

Cerebral Palsy in Rural Haiti:

The Story of Daphline Jean



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****Team Canada: Please see note on p. 7***

This past April, I had the privilege of going to Haiti as a member of Team Canada Healing Hands. Team Canada is an organization that sends rehabilitation teams to Haiti to provide care for patients and training for Haitian rehabilitation practitioners, most of whom are hired as therapists but lack formal training. I was able to accompany a team of 18 medical professionals and support staff from across Canada as the team translator. My primary assignment was to translate for an occupational therapist named Nancy. We were assigned to work in the coastal town of Jacmel, located on Haiti's Southern Peninsula. Nancy and I spent most of our time training teacher/therapists and treating children at Pazapa, a center for handicapped children, located on the main street of Jacmel's town center.

Pazapa was founded in 1987 by a group of American volunteers as part of the Siloé project. Since then, Jane MacRae, a Canadian woman has been working as its director. Its programs are sponsored by numerous individual donors and foundations. Because of its location, the community is well aware of Pazapa and one of its mandates is to "integrate handicapped children into the community at large." ¹ The school is in session Tuesday, Wednesday and Friday; on Thursdays the teachers each visit the homes of a few children who have not attended the center for some time. Nancy and I accompanied a teacher, who will be referred to as Marie, on two such visits. It is the second of these two outpatient visits that is described here below.

The 11 year old girl whom we visited will here be called Daphline Jean. From her chart we read that she was brought to the center many months previous and had been diagnosed with Cerebral Palsy - right sided hemiplegia. She had not returned to the clinic since. Daphline lives with her extended family in a small home in St. Cyr, a rural village outside of Jacmel. To arrive at the Jean home, Nancy, Marie and I took taxis – this was not a conventional taxi ride, but a ride on small motorcycles (Marie and I shared one, with its driver of course). It took close to half an hour to drive through the (few) paved city streets followed by the wide, unpaved rural thoroughfare and up the small, dusty mountain path. Upon arrival we saw the relatively large stone hut, painted bright green with a tin roof. On one side of the porch there was a small girl

sitting by herself, playing with her saliva in the dirt. Adjacent to her, at the other end of the porch there was a group of three women and several children.

As we approached from the street, Marie greeted the women and said that we were here from Pazapa to see Daphline. As they vacated a couple of chairs for Nancy and me, I heard one of the women mutter under her breath *“I don’t know why you waste your time coming here.”* None of the women clearly distinguished herself as Daphline’s mother, though one of the women walked over and picked up Daphline and set her down on the ground in front of us. She said *“Here she is”* and returned to her conversation with the other women.

Daphline was without question the smallest 11 year old I’d ever seen in my life. I was in absolute shock at how underdeveloped she was; she stood about 3’ tall and weighed no more than 50 lbs. She was also very distracted; you could not catch her attention, not to mention keep it to have her perform a task. To confirm the information in the chart, I asked the group of women how old she was. The group turned to look at one woman, who responded that she was *“10 or 11, even though she looks 5 years old”* I then asked this woman if she was Daphline’s mother, with reservation, Mme Jean responded in the affirmative.

Before we began any treatment Nancy wanted to get a better feel for the situation, so Nancy asked the mother if Daphline was completely non-verbal, which she confirmed, so we proceeded to interview Mme. Jean. From our findings we learned the following: Daphline’s father is often away and when present he goes out of his way to avoid Daphline. Mme Jean needs to provide for her other children and does so by going into town to buy and sell goods many times per week. She goes during the day with other women who bring their children who are too young to leave at home alone. However, Mme Jean does not bring Daphline. When asked why not she responded: *“Because Daphline’s 11 and she’s like that- She’d just make a big mess.”* We found out that not only is Daphline left at home alone all day, but they lock her in the dark house in a baby’s crib. The mother stated that if they don’t lock her up then she will ruin the whole house by pulling everything off of tables and counters. *“She doesn’t know how to sit still; she’s*

always crawling around and going everywhere.” She claimed that when they leave Daphline unattended, she will crawl (as she is unable to walk) all the way down the street to see what everyone’s doing – *“She’s too nosy.”* Mme Jean feeds Daphline and doesn’t let her try to feed herself, as the teachers from Pazapa always tell her to, because it makes too much of a mess. Nancy tried to explain that it’s important that she practice developing motor skills and that she should try to assist Daphline in feeding herself. As Nancy was demonstrating techniques to provide feeding assistance, one of the women stood up, and as she brushed the dust off her dress she looked at us, scoffed and said: *“Daphline is kokobe [retarded]; she’ll never learn to do anything useful.”* This was the same woman who made the earlier disparaging remark; we later identified her as Mme. Jean’s sister. Shortly thereafter, a man came walking up to the house and seemed interested in what was going on. I asked if he were Daphline’s father. He was very quick and insistent on expressing that he was certainly not her father, but merely an uncle.

