

Arne H. Eide, SINTEF Technology and Society

**STUDIES ON LIVING CONDITIONS AMONG PEOPLE WITH DISABILITY IN LOW-INCOME COUNTRIES
AS A STRATEGY FOR MONITORING CRPD**

INTRODUCTION

The Convention on the Rights of Persons with Disabilities (CRPD) includes monitoring mechanisms at both the national and international levels, with the Committee on the Rights of Persons with Disabilities receiving periodic reports from States and other interested parties such as national monitoring mechanisms and civil society organizations. States have to establish or designate a framework that includes one or more independent mechanisms to promote, protect and monitor implementation of the CRPD. While much can be done to establish a situation analysis through utilizing expert opinions and existing information sources, in low-income countries, the lack of data on the situation among people with disabilities hamper any monitoring effort. Systematic data collection over time is needed to support the existing monitoring mechanisms. This paper describes and discusses repeated household surveys as a source for monitoring of implementation of CRPD, with the case being national, representative household surveys on living conditions among people with disabilities in southern Africa that have been carried out over the last 10 – 15 years.

BACKGROUND

Based on a partnership between Southern Africa Federation of the Disabled (SAFOD), The Norwegian Federation of Organizations for Disabled People (FFO) and SINTEF (research institute), studies on living conditions among people with disability has been completed in eight countries and is currently ongoing in four. While the design has remained to a large extent the same over the years, the studies have also been strongly influenced by the adoption of the International Classification of Functioning, Disability and Health (ICF) (WHO 2001) and the work of the Washington Group on Disability Statistics (WG). The studies have been applied in different ways: i) building capacity among DPOs, increasing awareness on disability broadly and among policy makers and disability stakeholders, influencing on disability policies, feeding into the work of international organizations as WHO (WHO 2011), World Bank (Mont & Loeb 2008) and UNESCO (2012), and for publishing (Publications from the studies are listed under references below).

DISABILITY AND LIVING CONDITIONS

The concepts of “level of living” or “living conditions” have developed from a relatively narrow economic and material definition to a current concern with human capabilities and how individuals utilise their capabilities (Heiberg & Øvensen, 1993). Although economic and material indicators play an important role in the tradition of level of living surveys in the industrialised countries, an individual’s level of living is currently defined not so much by his or her economic possessions, but by the ability to exercise choice and to affect the course of his or her own life. The level of living studies have been more and more concerned with such questions and are currently attempting to examine the degree to which people can participate in social, political and economic decision-making and can work creatively and productively to shape their own future (UNDP, 1997). This development parallels both the evolvement of the concept of poverty (Wolfensohn & Bourguignon 2004), and the conceptual development within the field of disability research represented by the ICF.

Research on living conditions is comparative by nature. Comparison between groups or monitoring development over time within groups and populations are often the very reasons for carrying out such studies. The purpose is thus often to identify population groups with certain characteristics and to study whether there are systematic differences in living conditions between groups – or to study changes in living conditions within groups over time and to compare development over time between groups. Population sub-groups of interest in such studies are often defined by geography, gender, age – or characteristics such as disability.

The World Disability Report (WHO 2011) states clearly that individuals with disability are among the poorest of the poor in low-income countries, and for instance Yeo and Moore (2003) have suggested a rationale for the mechanisms that ties disability and poverty in a reciprocal circle: poverty produces disability and disability produces poverty. While there is strong support for the disability – poverty relationship in the literature, the empirical basis for how this appears in low-income contexts is relatively weak. In order to further entangle the disability – poverty relationship, which is crucial in the ongoing poverty reduction initiatives represented by the Millennium Development Goals (MDGs) (<http://www.un.org/millenniumgoals/>) , we need both a broad mapping of living conditions among individuals with and without disability, repeated measures over time, and designs that both reflect the current conceptual development and that can respond to the momentum created by the CRPD and the need for monitoring its implementation.

