



Thank You From All At MENCAFEP.



SHARING SMILES

**A SEMI ANNUAL PUBLICATION FOR FRIENDS OF MENCAFEP.
MENTALLY HANDICAPPED CHILDREN & FAMILIES EDUCATIONAL PROJECT.**

MENCAFEP.

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www.mencafepsrilanka.com

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BUBBLE FLOAT, BUBBLE FLOAT, BUBBLE FLY HIGH AND HIGH, TELL THE WORLD THAT I AM STILL HERE OR THE BUTTERFLY'S WILL DIE.



ARE YOU DEAF? ARE YOU BLIND? OR ARE YOU NOT BASICALLY KIND? BUBBLE FLOAT? BUBBLE FLOAT.

This Newsletter is sponsored by INTER-FASHION, Nuwara Eliya, Sri Lanka.

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**If you feel that you can help in anyway contact us on the above
or visit www.mencafepsrilanka.com**

A PROGRAMME FOR CHILDREN/YOUNG PEOPLE WITH LEARNING DISABILITIES.

**THE SPECIAL CHILD/YOUNG PERSON HAS A RIGHT TO LIVE AND BE PART OF THEIR OWN
COMMUNITY.**

HELP WANTED: IMPERFECTIONS ARE A BONUS.

Being disabled can mean missed opportunities. But MENCAFEP staff members Sarojani, Manike and Ayesha found that their disabilities were not disabilities at all at MENCAFEP.

“There’s a great belief that disabled people should be working with disabled people,” Ranji Stubbs project co-founder says.” They have more empathy.”

With that in mind, MENCAFEP practices “positive discrimination” when looking for employees. Ranji says: “All other things being equal, a disabled person will get the job.”

For different reasons, coming to MENCAFEP has helped all three women look toward the future with anticipation rather than fear. In Sarojani’s case, the job as MENCAFEP Housekeeper has meant a small income to feed and clothe three children. Sarojani was afflicted with polio as a child and has an atrophied leg to show for it. But it’s her ever-present smile – not the limp – that leaves a lasting impression. “It’s a smile, that Sarojani brought with her to MENCAFEP: a sign that she had already come to terms with her disability before she arrived. With Ayesha and Manike however, self-acceptance has taken time.

Ayesha began work at MENCAFEP after completing her schooling at MENCAFEP. Before this Ayesha was found abandoned in a Sri Lankan Government Home for the Mentally Retarded. From where she was brought to Nuwara Eliya. Ayesha has a condition called MicroCaphilli, which means she has an undersized skull, causing epileptic fits and intellectual disablement. Ayesha is presently working in the Integrated Pre –school (a mixed school for disabled and able children) as a helper. She has also had stints as a kitchen helper and garden worker; this has been to provide her with as broad a skill base as possible. Since starting work Ayesha has, “totally blossomed,” Ranji says. “Always giggling, joking and being positive.”



Ayesha with her Pre-school students – new hope – new life.

Manike, who was born deaf, spent most of her childhood in a residential school for deaf and blind children. There she learned to communicate through sign language. After she had completed school she returned home, to discover that people in her family and community could not talk with their hands! Though she had much to say, nobody was capable of listening! Frustrated and angry, she threw tantrums and acted like a child.

One of Manike’s aunts, who were working at MENCAFEP at the time, asked if her niece could be taken on as trainee – more for Manike’s benefit than the three deaf children at MENCAFEP during this time. At that time in MENCAFEP’s history staff members were very rusty with their sign language. What little they knew had been picked up from the deaf children and that was different than what Manike had learned at school.

Again in an environment where few people understood her, Manike withdrew into her solitary, silent world, keeping her feelings to herself. Eventually, however, she voiced her dissatisfaction in a nonverbal childish rage – kicking, biting and punching her peers at a staff party – that got it's point across.

Since then, the entire staffs have learned sign language, with staff members taking it in turns to sign for Manike at staff meetings. This has made all the difference not only for Manike, but all the children in MENCAFEP have benefited as MENCAFEP has developed its **TOTAL COMMUNICATION TECHNIQUE** (the use of every part of the body and surrounding environment to communicate with each other).

