

AFFIRMING THE VOICES OF DISABLED PERSONS: AFRICAN EXAMPLES

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NGOMA'S STORY

Ngoma is a young boy with a disability who uses wheelchair. He attends a school in his village 1.5 km away. His friends and cousins help him reach the inclusive school. However, every morning he does not eat breakfast or join the school feeding programme, as he will not be able to go to the school toilets, which are not accessible. So, for the whole day, he restrains from eating until he gets back home. He is an average student, but could improve if marginalisation was not perpetuated with negative attitudes, which also mean that he cannot join sports, and does not come to school when it rains, due to an inaccessible environment.

Ngoma has been able to make a difference in his community, as a member of the local disability association. The association was able to convince the organisers of the village free open air cinema to change its location to an accessible one that is still within the village market. Now more villagers, including older persons and women with children, find it convenient to attend the shows.

Ngoma's story resonates with other thousands of students, young boys and girls, and men and women with disabilities globally. Governments and development actors need to change to find ways to improve the lives of Ngoma and millions like him.

THE SUSTAINABLE DEVELOPMENT GOALS AND THE SIZE OF THE CHALLENGE

The year 2015 was a last lap, racing round the track with the stadium acknowledging that in the race, persons with disabilities were also competing as citizens who should be part of development goals. Organisations of persons with disabilities covered the full race, advocating across all continents for inclusion, and when the Sustainable Development Goals (SDGs) were finally adopted by the United Nations (UN) assembly in September 2015, they included several targets that aim to improve the status of persons with disabilities. The text specifically mentions persons with disabilities, rather than assuming that terminology such as 'vulnerable groups' would cover everyone, or leaving it to the interpretations of development practitioners.

The UN's new message promoting the SDGs, 'leaving no one behind', must be a reality and not a buzz phrase. Leaders of organisations of persons with disabilities, both large and small, are keen to be part of this change movement, but many are struggling to find out how they could move SDG advocacy to the next level. But one message that all are in unison with is that the 'leaving no one behind' mantra can only be achieved when marginalised groups, which includes persons with disabilities, are recognised in the planning, budgeting and implementation of programmes.

Though the World Disability Report, published by the World Health Organization and the World Bank, notes that there are a billion persons with disabilities globally, constituting 15 per cent of the world's population, unfortunately we still see glaring mismatch between this and the national data.¹ Around the world, three to eight per cent seem to be the national figures that state statistical offices are saying should be used when planning. But many of these data are over two decades old, and use out-dated medical methodology in defining disability, and thus leave millions of disabled persons out in terms of accessing education, health, rehabilitation and empowerment programmes, and the provision of accessibility.

Human Rights Watch and the South African Human Rights Commission's 2015 report, 'Complicit in Exclusion', exposed the magnitude of educational exclusion, assessing that there are 500,000 children with disability not in school.² The numbers are even higher according to UNICEF, going up to 95 per cent across many developing countries.³ The long term effect of the marginalisation of persons with disabilities is exclusion from decision-making processes and absence or lack of services because there is no data, promoting human rights violations and perpetuating poverty, including intergenerational poverty.

In many of these cases, the solution to access and ensuring that persons with disabilities are included is not rocket science; for example, with education, it's about teacher training, and supplying curriculum and teaching support systems within schools that are inclusive, thus making education universal for all.

THE MAINSTREAMING CHALLENGE

The greatest impediment to the delivery of disability services is the lack of knowledge on how to plan or budget for disability across government ministries, other than the traditional dockets such as education, health and disability services. It is common to get such answers as, "How can we include persons with disabilities, as our ministry have nothing to do with disability?" But such arguments immediately collapse when persons with disabilities expose them to disability mainstreaming, when they are trained to use disability lens and disability response actions, or when persons with disabilities are consulted and participate in development planning.

Despite these challenges, it is worth noting that the disabled persons' organisations are seeing a shift in attitudes, and more effective implementation of inclusive programmes by government officials, particularly when officials have acquired knowledge

1 'World report on disability', World Health Organization, June 2011, <http://bit.ly/1sy4ZLc>.

2 "'Complicit in Exclusion.'" South Africa's Failure to Guarantee an Inclusive Education for Children with Disabilities', Human Rights Watch, 18 August 2015, <http://bit.ly/1fr7YOr>.