STUDIES ON LIVING CONDITIONS AMONG PEOPLE WITH DISABILITY IN SOUTHERN AFRICA

The following describes the key elements in the studies on living conditions among people with disability in southern Africa, implemented over the years from the early beginning in 1998 until the current ongoing studies in four countries.

Studies on living conditions among people with disabilities in southern Africa

- Namibia (2003)
- Zimbabwe (2003/13)
- Malawi (2004)
- Zambia (2006)
- South Africa (2006)
- Mozambique (2009)
- Lesotho (2010)
- Swaziland (2011)
- Botswana (2014)
- Angola (2015)
- Nepal (2014/2015)

www.sintef.no arne.h.eide@sintef.no



Picture 1: Studies on living conditions in southern Africa

1. A participatory approach

The living condition studies have from the start taken a participatory approach to research. This is partly due to the "sitz" of the studies as they are funded and initiated by the disability movement, but also due to the experiences of SINTEF and not least due to the very positive experiences with combining/integrating a development goal (increased capacity of DPOs) with research. In practice, the participatory approach has implied:

- Funding and thus control by the disability movement
- A co-ordination role for the national DPO (in each country)
- Extensive consultations between researchers and DPOs
- An adaptation process run by the responsible DPO and involving a broad range of stakeholders in each country
- Reference Group and/or Technical Committee led by the DPO
- Individuals with disability involved as supervisors and research assistant during data collection
- Necessary resources, such as national statistical offices and national research groups, sub-contracted by the national DPO
- Capacity building to better enable DPOs to engage in research and with researchers, thus increasing the capacity to influence the content of research as well as the application of research
- Research followed by an Awareness Building Campaign in each country, run by the national DPO supported by the international DPO

Major success factors has been long-term funding, the continuity among the three main partners, continued support from researchers after the research is finished, excellent DPO leadership, and engagement of a local/national research group to be technically responsible for the data collection.

2. Design

Questionnaires

The questionnaires applied in the studies were originally based on two previously applied instruments: A study on living conditions in the general population in Namibia (NPC 2000) and a national disability survey carried out in South Africa (Schneider et. al., 1999). Over the years, and in particular in the first couple of studies in Namibia and Zimbabwe, a lengthy process involving all stakeholders was carried out to align the content of the questionnaires with the context and priorities of particularly the disability movement. A disability-screening instrument was included, in the early phases drawing on the discourse preceding ICF, in later phases using the WG 6 screening instruments directly. The "ICF matrix" on activity limitations, participation restrictions and environmental barriers was also included.

Four separate questionnaires are applied:

- i) Household study on living conditions – a set of core indicators of living conditions for all permanent members of the household (including control households)
- ii) Screening for disability; WG 6

- iii) Detailed Questionnaire for people with disabilities including the Activity and Participation Matrix drawn from ICF
- iv) Detailed questionnaire to individuals without disability (controls)

The questionnaires are all developed in English language and translated into local language(es)

The generic household questionnaire covered the following topics:

- Demography and Disease burden
- ☐ Education and Literacy
- ☐ Economic activities of household members
- ☐ Reproductive Health of Females aged 12 to 49 years
- ☐ Household amenities and housing conditions
- ☐ Household access to facilities
- ☐ Household asset ownership including land
- ☐ Household Income and its main source
- ☐ Household food production
- ☐ Household monthly Expenditure and rankings
- ☐ Death in the households

The detailed Disability Questionnaire covered the following topics:

- ☐ Activity Limitations and Participation restrictions
- ☐ Environmental factors
- ☐ Health
- ☐ Awareness, need and receipt of services
- ☐ Education and employment / income
- ☐ Assistive devices and technology
- ☐ Accessibility in the home and surroundings
- ☐ Inclusion in family and social life
- ☐ Health and general well-being
- ☐ Knowledge of HIV/AIDS, Malaria, TB and Diabetes.

