THE 2010 LARISSA AWARD

Missing Voices: Children with Disabilities in Africa

Africa is a continent which has been contending with a litany of interrelated challenges, among which can be cited are poverty, conflicts, HIV/AIDS and disability. But from all these, disability has a different look and texture: it is hidden and elusive, seldom reported in countries' statistical surveys. Yet, the little evidence available shows that it is a formidable challenge.

According to UNICEF figures[1], as many as 35 per cent of two to nine years olds in Djibouti, 31 per cent in Central African Republic and 23 per cent in Sierra Leone and Cameroon live with at least one reported disability.

In most countries, at least one person out of 10 is disabled by physical, mental or sensory impairment, and at least 25 per cent of any population is adversely affected by the presence of disability. It is also estimated that half a million children go blind every year, of which 60 per cent die in childhood, leaving a total of about 1.5 million, of whom four-fifths live in the developing world.[2]

These figures are staggering indeed. But even more staggering is the fact that disability among children in Africa is mainly the result of preventable causes. Some of these causes are the result of exposure to toxic substances or due to lack of access to rudimentary amenities. Others are the result of lack of access to basic preventive and curative healthcare services.

- Estimates show that only one in every hundred children with disabilities gets access to education in Africa[3].

[1] UNICEF 2007. The State of the World's Children 2008: Child Survival, UNICEF
[2] Wilson 1992, cited in Mittler 1993:6
[3] UNESCO, 2006. *Education for All* Monitoring Report 2007. Strong Foundations: Early Childhood Care and Education. Paris:UNESCO.

- The ACPF survey[4] revealed that the leading causes of disability among children in the surveyed countries[5] (35% to 50% of respondents) were illness acquired before the age of 5 years or disabilities acquired due to accidents.
- According to WHO, 85% of visual impairment and 75% of blindness (the vast majority occurring in developing countries) can be prevented or cured.[6]
- Pregnant mothers exposed to hazardous pesticides, solvents and organic pollutants place their child at risk of having a birth defect or disability.
- Maternal iodine deficiency leads to 18 million babies being born with mental disabilities and deficiency in vitamin A leaves about 350,000 children blind in developing countries.[7]
- About 70 per cent of cases of Spina Bifida – a disability that affects from 1000 to 3000 children per million in Africa – are preventable if folic acid supplements are taken by women before and after pregnancy and during the first trimester.[8]
- Asphyxia during birth, often resulting from the absence of a skilled attendant, leaves an estimated 1 million children with impairments such as cerebral palsy and learning difficulties.[9]
- In Africa, on average, there is only one eye health worker for every million people. "Of the more than 2 million children in Africa which are considered blind, some attend schools for the blind but many simply need an eye exam and a pair of strongly powered glasses."

[4] *Documenting the Realities of Children with Disabilities in Africa*, ACPF 2010
[5] South Africa, Zambia, Uganda, Sierra Leone, Senegal
[6] WHO 2009
[7] Micronutrient Initiative *et al*. 2009, cited in UNESCO 2010:181
[8] Spina Bifida Association of America 2009

[9] UNICEF 2008b

Yes, the continent counts a large number of children with disabilities. And yet their large number seems not to have generated the necessary public and government spur to meet their needs and to do whatever it takes so that they enjoy equal rights as other members of the community. Mostly their needs are footnoted in law and policy documents and put at the tail of budget priorities. In large parts of the continent, many children with disabilities are still being labeled defective and abandoned, or accused of witchcraft and driven out of their homes; or they are singled out in special schools or mental institutions. Still many are hidden from public view for years - denied of both physical and spiritual contact with the world of light and sunshine.

Many countries of the continent have ratified the African Charter on the Rights and Welfare of the Child (ACRWC), the United Nations Convention on the Rights of the Child (UNCRC) and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) - and by so doing have, in principle, made pledges to willfully respect, protect and fulfill the rights of children with disabilities. Many countries have put in place constitutional guarantees for protecting the rights of persons with disabilities. But sadly, most of these generic protective provisions have seldom found their way into legislation and specific sectoral plans.

All these challenges are furiously fueled by household poverty. There is a well-documented symbiosis between disability and poverty. Poverty is both a cause and consequence of disability. Households with a member with a disability can't afford to go to work; even if they do, they can only work for limited hours hence earn very little. One of the immediate results is that most children with disabilities support their families through begging on the streets and are exposed to violence.

Then, the crucial question of all remains: what can and shall we do to build an Africa that is equally enjoyed by all - children with and without disabilities alike?

- achieve a clear shift from a deficit and 'blame the child' mindset to one where differences are celebrated as blessings to tap on. We must ensure that the discourse that we unleash through our law and policy documents trickle down to positively influence lay discourse and attitude.

