



Being disabled in Guatemala and the story of Paula García

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Summary

For a variety of reasons, the incidence of disability is increasing in Guatemala. Conditions are harsh; most children with disabilities do not attend school and fewer than 2% of adults with disabilities are in work. Paula García, disabled from birth was eventually helped by the charity **Transitions**, which is itself supported by **emerge poverty free**. Paula now lives much more independently and aims to be a teacher.

An incredible 14% of Guatemalans have a disability and yet Guatemala could be the worst place in the world to live with a disability. There is almost no government help and many people with disabilities live isolated lives hidden away from public view.



Paula García (All photos courtesy of Fotokids)

Living with a disability is challenging but most people with disabilities in the UK lead full and rich lives nonetheless. Rights at work, access, education and anti-discrimination legislation have

been hard won but, without these, life would be very different. Strong concerns over the proposed Disability Living Allowance (DLA) eligibility assessment recently prompted Richard Hawkes, the chief executive of Scope, to point out that 'DLA is not a benefit, but a basic recognition that it is more expensive to live as a disabled person in our society'.

Nowhere is this made clearer than in Guatemala, Central America, where those living with disabilities must also face poverty, a combination which leads to terrible hardship. Most children with disabilities in Guatemala do not attend school; fewer than 2% of adults with disabilities are in work. But there is no DLA in Guatemala. Only a tiny minority of paraplegics have wheelchairs with most relying on being carried from one place to another by a family member.

In the developing world, poverty and disability interact as a vicious circle. Low income, inadequate access to health services and unsanitary and unsafe living and working conditions mean increased vulnerability to disease and injury. In turn, disability intensifies the barriers faced by poor people and creates new and often insurmountable obstacles. The outcome is increased dependence on family members, vulnerability and insecurity, and a shift into deeper poverty. A major contributor to the high level of disability in Guatemala was the civil war, which lasted over 30 years. Thousands were left with disabling injuries, their plight compounded by the stigma attached to participants in the conflict.

Ironically, a drop in the infant mortality rate has also contributed. More children are surviving who have severe mental and physical disabilities due to prematurity, malnutrition, birth defects, birth injury, and other causes. In the past, many of these infants would simply have died. Diet may also be to blame with toxins associated with corn tortillas, the Guatemalan staple, being linked to a high incidence of birth defects such as spina bifida. Finally, gun crime is a major factor. Guatemala has the second highest rate of shootings in the world (after Columbia) and survivors are often left with terrible injuries.

One such survivor is Alex Galvez, the founder and director of Guatemalan disabilities NGO, **Transitions**. When Alex was 14 years old he was shot by a gang member with no apparent motivation. The bullet hit his spine and from that moment onwards Alex was unable to feel his legs. Poor treatment inhibited Alex's recovery from the accident. He was discovered, covered in bed sores, by John Bell, a volunteer from the US. John took Alex to the United States, where he received a series of operations and rehabilitation. He returned to Guatemala with a new lease of life and a new mission.

Transitions is one of the few providers of help to people with disabilities in Guatemala. The organisation provides special education, healthcare, skills-based training and aid with social integration. A key aspect of its work is the manufacture of wheelchairs in a workshop staffed entirely by wheelchair users. Each wheelchair is customised to the individual user and they are either given or sold for a nominal fee to people with disabilities in the community. **Transitions** also runs a Prosthetics and Orthotics clinic offering free fittings by a trained technician. Around 400 people benefit from these services each year, their lives completely transformed by the gift of mobility and freedom. One such person is Paula García.



Paula with her mother

Paula lives with her parents and two brothers in Santa Maria Cauque, a small village near the agricultural city of Chimaltenango. Working as farmers, the family live below the poverty line, earning a combined income equivalent to just \$3.00 a day. 22-year-old Paula is extremely determined to improve her family's situation by finding work but having a disability limits her chances in doing so.

When she was six years old, Paula was diagnosed with Spina Bifida, a fault in the development of the spinal cord and surrounding vertebrae. Deformity of her legs left her unable to walk, severely limiting her developmental opportunities. Paula could see all the things that other children were able to do, and had no hope that she would ever be able to join them. Paula's mother took care of her, carrying her around in her arms as a child. As the family could not afford a wheelchair, when Paul grew older, her mother used a cart to get her from one place to another.

For the first nine years of her life Paula depended entirely on others, she could not leave the house unattended, or go to school like other children. Paula described her early childhood:

Maybe I didn't have a very happy childhood, but my mom did everything she could and gave me what I needed. She took me out, she carried me.

When Paula's mother heard about Transitions she approached the organization for help and at 15 years old Paula received her first wheelchair. After several medical examinations, she underwent an operation to amputate her legs, making her suitable for prosthetic limbs. She says:

Transitions gave me hope of a miracle; they told me that with the help of prosthesis I could be able to walk.

With prosthetic limbs Paula was able to make a dream come true and go to school; finally learning to read and write. She has been able to find work one day a week at a store which enables her to buy school supplies. She now has freedom and independence.



Paula walking independently

Transitions provides Paula with an educational scholarship, paying all her monthly school fees. Paula is now finishing seventh grade and is happy and proud to be studying. She says:

Thanks to Transitions, I have graduated from the elementary school in Chimaltenango, and continue to study to try to keep moving forward. My mom tells me, 'Keep studying, studying, studying, one day you will have the opportunity to improve your future.' I think that if I keep studying, someday I may have something better.

Transitions also continues to support Paula with her health needs. She is provided with new prosthetics when she needs them, at no cost to her family.

There are still challenges for Paula, such as the difficulty of finding a full-time job and teasing from other girls her age. Despite this, Paula remains positive, and is determined to graduate from her studies and become a teacher.



Paula preparing food...



...and feeding the chickens

UK-based international development charity **emerge poverty free** has supported the work of **Transitions** since 2002. Alex Haxton, Chief Executive of **emerge poverty free**, said:

Living with disability is often a forgotten issue in overseas aid, but 75% of people with disabilities are living in the developing world. Inadequate provision means that these people are often the poorest of the poor.

In a country where disability remains largely excluded from development, organisations like **Transitions** are leading the way for positive change. The full and equal participation of people with disabilities in ordinary life is a long way off for Guatemala but, for those lucky enough to be helped by **Transitions**, life is improving.

To learn more about **emerge poverty free** go to <http://www.wer-uk.org/>