The Control questionnaire for individuals without disabilities is a reduced version of the questionnaire applied to individuals with disability

Sampling

A two-stage cluster sampling procedure was applied using the National sampling frame in each country, in close collaboration with the National statistical offices who also did sample size calculations to ensure representativity at regional/provincial level. A required number of geographical units (often called Enumeration Areas, EAs) are thus sampled, with all households in these areas included in the first stage of the sampling. Then follows screening where all households in the selected areas are interviewed (normally the head of the household) using the WG 6 screening instrument.

Recruitment and training

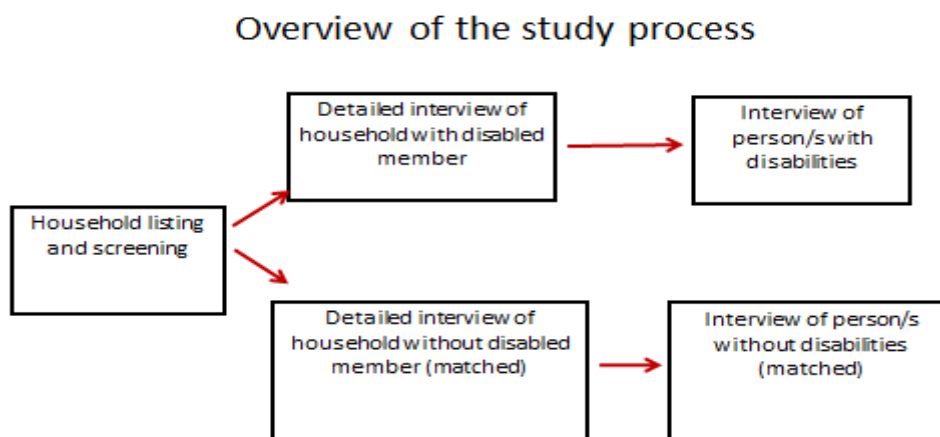
Recruitment of research assistants are carried out by the responsible body in each country (e.g.

Technical Team). Specific requirements for research assistants are set in each country, including minimum formal education. Individuals with disability are particularly recruited for the data collection, but the number can vary according to the strength of the national DPO. The number of research assistants and supervisors will vary according to geographical composition of a country and the size of the population.

Screening and Data collection

Research Teams of approximately 5 – 7 persons with one vehicle and a driver travel together and collect data within pre-determined geographical as for instance a Province. Screening is either carried out as a separate activity or directly linked up to the data collection in one operation. In all the sampled areas, every household is visited and the head of the household responds to the screening question. The data from the listing/screening are entered into a data entry program. Disability prevalence is calculated from this file. Any persons who are presented with at least one "some problems" in one of the WG 6 items below qualifies as being disabled. This threshold is chosen to obtain maximum sensitivity of the screening instrument, and the responses to the 6 questions can later be applied to distinguish between impairment types and severity of disability.

Among households with at least one disabled member, a pre-decided number of households in each EA is randomly sampled. Additional EAs are drawn during the sampling process to be used whenever too few households with disabled member(s) are identified in an EA.



Picture 2. Overview of the study process

Following the listing/screening, full household interviews are carried out with the household head in the "case" households", and each individual who have been identified as being disabled during the household interview are interviewed in person (eventually by proxy when necessary) using the disability questionnaire. A control household is chosen next door to the case household, applying the

same household questionnaire and a control questionnaire for individuals chosen on the spot to match (age and gender) the individual with disability in the previous household. When completed, all questionnaires are controlled by the Team Supervisor who keeps the filled in questionnaire safe in the vehicle until handed over to the technical responsible organization/research team.

The research team is responsible for organizing data entry, cleaning and submission of the data file for analyses, which is carried out by SINTEF in collaboration with the local/national research group. A final report is then produced, followed by a dissemination workshop with high-level representation and press coverage.

Following the dissemination workshop, FFO and SAFOD in collaboration with the national affiliate of SAFOD use the results from the study on a two-year Awareness Building Campaign, combining a broad dissemination strategy in the communities where data have been collected with specific dissemination towards policy makers and key stakeholders in the disability field.

