

Fear for the fearless

A MOTHER SPENDS YEARS FIGHTING FOR HER DISABLED SON, BUT WHEN SHE LOSES HER JOB, SHE MUST LET GO TO RELY ON HIM.

By Ella Roberts

Aura Marina can feel the turning heads and piercing glares of the other villagers as she makes her way along the streets on her way to work. She burrows her 7-year-old son's body against her breast, his weight dragging her down, closer to the cobblestones. Her eyelids hang and her feet drag behind the rest of her body, her torso angled forward. She doesn't know how much longer she can carry this weight, but she tries to remain strong. Marina fears the day she will have to let go, forcing her son to face discrimination as a disabled boy in the *pueblo* of San Juan del Obispo.

Twenty-three years later, Marina, now 52, is a single mother of three who sells flowers on the streets outside her home. Her husband left her. She lost her job as a waitress. She scrambled to pay hospital and physical therapy bills for her kids.

"I would walk on fire for them if I had to," she said.

On top of all that, her sister-in-law died during the pandemic, so she'd taken on the role of caretaker of three more children, and other nieces and nephews show up at her door, too, as the extended family works together to survive..

Despite her stress, she doesn't have to worry about that 7-year-old she used to carry everywhere, and he hopes to someday carry the family himself.

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Estuardo Jimenez, 30, Marina's youngest son, needed her the most when he was born. Jimenez grew up with spina bifida, a birth defect in which a developing baby's spinal



Estuardo Jimenez believes being positive is important because the obstacles he faces are more mental than physical. This is something that was instilled in him at a young age. "I get inspired by my family, because many of them had to start from scratch and I admire that," Jimenez said. | Photo by Savannah Heeren

Transiciones nonprofit

Donations create tangible results for the wheelchair-building nonprofit organization in Antigua.

\$450 provides a new wheelchair, in addition to individual client fitting, health education, a lifetime guarantee and follow-up care.

For **\$1,500 – \$3,000** you can provide a custom-made prosthetic with follow-up care and ongoing case management.

\$960 / year (or \$80 per month) provides a quality education to a Guatemalan child or young adult with special needs.

\$15/month funds special education field trips for children in Transitions' Special Education Program.

\$25/month provides anti-seizure medication for a child with epilepsy in Transitions' Special Education Program.

\$30/month builds an emergency medical fund for a Guatemalan with special needs.

\$45/month will help support vocational training in Transitions' Wheelchair Workshop and Print Shop.

cord fails to develop properly, and he had to learn to live with it, which meant living in a brace until age 16 and, when his condition worsened, moving to a wheelchair.

After a public school rejected her son because of his disability, Marina found a small school for Jimenez to attend.

"He wasn't accepted because they told me he needed a lot of help and that someone always had to take care of him, but in reality he was very independent. He was capable," Marina said.

One day, coming home after school at age 11, Jimenez told Marina he didn't want to study anymore because he was being bullied.

You don't belong here.

You shouldn't be here.

You're different from us.

"They see you as a phenomenon," he said.

Jimenez found himself never being chosen for the playground games in elementary school. He was constantly having to take another path literally and figuratively, feeling like a burden or less capable. And always on the margins.

"It was hard to have a life without being included," Jimenez said. "There are always going to be people who are going to make you feel bad about yourself, but those are the people you shouldn't pay attention to."

Before he received a wheelchair in high school, Jimenez hoped physical therapy could treat his condition. Spina bifida can happen anywhere along the spine where the tube of

bones that protects the spinal cord doesn't close all the way. Often, the spinal cord and nerves get damaged, which might cause mild or severe intellectual and physical disabilities.

Intellectually, his boss calls Jimenez a quick learner. No problems there.

Physically, he can't walk, but he can dominate his boss on the basketball court.

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In order to pay for her son's therapy, Marina had to put in extra hours waiting tables. On her way to work, she would drop Jimenez off and pay for a three-wheeled tuk tuk to return home. Sometimes, she would give the driver the money in advance to pick up her son, but he would sometimes take off with the quetzales without picking up Jimenez, who spent many days sitting alone on the bench outside school, waiting for someone to get him.

Eventually, he told Marina he didn't want to go to therapy anymore.

