

**DISABILITY & SOCIAL RESPONSES
IN SOME SOUTHERN AFRICAN NATIONS:
Angola, Botswana, Burundi, D.R. Congo (ex Zaire), Malawi,
Mozambique, Namibia, Tanzania, Rwanda, Zambia, Zimbabwe.
A bibliography, with introduction and some historical items.**

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*** INTRODUCTION & ABBREVIATIONS**

This bibliography, currently with approx. 1400 items, began in 1996 with a focus on the development of non-medical services concerned with mental retardation (mental handicap, learning difficulties, intellectual impairment) in Zambia. The development of services for people with other disabilities, and for children, and childrearing and language use, and then developments in neighbouring countries, soon began to be added. Then the weight of the new material outgrew the initial focus. Some biomedical papers have been added for their social contents or where a community-based or health education program concerned with biomedical conditions seems relevant to the development of disability awareness in communities. Newspaper and magazine-type articles have mostly been omitted.

About 300 references to reports, studies and data on disability, responses and formal services, deriving from the 16th century up to about 1965, or written since then as historical studies, are collected in the final section, extending broadly across sub-Saharan Africa. (The cut-off date of 1965 is arbitrary. Items printed in that year may cover the scene through 1963, i.e. 40 years ago. Authors then were probably at least in their late 20s or much older. Memories of disability-related events in Africa in those times are already scarce. They have become 'history').

Some representation appears of mental illnesses, which are often seriously disabling; but these have already been given significant coverage in an annotated bibliography by David Westley (1993) on mental health and psychiatry in Africa; also by Armando Favazza & Mary Oman (1977) with 50 years' worth of publications on anthropological and cross-cultural themes in mental health, among which Africa is well represented.

A comprehensive bibliography on Africa and Disability would certainly exceed 10,000 items, a task that would require a multilingual team with access to materials across the continent and to internal papers and reports of government and UN and NGO agencies. A recent development may facilitate this eventual goal: some major African university libraries now

have OPACs (online public access catalogues) that are searchable worldwide, in which many theses, unpublished documents, and other grey literature can be found. Increased internet development and accessibility should eventually cause more African disability material to reach those who are interested. It is curious that most African university libraries contain research theses on some aspects of disability, for which the authors have spent months or years of painstaking enquiry and writing, the end result of which is never published or distributed in any form; whereas the national European-language newspapers of urban Africa regularly carry articles concerned with disability, which are perhaps well-intentioned but are of ephemeral interest and express views that very seldom indicate any depth of investigation or critical reflection.

1.1 Geographical extent

The African region covered is shown on the map:



This is not a standard region for which any convenient name exists. It represents an area of some 8 million sq.km. with an estimated population of around 180 million. (For comparison, the USA is approx. 9.4 million sq.km., 280 million pop.; Europe, apart from the former USSR, is 5 million sq.km., 450 million pop.) Over 50% of the region's land and population comprises Angola, D.R. Congo and Mozambique, yet these countries at present provide less than 10% of the material in this bibliography, and most of the non-English material.

The grouping of material in country sections, i.e. * Botswana, Namibia and General Items; * Malawi, Tanzania, Zambia & Zimbabwe; * Angola, Burundi, DR Congo, Mozambique, Rwanda, arose with the thought of presenting internet files of an easier size to download. The historical (pre-1966) material has been kept together for the convenience of those interested in history, and here the geographical area extends more widely.

1.2 Need for Listings

Outside the region there has been little awareness of the extent of disability, social responses and service developments, and even less awareness of African cultural resources for accommodating disability, or of the voices of disabled Africans. Very few well-informed overviews have been available internationally - the present bibliography might assist anyone planning to fill that gap. The image of 'disability service development' in the region has largely comprised missionary efforts, the battle against polio and eye disease, some

innovative work with blind people, the Jairos Jiri movement, and rather mixed views about 'Community Based Rehabilitation'. Colleagues in the disability field to whom earlier drafts of this bibliography circulated were uniformly surprised at the extent of materials listed. It is intended that such material, and the research and thought it represents, may assist efforts to plan better services and to formulate realistic ongoing research goals.

