

The Mental Handicap of a Hostile Environment

HANNAH P. ROCHE

Bachelor of Health Sciences (Honours), Class of 2017
Correspondence should be addressed to hannah.roche@learnlink.mcmaster.ca

GLOBAL PERSPECTIVE



ARTIST
David Hu

DEFINING DEVELOPMENT

As the Western world continues to progress to new heights of development, the emphasis on the care and rehabilitation of children living with physical and mental disabilities becomes more focused. In schools across the developed world, clubs and societies are formed to promote the integration of students with disabilities. Many educational and social institutions have a zero tolerance policy concerning discrimination against children with mental and physical challenges. Innumerable charities, companies, and organizations raise funds and awareness in support of these children. However, this is not the case in the vast majority of the world. In cultures where 'different' is commonly associated with 'unwanted', children with mental and physical disabilities are often abandoned, neglected, and tossed aside. How is it that something that defines the word special in certain places can be the same thing that makes children undesirable in others? Perhaps the answer lies in the child's environmental, social, and economic environment.

Guinea is a small country located in West Africa with a beautiful coastline on the Atlantic Ocean and a vast potential for wealth in its rich mineral deposits. It is also a country ravaged by civil war, continued political instability, many forms of injustice, rampant corruption, and an unending cycle of poverty.¹ Despite being the top bauxite exporter in West Africa² and having the potential to be one of the wealthiest African nations, 77% of the Guinean population lives on less than two dollars a day.³ Guinea is ranked 178th out of 187 countries on the Human Development Index (HDI) of the United Nations Development Programme (UNDP).⁴ This ranking is a globally standardized way of classifying countries according to life expectancy, education and income. Higher ranking indicates increasingly advanced development. A result of these circumstances is that having a disability of any kind in a country like Guinea is a severe disadvantage for something we in the developed world take for granted every single day – survival.

When we think of orphanages and childcare in developing countries such as Guinea, we tend to focus on the number of children affected and their current situation, overlooking the crucial question of how these children came to be where they are today. For children like Alice* and Jerry*, who are living in a centre in Guinea's capital city, Conakry, their circumstances were not a result of parental death. Rather, both children were abandoned by their families as a result of being born with physical and mental impairment due to cerebral palsy (CP) – a neurological condition resulting from brain damage during in utero development, at birth, or in early childhood.⁵ The

name cerebral palsy comes from 'cerebrum', which is the area of the brain that is affected, and 'palsy,' meaning paralysis.⁶ Since, the average Guinean family makes less money in a day than a Tim Horton's coffee costs, the result is a desperate and heartbreaking one – the child is often left to die.

In North America, cerebral palsy affects approximately 2-3 in every 1000 children.^{5,6} Due to paucity of data, the cerebral palsy statistics for Guinea are currently unknown or inaccurate.⁷ However, a study published in *Pediatrics* (Official Journal of the American Academy of Pediatrics) indicates that the prevalence of CP was higher among children whose families lived in low- and middle- socioeconomic communities than among those whose families lived in high-income communities.⁸ A study of California births in 1983–1985 suggested that African-American ethnicity is associated with increased risk of CP.⁹ As the vast majority – more than three quarters – of Guinean children are from extremely low-income families³ and of African ethnicity, one may suggest that the prevalence is higher.

WALKING ALONGSIDE

I was given the unique opportunity to travel to Equatorial Guinea this past year, and live in a humble centre that became my home for four months. The Kids in Crisis Centre, located in Guinea's capital of Conakry, offers a home, love, and a family to the least wanted and most fragile children in Guinea. I worked as a nutrition and health counselor alongside children from all health and family backgrounds. Alice* was found by the side of the road at the age of 3, unable to walk or talk and extremely malnourished. Jerry* recently turned two years old, yet most who saw him assumed him to be no older than 6 months old. I had the immense privilege of walking – literally – alongside these children throughout their struggle for normality. Some non-profit organizations are able to assist children like Alice and Jerry by providing physiotherapy or assistive devices to aid in physical development. A walker was donated to the centre, which Alice and I would use to practice walking up and down the compound. Day after day she grew stronger, and the new challenge became to help her put her 'walker days' behind her and teach her to take her first steps on her own two feet. What we take for granted every single day, she has to fight for. Jerry is a beautiful two year-old boy, but while other boys his age were eating rice and curry, going down slides, and learning how to ride tricycles,

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*Names have been changed to maintain anonymity.

