Stigma holds back the disabled in Haiti

Orla Ryan in Jacmel DECEMBER 28, 2012

Jesusla, 22, spends most days alone with her mother, Marie Bonel Mericia, in their simple tin-roofed house shaded by coconut and palm trees in Jacmel, a town on the coast of the Caribbean country of Haiti.

But once a week Jesusla, who has cerebral palsy and epilepsy, receives a visit from Mona Charles, a teacher who works for Pazapa, which provides healthcare and education to disabled children and is backed by the Global Fund for Children, the Financial Times’ partner in this year’s Seasonal Appeal.

Over the past 14 years Ms Charles and her colleagues have played and sung with Jesusla, taught her how to solve jigsaw puzzles and how to dress and feed herself. She is one of 13 people around Jacmel to receive weekly home visits from Pazapa. More than 100 others benefit from its outreach clinic in remote areas and another 160 attend its school.

Without help from Pazapa, Ms Mericia says, she does not know what she would do, not least because disability remains deeply stigmatised in this corner of the Caribbean.

At times, she has to chase off children who shout abuse at Jesusla, pleading with them to understand that it is not her daughter’s fault; she was simply born that way.

Superstition and blame greet the birth of disabled children, says Marika MacRae, a Canadian woman raised in Haiti who runs Pazapa, which means step-by-step in Haitian creole. “We have parents who want to hand in the child and leave,” she says. “How do you live with giving a child a disability?”

Shocked by the lack of facilities for disabled children, a group of US volunteers set up Pazapa in the early 1980s. At first, they went door to door to search of children with disabilities. Sometimes they were told how many children a family had, only to later spy another, uncounted because of their disability.

Ms MacRae’s mother Jane took over the project in 1987 and, on her death in 2008, her daughter took her place. Nearly 25 years since her mother began, progress has been made. “We are not looking for them any more,” said Ms MacRae. “They are coming to us.”

Her task was made difficult by the January 2010 earthquake, which killed more than 300,000 people across the island and devastated the school. Two years later, after Pazapa had re-established
itself in tents and makeshift buildings on a field on the outskirts of Jacmel, Hurricane Isaac blew up the coast in 2012 and shattered the roof. The GFC stepped in with an emergency grant of $1,500, part of the $67,000 in total it has given Pazapa since 2007.

In this corner of the Caribbean, you are vulnerable says Ms MacRae: “When the forces of nature start to show their strength, there is nothing you can do.”

In December, work starts on a $1.2m school but Pazapa still needs $270,000 if it is to complete it. “Our main challenge is to rebuild. We can’t continue the way we are,” she says.

For now, 133 special needs children and 30 deaf children attend school at Pazapa every day. Few Haitian schools accept disabled children and, without education, they struggle to earn money to support their family or themselves. “They need to be better integrated into society,” Ms MacRae says.” We want children to provide for family if they can.”

There are many for whom education or employment is a distant dream. For some parents, helped by small loans from Pazapa, their children are so severely disabled that “they are slaves to that child as long as they live”, says Ms MacRae.

Once Jesusla’s mother sold goods in the market but now Marie, who is married and has four sons, spends her days caring for her daughter. “I am not the only mother to have a disabled child,” she says. “But life is hard.” Jesusla’s seizures worsen at the time of the full moon, she says. and her mother has to throw water in her face to calm her down.

But progress, though slow, is visible, says her mother. When Jesusla was eight, she could sit up straight, Marie recalls. When she was nine, she could walk. Now Jesusla brings out chairs when guests arrive and when she cleans the yard the job is better than when her mother does it, Marie boasts.

Ms Charles and Jesusla joke on wooden benches outside her home, shaded by the trees above. In the coming weeks and months, Ms Charles will teach her how to wash herself. Looking after Jesusla is not easy, her mother says, but she says her daughter is improving all the time.