“We’ve learned to communicate with her, and she’s learned to communicate with us,” Ranji says. ‘She helped bring communication to the MENCAFEP family.’ Thank you for taking the time to go through this small story.



Manike and Sarojani taking a break from work.

MENCAFEP PARENTS: ‘What will happen when I die?’

Multiple disabled children need respite care.

In one corner of the aptly named ‘soft room,’ Haridha lies on a specially designed mattress, her head in the lap of one of MENCAFEP’s special care workers. A radio cassette on the floor plays Sri Lankan pop music, the kind of upbeat tune that routinely inspires roadside dancing among young Sri Lankan men.

Haridha, too, is dancing – flat on her back. Her arms and legs twisted and very stiff, her mouth twisted into a smile with her tongue poking out. But her head and certainly her eyes are trying to move with the music. Suddenly her entire body convulses; the pained, puzzled look on her face smoothes into another twisted, smiling face, with the head and eyes getting back into the music.



Haridha communicating in her own special way.

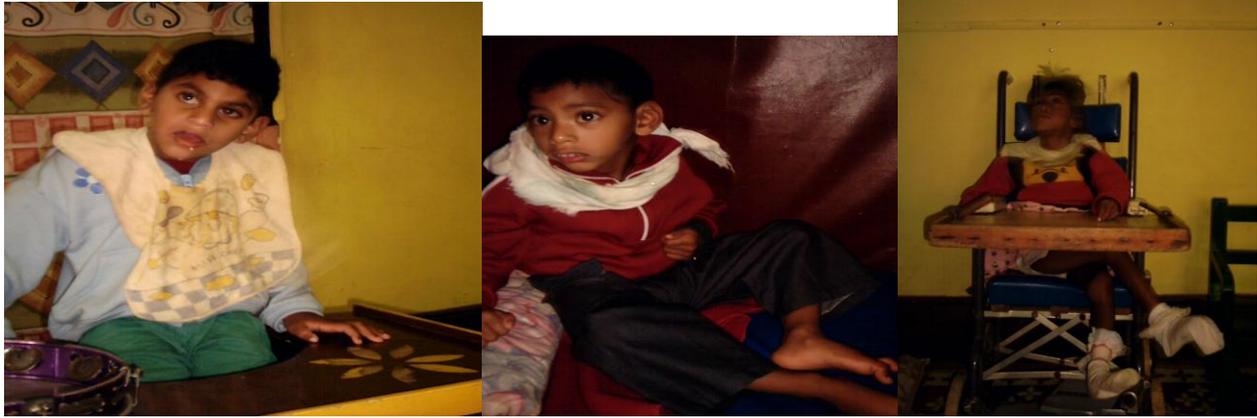
A moment like this makes you wonder what might trigger another convulsion? Was she aware what was happening? Was it a pleasant experienced for her?

If Haridha can answer such questions – and MENCAFEP knows that she is trying – it’s a language we are still learning, to understand her fully.

“We are really working on the language ‘thing’ with children like Haridha,” says Ranji Stubbs, Coordinator of MENCAFEP, about interpreting the body language and the verbal utterances of a child like Haridha. “Obviously, the beautiful smile means that she is happy.”

Haridha has a form of cerebral palsy known as spasticism. Her body’s motor nerves, that control her muscles don’t always listen to what her brain tries to tell them, resulting in jerky and uncontrollable movements. At age 7, she can’t walk or talk (in the conventional manner) or go to the toilet by herself; when helped into a sitting position her body spasms uncontrollably.

MENCAFEP has 8 such children/young people, including Haridha classified as multiple disabled. They range from 3 years to 22 years old. Although their disabilities differ, all these children share a disheartening reality; in a society where a very low priority is given to rehabilitating disabled children, with finding help a daunting task. Children/young people like Haridha are going to need full-time care for the rest of their lives. To keep these children/young people in the community MENCAFEP is looking at setting-up a Respite Care Centre. Giving parents and families a break from caring for a multiple disabled child/young person for up to one month, then back to the family until another break is needed. To get this of the ground MENCAFEP needs funds, any help or assistance in this venture is greatly appreciated.



Three of Hiradha's friends Deva, Jonathan & Urtsila.

