

**Paper name:** Working with Deaf children, young people and their families in the central mountains of rural Sri Lanka

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### **Synopsis**

MENCAFEP provides community-based care and support to children, young people and their families. This article provides a detailed account of the way MENCAFEP works with children and young people who are deaf and those who have additional impairments. Efforts to promote education in local schools and to secure employment are described. In the long-term MENCAFEP plans to secure the involvement of deaf young people in the running of the organisation.

### **Introduction**

MENCAFEP is a day-care school and day centre for disabled children and young people, situated 6,000 feet (2,000 metres) up in the mountains of Sri Lanka. It has been functioning for over 16 years and deals with a wide range of disabilities; Down's Syndrome, Poland Syndrome, Rett's Syndrome, Spina Bifida, Autism, Cerebral Palsy, Blind/sight impairment, Hydrocephalia, Microcephalia, Hyper Activity, various ranges of brain damage, multiple disabilities, and Deaf/hearing impairment.

MENCAFEP has four units, these units being; Integrated Play/Pre-school (able and disabled children, including deaf children), Profoundly disabled section (multiple disabled children/young people, including hearing impaired), Education section (majority of the deaf children in this section) and Vocational training/Sheltered workshop section.

Out of the 100+ children and young people that attend the centre, 14 have varying degrees of deafness. MENCAFEP, through its overall philosophy, vision and strategy, has taken on its work with deaf children and young people and their families, in what it believes is an open, positive, exciting and beneficial way for all concerned.

Although since MENCAFEP's inception, the Sri Lankan philosophy of 'out of sight, out of mind' for disabled people has changed in some aspects, especially for deaf people. The overall thinking in Sri Lankan society still leans towards its traditions of 'karma'. People believe that if you have a disability, it is because

you, or your parents, have done something bad in a previous life and you are being punished for it in this life, and therefore you deserve your disability.

With its vision and strategy MENCAFEP has tried to balance this tradition of karma, by looking at the positive aspects within any person, able or disabled.

### **MENCAFEP's way of working**

MENCAFEP provides non-institutionalised care for deaf children/young people, by caring for them in their own communities, with their families.

This allows deaf children and young people to be in their home environments, allowing them to live with their families and gain acceptance in their communities. It also provides an opportunity for them to interact with the whole community.

MENCAFEP helps deaf children and young people, and their families to develop through its Day Care Centre and School. We expose them to stimuli and experiences that might not be provided. This includes music, exercise, constructive play, total communication, education, social skills, vocational training, job experience and employment. Through this exposure, they are more prepared for adulthood.

MENCAFEP's home visit programme involves the education of families and communities and encourages the following:

- Making families and communities aware, of all they have to offer deaf children/young people, and what deaf children/young people can offer their families and communities.
- Helping families and communities of deaf children/young people understand that the stigmas associated with bad karma are unnecessary burdens, which hinder the development of the children, young people, families and community.
- Establishing family support groups, which enable families to help each other and meet the challenges of caring for a deaf child or young person.
- Developing a resource centre for training and for supporting other groups interested in community based rehabilitation for deaf children, young people and all other disabled groups. Outreach work is part of this process.

### **Total communication**

Over the years MENCAFEP has developed what it terms 'total communication'. This not only helps deaf children and young people, but also those with other disabilities, and especially profoundly disabled children and young people who have hearing impairments.

### **What is 'Total Communication'?**

For MENCAFEP total communication means communicating with another person or a group of people with all the resources one has around one's self. This total communication could include speech, sign language, touch, hugging, facial expressions, mime, symbol systems (pictures, pictograms).

Disabled children, whether they are deaf or not, who fail to establish effective ways of making their needs understood, almost certainly will develop problem behaviour. For example, when MENCAFEP is assessing a multiply disabled child who they believe may have a hearing impairment, certain aspects of communication are assessed. These are as follows:

1. Is it possible to converse vocally or is it only possible to communicate with no verbal communication?
2. If speech is not possible, should a physical movement, such as speech-supporting movements be used, or a symbol scheme, such as pictures and pictograms, or both together?
3. If speech is not possible, MENCAFEP staff then have to choose which movement, touch and/or symbol structure is most suitable.
4. When it is clear what communication system should have priority, MENCAFEP staff consider what contents and methods should be used. Using as guidelines, through assessment, about the child's interests and needs. In MENCAFEP's experience, most profoundly disabled children tend to show interest in things that they can eat. In the past this interest was used as part of behaviour therapy, teaching children that they can accomplish something by asking for various foods. In the past, if a child communicated that s/he wanted a mango, the reward would be a spoonful of sago. MENCAFEP tries to ensure that when a child points to a symbol of a mango they get a mango and a very big hug!

