

Disability and development: learning from action and research on disability in Southern Africa

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Some issues which are well known

- There are about 1 billion people with disabilities in the world which is about 15% of the global population. Eighty percent (80%) of the persons with disability live in developing countries.
- SINTEF has conducted studies in Southern Africa which demonstrate that in this region the population of persons with disabilities is quite significant.

Some issues which are well known

- Literature is also quite clear about the link between poverty and disability. These two are interlinked: disability, because of (e.g. lack of employment and education) can worsen the poverty situation.
- On the other hand poverty can also lead to disability: the lack of immunisation, failure to seek treatment for severe malaria in children due to poverty have led to development of disability.

Some issues which are well known

- Studies conducted in the region including the living conditions surveys demonstrate that persons with disabilities in Southern Africa experience extreme conditions of poverty and have limited opportunities for accessing health care, education, employment, good housing and other social services.
- The majority of persons with disabilities do not enjoy their rights to education, employment, health care as is the case with other population groups.
- Data is available in the reports on living conditions and other studies clearly demonstrating these challenges.

Some issues which are well known

- Development is supposed to improve the living conditions of all human beings and empowering them to participate fully in the economic, political and social arena.
- However, it is evident from studies conducted in the region that while persons with disabilities have the right to fully participate in development, they do not enjoy this right. This is because they are excluded from the mainstream development programme/agenda.

Some lessons

- Research is important in order to understand for example the challenges persons with disabilities are experiencing, the interventions which are currently being implemented, whether these interventions are working and what else needs to be done in order to address the challenges?
- Persons with disabilities have knowledge of the interventions which need to be implemented in order to ensure that they participate fully in development.
- It is high time we started interrogating some of the interventions we are currently implementing? e.g. the provision of financial resources for IGAs; what sort of interventions would be appropriate for a poor community?

Some lessons

- While many studies have been done on disability in the region, the challenge which we have is that there is lack of utilization of research findings to inform programming.
- The conduct of research should not be the end in itself: how do we ensure that these results are disseminated and used for programming and policy development which ultimately will improve the living conditions of persons with disabilities.

Some lessons

- National development plans are aimed at improving the living conditions of human beings: you will find that they do not mention anything about disability.
- Anything which is not included in the national development plans is not a priority and this implies that it will not receive adequate funding.
- For example in the just ended Malawi Growth and Development Strategy reviews showed that it did not really include disability as a priority sector. A new one is being developed and hopefully disability will be prominent.

Some lessons

- People with disabilities should fully participate in the development of national development plans as well as national policies in order to highlight the issues which matter to them and how they should be addressed.
- In most countries their right to participate in the development of these plans is not adhered to except when a disability policy or disability related strategic plan is being developed: on all other policies and plans they are excluded.

Some lessons

- Data is required in order to develop new policies or change policy.
- Policy makers are more interested in numbers and not stories from qualitative studies. They are interested to know the magnitude of the problem. But qualitative data is data too!
- Living conditions study has been used extensively to inform policy and programming. This is because a wide range of stakeholders were involved right from the beginning.

Some lessons

- The development of interventions should be informed by research evidence.
- Interventions are not supposed to be imposed on persons with disability: Government, development partners and CSOs should not develop interventions for persons with disabilities; they should be involved.
- Persons with disability know and understand better the challenges they experience and they are in a better position to contribute towards the development of effective solutions. In most cases this is not the case in most of our countries.

Some lessons from 2 previous studies (I)

- The Equitable project: A study done in 4 African countries: South Africa, Namibia, Malawi and the Sudan. It was aimed at exploring issues around access to health care by vulnerable groups including persons with disabilities.
- One of the major outcomes of this study was the development of the EquiFrame: a tool for analyzing the extent to which policies and development plans are inclusive.

