Man Travels The World Seeking Help For His Sons
| CPD

Sue Reeves
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Osama Abu Al-Ghanam, a mosaic artist from Madaba

How far would you go to find help for your child?

For Osama Abu Al-Ghanam from Madaba, Jordan, the answer is “halfway around the world.”

Abu Al-Ghanam, a mosaic artist, recently visited Utah State University’s Center for Persons with Disabilities to learn more about autism, advocacy for people with disabilities, and assistive technology. He was in the United States as a guest of Chris and Bobbie Coray of Garden City, whom he met when the couple served an LDS mission in Jordan.

Abu Al-Ghanam’s two sons, Mohammed, 8, and Bashir, 6, have been diagnosed with the same rare combination of autism, cystic fibrosis and some other genetic condition, possibly a form of muscular dystrophy. Only one other person in the world, a child in Singapore, is known to have the same combination of conditions. Al-Ghanam has offered blood and tissue samples to researchers around the world in the hope that some answers—any answers—can be found.

Gifts from God

In a culture where people with disabilities are normally hidden from view and ignored, Abu Al-Ghanam and his wife, Huda, see their children as gifts from God.

“I’m happy. If you ask why, it’s because my God, He likes me. He gives me something special, something He doesn’t give to all people,” Abu Al-Ghanam said. “I’m happy because He knows me; He had a plan for me and my kids before we were born. He gives me a weight, knows I can carry it. At the hospital, when I was given kids, He knows I take care of them. For me and my wife, He gives kids to take care of.”

Doctors in Jordan did not expect Mohammed to live long, so his parents took him to the Great Ormond Street Hospital in London for treatment. Abu Al-Ghanam worked night shifts in the clinic and they struggled to pay the 1,200-pound weekly free. Doctors in London said that even if Mohammed lived, he would always need a caregiver. The couple decided to have another child, whom they named Bashir, which means “bringer of good news” in Arabic. Soon after birth, Bashir was also diagnosed with his brother’s rare combination of disorders. The family stayed in London for two more years, until doctors said there was no more to be done for the boys.

They returned home to Madaba, where Osama joined his brother Malik, also a mosaic artist, in business.
Abu Al-Ghanam works hard at the mosaic shops, he said, so he can pay for the things that can improve the quality of life for his children. They have iPads and laptop computers and have become accomplished in their use, although Bashir learns more quickly than his older brother.

Mohammed does not speak, Abu Al-Ghanam said, but Bashir is speaking in short sentences … in English. He credits the nurses at the hospital in London for spending so much time talking and interacting with Bashir.

In Jordan, he doesn’t trust the care of his children to anyone but Huda, he said. Schools for children with disabilities are rare, and children are parked in front of a television or given Legos to play with. There is no interaction or stimulation, he said, and teachers have no training in disabilities.

Huda cares for the boys all day, every day, without complaint, while he is working at the mosaic shops. She cleans and changes their feeding tubes, administers medications, plays with them, talks to them and teaches them.

“God has blessed me with a good wife, a smart wife,” Abu Al-Ghanam said.

**CPD research and information dissemination**

In the Autism Support Services: Education, Research and Training (ASSERT) classroom at the CPD, Abu Al-Ghanam witnessed first-hand the power of applied behavior analysis on young children who have been diagnosed with autism. ASSERT program coordinator Lyndsay Nix explained the basics of ABA—that the teachers reward desired behavior and ignore the problem behavior.

He watched as the preschool students worked with their teachers, communicated via iPad, had meltdowns and practiced social communication. It’s very different than in Jordan, he said.

In the Assistive Technology lab, coordinator Clay Christensen demonstrated several iPad apps and computer software programs that could aid the boys in communication including Dragon NaturallySpeaking, a voice recognition program, JAWS, a screen reader, and Sign 4 Me, an app that teaches American Sign Language.

**Future disability advocate?**

Abu Al-Ghanam’s interest in helping people with disabilities does not end with his children. Several years ago, he and his brother began to teach people with disabilities the time-consuming process of creating mosaic art. Then they opened PEACE Mosaic Workshop to organize the growing number of mosaic artists who had disabilities. They now employ about 65 people with disabilities as mosaic artisans.

But he wants to do even more. He wants to meet with parents of other children with disabilities to talk about social and educational opportunities, to share experiences. To make a difference in the lives of people with disabilities.