Ideally every entry should have an abstract or annotation and information about access to the material, but the time and resources have not been available. The bibliography appears now as a working tool with its various limitations, to encourage people in the region to make further efforts. Anyone interested in disability in Africa, whether as researcher, service planner or user, or development worker, should benefit in their search for formally recorded knowledge, and also in awareness of the range of relevant material, and the type of documents produced by governments, UN agencies, NGOs, universities etc. It may also introduce to a wider audience the many writers, researchers and reflective practitioners in the region who are concerned with disability and social responses.

1.3 Location of Materials

No central collection exists of disability-related materials, particularly of a non-medical nature, in sub-Saharan Africa; yet the determined searcher may be able to gain access to a substantial amount of the listed material. Roughly 70% of this material has been published in national or international journals, or by a university or other national-level institution, or by governments or international bodies. The remaining 30% comprises unpublished theses or conference papers, some of which can be obtained in microform, or may necessitate correspondence or visit to the organisation that originally produced them.

1.4 Historical Sketch

No comprehensive history has yet appeared of social responses or disability service development in Africa, but the extensive references scattered by Iliffe (1987) across his history of 'The African Poor' show the possibilities. Formal services in a few countries (e.g. Egypt, Ethiopia) have been recorded since antiquity, but lie outside the region here considered. Folk stories and proverbial lore within the region give some indications of background social views of disability. Portuguese explorers opened the first small 'hospital' in 1507 in what is now Mozambique, and later in that century a 'Misericordia' in Angola (Iliffe, 1987, 95-96). These probably served some people with disabilities during their time. A few notes exist on disabled individuals from the 1590s (Dos Santos, 1609). The first specific disability service may have been the leprosy colony near Cape Town some time before 1817 (Iliffe, 102). A leprosy settlement in Northern Rhodesia opened in 1893 (ibid, 219). There have been several centuries of potential interactions between African and European notions of health and welfare provision and the development of institutions.

The actual benefits derived from formal services at any given time can of course be questioned, and latterly there has been an increasing awareness that the available records derive largely from able-bodied and able-minded travellers, administrators or service providers. Such sources were usually inclined to take a positive view of the development and efficacy of formal services, and sometimes to make an exaggerated contrast with the supposed indifference of society as a whole. The voices of service users, of providers of informal home care, and of disabled people managing their lives without any assistance, have

been almost entirely absent from the literature until very recently. There is therefore some danger that, by listing available material, an unbalanced picture may appear, e.g. of heroes and heroines contributing to an uncontested pattern of 'progress'. An opposite risk is to present the African cultural heritage as though it derived from an earlier Golden Age when no disease, disability or suffering existed, before the Arabs, Europeans and Asians came and ruined everything. This conflict of viewpoints, vigorously pursued in the broader field of African cultural histories, has hardly yet surfaced in disability histories. Within the documentable period of the past several hundred years, there are not many researchers who would honestly prefer to return from the present to live and bring up children with the services and living conditions available 50 years ago, let alone 100 or 200 years. Yet the dangers of source bias in European-language literature should be borne in mind.

(a) *African indigenous practices*

The history of indigenous disability practices has attracted comparatively little research. Kisanji (1995) has developed studies of disability-related proverbs, presumably reflecting accumulated folk wisdom. Burck (1989, 60-67) cites observations of indigenous practices with disabled Africans since c. 1900, across a wide range from infanticide through to tolerance and provision of legal protection. An official study (Blindness, 1948, 7-8) endorsed positive views of traditional family and clan care. Tolerance and care towards disabled people could diminish sharply in times of famine. Latterly, more systematic anthropological studies of African disability have begun (see e.g. Ingstad & Whyte, 1995). Despite the apparatus of modern scholarship, such reports require critical scrutiny - trained observers still record data reinforcing their own beliefs or political stance.