Reflections

Different types of initiatives have been or are currently taken to improve disability statistics in low-income countries; Washington Group on Disability Statistics have developed screening questions, extended set of survey questions and recently a child module to improve data on children with disability; WHO is underway with their Model Disability Survey (<http://www.who.int/disabilities/data/mds/en/>); The World Health Survey included questions on disability (Mitra, Posarac & Vick 2011). These and other initiatives respond to the guidelines in the UN Convention on the Rights of Disabled People (CRPD) (<http://www.un.org/disabilities/default.asp?navid=14&pid=150>) as well as previous major international disability policy documents. It is argued that a more systematic approach to data collection nationally and internationally is needed in order to effectively monitor implementation of the CRPD.

While there are many ways to measuring and monitoring key aspects of the CRPD, there are several factors that brings support to carry out broad household surveys on living conditions among people with disabilities that tap relevant information. Firstly, there is a general lack of good data to support any monitoring effort, and survey methodology is an efficient way of generating knowledge also in resource poor contexts. Secondly, the methodology described above caters for the need to involve individuals with disability and their organizations in the research. Thirdly, the design is flexible in the sense that it can be further developed to better reflect monitoring needs in specific contexts. Fourthly, studies on living conditions are in essence of a comparative nature, providing evidence for discrimination and for setting specific targets. Fourthly, repeated surveys will provide data on development over time in a broad range of areas.

Household surveys like the one described above could form an important supplement to the current monitoring of the CRPD. Further development is needed to produce an instrument that better reflects key aspects of the convention.

REFERENCES (1)

- Heiberg M, Øvensen G (1993) Palestinian Society in Gaza, West Bank and Arab Jerusalem. A Survey of Living Conditions. FAFO Report No. 151. Oslo: FAFO Institute for Labour and Social Research.
- Mitra S, Posarac S, Vick B (2011) Disability and Poverty in Developing Countries: A Snapshot from the World Health Survey. SP Discussion Paper No. 1109. DC: The World Bank.
- Mont D, Loeb M E (2008) Beyond DALYs: Developing Indicators to Assess the Impact of Public Health Interventions on the Lives of People with Disabilities. SP Discussion Paper No. 0815. Washington DC: The World Bank.
- NPC (2000) Level of Living Conditions Survey. Windhoek: National Planning Commission.
- Schneider M, Claasens M, Kimmie Z, Morgan R, Naicker S, Roberts A, McLaren P (1999) We also count! The extent of moderate and severe reported disability and the nature of disability experience in South Africa. Pretoria: Community Agency for Social Enquiry.
- UNDP (1997) Human Development Report 1997. Oxford: Oxford University Press.
- UNESCO (2012) EFA Global Monitoring Report. Youth and Skills. Putting education to work. Paris: United Nations Educational, Scientific and Cultural Organization.
- Wolfensohn, J.D. & Bourguignon, F., 2004, Development and poverty reduction: Looking back, looking ahead, The World Bank, Washington DC.
- WHO (2011) World Report on Disability. Geneva: World Health Organization and the World Bank.
- WHO (2001) International Classification of Functioning, Disability and Health. Geneva: World Health Organization.
- Yeo R, Moore K (2003) Including Disabled People in Poverty Reduction Work: “Nothing About Us, Without Us”. *World Development*, Vol. 31, No. 3, pp. 571–590.