“ It comes up at least once at every parents meeting,” Ranji says. “(Parents) ask us ‘What are they going to do when we die?’ “

In many western countries, technological advances have made caring for, communicating with and educating multiple disabled children much easier. Staff and parents in the MENCAFEP family, however, manage with locally available resources. After all, things like smiles, cuddles and hugs do not cost a single rupee!

“ I've taken my son all over (Sri Lanka),” a mother of a multiple disabled child, who attends MENCAFEP, says. “I've gone to government places, private places. But I've never seen such love and dedication, such a lot of happiness, in a place as there is here.”



What's on your mind Urtsila?

At the MENCAFEP centre, the multiple disabled spend most of their day being stimulated to reach their full potential, whatever that maybe. Staff member's massage, stretch and exercise uncooperative muscles and limbs, constantly prodding children to explore new positions. Curled over a log-like cushion one minute, seated in a corner with walls and a staff member's hand for support the next. Staff constantly talking or singing, cuddling, hugging and encouraging the children to bring out what they have inside them.

Learning basic life skills, such as grooming and dressing themselves, or academic skills such as reading and writing will come later for these children – if at all!

‘It's pretty much, where do you begin?’ Ranji says. “ It's really hard work, but when you get that little spark that something has been understood, there's such a glow inside yourself.”

Ranji recalls the day when Chris (Stubbs), MENCAFEP Community Development Coordinator, surrounded Sudu, lying on a mat with the MENCAFEP pet rabbits. The then 10 year old, she is now 22 years (see her story in Sharing Smiles Number 18), who is severely profoundly disabled, was enchanted enough with her new playmates that she stopped licking her hands – something neither the staff nor her mother had been able to get her to do for very long. “She was really gob smacked for 10 minutes,” Chris says. “All those little furry things sniffing and licking her.”

MENCAFEP’s programme for the profoundly disabled also includes a lot of creative activities. Such as playing with paint and clay, the exposure to new stimuli or familiar stimuli in a different way, such as sights-and-sounds with coloured strobe lights and interesting music.

“For years I was virtually a prisoner in my own home,” says another mother of a multiple disabled child. I never went out anywhere. Being part of the MENCAFEP family has opened up my life.”

Working with the profoundly/multiple disabled has been called the ‘ultimate challenge’. For professionals, parents, family and the community at large. With your help MENCAFEP has taken on the ‘ultimate challenge’, with your help MENCAFEP is beginning to succeed in the ‘ultimate challenge’.

Thank you for taking time to read about what we believe is invaluable work, for the lost and forgotten children/ young people of developing societies.



Haridha, her family & MENCAFEP have taken on the ‘ULTIMATE CHALLENGE’!

A LETTER SENT TO MENCAFEP TO CELEBRATE ITS 16TH BIRTHDAY ON JANUARY 25TH 2004.

Dear Chris and Ranji,

I am happy and proud of all your achievements over the years from humble beginnings. All great things start from a small idea and with a good "VISION", so it's with you and MENCAFEP. It's not easy, it demands a lot, lots of sacrifices, humiliation, and criticism and denies many things that you would like to do. You through your dedication commitment and loyalty have displayed that "Nothing is Impossible".

Ranji your journey has never been smooth and don't expect it to be either, you will face obstacles, rough patches and turbulent times. Every time you face such a situation you will sit back and think is it really worth all your efforts and sacrifices? Maybe you even want to call it a day. But my dear Ranji and Chris, when you think of those innocent children whom you all care for and the love and happiness you share with each other is far more valuable and cannot be measured.

Chris & Ranji always remember that in this journey you have each other to share your troubles. Which makes your path smoother, which means you are not alone at the receiving end of emotions. Keep up your good work that you do with all your might. Entrust your plans to God and he will guide you in your journey in helping these innocent children of Nuwara Eliya, Sri Lanka and maybe the someday the world.

Good luck & love always, ...(The sender has requested for her/his name not to be printed).

MENCAFEP GOES TO INDIA.

Our school is MENCAFEP it is a school and Day-Care Centre for special needs children, we all live in the mountains of Sri Lanka.

