'Label jars not people'

Having crossed many hurdles himself, Chandima Rajapatirana along with his mother and three teachers reach out to fellow autistic people and their families to realize their dreams through the gift of communication

By Smriti Daniel, Pix by Gemunu Wellage

A single sentence on the back of Chandima Rajapatirana’s t-shirt reads ‘nothing is impossible’. As far as personal mottos go, this one suits its wearer to a tee. Diagnosed with autism and apraxia as a four-year-old, Chandima has defied the prediction of specialists. The man who they recommended should be institutionalised is today a poet, writer, activist and teacher. Having been silent for 18 years of his life, it took a simple technique known as Facilitated Communication to allow him to begin communicating for the first time. Letter by letter, he typed out his heart’s desire – Chandima wanted to live a life purpose.

In 2007, The Sunday Times ran our first story about Chandima. A month later, in September, he and his mother Anoja co-founded E.A.S.E (Educate, Advocate, Support, Empower) and got down to the hard work. First with house visits and more recently at a rented space off Malabe road, the two have been working not only with families and children but also with groups of young trainees and teachers. They’ve addressed specialists at international conferences and children in school auditoriums – arguing for the rights of the differently-abled.

Chandima is, more often than not, a revelation to those who meet him for the first time. He does many things other autistic people do – he avoids eye contact, gets trapped in repetitive motions, makes strange vocalisations and will abruptly take off on a run around the room – but when Chandima is typing to you, it’s obvious he’s both capable and intelligent. At a recent conference, Chandima was asked how disabled people could be identified. Refusing to do so, he explained: “Those of us in the disabled field say, ‘label jars not people.’ Dear friends, think about it. ‘Tomato soup’ tells you what is in this can. ‘Autism’ does not tell you what is in me.”

Chamira Gunatilaka is nearly 14 years old and today he and his mother Nirosha Gunatilake have taken a two and a half hour bus ride for their bi-monthly session with Anoja and Chandima. Mrs. Gunatilake tells me the boy sitting calmly on the chair beside her used to be nearly unmanageable – so much so that no one else was willing to take care of him and she had to quit her job to stay home with her extremely hyperactive son. Just six months into his visits with Anoja and Chammi, things have changed for the better, in part because Chamira has learned how to use two words – ‘yes’ and ‘no’.

That gifts of communication, choice and respect, have turned Chandima’s life around and he clearly recognizes what it can do for others trapped in the ‘silent abyss’. Without exception, the parents talk about children who were so hyperactive and disruptive that they required dedicated attention – one says her child would smash everything he could lay his hands on at home, another confesses that she tried to punish such behaviour out of her son but did not succeed.

Yet, as they have been shown new ideas to engage their minds and as they have found ways to make themselves heard on the simplest things, each child has changed their difficult behaviours without that ever having been directly addressed.

Like Chamira, 11-year-old Malitha Gunasinghe has mastered ‘yes’ and ‘no’ and seems to delight in simply communicating with his mother, Nirosha Gunasinghe. Today, he heads straight to his classroom and seems surprised that class doesn’t start right away. Before she met Chandima, Mrs. Gunasinghe says she was content to hope that her son would one day be able to take care of himself. Now, she has much greater ambitions for him. As if to indicate his agreement, Malitha laughs and vocalises from his perch on a chair nearby.

The two are among 16 families that regularly visit E.A.S.E. Three teachers: Achini Sooriyarachchi, Kanchanamala Seneviratne and S.M. Swarna Dayakanthi help Anoja and Chandima give each student individual attention. As they teach, they learn. Chandima is my boss, says Kanchanamala, smiling explaining that he gives them insight into their charges. Until we met him, we didn’t know that people like him could be competent or intelligent, says Swarna candidly, adding that it was from Chandima that they learnt that if people like him were different in some ways, they were the same in the ways that matter. In our society, if something is wrong with a person, we discard the whole person, she says explaining that now she knows differently.
Kanchanamala tells me that teachers here must master patience and Swarna adds that they must be strong, but Anoja also prizes other virtues—creativity and playfulness. When Nirmana Madiwela first came to the centre, he was just over three years old. His mother, Nirmala Jayaweera, couldn’t convince him to come in. He screamed for two hours she says, adding when she told Anoja that Nirmana loved water, they set up a small tub outside for him to play in. That’s where Nirmana stayed for his next three sessions until they found a way to entice him in.

Like the other children, he loves to play and may not always realise he’s being taught in the process. Several of the centre’s students are fans of Chandima’s iPad and love to play games on it. He’s more than willing to share with children like Dilan Sampath. Dilan is not autistic but may have Cerebral Palsy. He has learning problems, says his mother T.G. Selena but Dilan himself is unfazed – he wants to be a doctor someday. (Anoja is encouraging his family to put him in a regular school where she feels he belongs – E.A.S.E is meant only to support parents and children with a session or two every week.)

Anoja and Chandima believe that their protégés will learn best if, like Dilan, they choose to engage with their teachers. “When they play alongside us, imitate us and join us they have taken a step into our world, of their own free will, they feel safe,” says Anoja, adding, “Play is how a child learns, and it is the most important thing a child can do.” And the adults are no exception. Romesh Wijeyesekera is 37 years old, (the same age as Chandima) and he’s one of the first in this group to use FC. Rocking back and