REFERENCES (2) – Other publications drawing on data from the LC studies

- Eide A H, Khupe W, Mannan H (2014) Disability and development in Africa; poverty, politics and indigenous knowledge. *African Journal of Disability*, <http://dx.doi.org/10.4102/ajod.v3i2.75>
- Eide A H, Ingstad B (2013) Disability and poverty – Reflections on research experiences in Africa and beyond. *African Journal of Disability*, 2, 1. Doi:10.4102/ajod.v2i1.31
- Eide A H, Jele B (2011) Living Conditions among People with Disabilities in Swaziland. A National, Representative Study. SINTEF A 20047. Oslo; SINTEF Technology & Society.
- Eide A H, Loeb M E (2011) Living conditions among people with disabilities in southern Africa. A comparative analyses. In: Eide & Ingstad. *Disability and Poverty*. London; The Policy Press.
- Kamaleri Y, Eide A H (Eds.) (2010) Living Conditions among People with Disabilities in Lesotho. A National, Representative Study. SINTEF Report No. A17239. Oslo: SINTEF Technology & Society.
- Eide A H, Øderud T (2009) Disability and Assistive Technology in Low-income Countries. In: M. Maclachlan & L. Swartz (Eds.) *Disability and International Development: Towards Inclusive Global Health*. New York: Springer.
- Eide A H, Kamaleri Y (Eds.) (2009) Living conditions among people with disabilities in Mozambique. SINTEF Report No. A9348. Oslo; SINTEF Health Research
- Jelsma J, Maart S, Eide A H, Ka’ Toni M, Loeb M E (2008) Who gets the disability grant in South Africa? An analysis of the characteristics of recipients in urban and rural areas. *Disability and Rehabilitation*, 30, 15, 1139 – 1145.

Loeb M, Eide A H, Jelsma J, Ka' Toni M, Maart S (2008) Poverty and disability in Eastern and Western Cape Provinces, SA. *Disability and Society*, June; 23, 4, pp 311 – 321.

Loeb M E, Eide A H, Mont D (2008) Approaching disability prevalence: the case of Zambia. *European Journal of Disability Research*. 2, 32 – 43.

Eide A H, Jelsma J, Loeb M E, Maart S, Ka' Toni M (2007) Exploring ICF components in a survey among Xhosa speakers in Eastern & Western Cape, South Africa. *Disability and Rehabilitation*, 30, 11, 819 – 829.

Jelsma J, Eide A H, Ka' Toni M, Loeb M, Maart S (2007) The determinants of health-related quality of life in urban and rural isiXhosa-speaking people with disabilities. *International Journal of Disability Research*, Jun; 30 (2): 119 – 126.

Maart S, Eide A H, Jelsma J, Loeb M, KaToni M (2007) Environmental barriers experienced by urban and rural disabled people in South Africa. *Disability and Society*, Jun, Vol. 22, Issue 4, pp 357-369.

Eide A H, Loeb M E (2006) Living conditions among people with disabilities in Zambia. A national representative survey. SINTEF Report No. A262. Oslo, SINTEF Health Research

Eide A H, Loeb M E (2006) Reflections on disability data and statistics in developing countries. In: B. Albert. *In or out of The Mainstream? Lessons from Research on Disability and Development Cooperation*. University of Leeds, The Disability Press.

Loeb, M. E., Eide, A. H. (2006) Paradigms lost: is disability politically incorrect? *Research in Social Science and Disability*, 4, 115 – 134.

Eide A H, Loeb M (2005) Data and statistics on disability in developing countries. SINTEF Report No. STF78 A054506. Oslo, SINTEF Health Research.

Loeb M, Eide A H (Eds.) (2004) *Living Conditions among People with Activity Limitations in Malawi*. SINTEF Report no. STF78 A044511. Oslo, SINTEF Health Research.

Loeb, M. E., Eide, A. H. (2004) *Studying disabled peoples' living conditions*. Studentlitteratur, Lund.

Eide, A. H., Nhiwatiwa, S., Muderedzi, J., Loeb, M. E. (2003) *Living conditions among people with activity limitations in Zimbabwe. A representative regional survey*. SINTEF report no. STF78A034512. Oslo, SINTEF Unimed.

Eide, A. H., van Rooy, G., Loeb, M. (2003) *Living Conditions among people with Disabilities in Namibia. A National, Representative Study*. SINTEF Report no. STF 78 A034503. Oslo, SINTEF Unimed.