From our brief dialogue with Mme Jean and our encounters with two of Daphline’s relatives, one may suspect that there is somewhat of a stigma accompanying physical disability of this nature in this particular community. When we first arrived, it seemed as if she had hoped that we would come and go without singling her out as the mother of the child. She seemed to be ashamed to be seen outside of her community or in the market with her handicapped daughter. It appeared as though she was not even aware of Daphline’s true age. The stigma is suggested by her disdain for Daphline’s curiosity and unwillingness to help her feed herself. It is not only Mme Jean’s comportment that shows the social nature of Daphline’s condition; the aunt’s comments and the uncle’s prompt response further demonstrate the stigma associated with the child, not to mention the father’s trying to dissociate himself from the child. Erik Jacobson writes that when a man fathers a disabled child, he may try to impregnate another woman to prove that the child is not disabled as a result of his own wrong doing.²

We asked the mother how long it had been since Daphline had been to the center for treatment. She said it had been many months and they had not returned since the initial

diagnosis. However, the teachers from Pazapa make it to her house approximately every month. It turns out that Mme Jean had heard of Pazapa from someone in a neighboring community who had heard that there was a school in town for handicapped children where there was a visiting team of Canadian doctors treating and diagnosing children. She was likely anticipating an instantaneous cure from the highly respected foreign doctors, Jacobson states such a belief as being common among Haitians.³ When informed that there was no such instant cure and that the only way to help Daphline would be through repetitive stretching and strengthening, she likely decided that it was not worth her while to take Daphline all the way into town.

Haitian ethnomedical studies have well documented the stigma that surrounds physical and mental disability. A belief held by many is that the birth of a handicapped child is the result of a sinful act on the part of the parents. This view is held by adherents of both Vodun who believe that the loa (spirits) are angry, and Christianity who believe the parents have committed a grave sin.⁴ This may account for the behavior of Daphline's father, as well as that of her uncle when asked if he was the father, and that of Mme. Jean – her desire not to bring Daphline to the market or to the center for fear of being seen with a disabled child, knowing that such is believed to be the parent's fault. Many parents of disabled children who send their children into town for some reason do so with a sibling or cousin to avoid being seen as the parent of a disabled child.

Following our interview with Mme Jean, Nancy proceeded to demonstrate a stretching regimen for both Marie and Mme Jean. If repeated regularly, it would greatly relieve the pain caused by Daphline's contractures. Unsuccessfully, Nancy tried to impress upon Mme Jean the importance of doing these exercises. She was rather inattentive and it was apparent she had been shown similar exercises numerous times previously. It was also obvious that there was little compliance and that the routine was not being performed at home. This was obvious as Daphline was in such excruciating pain that at one point she attempted to bite Nancy, who was manipulating her contracted arm. It was evident that Mme Jean had very little hope of Daphline's condition improving, by Western medical practices at least; it seems that in her mind Western

medicine lost its legitimacy because of her experience of not having Daphline's condition immediately resolved by the Canadian practitioners at Pazapa, many months earlier.

Marie, on the other hand, was engaged with every instruction from Nancy. It is likely that just a few years ago Marie had held the same beliefs about disability as did Mme Jean. Since she has been working at Pazapa, she has had her eyes opened to many types of disability, and has been able to step away from the typical Haitian social construction of it. When we left, she too expressed her disapproval of the way in which Daphline was treated by society and her family.

Nancy and I were happy for the experience gained from making a home visit. However, we were also saddened because of the state of this child's life. Daphline's social behavior and unwillingness to make eye contact caused Nancy to suspect autism spectrum disorder and behavioral problems as a result of decreased family involvement, and a lack of cognitive, emotional and physical stimulation. Nancy was concerned that when compared with the picture in her file, Daphline had declined physically because of malnutrition and because she was not attempting to ambulate. Daphline's state was so sad that it caused Nancy and I to ponder whether her life may even be improved by living in an orphanage, which may be seen as a drastic statement when one sees the sad state of many Haitian orphanages.

The unfortunate part of rehabilitation medicine is that improvement requires continued therapy, rather than the simple administration of a one-time treatment. Both Nancy and I agreed that we felt that little adjustment would be made following our visit. Despite our efforts to educate Mme Jean, it is unlikely that after years of neglect, she would begin to comply with the prescribed program for Daphline's rehab. Daphline's story illustrates how illness is very much a construct of social and cultural beliefs. It also shows that Western Medical interventions will be much more successful when accompanied by an ethnospecific re-education of the community which builds on existing beliefs and encourages compliance in a manner which is meaningful at the local level. Presumably, following our visit from Canada, life in St. Cyr went on as usual for Daphline and the Jean family in their tin-roofed hut.

References

- 1 Pazapa Center for Handicapped Children web site, retrieved 25 June 2007, from,
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- 2 Jacobson, Erik. “An Introduction to Haitian Culture for Rehabilitation Service Providers.”
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- 3 Jacobson, Erik. “An Introduction to Haitian Culture for Rehabilitation Service Providers.”
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Members of Team Canada Healing Hands: Please note that my feelings stated in Daphline’s Story are not indicative of my feelings towards all of Team Canada’s initiatives. I believe that we accomplish a great deal of good in Haiti and in people’s lives. However, I do believe that in some cases—such as Daphline’s—little progress in educating parents and practitioners can be made without an understanding of local culture.

Note that although I state that I feel little would be changed in Daphline’s life as a result of our visit, I don’t believe that our visit was a waste of time or effort, as I believe it had a great impact on “Marie.”

I hope that this and other papers I have written and posted on the website can provide members of the team with a few insights into Haitian medical culture which will aid with our programs in Haiti.