male, with 5 Vocational Training Students paid a stipend for the work they do in this unit and around the Centre. Of this staff group 19 work directly with the children, 2 male and 17 female, one of which is a part time volunteer. The MENCAFEP-Batticaloa Project will add 9 more staff to the overall MENCAFEP cadre.

Each Unit has a Section Head; these are Senior Staff within the organisation. The Co-ordinator, Deputy Coordinator and Community Development Coordinator monitors the work of each section, through planning books, reports, their own observations, consultation with Senior Staff, staff, children and parents. The units working on the administrative side and directly with clients in Batticaloa will have a Project Coordinator heading the project with a Project Manager managing the project. With staff working in training, support, assessment, counselling, home visit and outreach work. Along with an administrator, driver, security and housekeeper.

Most staff, before joining MENCAFEP has been unemployed. Educationally the majority has been educated up to O/level and A/level standard, with other staff members drawn from the MENCAFEP student body.

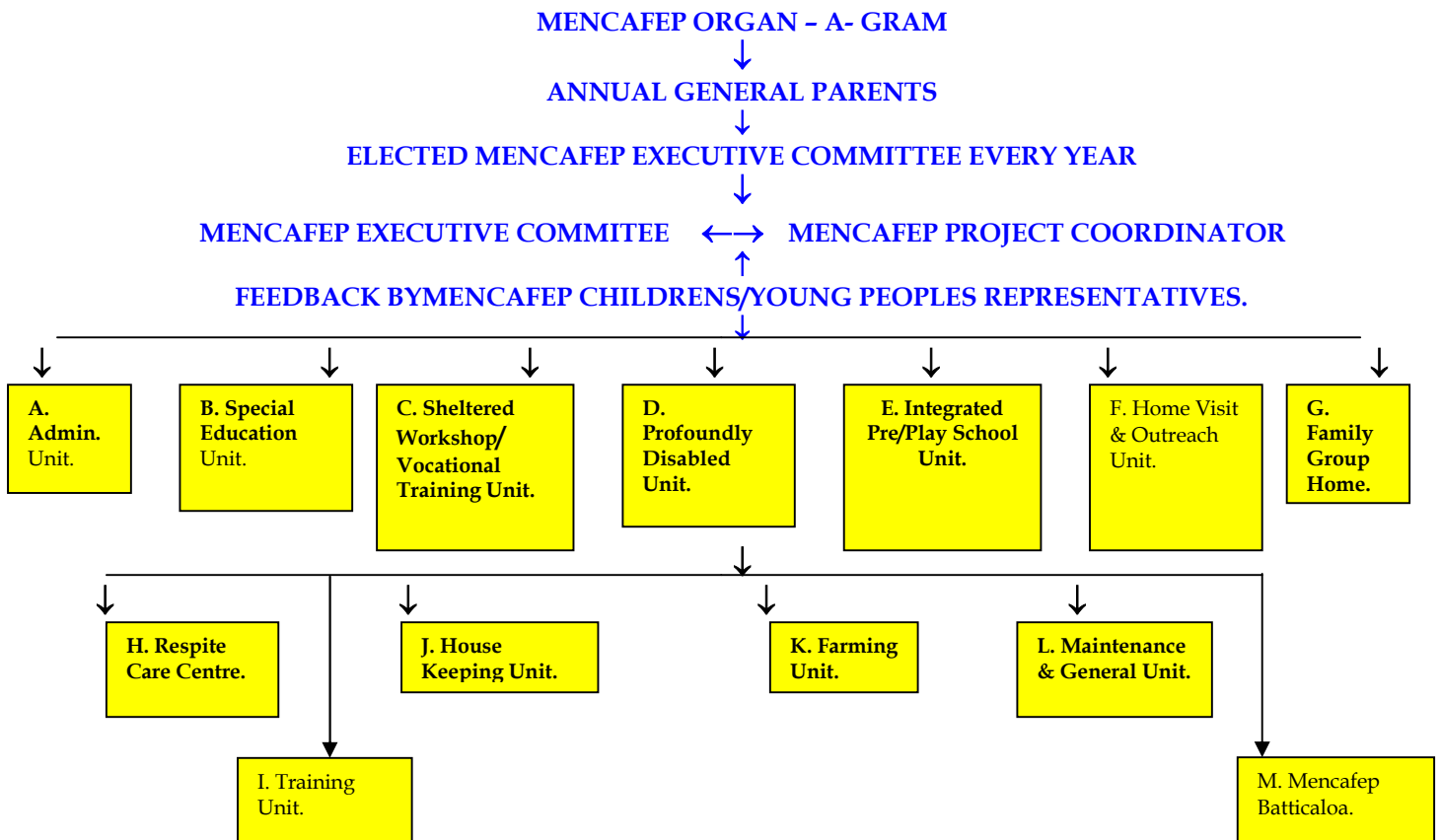
Eighty per cent of the staff has been with MENCAFEP for over 10 years, as has been mentioned continuous on the job training takes place around the year. Resource people in different skills have been brought to Nuwara Eliya, to train staff. Staffs also attend many training courses in Colombo, run by different organisations.