### **Parents/Carers as experts**

MENCAFEP believes that parents/carers are on the 'front line', when it comes to working with deaf children/young people. MENCAFEP help begins by trying to understand what parents/carers believe, expect and need. This is the foundation of MENCAFEP's work with deaf children/young people and their families.

MENCAFEP deems that it is very necessary to listen to parents/carers, trusting them to be competent and capable. As one of MENCAFEP's parents of a deaf child said, ... "it is easier to receive when you are giving."

In MENCAFEP's work to empower parents/carers four clear steps are adopted:

- Create family centred approaches which are supportive of an integrated/inclusive environment.

- Make sure that parents/carers do not feel isolated and/or helpless.
- Understand that parents/carers are able to share experiences and skills.
- Recognise that parents/carers are a valuable resource.

### **Positive outcomes of the MENCAFEP philosophy**

Although MENCAFEP is working with 14 deaf children/young people, we have found work in the last two years for four of our young deaf people (male). One works in a hotel, another in a garment factory, the third works as a tailor, and the fourth works in a vegetable shop. This has not been an easy task in an area that is seen as one of the poorest in Sri Lanka, with high unemployment rates. Where non-disabled people struggle to find work, it is an even greater struggle for deaf and disabled people.

MENCAFEP has always encouraged deaf adults to work within its organisation, and not only with the deaf children/young people, but also with the other disabled people. At the moment we only have one deaf adult (female) working in the MENCAFEP delivery services. However, plans and discussions are taking place with two young deaf people (female and male) who have attended the MENCAFEP centre since they were 4 and 6 years respectively. Both are over 18 and are about to take their final school exams (O/levels) in December. Once they have taken their exams, the plan is that they should go through teacher training. They could then join the MENCAFEP staff, primarily to work with our deaf children, but also with MENCAFEP's other groups of disabled children.

The deaf children/young people play a very active part in MENCAFEP's extra curricula activities. They are in the school band, and participate in musical shows and drama productions. Two of our young deaf people travelled to India recently to participate in a sports event.

MENCAFEP's links and networking with other organisations working with deaf children and other disabled children are not only in Sri Lanka, but also worldwide. Over the past year MENCAFEP has been involved with the Commonwealth Educational Fund (CEF), through Save the Children UK. This is linking NGO's working in different provinces of Sri Lanka, working with vulnerable/at risk children, their families and communities. To work towards education for all children aged between 5 years and 14 years, by 2015. MENCAFEP is one of three projects that is representing disabled children in Sri Lanka, with MENCAFEP being one of two working with the deaf child.

MENCAFEP's relationship with the majority of local schools has helped in identifying hearing impaired and disabled children who have been struggling in these schools and have dropped out. Through this relationship we have been

able to identify disabled children who are lacking certain educational skills and a place to learn - therefore going some way to meeting the CEF initiative of education for all.

Another important link for MENCAFEP is the local government hospital, which covers the Nuwara Eliya District. Some years ago the Japanese Government donated a hearing testing machine and trained three of MENCAFEP's staff to operate it. This is the only testing machine in the whole of the district which has a population of over a million. Therefore the hospital uses MENCAFEP as a service for their patients.

### **Difficulties with inclusive education**

Although MENCAFEP has good relationships with the majority of local government schools, it has had many, many frustrations with them. Over many years MENCAFEP has at times tried to integrate deaf children into the local government schools. Even when MENCAFEP staff prepare, and work alongside, the teacher and class when a deaf child has joined them, it has proved near to impossible to achieve.

The majority of rural local schools have class sizes of 50+ and the majority of teachers are untrained. Deaf children, along with other disabled children, (apart from one) became invisible. Being neglected, pushed aside and forgotten about, necessitating in us having to bring them back into MENCAFEP. In some cases head teachers have refused to take children because of their disability or deafness.

The few schools for the deaf that exist in Sri Lanka are located in the major cities. These schools are residential, fee paying and exclusively for the deaf or deaf and blind.

### **Conclusion**

One major conclusion that we have come to over our years of working with deaf and other disabled children, is that MENCAFEP staff members must also serve as social workers, health care providers and friends of the child, family and community – in addition to being teachers.

MENCAFEP is learning and developing everyday in its work with deaf children and young people, their families and communities. How we work with deaf children and young people has been very much influenced by the deaf child and their families. With a very strong belief that disabled children should live in and be part of their community with dignity being another major driving force behind our work.

MENCAFEP through its philosophy of working with deaf children certainly does not have all the answers. Its work is open to constructive criticism and new

learning and teaching techniques. If you have any queries, questions or criticism, please contact me at the following:

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