A response was noted nearly fifty years ago, in terms neither of government nor NGOs but of the urban African 'almsgiving public':

"The intermediate stage between family responsibility and the assumption by the State of responsibility for the welfare of the blind has, in the course of centuries, been reached in many parts of Colonial Africa. Its characteristic is the emergence of a class of blind beggar in the large towns, in centres of detribalisation and in areas where Christianity or Mohammedanism have created an almsgiving public by extolling the virtues of charity." (Blindness, 1948, 8)

Blind people organised in begging guilds were noted in Muslim regions of West Africa and the Eastern coast, and the report described the Muslim differentiation between 'religious' and 'secular' beggars. Yet while appreciating the 'almsgiving public' as a resource, the official reporters hoped for the day when "the greater advantage of contributing to organised charities" would be perceived (Blindness, 9).

(b) *Missions, doctors, census, law (1860s - 1950s)*

The earliest types of formal service by missionaries were with people suffering from leprosy, blindness or deafness. Some of the pre-institutional work has disappeared from the record - e.g. Moon's embossed script was used by Hoffman, an American working with a few blind people in Liberia, from 1863 until his premature death (Moon, 1877, 58-64), in the same year as "Dominican sisters pioneered schooling for the deaf and dumb" in Cape Town (Iliffe, p.102). Both preceded an Institute for Deaf and Blind opened at Worcester, S.Africa in 1881 (Wagg & Thomas, 1932, 59), which took up the Braille script, and a society for the 'feeble-minded' at Cape Town in 1908 (Dunstan, 1921). Mrs Hofmeyer taught blind people in Northern Rhodesia from 1905 onward - and Lazaro Banda, a blind man, continued the classes

on her death in 1910, until the redoubtable Ella Botes took up the task (Snelson, 1974, 72, 79-80; Cronjé, 1955; Landman, 1993). Blind, deaf and epileptic people were enumerated in colonial censuses of the 1930s, gaining a more 'official' existence (see e.g. Union of South Africa, 1937), to complement an early report on 'mental subnormality' in schools (Cape, 1932, 68-70). Some legal provisions have existed from an early date, for the protection or exclusion of disabled persons; while medical papers covering disability topics have appeared for at least 150 years. The official report *Blindness in British Africa* (1948) was perhaps the first extended study of the region to be published. One of its recommendations was that special classes for blind pupils be attached to mainstream primary schools, with some integrated activities (pp. 47-8).

An international meeting on rehabilitation in Africa (*Disability Prevention - Rehabilitation*, 1963, 394-407) reviewed efforts to date, with an emphasis on simple, low-cost prosthetics and orthotics, quickly made, easily repairable by local craftsmen. The need was recognised not only to get polio-lamed people walking, but for them to be integrated into normal patterns of agricultural employment (*ibid.*, 403-405). Sophie Levitt (*ibid.*, 405-406), working with cerebral palsied children, noted the need to "search for what is African and synthesise this with the contributions of developed countries." African parents began to appear as partners, learning "how to handle their children in the home as well as our treating the children at the clinic" (*ibid.*, 406). The same meeting heard of Jairos Jiri's work, "probably the first rehabilitation effort made by an African on his own initiative" (*Disability Prevention - Rehabilitation*, 1963, 406-407) -- the "first" effort apart, of course, from the daily informal efforts of rehabilitative care in millions of families with disabled members since time immemorial. During the 1950s, schemes to train blind East Africans to earn their living independently as cultivators achieved notable success, reported by a blind European farmer and advisor (Mackenzie, 1960). A key factor was the constant travel of the resettlement team, headed by a blind African, visiting and encouraging the ex-trainees in their villages (Anderson, 81)

(c) Schools and non-institutional development (1960s - 1990s)

From the 1960s, when many countries gained independence, more extensive disability literature exists. Wilson (1963), after an official tour of work for blind people across Africa, made recommendations emphasizing independence and training for agricultural self-support, anticipating by 20 years some of the features of Community-Based Rehabilitation. Successful home-craft training for physically disabled women was also noted by the MacGregor Committee (Zambia, 1967), during a detailed study of education for disabled Zambians. In 1967, Anderson produced a similar study for Tanzania, Kenya and Uganda, while Eedle's review (1972) of Commonwealth special education included data from Uganda, Kenya, Tanzania, Zambia and Malawi. These three substantial reports described a growing number of urban special classes or 'integration units' in mainstream schools, as well as special schools and sheltered workshops, and a slow development of skills training for teachers. They also recognised that some children with mild to moderate disabilities were casually integrated without any attention being paid to them.