- demonstrate an unreserved political commitment to the cause of persons with disabilities concretely reflected in the laws and policies we enact and the budgets we allocate and in the services we deliver. a) eliminating attitudinal prejudices that stand in the way of accessing services by persons with disabilities, b) avail free or low cost assistive and adaptive devices for the benefit of children with disabilities; let's give as much attention to prevention of disability to the provision of services to persons with disabilities;

- uphold the exemplary work of organisations and individuals who have dedicated their life and resources to the cause of children with disabilities.

  The 2010 Larissa Award for outstanding service in protecting, caring and providing for children with disabilities in Africa demonstrated that Africa lacks no men and women brave enough to stand in the way of discrimination and oppression; neither does it fall short of organisations that have broken through attitudinal barriers and stand up and stand out protecting children with disabilities. The many nominations made for the Larissa Award from across the continent – all shining in their own right - bear witness to the fact that we are indeed blessed with organisations of altruistic service.

  On this occasion, on behalf of its International Board of Trustees and its funding partners, ACPF congratulates the winner of The 2010 Larissa Award, the ***Katalemwa Cheshire Home,*** from Uganda.

Winner of the Larissa Award 2010

Katalemwa Cheshire Home – Uganda

Who we are

Katalemwa Cheshire Home for rehabilitation services (KCH) is a development Non-governmental organisation in Uganda involved in the rehabilitation of children with disabilities and fulfillment of their rights since 1970. KCH Programme focuses on medical and social rehabilitation with consideration of HIV/AIDS, OVC interventions and gender mainstreaming, provision of assistive devices, promotion of quality inclusive education and livelihoods programs to enable CWDs live independent lives. Each year, the organisation directly supports over 50,000 children with disabilities and their families.

Mission and vision statement

Our mission is to ensure access to quality and holistic rehabilitation services by children with disabilities and their families.

Our vision is to become a regional leader and partner in rehabilitation and fulfilling rights of children with disabilities.

Our Goal is to have children with disabilities and their families included in society.

Key response principles and values

- Child Centered
- Purposeful partnerships
- Organisational learning
- Creativity and innovativeness
- Professionalism
- Honesty and integrity

Strategic objectives

- Children with disabilities, their families and local communities empowered and enabled to participate in the rehabilitation and fulfillment of disabled children's rights.
- Knowledge, attitudes and practices concerning disability within the community, including policy makers and service providers, improved.
- Increased implementation and enforcement of government policy provisions and legislation regarding disabled people.
- Partnership and networking with other organisations strengthened to improve service provision through shared learning.
- Increased capacity of Katalemwa Cheshire Home to fulfill its mission and realise the vision.

Model of programme implementation

KCH's model of Programme implementation is through innovative Community Based Rehabilitation (CBR) which emphasizes on direct service delivery so as to increase children's access to quality rehabilitation services. Besides direct service delivery, the programme also address issues of policy, attitudes and partnerships as a means of creating an enabling environment for fulfillment of children's rights.

The organisation operates countrywide and to the neighboring countries of Southern Sudan, Eastern Congo, Rwanda and Tanzania through partners situated in specific sites in areas of operation.

Special services provided at the Center and in Community

1. Physiotherapy
2. Occupational therapy
3. Orthopedic therapy
4. Pre and Post operative care
5. X-Ray
6. Neurological
7. Psychiatric
8. Pediatric
9. Speech therapy
10. Surgery (Plastic, Neurologic, Orthopedic)
11. Early child development and education
12. Disability Appliance provision and fitting
13. Training in disability appliance fabrication
14. Training community workers in child rights
15. Economic empowerment programmes

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Report from the Jury

Katalemwa Cheshire Home (KCH)has been selected as the winner of the 2010 Larissa Award for its comprehensive and holistic interventions that are remarkably innovative, for its success in engaging parents and other stakeholders, and also for depending on local experts who are always kept up-to-date with fast evolving disability programming through training and capacity building. KCH was able to seamlessly synchronise the rights-based approach to disability and policy advocacy with badly needed and equally significant rehabilitation interventions in its 40 years' of community service.

KCH has a holistic array of services including medical and social rehabilitation services (pre-operative care, reconstructive surgery, post-operative care, specialised clinics, nutritional therapy, and psycho-social support), economic empowerment of parents, awareness on HIV/AIDS, gender mainstreaming, etc. It reached out to more than 52,000 children in 2009 through its 15 special services. Its community based rehabilitation approach to service delivery and its networking with NGOs, parents, politicians, community leaders, government institutions, and civil society organisations partly explain its ability for achieving such a wide service coverage.

KCH makes very encouraging efforts at producing disability appliances/aids such as Steenbeek Foot Abduction Brace using locally available raw materials.

