Treatable birth defects are still overlooked: why Africa needs better surveillance

Karen Mara highlights the challenges of treatable birth defects in Africa with special emphasis on Club foot.

A baby with club feet.

Across Africa, thousands of children grow up with lifelong disabilities caused by treatable birth defects such as clubfoot. Health experts say weak surveillance systems, under reporting and gaps in early diagnosis obscure the true scale of congenital anomalies on the continent, limiting access to timely and effective care.

Health experts warn that Africa's failure to systematically track congenital anomalies has created a dangerous blind spot in public health planning. The result is a silent crisis, preventable disability hidden in plain sight.

Globally, an estimated 6% of babies are born with birth defects, according to the World Health Organization [1], with Africa bearing a disproportionate share of the burden. Yet despite the scale of impact, congenital anomalies remain marginal in health policy debates, often eclipsed by infectious disease priorities.

The neglect comes at a high cost. Research published in the PLOS Global Public Health journal ranks congenital anomalies as the fifth leading cause of death worldwide for children under five, with 38% of these deaths occurring in sub-Saharan Africa[2].

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The WHO estimates that 94% of congenital disorders occur in low- and middle-income countries, driven by factors such as limited antenatal care, poor maternal nutrition, exposure to alcohol or tobacco, infections and environmental contaminants. Crucially, around half of congenital disorders have no identifiable cause, making early detection and treatment even more critical[1].

Many conditions can be prevented through vaccination, fortification of staple foods with nutrients such as folic acid and iodine, and adequate antenatal care. While some congenital conditions are life-threatening, many including clubfoot, cleft lip and palate, and hernias are highly treatable when identified early. However, when untreated, the consequences are lifelong: limited mobility, barriers to education and reduced economic opportunity.

The data gap hiding preventable disability

Despite the scale of the problem, systematic population-level data is severely limited. According to the Sub-Saharan African Congenital Anomalies Network, 66% of countries in the region have no published research on congenital abnormalities.

In South Africa, there is still no effective country-wide surveillance system for registering birth defects

and disability-related conditions. A study published in the *Journal of Community Genetics* describes congenital disorders as "an unprioritised health care issue in South Africa", with national surveillance underreporting by more than 95%[3].

Researchers attribute this gap to "failure to diagnose, misdiagnosis, inadequate surveillance systems, and the persisting parallel burden of infectious disease masking the CD burden".

The resultant lack of data contributes to the congenital disorder disease burden being underestimated, resulting in a lack of services for those affected, the study shows.

Disability and poverty: a reinforcing cycle

A November 2025 United Nations Conference on Trade and Development (UNCTAD) working paper examines the profound link between disability and poverty among working-age adults in Africa, using surveys from 27 countries.

The *Poverty and Disability: Evidence from Africa paper* highlights that even after adjusting for sociodemographic factors, adults with disabilities are, on average, 9.4 percentage points more likely to be multidimensionally poor (suffering deprivation in education, health and living standards) than those without disabilities[4].

The gap is widest in Tunisia; the poorest adults are four times as likely to live with functional limitations as the wealthiest. In Eswatini, Kenya and Nigeria, the poorest are more than three times likelier to live with functional limitations than the wealthiest; and in South Africa, Ghana and the Gambia, the prevalence of disability among poor adults is more than twice as high as that among the wealthy.

The paper calls on governments to strengthen continuous data collection linking disability, poverty, and socioeconomic conditions, stating that expanded information is especially important for analysing pathways between disability and poverty and for designing better policies.

What the research shows

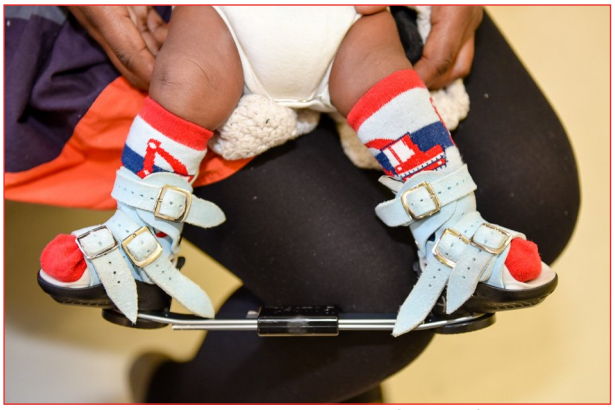
The South African Medical Research Council warned in its Disability Data Report 2023 that disability information is "rarely disaggregated", leaving many people effectively invisible in planning and policy. Where studies do exist, they point to a far higher burden than official figures suggest[5].

Research published in the *Pan-African Medical Journal* in 2020[6], analysing birth-defect prevalence from data across 25 studies in nine sub-Saharan African countries, suggests that birth defects occur in roughly 20 per 1000 births, with musculoskeletal conditions the most prevalent.

A subgroup analysis shows the highest prevalence in southern Africa, at 43 per 1000.

The analysis found strong links between birth defects and lack of folic acid supplementation, chronic disease and intake of drugs during pregnancy.

A study conducted at 18 hospitals in Botswana, published in BMJ Paediatrics Open in January this year, found 1066 newborns with at least one major congenital abnormality per 10 000 births. Limb and major nervous system defects accounted for most cases, with clubfoot identified as the most common limb defect, affecting 18.5 per 10 000 births[7].