3 'Children and Young People with Disabilities', UNICEF, May 2013, <http://uni.cf/1MxUifs>.

and skills on disability. This success has been possible in countries where expertise on disability has been sourced and used from disabled persons' organisations by government departments and other civil society organisations (CSOs).

A case in point was seen in 2015, when the government of the kingdom of Lesotho worked closely with and tapped the expertise of the Lesotho National Federation of disabled persons to develop a costed disability mainstreaming strategy, together with monitoring framework. Through the strategy, each department developed a plan and affirmed the existence of opportunities that could enable the participation of persons with disabilities through their departments and ministries.

Other good practices worth singing about have been seen in Kenya and South Africa, where governments ensure the participation of persons with disabilities through procurement policies that are inclusive and which ring-fence tenders for marginalised groups. These economic affirmative policies have been able to open up spaces and enable groups and individuals with disabilities to provide goods and services as suppliers. For example, Sindi, a horticultural farmer with a disability living outside Pretoria, South Africa, has emerged as a businesswoman supplying major supermarkets and stores as a result of this kind of opportunity. These successes offer evidence that is being showcased and used to bring out and make heard the voices of persons with disabilities.

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There is more evidence and good practice on inclusion that needs to be replicated across countries. This can be more effective if more awareness is created persons with disabilities and their organisations, so that many more government ministries are seen to be coming up with dedicated inclusive programmes. Ministries such as those of culture, sports, agriculture, technology and trade and industry should be able to set indicators that facilitate disability mainstreaming, thereby enabling the attainment of disability targets within ministerial mandates. "It is unbelievable how we were able to come up with innovative disability indicators in our ministry of culture and heritage," stated one surprised Lesotho government official after developing their plan.

However, it is not well on all fronts. Disability rights CSOs are concerned that successes that have been gained are now being eroded. The gains brought about through advocacy and disability mainstreaming campaigns, which resulted in the establishment of dedicated offices in government systems, with some mainstreaming desks being located in the presidency, prime minister's office or government coordination offices, are being challenged. These mainstreaming gains came as a result of the embracing of disability issues as crosscutting and being about human rights. The philosophy of restructuring in many governments seems to be fuelling these relocations, with disability often the casualty, while a focus on other marginalised groups such as women and young people has been preserved following protests from their political wings. These shifts have real impacts on resources and take disability back to a social thematic cluster in governments. This is being seen with the relocation of the drivers of disability mainstreaming messages and planning in government, while some governments have relocated directorates back into ministries of social development or welfare, turning the clock back a decade.

A disability activist and leader from South Africa, Mr Dan Kekane, shared his worry: "The mainstreaming battle is being lost in certain fronts, especially when new government administration drives the thinking that disability should be well served in the social cluster." Restructures have a negative bearing on budget allocations and the monitoring of implementation. Many departments are going back to sleep, because no memo from a coordinating ministry is demanding that they account for their disability targets.

Fortunately, we have seen the voices of disabled persons and their organisations loud and firm in this discourse. They have made submissions to parliament, petitioned cabinet offices and staged demonstrations on the doorstep of their president's office. This advocacy must be sustained to conscientise the body politic. Experts on governance and the central commands of political parties should be exposed to disability consciousness and reflect this in the architecture of governance.

LOOKING AHEAD

The agents of change here are in the vanguard of the disability rights movement. They carry with them the soul and scars of exclusion. Organisations of persons with disabilities must now be proactive, deploy more experts to work with agencies on mainstreaming, and help political parties understand disability, as in many instances, they are unaware. By presenting disability position papers, an important perspective which has been left out can get a hearing in development of solutions. The wider CSOs have no excuse not to reach out to disabled persons' organisations and, in partnership and coalitions, promote, protect and defend the human rights of persons with disabilities.

Looking ahead, I see more dialogues between government departments and disabled persons' organisations. I see departments developing mainstreaming plans and piloting methods to include persons with disabilities. I see the family of civil society more aware and working closely with disabled persons' organisations on disability rights. I see that we are living in good times, and that no department will want to be left behind in the experiment of disability mainstreaming.