

The Double Disability of Refugee Children

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“MAJI?” I CALLED, standing in the full waiting room as I prepared to see the next patient in the clinic. “Is Maji here?”

I glanced down at the chart in my hand to confirm the name and review the referral note. “Maji... Ten year old male. Afghani refugee. Will need interpreter. Please see for developmental assessment and services,” I read.

As I looked up from the chart, I saw a boy with a huge grin hopping toward me on his left foot, his right leg folded up into his lap. “Are you Maji?”

He responded with a big thumbs-up and a grin. The boy was followed by his mother, father, older brother, and interpreter.

“I’m Doctor Minhas. I’m one of the fellows in the developmental pediatrics clinic today.” I paused for the interpreter to catch up. “It’s good to meet you.”

We filed into the clinic room and discussed the purpose of this initial visit.

The story that unfolded over the next hour was unsettling. Maji had been 2 years old in Afghanistan when a doctor told his parents he had an infection that necessitated an antibiotic injection in his hip. In the days that followed, the injection site had grown swollen, red, and extremely painful. The medical opinion was that an abscess had accumulated, and that the site required urgent surgical drainage with general anesthesia. His family scraped together funds for the procedure, which irreversibly damaged his sciatic nerve. Two-year-old Maji was left with no control of his right leg and consequent contractures in the years that followed.

Over time, Maji’s developmental deficits appeared to be more than just motor in nature. He also exhibited significant difficulty in learning to communicate verbally, to care for himself, and to undertake new tasks. This required round-the-clock support from his mother for bathing, feeding, and toileting.

Despite their concerns with Maji’s lagging developmental trajectory—particularly in comparison to his siblings—his parents had been able to make only one

discouraging visit to a local village physician, who had told them there was nothing to be done about “children like him.”

As a result of the dangerous living conditions and civil strife, aid agencies moved Maji’s family out of Afghanistan to multiple transitional homes in Southeast Asia and the Middle East. Unfortunately, these places were rarely safer than home had been, as the family was usually housed in low-income, high-crime neighborhoods.

Concerned about his safety and fearing social exclusion, Maji’s parents decided to keep him at home while his siblings attended school. Already in a country not their own, where they were clearly seen as different, his parents did not want Maji to have a double disability—one physical and one social. It was dismaying to consider that this 10-year-old boy had never set foot in a school.

His parents explained that their family had stuck out ethnically like a sore thumb, and they constantly felt ostracized and endangered in their host communities. Over the years, their home had been robbed multiple times of the meager belongings they had accumulated, and Maji’s siblings were often teased at school for their appearance, language, or attire.

“It was very bad for the rest of our family being in a foreign place and being targeted as being different... we did not want Maji to be targeted too. We wanted to protect him,” the interpreter said, translating Maji’s father’s words. The challenges of their experiences were evident in his tired eyes. “It was the right thing to do for him.”

So Maji had stayed home. No school. No social interactions. No opportunities to explore his environment beyond the walls of his home.

If he could have gone to a school... seen a doctor, had therapy, or orthotics, I thought, his functioning would not have been so devastated.

I had read about the concept of double disability before, but actually hearing about Maji’s story and his family’s difficult choices was painful. I tried to grapple with the injustice he faced. Learning to cope with his physical and developmental disabilities seemed tragic enough, but he had become further disadvantaged because of his ethnicity, socioeconomic status, and immigration status.

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“I’m sorry, Doctor, but I have another appointment I must get to,” said the interpreter, a finger on his watch.

I had lost track of time. I made arrangements for a follow-up appointment to complete the assessment, and the smiling boy gave me one last thumbs-up before making his way out of the clinic.

I quickly completed some initial referrals: occupational therapy to help with his self-care, physical therapy to assess his contracted leg, psychology, speech and language therapy, dentistry, and social work.

In my training as a developmental pediatrician, I had learned about children’s development and about disabilities, and how to rehabilitate minds and bodies and maximize potential. As I watched Maji and his family leave, however, I wondered what I could offer them to address the second half of this double disability. I knew that despite having access to educational and health care–related benefits, having refugee status in Canada also meant challenges in gaining funding for many of the referrals I had ordered; even transportation to the clinic could be challenging, in addition to all the cultural and language barriers Maji’s family faced.

We were able to advocate for funding support for Maji’s care with some success. In follow-up visits, Maji started therapy sessions to improve his functioning and communication and was waiting to be fitted for a wheelchair. Maji was also formally assessed by the district school board and offered a position in a classroom for children with special needs. After a visit to the classroom, however, his family declined the position; they thought Maji’s level of functioning was much higher than the students they met.

This was frustrating to hear after the long waits and advocating for placement. We wanted to get him into the right classroom as soon as possible. After further discussion around the results of his psychoeducational tests and his suitability for the curriculum, the family agreed to try the recommended classroom.

In the news, we often hear of the plight of refugees and displaced persons, and their struggles to survive. Accordingly, before arriving in Canada, fears of persecution had paralyzed Maji’s parents in seeking the best educational opportunities for their son. For me, Maji’s family emphasized the importance of starting to look past survival alone. Now that they were in a stable, safe home, they were able to focus on providing social and educational enrichment to Maji. Although they may have misunderstood the fit of the initial classroom placement, they fully understood that now he needed the right balance of academic supports and challenges, and they were ready to make it happen for their son. Such resilience is what initially motivated me to work with families as a pediatrician. However, it was not until I met Maji’s family that I realized how enduring this resilience truly could be. After everything they had been through, Maji’s family was not content with just any school. They fought for him to go to a school that would help him develop to his fullest potential.

I appreciate the choices that Maji’s family had to make. Now when I meet families and wonder why they did what they did for their child, I try to approach them with an open mind. With the challenges many of our patients and families face, I try harder not to judge their decisions but instead to understand their journeys.