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# Trapped by distance

It's heartbreaking when a child's entire future is blighted because of a lack of basic healthcare. In Sarawak, many remote villages are home to such sad cases. >2

ART CHEN/The Star

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## Body, Mind & Soul Indulge

Living in today's fast-paced world is tiring and saps you of energy and zest. To recover from the stresses and tensions of a hectic workweek, many look for ways of relaxation to restore balance to the body, mind and spirit.

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**StarSpecial**



Catherine Laleng and her husband still grieve for the lost future of their son Clarence.

# Out of sight,

When a river and a boat are your only practical means of transportation, getting basic medical care can be a challenge.

By CHIN MUI YOON  
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CATHERINE Laleng kept wetting down her six-month-old baby's feverish body with towels. But nothing she did could lower Clarence's temperature. She was living every new parent's nightmare: watching helplessly as her child suffered.

At the time, Laleng was living in Long Tungan in Ulu Baram, one of the most remote areas of Sarawak's interior. The nearest health clinic was in Lio Matoh, which was accessible by river.

A villager had a boat ready to take the distraught mother and her child to the clinic but the water was too shallow due to a dry spell. It was two days later before they could make the journey.

By then it was too late.

"The medical assistant on duty scolded me for not bringing my baby in immediately; I didn't know how to make him understand that there was no way I could come earlier," recalls Laleng, 40, in her current longhouse in

Sungai Dua in Baram.

"Clarence still couldn't stand when he was two. I knew something was terribly wrong with him then. His body was limp and feeble. He didn't crawl around like other children and would just lie still on the floor all the time.

"The Marudi hospital referred us to paediatricians in Miri who told us that Clarence was going to be that way all his life. He would always be a 'slow learner' because the fever had damaged his brain."

That was 18 years ago. Today, Clarence is a young man with bright eyes that stare at strangers curiously but without comprehension. His left side is paralysed and his mother cares for all his needs, including bathing him and attending to toilet calls.

"He is a good son and helps me whenever he can with things like throwing out the garbage. He is always in good spirits and seems to understand me. The schools refuse to accept him. And I can't read or write, so I don't know how to teach him at home.

"It breaks my heart to think of the life he could have had if he hadn't been sick, or if I could have got him medical care earlier. There is not a day that goes by that I do not feel grief and regret," says Laleng.

People in cities and towns – and even in small villages in the peninsula – take for granted basic healthcare that is still desperately lacking among remote riverine communities in Sarawak's interior where travel is mainly by boat along Sungai Baram and its tributaries, and that means journeys depend on prevailing weather conditions.

Sometimes the only way to get to a waiting boat is using notched tree trunks. How are the infirm to manage?



**No mobility:** Sim Sun Hong has spent her whole life confined to a wheelchair in her little home in Long Lama, Sarawak. Her father has passed away and her mother Tiong Sai Yuk, 70, is trying to apply for welfare aid for Sim. – Photos by ART CHEN/The Star



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## Deadly work

We're a little shaken here at Features Central. We'd just featured the winning World Press Photo 2012 images in our pages (Picture power, Feb 20) when we heard that one of the awarded photojournalists, Remi Ochlik, had been killed while covering the Syrian conflict. It was a stark reminder of the peril so many journalists face around the world every day. As a tribute, we're sharing Remi's first prize-winning photo essay on page 12.



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# out of reach

At Long Lamai, the most remote Penan village in Ulu (or Upper) Baram, the 500-odd villagers rely on rickety boats powered by diesel engines to get them to the nearest clinic in Long Banga, which is serviced by twice-weekly flights to Miri.

The boat trip takes nearly two hours across rapids and even whirlpools during the wet season. Along some stretches, passengers must disembark and walk along the riverbank while the boats manoeuvre between large boulders in the water. And if there are no flights at Long Banga, access to Miri requires strenuous eight-hour journeys on bumpy logging roads.

## So close, yet so far

Little red dots on a map provided by the Health Ministry indicate the availability of health clinics scattered around the Marudi district in which Baram is located (see page 5). They appear sufficient, with 30 government clinics serving a population of 60,000. Yet villagers still struggle to gain access, especially when they are ill.

