



**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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Carrying on from the last news letter on Autism MENCAFEP – Batticaloa would like to continue this theme by telling the story of Akshan, his mother, family and how they all worked together with MENCAFEP – Batticaloa to try and make his life, a little better for him and his family.

Akshan, at age four-and-a-half years, came to MENCAFEP – Batticaloa. When we observed Akshan at our school and centre, he was non-verbal, non-interactive, highly preservative in actions and sounds, and highly resistant to touch and language. Akshan screamed intensely from two to ten hours a day. He resisted personal contacts as if they were violent abuses. He was extremely sensitive to sounds and to almost any unexpected event; he also had epilepsy, which could hit him at any moment. He refused to allow us to approach him. In order to calm him, we talked with the mother from a distance of about six feet. We learned early to read Akshan’s boundaries and to enter them only very slowly.

So, MENCAFEP - Batticaloa asked itself, can we help a child like Akshan? Soon, we realized the answer was yes, because Fatima, his mother, family and MENCAFEP staff was very open to learning how to play in Akshan’s world. They had no question that Akshan could do much more. They realized he knew many things but also knew he responded to many traditional teaching approaches with noisy, frightened retreat.



**Akshan and his mother laying the foundation stone at the MENCAFEP Centre.**

A major problem here was that Akshan had such a low rate of interaction with people and such a narrow range of activities that he appeared locked in a world that kept him from learning anything from others. Our first task was to explain to Fatima and MENCAFEP staff that Akshan needed some skills before we could address his communication problems. He needed to stay in interactions with people who were willing to act in ways he could and who placed no demands on him other than to stay in back and forth contact. He needed to learn he could survive interacting with people.

Fatima and the MENCAFEP staff soon understood that for Akshan, staying in interactions was as critical for his coming into relationships as insulin is for the health of a diabetic. In our view, the world for Akshan was over stimulating to the point that he not only tuned out, but imposed such violent self stimulation, at times bringing on fits, that he was rendered out of perceptual contact for up to several hours. So, the dilemma was how to keep Akshan in interactions that seemed to put him into a state in which he could not hear, see, or cooperate enough to learn anything but to escape.

Once Fatima, her family and MENCAFEP staff realized that Akshan had to stay in interactions, they learned a few things; how to act like him, to reduce their language and their demands and keep just one goal in focus--to keep Akshan physically interacting back and forth more frequently and for a little longer as time progressed. We practiced with Fatima and MENCAFEP staff coaching them to do the following; act like Akshan then wait, gently keep him with them, wait for him to do anything positive, even the smallest steps in sound or action, then do it like him and wait again to repeat the cycle. The activities involved exchanging any sounds, actions or physical objects (like a doll) back and forth, teaching him three things; one, that he could survive interactions; two, that there was no option to staying; and three, that if he did just a bit more he would be free to explore as he wished.

A major breakthrough came in about nine months when he started staying without being physically held and initiating exchange games on his own. He was still interacting with some anxiety and resistant to staying with people, but he was staying and his mother was experiencing for the first time that she could have some effects on him and that he would finally give back some of her playful contact.



**Akshan on one of his first days at school.**

Fatima's and MENCAFEP staff attitude was inspiring to watch. Akshan vehemently resisted for several months, but Fatima and the MENCAFEP staff took the smallest gains and expected more. His mother often said, "I don't care what he does, but he's going to do more of it and he's going to do it with me."



**Akshan (in the chair) at school.**

A unique and forceful feature of Fatima's was her non-judgmental humour. She didn't take his rejections personally and she frequently laughed when she kept him with her as if to say "I know you don't want to stay, but I'm going to be so entertaining that you will." Fatima learned to ignore much of Akshan disruptive behavior and persisted in getting him to respond in any way he could. She did not view Akshan as doing anything wrong; rather she saw it as her responsibility to get him into her world by first getting into his.

When we commended her on her persistence through months of plateaus, setbacks, and downright disturbing periods, she said "I'm going to do whatever I have to -- I know there is a bright little boy in there and I don't expect it to be easy."

And it clearly wasn't easy. New people, situations, activities and most changes would invoke setbacks and sometimes monumental disturbances in their family of five. When we noticed Fatima pushing herself without much response from the boy, we prescribed a break for her. Then she learned that forgetting about interacting for a while led her to see how much she had learned to do habitually. She was pleased to see Akshan initiate and keep her interacting when she took a little vacation from focusing on it.

Once Akshan began to stay in interactions, that is, to take turns both imitatively and with behaviors of his own, we encouraged Fatima and the MENCAFEP staff to begin to hold out for more interactions. When he took a turn, by clapping hands or rolling a ball, MENCAFEP staff would wait for any sound before they took their turn. We discussed how effectively Akshan had been communicating with Fatima and MENCAFEP staff with tugs and pulls and soundless signs. He needed to learn that sounds are more effective communications. For now, he made sounds more for apparent self stimulation than to communicate. Until then, he didn't know the powerful positive effects sounds could have. And sounds were not quick to come. It took much waiting and prompting as well as having Fatima coach the family into the habit of imitating all of Akshan's sounds even if he was in a separate room. It took months to show Akshan that sounds got people's attention most efficiently. By now, he was choosing to play with his brothers, sisters and parents, of course briefly and often on his own terms. But he was joining the family.



**Akshan at school today.**

Once Fatima's and the MENCAFEP staff watching, waiting and keeping him there were stable habits, we began to teach them how to help him move from simple actions to interactions that were meaningful for Akshan and the people around him. They learned to treat his sounds and movements as his own special language and their job was to translate his actions and nonverbal communications immediately into single words. They learned that the exact time he was doing something or communicating with someone was the best exact time for him to learn a meaningful interaction for it. Akshan understood increasingly more words, but he was not using them. Fatima taught her family to reduce their questions and long sentences and to become a family of translators as if Akshan was a visiting foreign-speaking child.

Now, three-and-a-half years later, Akshan is eight and still coming into the world of his family and peers at school. He's making sounds more frequently and appropriately. He responds much less with fight and flight but he still needs to learn about people boundaries as he can be a pretty rough play partner. Recently on another one of our many home visits with Akshan and his father. His dad admits not seeing the problems his wife experienced. He is excited with Akshan's social gains and feels they have a strong, playful relationship in which he, the dad, gets a lot from Akshan who used to be a stranger to him.

Thank you Terre des hommes – Netherlands for supporting us in our work. If not for your support were would Akshan and his family be today? Your support has made us be there for Akshan and his family – thank you.



**Akshan making progress.**

Thank you Lei and Hanneke for always believing in MENCAFEP and the work it does - thank you.

Chris and Ranji Stubbs.  
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