One morning when we were in school, our teachers told us there was a chance that a few of us would get to go on a trip to India. However there was little time to organise it and we did not know who had been chosen. All of us were excited and wondered who the lucky people were to go on this dream trip!

In the end five of us were selected, two boys and three girls, along with two of our teachers. We were so proud that out of the 100+-children/young people that attend our centre we had been given the task of being ambassadors for MENCAFEP and Sri Lanka in India.

Our journey began on the 15 October 2003, we left MENCAFEP early that morning, by 12:30pm we had left the Sri Lankan Airport and arrived in India at Trichy Airport at 1:15pm. The excitement we had in all of us going to the airport, and then getting on to an aeroplane and flying was something that dreams are made off. The taking off and landing will be something that we will remember for the rest of our lives.

At Trichy we visited a few sacred temples, churches and other beautiful historical places, it was a very memorable and enjoyable time for all of us. After a day and a half of sight seeing we boarded a very comfortable night bus to Bangalore.

We arrived in Bangalore at 8:00am and were then taken to a beautiful educational centre run by Tdh-Netherlands in Matakondapalli Osoor. At the time of our arrival arrangements were being made to hold the Indian Trials for the 2004 Paralympics. We saw many sports events that disabled participants took part in; some were very new to us. We felt very much at home watching and playing in the massive and well equip sports

stadium, which again was completely new experience for us all. We met lots of other special needs people and made friends with them. We would sincerely like to thank Mr. and Mrs. Meru, all the staff and children at the MEC, for their kind hospitality, support and kindness.



Hey World we have been to India!
Ranji, Shyamalie and Vijaya (MENCAFEP staff) Nadeera, Anusha, Suganthi, Sivakumar, Prasad.

Our journey to India is one we will never forget. The food was very similar to Sri Lankan food, rice, rice and more rice! As a lot of us could speak Tamil and sign language we had little problem in communicating with people in India. There is no doubt about it that we are the luckiest young people in Sri Lanka, to have made such an extraordinary trip to India.

So, we would like to express our sincere thanks to Mr. Lei Brouns, Regional Director, Tdh-Netherlands and all connected with Tdh-Netherlands for giving us this best opportunity in the world. We also thank Chris Ayah who is always concerned about our future and us. We also thank Ranji Teacher, Shyamalie Teacher and Vijaya Teacher for taking care of us and bringing us back to Sri Lanka safely.

Thank you,

Prasad, Sivakumar, Suganthi, Anusha and Nadeera, the young people of MENCAFEP.
(Translated from the original written Sinhalese script.)

**DEAREST FRIENDS OF MENCAFEP FROM ALL OVER THE WORLD,
AS THE FOUNDERS OF MENCAFEP WE WOULD LIKE TO APOLOGISE FOR THE DELAY IN GETTING THIS
NEWSLETTER OUT. AS YOU WILL SEE WE HAVE COMBINED THREE NEWSLETTERS INTO ONE, SO THAT YOU
HAVE NOT MISSED ANY OF OUR ADVENTURES SINCE OUR LAST WORLDWIDE PUBLICATION.
WE HAVE NO EXCUSES REALLY, APART FROM ALWAYS CHASING OUR TAILS, COMPUTERS CRASHING,
EMERGENCIES HERE AND THERE AND NOT GETTING OUR ACT TOGETHER!**

**TO ALL OF YOU WHO HAVE SUPPORTED US AND CONTINUE TO SUPPORT US IN THE VERY SPECIAL WORK THAT
WE DO, WE THANK YOU ALL FROM THE BOTTOM OF OUR HEARTS.**

A SPECIAL MENTION MUST GO TO TERRE DES HOMMES - NETHERLANDS, WHO HAVE STUCK BY US SINCE

1990. HOPE FOR CHILDREN UK, SUJEEVA - SWITZERLAND. THE FRIENDS OF SRI LANKA ASSOCIATION UK,
WHO RAISED FUNDS TO START A DREAM. THE DREAM BEING THROUGH FUNDS RAISED BY FOSLA THE FIRST
RESPITE CARE COTTAGES ARE BEING BUILT.

FROM ALL AT MENCAFEP
THANK YOU, THANK YOU, AND THANK YOU.

CHRIS & RANJI STUBBS - MARCH 2004.