Anderson (p. 124) and Eedle (pp. 162-3) emphasized the role played by religious missions in developing formal services from the 1940s onward, while Iliffe (p. 199) notes their "entrenched position" from much earlier. Eastern and Southern African governments approved and partly supported their work, but until the late 1960s were unwilling to take the initiative or undertake more than token expenditure. The MacGregor Committee (Zambia,

1967, 4) considered the suggestion of nationalising mission-run disability work, but found it wiser that government should "rather imitate than replace" the level of "industry, dedication and, on the best stations, a sheer professional skill." However, the drawbacks of residential work with disabled children, often far removed from their families, have become clearer in recent decades. In 1976, Levitt again underlined the importance of involving families in home rehabilitation, decentralising skills, aiming for one person in each village who should be "trained to advise and instruct and publicize how to help the handicapped" (Levitt, 1976, p. 48). Cecile Cusson (1977) has described the practice of attentive listening to the beliefs of families with disabled children from the interior of Cameroon, then involving them in making assistive devices from local and imported materials. By that time more African governments were beginning to budget for development of urban disability services, but the rural populations were still practically untouched by formal infrastructure. The situation has changed little in 2003, even though some of the pioneers' ideas were adopted in the WHO's CBR scheme; but the African population has risen rapidly, and a higher proportion now lives in urban agglomerations where the 'traditional community spirit' of the village has been lost, while the 'urban advantage' of formal service provision has yet to be established.

(d) The 2000s, AIDS and Prospects

In the social stock-taking and planning at the start of the new millennium, it has become apparent that the rising tide of AIDS has already killed significant numbers of the 'parent' generation aged 18-45, and the situation will certainly get worse. AIDS orphans are absorbing more of the energies of the grandparent generation, with the result that entire countries have a seriously reduced margin for offering care to children or older people with disabilities. In the mid-1980s before AIDS took a serious grip, Feierman (1986, 210) in Tanzania noted that "Healing and nurturing have been mostly the job of the old", and "People beyond their productive years heal the sick, provide nursing, and oversee childbirth" while the middle generation produce food and earn cash. Yet the capacities of the 'middle generation' are now seriously being cut back in all the countries reviewed here, because 20% to 40% of this age group are HIV positive or have full AIDS. The supply of trained medical, social and educational workers, and local communities' margins for coping with additional problems, are being reduced and the prospects for developing stronger and more appropriate disability services are weaker. One of the few recent positive trends has been the wider recognition that most disabled adults and young people have considerable potential for self-help, whether as individuals or in associations; and that hundreds of thousands of them have quietly been getting on with their lives with no greater dependency on other people than is normal in the adult population.

Only the briefest sketch of slowly developing knowledge and practice has been attempted here. Much of the historical data is unknown to people working in the disability field now. There is no central collection of relevant documents. Library services and inter-country communications are weak, and historical studies have tended to concentrate on earlier African cultures, colonial economic exploitation, and liberation struggles. Aid agencies interested in disability in Africa are usually unaware of earlier history, and may assume that 'nothing was done for disabled people' before a phase of 'institution-building' in the 1960s, which they now wish to replace with CBR schemes and 'Inclusive' measures. To see current efforts against two centuries of previous activity and development may bring more realistic perspectives. The variety and complexity of disability-related NGOs, and the vicissitudes of their relationships with government, also have a lengthy history. This sketch can hardly elucidate the "baffling fragmentation and complexity" of welfare systems (Iliffe, 193); but

may at least challenge a few of the more simplistic notions.

1.5 Acknowledgements

Materials were seen or citations found in libraries of the Universities of Birmingham, Bristol and London (Instt. Child Health, Instt. Education, and School of Oriental & African Studies); the University of Zimbabwe; the University of Zambia; Zambia Institute of Special Education; UNICEF, Lusaka; offices of the Zambia Association for Children & Adults with Learning Disabilities, Lusaka; the University of Dar es Salaam; UNICEF, Dar es Salaam; at Selly Oak Colleges Main Library, Birmingham; in an unpublished bibliography by H Finkenfügel; in the British Library; and at various Internet sites. Further relevant material has kindly been supplied or suggested by L Clemente (UNICEF Mozambique), KE Hill, J Jelsma, J Marshall, E Medi, M Phiri, O Strand, CJ Zvobgo, and by A Robins, H Payne & V Richardson working with Healthlink & Source databases.