Mud-splattered trucks and 4WD vehicles constantly pull in for a break at Lapuk, a dusty town between Miri and Long Laput that serves primarily workers from the logging camps or massive palm oil plantations in the area. Only these vehicles can survive the punishing terrain.

The seriously ill, or pregnant women in their first trimester, cannot make the four-hour journey to Miri even in these sturdy vehicles because the unlighted, untarred trunk roads are among Malaysia's worst, providing a bone-rattling ride that jolts passengers against the vehicle's doors and even roof. When it rains, the roads become a dangerous quagmire of slippery mud.

While the old, the ill and the infirm find accessibility a challenge even in major cities, it is far worse for riverine folk living in such remote areas. Few villages have proper jetties; notched tree trunks are the only way down slippery, muddy banks to boats in the water.

In the Kayan village of Long Laput, Ajang Wan awaits death on a mattress in the corner of a room in his longhouse. At 98, he is the oldest resident in the village, which is surrounded by hectares of palm oil plantations.

His daughter, Lahong Ajang, 60, explains that he has been ill and paralysed for months and is now blinded by glaucoma.

"He can't sit up on his own any more. I hope there are no more complications because I don't know how we can get him down to the boat to take him to the nearest clinic in Long Lama," she says.

It takes about 20 minutes to get from Long Laput to Long Lama by boat but nearly two hours by road.

Her husband, Fletcher Siner, 67, a medical assistant in Long Laput in Middle Baram

in the 1970s, explains that the clinic in Long Lama serves a few villages but is inadequately equipped and manned only by medical assistants who cannot do much beyond providing first aid or treatment for cuts, wounds, sore eyes, and diarrhoea or vomiting.

A new hospital will be built nearby (near Long Laput) to serve the Baram district, which sounds like a solution – until Sungai Dua headman Jacob Lawai explains that this location is also difficult to access.

"I don't understand how the new facility was planned. These are riverine villages and our primary transportation is by boat. But the new facility has been shifted to the opposite riverbank so it is even more difficult to access.

"What we desperately need is a doctor stationed here (centrally located in Middle Baram). There have been cases where people died due to delayed medical assistance. Many people suffer from prolonged gastric problems and fever but these are deemed not serious enough to make that difficult trip to Miri so they just live with it.

"The authorities need to discuss their plans with the many kampungs so they are in line with our needs, not just cut ribbons and launch grand schemes, but seriously tackle issues on the ground. Ministers come here by helicopter. They don't understand how difficult it is to get around on the ground."

While Telang Usan assemblyman Dennis Ngau Jok says he does wish there were more clinics to serve the people, he points out that it is challenging to meet their needs due to the distance between each village.

"But there has been progress," he says. "We have mobile health teams that make scheduled visits to villages now. Additionally, the new hospital is strategically located so that residents do not have to make that long trip to Marudi or Miri."

## Lost possibilities

Every morning at the Pusat Pemulihan Komuniti (community rehabilitation centre) in Long Laput, children learn to twist strips of newspapers into baskets.

The centre teaches people with disabilities, or *orang kurang upaya* (OKU), skills like basketry, beading and sewing. This is the first centre in Sarawak to be located outside a town or city and to cater to the surrounding villages.

However, without proper medical diagnoses – most are simply classified as "slow learners" – or comprehensive, long-term developmental programmes, many of the OKU are deprived of any real chance for a better life.

Take Dominic Jok. He is 38, certainly no child, but he cannot live on his own. His mother, Puyang Urang, 80, is worried, as her health



At the Long Laput Community Rehabilitation Centre, 'slow learners' are taught skills such as weaving baskets from strips of old newspaper.



As she grows older and more infirm, Puyang Urang worries about the future of her son, Dominic Jok, 38, who is developmentally challenged.



Natalia (playing with her mum and dad) seems bright and expressive despite having been diagnosed as a 'slow learner' when she was younger.

is declining. "My son is completely dependent on me. My husband has died and I am ageing, who will look after Dominic when I am gone?"

Another child, Natalia, 12, never received a conclusive diagnosis of her condition beyond being classified as a "slow learner" – although she is bright and expressive now.