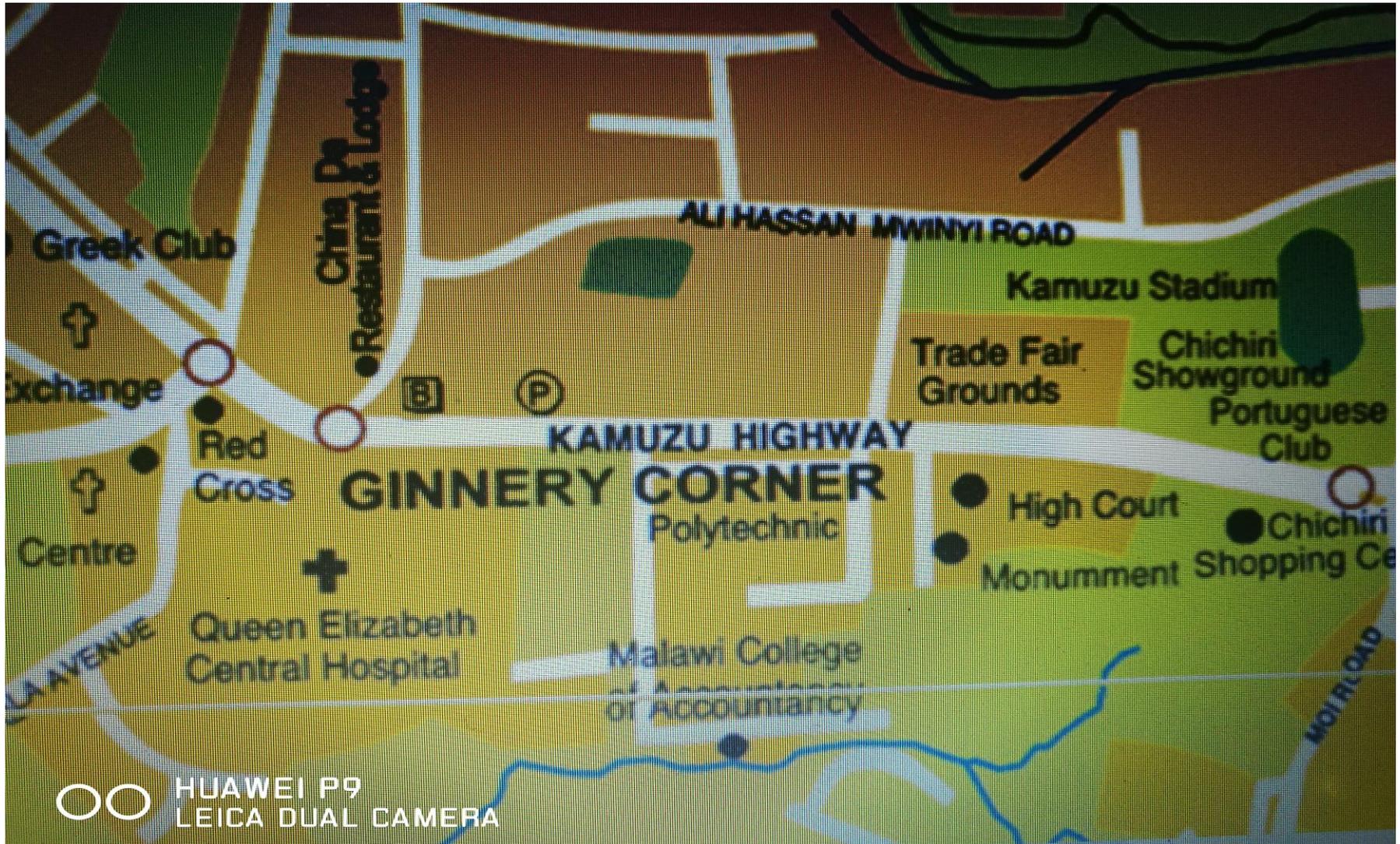
Some lessons from 2 previous studies (I)

- Over 70 policies and plans at national, regional and international levels. Some of the policies at national level scored very low in terms of inclusiveness.
- Some of the policies which scored quite highly included the National Disability Policies and the National HIV and AIDS – the major reason is that the development of these policies was quite participatory and that persons with disabilities were also involved.