Jerry could not eat solid food or sit up by himself. With physical therapy, love, and attention, Jerry began to show small signs of improvement. As the days progressed, he was finally able to support his own weight while sitting. He also began to eat more than simple formula.

“FOR A CHILD WITH CEREBRAL PALSY BORN INTO A DEVELOPED COUNTRY LIKE CANADA, THE OPPORTUNITIES FOR THERAPY AND DEVELOPMENTAL REHABILITATION ARE PLENTIFUL LIMITLESS. BUT IN A COUNTRY LIKE GUINEA WHERE SUCH THINGS ARE UNHEARD OF, LET ALONE ACCESSIBLE, THERE MUST BE A MOVE TO INCORPORATE REHABILITATION INTO THE EVERYDAY ROUTINE OF DAILY LIFE.”

I spent hours in hospitals and clinics where paper documentation was the only method of record-keeping and healthcare providers were often not even legally licensed to practice. Due to the constant instability in the Guinean government and the dire need for infrastructure in the health care system, accurate statistics for cerebral palsy as well as for treatment and prevention programs cannot be found.

FUTURE STEPS

A recent study by McMaster University, in conjunction with researchers at the University of Alberta's Faculty of Rehabilitation Medicine and Alberta Health Services in Calgary, has developed a new and successful program that focuses on the child's environment rather than the rehabilitation of physical bodies.¹⁰ This is called 'context-focused' intervention. The study divided children aged one to six into two categories of therapy: context-based and child-based therapy. Johanna Darrah, a Professor of Physical Therapy in the Faculty of Rehabilitation Medicine at the University of Alberta, said the experience with context therapy

was positive: "The benefits of working in the child's natural environment were striking."¹¹ For a child with cerebral palsy born into a developed country like Canada, the opportunities for therapy and developmental rehabilitation are plentiful. However, in a country like Guinea where such things are unheard of, let alone accessible, there must be a move to incorporate rehabilitation into the everyday routine of life.

In addressing the neglect of children with cerebral palsy and similar conditions in countries like Guinea, it is too easy to only see the superficial issues that evoke feelings of resentment and indignation in those of us who are outsiders. Unfortunately, the problem runs far deeper than social discrimination and cannot be explained away using cultural stigmas. This is not an issue of awareness but rather one of connectedness, as the argument for the symbiotic relationship between child and environment is indisputable. It is recognizing that the brutal and inevitable cycle of corruption, greed, and poverty results in the unjust accuracy of the statement 'the survival of the fittest'. Poverty, in this sense, stretches farther than economic terms and instead becomes a death-sentence to children with disabilities. Yet this is not where stories of children like Alice and Jerry should end. As people across the world from every social, economic, and ethnic status begin to see that the value of human life transcends physical and mental differences, we will begin to notice a shift towards a community that finds survival value in others rather than simply valuing survival. ■

Special thanks to Mercy Ships International for their continued guidance and support.

REVIEWED BY MEGHNA DUA

Meghna Dua received her undergraduate degree in 2011 from McMaster's Bachelor of Health Sciences Honours program with a specialization in Global Health. She then completed a MSc in Global Health at McMaster in 2012 and is currently an MD Candidate in the Class of 2015 at McMaster's Michael G. DeGroote School of Medicine. Her research interests are in maternal health within an international and global context.

EDITED BY BRANAVAN MANORANJAN

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