Campaigns, peer sensitisation through "Child to Child Voices" for promoting inclusive education, HIV/AIDS awareness programmes are part of KCH's participatory and innovative programmatic approach. Studies have shown that children with disabilities are more likely to be sexually abused or deceived into sex than their non-disabled peers, which might intensify their risk of contracting HIV/AIDS. Hence, such kinds of interventions that are unfortunately missing from most other disability interventions would have life saving implications.

Parents and children with disabilities are targeted in KCH's livelihood development interventions, complemented by vocational training and education and literacy programmes. Such interventions are able to break the vicious symbiosis of poverty and disability through enabling children with disabilities to live independent lives, as well as giving them the opportunity for socioeconomic integration.

KCH recognised the celebrated truth that parents are on the first line of care and support for their children with disabilities. In fact in many African societies, parents are the only resource available to provide support and care including pedagogic support to children with disabilities. Parents also need professional counseling to cope with the anxiety, and at times gloomy prognostic outlook, that onsets the first years' of their knowledge of having a child with a disability. Hence the engagement of parents through Parent Learning Committees and training of care-givers in Interpersonal Therapy is a perfect testimony to KCH's well-thought out programme framework.

On the knowledge building and dissemination fronts, the use of a Management Information System enhanced communication and sustainability within and without the organisation. Its various publications and its excellent website also bear witness to the KCH's commitment to sharing out its positive programmatic experiences to like-minded organisations.

In a nutshell, KCH's multifaceted activities are bound to bring about sustainable change and offer greater opportunities for social integration of children with disabilities. By selecting Katalemwa Cheshire Home as the winner of the 2010 Larissa Award, we the Jury are bearing witness to the inspirational role it could potentially play in spurring action and commitment among organisations on the forefront of the protection and care of children with disabilities.

Congratulations to Katalemwa Cheshire Home - Uganda

About the Larissa Award

The Larissa Award is dedicated to the memory of Larissa who passed away tragically at the age of five. During her short life, she brought immense pleasure to her parents, grandparents and friends. Larissa was highly sensitive, intelligent, kind and generous in her possessions. The Award symbolises the tragedy of one in five African children who die before their sixth birthday. Larissa would be content to know that this award bearing her name will advance the wellbeing of African children.

The Larissa Award is an instrument of The African Child Policy Forum (ACPF) to inspire the best and draw on the positive impulses in Africa and recognise those that have helped Africa to progress and become a better place for children. The specific purpose of the Larissa Award is to give recognition and encouragement to exemplary initiatives for the wellbeing of children in Africa. The Award may cover a broad range of activities such as health care, education, nutrition, and care of orphans. Each two years, a specific issue will be chosen. It is hoped that, through appropriate publicity and other means, the Larissa Award will encourage the expansion and replication of such initiatives.

The conditions for nominations determine that the Award should go to an individual or organisation that has provided an outstanding service to children. Although nominees from Africa are especially welcome, the Award is open to all who have contributed to the promotion of the wellbeing of children in Africa.

The Larissa Award consists of a Statuette of Larissa and a modest financial contribution towards the winner.

2010 Larissa Award Programme

December 8, 2010 – Addis Ababa Hilton Hotel

18:30	Arrival and Registration
19:00	Welcoming Remarks Mr. David Mugawe, Executive Director, ACPF
19:05	**Missing Voices: Children with Disabilities in Africa** Shimeles Tsegaye, Senior Policy Research Specialist, ACPF
19:15	**Promoting and Protecting the Rights of Disabled Children in Africa** Honourable Agnes Kaboré, Chairperson, African Committee of Experts on the Rights and Welfare of the Child
19:25	**The 2010 Larissa Award Announcement** Mr. David Mugawe, Executive Director, ACPF
19:35	**Presentation of The Larissa Award** Advocate Bience Gawanas Commissioner for Social Affairs, African Union
19:40	**Acceptance speech by Katalemwa Cheshire Services - Uganda**
20:00	Reception
21:00	Closing

The African Child Policy Forum (ACPF)

The African Child Policy Forum (ACPF) is an independent, not-for-profit, pan-African centre of policy research and dialogue on the African child.

ACPF was established with the conviction that putting children first on the public agenda is fundamental for the realisation of their wellbeing and for bringing about lasting social and economic progress in Africa.

ACPF's work is inspired by universal values and informed by global experiences and knowledge. Its work is guided by the UN Convention on the Rights of the Child, the African Charter on the Rights and Welfare of the Child, and other relevant regional and international human rights instruments.

ACPF aims to specifically contribute to improved knowledge on children in Africa; provide a platform for dialogue; collaborate with governments, inter-governmental organisations and civil society in the development and implementation of effective pro-child policies and programmes and also promote a common voice for children in and out of Africa.