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1.6 Apologies

Data in square brackets [] has some uncertainty. The publication status of some papers remains unclear. A few authors' names may have been inverted through the compiler's lack of familiarity with African names. Some accents may have gone astray in languages other than English. (NB a circumflex originally shown on the 'w' in 'Malawi has been omitted, as it tends not to convert well on Internet screens). The bibliography is issued as a working tool, with apologies for any flaws and with a request for corrections and for relevant additions.

*** NO POLITICAL OR RELIGIOUS VIEWPOINT IS INTENDED OR IMPLIED IN THE COMPILATION OF ANY PART OF THIS BIBLIOGRAPHY ***

MAIN ABBREVIATIONS

ACHAC	Association des Centres pour Handicapés d'Afrique Centrale.
Afr.	Africa, African
AJSNE	Africa J. Special Needs Education
App.	Appendix, appendices
ARJ	African Rehabilitation Journal
Assoc.	Association (of)
BMJ	British Medical Journal
Bull.	Bulletin (of) (the) (de la)
CAJM	Central African Journal of Medicine
CftH	Council for the Handicapped
Ch.	Chapter
Cncl	Council
Coll.	College
Comm.	Committee
Cwlth	Commonwealth
Dept	Department (of)
DeS	Dar es Salaam
Dev.	Development, developmental
Disab.	Disability, disabilities
diss.	dissertation
EAMJ	East African Medical Journal
Econ.	Economic(s)
Educ.	Education
Educl	Educational
Fndn	Foundation
Gab.	Gabarone
Govt	Government (of)
GoB	Govt of Botswana
GoM	Govt of Malawi
GoN	Govt of Namibia
GoZ	Govt of the Republic of Zambia
GURT	Govt of United Republic of Tanzania
Handic.	Handicapped
HDRU	Human Development Research Unit
Hlth	Health
Hrr	Harare
IAS	Instt. for African Studies (now Instt. for Economic & Social Studies, UNZA)
IJSE	International J. Special Education
ILO	International Labour Organisation
Incl.	Includes, including
Instt.	Institute (of)
Intl	International
IJRR	International J. Rehabilitation Research
J.	Journal, Journal of
Ksa	Kinshasa
Lab.	Labour
LR	Leprosy Review

LRR	Lands, Resettlement & Rehabilitation
Lsk	Lusaka
MMJ	Malawi Medical Journal
Med.	Medical, Medicine
Min.	Ministry, Ministry of/for
N.	Northern
n.d.	no date given
nps	no publisher shown
n.s.	new series
NASCOH	Natl Assoc. of Societies for Care of the Handicapped.
Natl	National
Prog.	Programme
Psychl.	Psychology
p., pp.	page, pages (or leaves)
q.v.	"see elsewhere" in this Bibliog.
Qly	Quarterly
Rehab.	Rehabilitation
Res.	Research
RLJ	Rhodes-Livingstone Journal
SAMJ	South African Medical Journal
Sci.	Science
SEBESA	Special Education Bulletin for Eastern and Southern Africa
Serv.	Services
SIDA	Swedish International Development Agency
Soc.	Social
Soc.Sci.M.	Social Science & Medicine
Socy	Society
Spec. Ed.	Special Education
T&GM	Tropical & Geographical Medicine
Trng	Training
UDSM	University of Dar es Salaam
UNBO	University of Botswana
UNISE	Uganda National Institute of Special Education
UNMA	University of Malawi
Univ.	University (of)
Unpub.	Unpublished
UNZA	University of Zambia
UNZI	University of Zimbabwe
UP	University Press
WAMJ	West African Medical Journal
Wdk	Windhoek
Welf.	Welfare
WHO	World Health Organisation
WTC	Without the Camp. J. Mission to Lepers
#	(not known)
§	(indicates a bibliography)
[]	(indicates uncertain status)