A baby undergoing correction for club foot

Noting that the study was, to the best of their knowledge, the largest surveillance study of major congenital abnormalities in Africa, and the first in Botswana to describe the associations between such abnormalities and seasonality, calendar year and delivery site, the researchers stated that their method of surveillance using routine newborn examination combined with expert photographic review was simple and relatively low-cost, making it feasible across many settings.

However, a system that also included longer follow-up of infants to capture major congenital abnormalities detected after birth would provide a more complete understanding of their burden in low and middle-income countries, they noted.

The study findings support WHO recommendations for ongoing surveillance of congenital disorders, particularly in low- and middle-income countries, to monitor their occurrence and provide evidence to support the implementation of preventive interventions.

The research also concluded that Southern Africa may experience increased heat extremes, decreased crop productivity, and greater food insecurity because of climate change, and that close monitoring of birth defect trends can therefore provide critical information to help address these emerging challenges.

Clubfoot; common, treatable and still missed

Clubfoot (also known as *talipes equinovarus*) is one of the most common musculoskeletal birth defects worldwide. Babies are born with one or both feet twisted inward and downward. Left untreated, the condition can cause pain, poor mobility and permanent disability, yet it is fully correctable with early treatment.

Globally, clubfoot affects around 174 000 children every year, with 91% of cases occurring in low- and middle-income countries, according to the BMJ Global Health journal. Prevalence varies across the region, from 1.2 per 1000 live births in Uganda to two per 1000 in Malawi[8].

New figures published in The Lancet's *eClinicalMedicine journal* by a team of researchers from

the London School of Hygiene & Tropical Medicine (LSHTM), Stellenbosch University and the University of Oxford estimate that 1.18 babies per 1 000 births are born with clubfoot[9]. The rate is higher for low- and middle-income countries: in Africa, the prevalence is 1.31 per 1 000 births.

The researchers, who reviewed studies reporting the prevalence of clubfoot across the world in the past decade, encompassing 36 countries and five WHO regions, caution that stigma surrounding disability means these figures are likely still underreported.

According to the *eClinicalMedicine* study, nine congenital conditions can benefit from early rehabilitation and assistive technology. Among these, clubfoot is one of the most common. Others include limb reduction (an absent or shortened limb), spina bifida, cleft lip and cleft palate, cleft lip alone, cleft palate alone, microcephaly, microtia and anotia (where the outer ear is either malformed or missing), and encephalocele (where part of the skull has not formed properly).

The researchers note that screening for clubfoot at birth is important, as treatment is most effective when started early. Nurses, midwives, birth attendants and community health workers should be trained to recognise the condition from birth, educate parents and refer them to treatment centres. They also call for a clear case definition and robust screening methods to allow for comparison of epidemiological data.

LSHTM associate professor Dr Tracey Smythe, who led the study, said: "An improved understanding of the global birth prevalence of clubfoot is needed to inform public policy, health planning and allocation of limited health-care resources for early intervention and treatment.

"These insights aren't just numbers; they are the roadmap to breaking down care barriers, spotlighting inequities and partnering with affected children and their families to provide effective care."

With limited access to treatment, curable conditions such as clubfoot go untreated, leaving people with unnecessarily lifelong disabilities and trapping them in a cycle of poverty.

Proof that early treatment works

Across South Africa and neighbouring countries, STEPS, an award-winning non-profit organisation, demonstrates what is possible when children are diagnosed and treated early. Founder Karen Moss set up the NPO after her son was born with bilateral clubfoot, with limited treatment options available at the time.

STEPS has four pillars of impact to support children through four years of treatment to full mobility with the best chance to live happy, healthy lives: patient-centred clinic support; training in clubfoot care for health workers in partnership with the South African Paediatric Orthopaedic Society; education around clubfoot to promote early diagnosis and treatment; and the distribution of vital clubfoot braces that form part of the treatment.

"No parent should face clubfoot alone. Every child deserves the dignity of movement," Moss says.

STEPS endorses the Ponseti Method, a non-invasive technique that uses gentle casting and bracing to guide and maintain infants' tiny feet into the correct position. The method has a success rate of more than 95%. Since launching in 2005, STEPS has directly supported the treatment of more than 12 000 children, trained over 2 000 healthcare professionals and built a network of 48 partner clinics.

The organisation has a practical, ethical surveillance approach integrated into these public health clubfoot clinics across all nine provinces in South Africa.

"This approach has ensured that data is captured anonymously in a POPIA-compliant fashion. The trends emerging over time are strengthening the national clubfoot programme, guiding where clinics are needed, and helping shape training and support for health workers," says Moss.

A call to action

Health experts agree that stronger data systems, national surveillance and expanded access to early treatment are essential to breaking the cycle of preventable disability caused by treatable birth defects such as clubfoot.

Dr Emma Kalk of the University of Cape Town's Centre for Infectious Disease Epidemiology & Research notes that most children with conditions such as spina bifida, cleft lip and palate, congenital heart disease and clubfoot survive early childhood. However, without early identification, intervention and ongoing rehabilitation, the level of disability they experience can be significantly worse.

Moss adds: "We can't treat what we can't count." She believes there needs to be a shift from basic disability prevalence numbers towards better disability-disaggregated data, rights monitoring and integration into development, health and poverty research.

Without investing in counting every child and acting on what the numbers reveal, thousands will continue to live with preventable disabilities.

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