Some lessons from 2 previous studies (i)

- One of the policies which scored very low was the draft National Health Policy for Malawi. In November 2010 the Ministry of Health invited the members of the Equitable Consortium to a workshop in Malawi where a presentation was made on the Equiframe and why the National Health Policy scored very low.
- We worked with the Ministry of Health and Abt Associates to review the draft and ensure that it was inclusive. The analysis of the new draft policy shows that the policy is quite inclusive but yet to be approved.

Installation of disability friendly traffic lights and a tactile pathway into a referral hospital in Blantyre



Some lessons

- In 2002-2003 we worked with Transport Research Laboratories in urban Blantyre on a project titled “Enhanced accessibility for people with disabilities in urban areas: a small scale demonstration project in Blantyre”..
- We worked with Transport Research Laboratories and FEDOMA at Ginnery Corner in Blantyre.
- In this study we interviewed people with disabilities on the major challenges they were experiencing in urban Blantyre. One major challenge was to do with transport and transport related issues such as crossing very busy roads and finding ways to get into a large hospital.

Some lessons

- We identified a very busy place in Blantyre close to a large referral hospital which also houses an eye hospital. There were a lot of people with disabilities who crossed the road from one side where there were shops to the other side where the hospital was.
- We asked persons with various forms of disabilities on the problems they had around the area: persons with visual impairment had problems crossing the road on their own and going into the hospital. There was also a bus stop but the facility was not disability friendly.
- Persons with disability made suggestions: 1) installation of traffic lights which would make a lot of noise when it turns green; 2) the construction of a tactile pathway into the hospital; 3) the construction of a disability friendly bus shelter.

Some lessons

- The bus shelter and the pathway were constructed and the traffic lights were installed. The project costed very little money to construct.
- Persons with disabilities welcomed the project and they no longer had problems around this area.
- The interventions were suggested by persons with disability themselves. However, a new road has been constructed and all these structures have been removed.
- Did the designer of the new highway really understand why these structures were designed?

Some lessons

- The demonstration project that we had in Blantyre demonstrated that persons with disabilities know the problems that they experience and they understand better the interventions which can address the challenges they experience.
- Human-centred approach to development is a preferred way of addressing some of the development challenges being experienced by our communities. It's a process that starts with the people you're designing for and ends with new solutions that are tailor made to suit their needs.

Challenges

- The lack of participation of persons with disabilities in the development of national policies and national plans.
- Most countries have very good policies and strategic plans and some have domesticated the CRPD. We have examples in the region e.g. South Africa. This is something that this region is known for. However, the challenge is that these policies and plans are never implemented fully.
- Negative attitudes towards persons with disability: there is still a lot of stigma and discrimination against persons with disability.

Challenges

- While Governments in the region are becoming aware of disability issues, overall disability is not a priority in most of our countries.
- People who are involved in the development of national policies and plans and later on implementation do not completely understand disability issues; some have not even been trained in disability issues.

Problems

- General lack of funding for implementation of policies and plans. Not much is allocated to the disability sector in the region.
- Government ministries and departments have budgets for improving education or health but these do not include disability.
- Disability data collection has not been integrated into existing data collection systems: Demographic and Health Surveys; Welfare Monitoring Surveys etc.
- Some countries have included some questions on disability but data collected is quite limited.

Some key issues in this presentation

- There is a lot of evidence on challenges being experienced by persons with disability but the utilization of evidence to inform programming and policy development is lacking.
- While policies and national development plans have been developed and some have domesticated the CRPD, implementation is an issue.
- The need for persons with disabilities to contribute towards the development of interventions to address the challenges they experience.
- Many studies are being done on disability. There will be a need to build the capacity of DPOs to be able to utilize research evidence to inform policy and programming.

Conclusions and recommendations

- Disability has not been included in most national data collection systems such as Demographic and Health Surveys, Integrated Household Surveys. This will be important in order to monitor whether there are any improvements in living conditions of persons with disability
- There is a need for the development of a disability research agenda for SAFOD.