"I prefer to stay in a wheelchair," he told her at age 16.

However, Marina couldn't accept this fate for her son. Her anxiety never subsided when it came to her son's safety.

"He is a person with a lot of enthusiasm and optimism, because for him there is nothing impossible," she said. But for her, there are many impossible things. Paying bills, getting a car, parenting alone.

But still, Jimenez insisted.

"Don't worry about me. There is nothing that is impossible for me," he would tell her from the chair.

After graduating from high school, Jimenez started going everywhere in his wheelchair. He learned how to move around by himself. For six years, Jimenez traveled in his wheelchair 8.5 miles a day to work, round trip, from San Juan del Obispo to Antigua, taking him 45 minutes to arrive and an hour to go back. Without laws requiring for ramps on street corners, and with narrow sidewalks often obstructed by protruding window sills, Jimenez pushed himself up hills of cobblestone, dirt roads, flooded rivers and dangerous traffic.

He bulked up.

Sometimes, Jimenez says, people offered rides. He liked to hop in the back of a stranger's truck or hang on by the handlebar of a motorcycle. Sometimes, the driver accelerated too much and – upon hitting a bump in the road – he would let go, taking flight into the street.

He toughened up.

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Jimenez hopes to share his determination with disabled children through his work at Asociación Transiciones, a nonprofit organization started in 1996 that advocates for the rights and social inclusion of Guatemalans with disabilities by providing access to social development programs, mobility equipment and opportunities for independent living. The nonprofit's building houses a wheelchair factory of adaptive equipment because the employees work with disabilities of some kind, most of them working from their own wheelchairs.

They know what people want in functional wheelchairs.

At the start of his work day, Jimenez rolls his way to tables and power



Estuardo Jimenez works as a welder for Transiciones, where he uses modern TIG welding and other fabrication equipment and maintains computerized records on each client so he can respond quickly to needed changes or repairs. Transiciones modified many of their work spaces to the appropriate height for their employees in wheelchairs, so that everything is accessible to them. "He is very delicate and precise," Alex Gálvez, Jimenez's boss, said. | Photo by Savannah Heeren

Changing people's perspectives of people with disabilities is very important for our country.

Alex Gálvez,
Executive Director



Aura Marina beams with pride when she talks about her son, Estuardo Jimenez. After struggling for years to find him the necessary care and facing discrimination, Marina is proud of the man Jimenez has become. “We would’ve never imagined him to be this successful. He was able to pursue something bigger than they expected,” Marina said. | Photo by Savannah Heeren

equipment that have been adapted to wheelchair height and straps on his toolbelt to bend aluminum, weld parts together and shape a high-end wheelchair, all from the seat of his own wheelchair.

He reaches for six meters of aluminum tubing off shelves and runs it through stations of loud power tools that spray sparks and drown coworkers’ jokes. He takes his wheelchair frames up the five ramps to the factory’s second floor to be fit with handmade fabric seats and professional-grade wheels.

Nobody helps him up the ramps. They can’t. He chooses not to have handles on the back of his wheelchair.

Jimenez started as a client of Transiciones when he was 7 after

running into one of the founders on the street. At the time, he needed crutches and braces. The bosses also provided him a scholarship in order for him to continue going to school. Years later, he started a fellowship and the manager felt that Jimenez could be a future leader. Jimenez first started working in the company print shop when he was 19. Executive Director Alex Gálvez says Jimenez was not always easy to work with, but during the last four to five years he has matured and is now a manager on the welding team.

Transiciones has trained 30 employees, roughly 75% of them disabled, who all started as clients in Transiciones programs. Funding for much of their equipment, tools and materials has come from a Rotary International Foundation Grant, coordinated by the Portland Rotary Club, and from other donors. Donations received go toward better machines which allow for more precision and less waste of materials.

In 2008, the workshop provided more than 100 new and refurbished wheelchairs. The shop makes six different types of wheelchairs, taking two days’ of work to produce. Wheelchairs made with metal are donated to those in need and those made with aluminum or iron can cost up to \$1,300. What starts as six meters of scrap material paired with a mold and 48 hours’ worth of work turns into a wheelchair well-suited for the rough terrain of Guatemala.

