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## FRANKLY SPEAKING

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**Widespread speech and swallowing disorders often go unrecognised, leaving those affected isolated and misunderstood, but innovative new programmes are finally breaking the silence**

By **Joanna Mayhew** Photography by **Anna Spelman**

Thirteen-year-old Ouk Lin is a walking, talking miracle. Living with cerebral palsy, until the age of seven he could not move or eat independently. When he attempted to speak, his words were garbled and impossible to decipher. He was limited to communicating his needs and desires – banana, rice, toilet – via pointing. His parents had to constantly monitor him, and with each of the frequent hospital visits to seek answers about his disability, they grew poorer and more discouraged.



Aloud and proud: Ouk Lin reads with his mother, Chhan Lam, a practice encouraged by Cabdico staff. Photo: Anna Spelman

Six years later, Ouk is full of energy, movement and – more recently – words. On the dusty outskirts of Siem Reap town, with his limbs folded slightly inwards, he ambles to the far side of his family’s cement and wooden house to showcase his independence. He washes from a water pot and dresses for school. Well versed in his continued limitations, he asks for help with the buttons of his pressed white shirt.

Local NGO Cabdico, which focuses on early childhood development for children with disabilities, has worked with Ouk for years on physical development. But the organisation’s recent expansion into speech therapy has accelerated Ouk’s communication. Having gained these skills, his personality has exploded, as if making up for lost time. He laughs easily and says he has “too many” friends at school. And he adds, matter-of-factly, that they do not kick him.

That statement is indicative of Ouk’s journey to integrate with his peers. Lacking communication skills, he initially faced discrimination, violence and loneliness upon entering the education system. “It was difficult to speak and to listen,” Ouk says, holding his fingers as if to keep them under control. “I would ask someone to take the ball. I’d ask repeatedly. I was sad when they couldn’t understand me.”

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Bucket bath: before treatment, Ouk Lin’s family had to help him do everything, but now he is able to bathe himself. Photo: Anna Spelman

Scores of individuals across Cambodia face similar difficulties, with an estimated 536,000 people affected by communication and swallowing disorders. As the country is without a university speech therapy degree, there are currently no trained national speech therapists and only a handful of foreign therapists based in the capital. Considering those with cognitive impairments, epilepsy and learning difficulties, more than 600,000 people could benefit from speech therapy interventions, according to Cabdico.



Communication and swallowing disorders often go hand-in-hand because of their association with impairments of the brain, such as cerebral palsy and Down’s syndrome. Communication disorders are highly complex, as they can be both developmental and acquired. And their effect on a person’s hearing, language or speech can result in low self-esteem and limited social participation.






“It means you can’t interact on any level with society,” said Weh Yeoh, disability consultant for Cabdico. “Can you imagine not being able to go to school, go to work, interact with your community and neighbours? What’s the point of living, really, if you have to live like that?”

Though the need is great, a lack of understanding about these disorders and subsequent lack of recognition fuels the problem further, and children with communication problems can be dismissed as simply being badly behaved. “This means these children miss opportunities they should fundamentally be allowed to have,” says speech therapist Laurie Clarke, formerly with Phnom Penh-based Indigo Psychological Services. “It’s a human right to be able to communicate. Without that, they’re living a shadow of what they could potentially be doing.”

Swallowing disorders, though, are far more dangerous, resulting in malnutrition and the increased likelihood of aspiration pneumonia and choking. Those with untreated swallowing problems, known as dysphagia, are 13 times more likely to suffer premature death than those without the disorder,

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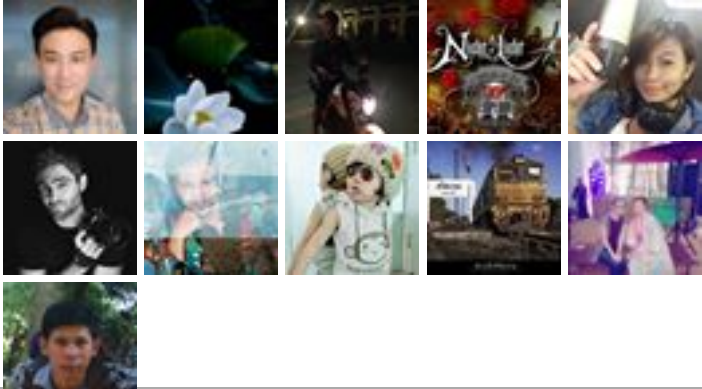
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according to Cabdico.

