

Life is never easy, but I'll never stop trying.

An inspirational message delivered by “Samira,” a 19-year-old young lady who struggles to be included in a community that still attaches stigma to persons with disabilities.

Samira and her brother, “Atta,” who is 25-years-old, were both born with a physical disability that requires the use of a wheelchair for mobility. This is a reality that their father found hard to accept, and ultimately led to his abandonment of Samira, Atta, and the rest of their family of six in the pursuit of forming a new family.

Samira came from Dara’a, Syria, with her mother, two sisters, and two brothers 10 years ago, when Samira was just nine. The family currently lives in Irbid. Samira’s family was forced to leave Syria when their home was destroyed after a bomb exploded. Thankfully, no one was injured, but Samira’s sister said, "That was the breaking point in which we decided to relocate to Jordan." They made their way first to Za’atari camp, in the north of Jordan, but lasted only a couple of weeks before relocating to Irbid. Samira’s mother lamented about how difficult it was to survive in Za’atari with two children having such severe physical disabilities, and where accessibility for persons with disabilities was limited.

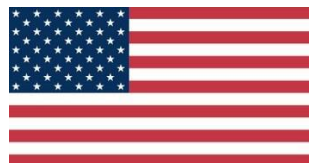
Upon their arrival to Irbid City, people started helping Samira’s family to settle down and provided them with some basic needs. The family lived on the third floor, but soon they had to move to another building, as there were no elevators for Samira and her brother’s wheelchairs, and it was challenging to carry both of them up the stairs.



When Samira was five years old, she was diagnosed with muscular dystrophy, a rare genetic disorder that causes progressive weakness and breakdown of skeletal muscles over time. Her brother was diagnosed with the same when he was the same age. Samira’s mother stated that they visited many physicians, both in Syria and again when they arrived in Jordan, hoping to find a cure for her children’s disabilities. She discovered that rehabilitation sessions to maintain the muscles’ function was the only available treatment option, as there is currently no cure for the condition.

In 2019, Samira’s sister took her to a doctor in Irbid for rediagnosis. “Without any testing, the doctor looked at old test results and told me, in front of Samira, that there is nothing that can be done, and her physical state

Figure 1 Samira working with OT specialist at Irbid clinic.



will not get any better." This blunt assessment, coupled with the family trauma from her father's abandonment, caused Samira to enter a severe depression. "She stopped eating and communicating, and refused to go out of the house for a year," her sister said.

In January 2021, one of the Institute of Family Health's (IFH) community-based workers who is participating in PRM's project, in partnership with International Orthodox Christian Charities (IOCC), reached out to Samira's sister and explained the project's goals and services. Samira agreed to the assessment and was subsequently enrolled in the rehabilitation and psychosocial support (PSS) services. She is currently receiving occupational therapy (OT) and PSS sessions to improve her physical and psychological conditions and to increase her independence in daily activities. Specialists have indicated that most of Samira's struggles were caused by a lack of trust, motivation, and awareness of her own capabilities even with this disability.

Following therapy sessions, Samira started reinvesting more in life, communicating, reading poetry, propelling her wheelchair on her own, and taking overall better care of herself, as well as learning new things, such as playing mobile games. "I've never seen Samira so determined to improve her skills like this before," Samira's sister reported. And although, as Samira stated, life is never easy, it is this newfound willingness to try that will ensure Samira achieves a life full of possibilities.



Figure 2 Samira performing mobility exercises with the OT specialist at Irbid clinic.