This, Jimenez says, is what makes the company he works for so special. They are able to customize wheelchairs specifically for a region that would not be able to function properly in the ordinary wheelchair. Details down to the angles, precision and heart are what provide the most practical wheelchairs for kids with disabilities – for example, a child with paralysis, a current client that Jimenez is building for. Jimenez explains that when a client comes to the shop, they encourage them to be more independent because “people are not going to be there the whole time” to take care of them.

According to Jimenez and Gálvez, the number of people with disabilities in Guatemala is increasing and yet the government doesn’t pay attention.

“It’s a problem that should be seen,” Jimenez said.

Transiciones’ mission during the last 30 years has been to draw awareness to the “corruption” within the government in terms of people with disabilities. To the workers, it’s not about the money, but about using the tools they are given to help anyone they can. Gálvez stresses to his employees that in order for them to have the best chance to help others, they must learn to approach the job from the client’s perspective.

“Sometimes they take it for granted because they’ve been here for so

many years. People like what we do and we should keep doing it for people that don’t have the same opportunities, right?” Gálvez said.

It’s one thing to also have a disability, he says, but what about those who live in rural areas, or among the volcanoes?

The employees of Transiciones have specialized chairs they created for competitive wheelchair basketball. The players have traveled to El Salvador, Nicaragua, Costa Rica and Mexico to compete.

“Changing people’s perspectives of people with disabilities is very important for our country,” Gálvez said. “It’s a great channel to be independent in our country. This is a program that helps to break boundaries in our community.”

After spending their week among the loud noises and sparks of wheelchair construction, Jimenez and his coworkers visit a nearby basketball court on Fridays, but only if their work is done.

Often, someone gets plowed over and tossed out of their chairs after pushing and shoving one another.

Jimenez works out every morning, lifting weights, doing uphill chair sprints and shooting hoops. He plays defense, but can play any position well with his speed, he claims. He has the smallest wheelchair on the

I want to be by her side all the time. I want to give back to her a little bit of the huge amount that she has given me.

Estuardo Jimenez, Transiciones employee and athlete



Estuardo Jimenez and his mom, Aura Marina, have a good relationship and have always been very close. One of the hardest things for Jimenez was to watch his mom struggle with his own disability. "I admired most the strength she had. I'm grateful for my mom. I'm in a good place because of her," Jimenez said. | Photo by Savannah Heeren



team, allowing him to be closer to the ground to use his arm and core strength. In the golden hour of Friday afternoons, in a valley between puffing volcanoes and in front of the weekend, players fly up and down the court, tossing the ball onto one shoulder and gliding it across to the other.

Jimenez likes to throw the ball in front of him, igniting a fast break, and pulling away from every other player behind him.

Jimenez has learned many lessons over the years while working and playing for Transiciones. Although his condition has affected him physically, his curiosity and activity have not been hindered. He explains that if anything, a physical impairment is more mentally debilitating than physically.

"The mind is a barrier and this stunts growth sometimes," he said. Not having the same opportunities such as access to a wheelchair or a supportive family also have a huge impact, he says. He couldn't be independent without them.

"My mom was the one who always tried to find opportunities for me," Jimenez said.

Like the adaptive sports car he got six years ago, the physical therapy she arranged, the multiple hospital visits and his education.

"He was able to pursue something bigger than [society] expected," she said.

From a young age, Jimenez watched his mom struggle. When her husband left, Marina didn't think she would be able to pay for her kids' college, so Jimenez and his brother both dropped out. Now, Jimenez understands the sacrifices his mom made for him and his siblings and dreams of the day he can take care of his mother the way she took care of him.

"I want to be by her side all the time," he said. "I want to give back to her, a little bit of the huge amount that she has given me."

Jimenez's current ambitions include building a second level to his mom's home so that she can have a whole floor to herself and to build a ramp so that he can go up and down the stairs, too, without anyone's help.

Although Marina is skeptical and has a hard time understanding his somewhat daunting aspirations, Jimenez continues to weld, climb ramps and start fastbreaks with his mom always in his mind. Marina struggles to admit she must rely on her son to make it by, but to Jimenez, he is simply returning the favor. ✕

(Additional reporting by Estefania Rosal, Matt Tieglund and Savannah Heeren.)