The Co-ordinator, Deputy Coordinator and the Community Development Coordinator (when asked), with an external accountant, are checking the overall accounts each week. With the accounts of each section being checked each month. Accountability is to the donors, bank accounts operated by MENCAFEP have two signatories, all staff is involved in payments and purchases. The Project Coordinator along with the Project Manager and Administrative Officer, will keep

accounts in Batticaloa, but these will be overseen and supervised by the MENCAFEP external accountant in Nuwara Eliya.

As mentioned, the Co-ordinator and staff meet once a week or more if needed, to plan for the coming week. The staffs that participate are those working directly with the children/young people. The staff on a daily basis plan and do lesson plans. The ancillary staffs meets separately, with the Coordinator and Senior Staff. To start with in Batticaloa, weekly planning meetings will take place (more if needed), to plan and fed back on work.

The Co-ordinator and Community Development Coordinator evaluates staff on a six monthly basis. Trainee staff is assessed every month during their six-month probationary period. With the Coordinator and Community Development Coordinator being judged on their performance by the planning, reports and fundraising they do, along with what is written in the internal and external evaluation reports. The Coordinator and Community Development Coordinator provide group and individual counselling for all the staff.



Has as been mentioned, MENCAFEP Nuwara Eliya will take the above structure and adapt it to the needs of MENCAFEP Batticaloa. This will be done in stages as MENCAFEP Batticaloa develops. Although MENCAFEP as a whole has some information on the situation for disabled children and their families in Batticaloa District, it does not have the full picture. With the situation that has developed in Batticaloa it is going to take time to feel and see what the exact needs of the community are.

## **5. WRAPPING UP ABOUT MENCAFEP - BATTICALOA:**

In January 1988 when MENCAFEP started, the project was working with 6 children and their families; today MENCAFEP is working with 120 children/young people. During the last 17 years the programme has helped another 220 disabled children and their families.

MENCAFEP has by no means the answer to everything, it is learning and developing everyday, MENCAFEP believes that this is a never-ending process.

As can be seen by the problems; Batticaloa District even before catastrophe hit on 26 December 2004 was in a deprived state of affairs. Although with nearly 3 years of a cease-fire being in place, 'light was being seen at the end of the tunnel.' After the 26 December, Batticaloa like all the other communities, hit by the tragedy, the District was shaken to its foundations once again.

How Mencafep-Batticaloa came about and how Mencafep works, outlines the work MENCAFEP has started and will be doing. A School and Centre as such, like in Nuwara Eliya, with a more community based approach, helping the community to help themselves. The community of Batticaloa need help and assistance; MENCAFEP's expertise is in disability, especially the intellectually challenged child. MENCAFEP will make a big difference to the disabled child and their families in Batticaloa. It will also put disability on the map in the district, so it is not seen as the 'ugly sister' of development and the rebuilding process that needs to take place.

As can be seen from the Nuwara Eliya Project there is a very strong parent input; MENCAFEP could not function if it did not commit itself to working towards, the programme belonging to the children, parents, and staff, with it also being a resource for the community as a whole. MENCAFEP Batticaloa will continue this process, along with enabling all classes and castes to be integrated, from shop owner to street cleaner, disability does not discriminate. However, priority will be given to children and their families coming from very vulnerable and at risk backgrounds, with poverty being the blight of their lives.

MENCAFEP has grown into a world-renowned organisation for working with disabled children and has as been mentioned especially those that are intellectually challenged, in a developing country. MENCAFEP can do a job in Batticaloa the can not only help, but give dignity, care and understanding to those that have been deprived of it, due to their disability.

MENCAFEP will keep developing its work with disabled children in an innovative and caring way. With MENCAFEP fighting for the dignity and total inclusion of the disabled, specifically the child and his/her family, into the overall structure of society.

MENCAFEP has always tried to diversify its funding, this is very much going to have to be the case for the foreseeable future. That is to say that MENCAFEP is going to have to rely on the help of others, to keep its work functioning at the high level it has achieved. As well as allowing the project to develop in it's own very innovative and unique way.

Especially when it comes to finances, as in many other developing countries, when it comes to resources being given out, the disabled, especially the mentally disabled are at the bottom of the pile

**Ranji and Chris Stubbs.  
September 2005.**