Three-year-old Lihour Srean is at risk each time he attempts to eat or drink. Lihour’s mother, Sophal Sok, spends her days watching over him in their simple thatch-roofed home. Lihour suffers from severe cerebral palsy, and Sophal worries about what it will mean when he is fully grown and not capable of caring for himself.



Phearom visits her regular patient, three-year-old Lihour Srean. Photo: Anna Spelman

Sporting camouflage shorts and a matching shirt, Lihour spasms when excited, revealing high dimples in his strained grin. Sophal sits with her left arm calmly and firmly linked around his head to reduce the erratic movements. Though she smiles politely, dark circles below her eyes reveal the toll of the disability. But interventions under Cabdico’s recent pilot project have already helped Sophal mitigate the swallowing complications. “I feel better than before with feeding him,” she says, adding that he can now retain more water and eat soft foods. Lihour has gained weight as a result. She squeezes the sides of his mouth and moves them up and down to demonstrate a technique she learned, laughing self-consciously but saying it works.

Cabdico’s pilot, launched after observing that 60-70% of their disability clients have these disorders, uses a basic curriculum that builds the skills of their community workers to improve communication and swallowing for affected children. Six months in, Cabdico has already recorded encouraging improvements; they hope the project provides evidence that speech therapy can work in a Cambodian context.

In a sparse wing of the Khmer-Soviet Friendship Hospital in Phnom Penh, the neurology department also tackles swallowing problems. The hospital’s Cambodian medical personnel were trained by NGO Speech Therapy Cambodia – an organisation that, unlike most in the country, focuses on adults and partners with the public hospital to target poor patients. Communication and swallowing disorders in adults usually occur as a result of accidents, strokes or degenerative neurological diseases, according to the organisation’s director, Elizabeth Chafcouloff. Of the patients, most of them males aged 35-60, filling the department’s 24 beds, approximately 30% have swallowing problems, says Chafcouloff. Doctors and physical therapists are trained in positioning, mouth hygiene and choking. “Before, we didn’t know how to treat swallowing,” says Dr Chhour Channara. “We knew they had a swallowing problem, but why and how? Now we know how to evaluate, how to treat. And it works.”

The doctors also pass this knowledge on to patients’ families, who typically provide food and care. With only brief stays possible at the hospital and without specialists to provide follow-up care, “families become the therapist”, says Chafcouloff.





On paper: at a Cabdico training session, child rehabilitation officers and teachers brainstorm about the consequences of disabilities and how they can help their clients and students. Photo: Anna Spelman

Much of this education involves dispelling the notion that treatment must mean medication. “Everyone wants medication,” says speech therapist Alice Smith, who has developed local materials for parents to practice speech with their children. “I can give a whole rundown of how you practice sounds and, invariably, somebody sticks their hand up and says: ‘Can’t you just give them medicine?’”

Changing this mindset is just one of many challenges in addressing the disorders. Coordination between intervening groups has previously been lacking, with international players often contributing short-term but unsustainable efforts. Human resources will also remain a major obstacle until Cambodia can launch a speech therapy degree. Discussions have been held with the University of Health Sciences, according to Cabdico, but the timeline and resources for this remain unclear.

The government has recently shown support for addressing the disorders by setting speech therapy as a priority area in its 2014-2018 National Disability Strategic Plan, according to a Disability Action Committee Secretariat General spokesperson. Among other plans, the government intends to establish a working group to develop a study of the disorders and integrate it into paramedical and medical schools, says deputy secretary general Neth Un.

In the meantime, stopgap efforts to increase understanding and provide treatment remain crucial. And though interventions have been piecemeal, they represent an important start. “I had a professor who used to say that when you do therapy with somebody who stutters, they stutter all over the place. But if you can teach them to be fluent – people who stutter are often fluent when they sing or pace themselves – you create these islands of ability. I think that’s what we’re doing here,” Smith says.



Ouk Lin plays and laughs with his neighbours. Photo: Anna Spelman

For Ouk at least, the effort is paying off. He continues to practice three words per day, as well as his reading and writing, which still need improvement. He hopes to become an architect, and to marry rich, he says. He flaunts his abilities once more by singing a traditional Khmer song, his voice shaky and sweet, before announcing he is bored. He teeters away to join a nearby game of tug-of-war with a



group of friends, who automatically and wordlessly shift to make room for him.

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