Her mother, Helen Laing, 35, who volun-

teers at the Long Laput rehabilitation centre, recalls that she'd first noticed her daughter's odd behaviour when Natalia was three months old. Doctors in Miri said Natalia's brain did not seem to have developed consistently with her age. Congenital rubella and delayed development were recorded in



Lahong Ajang, 60, caring for her father Ajang Wan, 98, in their longhouse aided by her husband Fletcher Siner, 67.



**What about me?** What's in her future? This little Long Lamai village girl lives in a typical longhouse community comprising several families.

# Dying villages

> FROM PAGE 3

Natalia's file, along with the note "requires further tests".

Given no explanation beyond that, "I kept feeling it was my fault somehow," says Laing.

"I felt so sad that Natalia's future would be so limited, especially as life is already tough," Laing adds, explaining that her husband is frequently away, working on offshore oil rigs.

"Raising Natalia has been challenging. No medication has helped. She needs constant care and attention, so much so that I have often been forced to neglect my three other children. We have no money to send her for special education all the way in the city."

As for little Albee Boon Chai, three, who was born with a hole in her heart, doctors have identified her as "an extremely bright child", and have recommended special education to give her the best chance to take advantage of her natural intelligence.

"But both her parents are struggling to make ends meet in Miri. They can't afford the luxury of putting her in special schools or hiring someone to look after her while they work," says her grandmother, Tracy Anyi, who is in her 40s.

These limited options for the young among the longhouse communities frustrate Lawai, who says that the communities are seeing an exodus to towns and cities, leaving some villages "dying" - over half of Sungai Dua's estimated 1,000 residents are above 55.

"It has been so many years and we have voiced our needs to the authorities countless times," says Lawai. "We are still getting untreated rainwater. Why can't the electricity lines be extended to our communities? Each home has to pay RM10 for a gallon of fuel to run generators each night if we want electricity.

"There is absolutely no access to the Internet. We need to draw the young and educated back to help develop our communities. But what is there for them back here? They have no future. How does anyone earn a living to survive?"

Another villager from Long Laput, Philip Jau, adds: "Our schools are rundown and not conducive for learning. We are lucky if we finish Year Six or Form Three. Many promises were made during elections before, such as funds to build roads and upgrade basic facilities, but we haven't received a sen despite enquiring many times."

Various government efforts to provide financial assistance, such as the BR1M scheme (Bantuan Rakyat 1Malaysia, which entitles those with monthly incomes below RM3,000 to receive a one-off RM500 payment) or the e-Kasih programme (rural households that earn less than RM1,000 per month are eligible to apply for financial aid) are also not reaching the people who need it most.

**What is there for them back here? They have no future. How does anyone earn a living to survive?**

-SUNGAI DUA HEADMAN, JACOB LAWAI



Jacob Lawai says authorities should consult users of healthcare facilities before planning where to site them.

"How do you classify an OKU to apply for monthly allowances? Are the bedridden, the widowed or the elderly entitled?" asks Lawai.

"I have submitted various forms appealing for assistance; nobody seems to know what happened to them. I've even travelled all the way to Marudi. Many villagers have gone to the Long Lama sub-district office to submit forms and waited all day long - and without eating even, because they have no money."

Telang Usan assemblyman Dennis Ngau Jok explains that miscommunication can happen; however, teams from the rehabilitation centre have frequently visited each village to explain about, and encourage, registration for social welfare schemes.

"It is nonsensical for anyone to claim they are unaware of the availability of such assistance," he says.

But who exactly is eligible for the schemes remains a grey area and hopes of a better future remain elusive, especially for those who are as marginalised as Sim Sun Hong.

Malaysia is entering its 55th year of independence but it makes no difference to 53-year-old Sim, who has spent her entire life confined to a wheelchair inside her wood and attap house in Long Lama; she left it only once to visit the Miri Hospital.

Sim was a premature baby vaguely diagnosed as having some sort of a "neurological disorder" at birth, according to her records. The disorder remains unidentified: though further tests had been recommended, her mother, Tiong Sai Yuk, now 70, says it had been such a harrowing trip to Miri that she could not take her daughter back to the hospital again.

Only neighbours close by have seen Sim over the past 53 years. To the rest of the world, it's as if she never existed.

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