Applied Research on Disability in Africa Mapping - East Africa

This mapping was carried out by Mary Ann Waddell in partnership with Advantage Africa, FIRAH and the Resource Center Applied Research and Disability





Fondation Internationale International Foundation de la Recherche Appliquée sur le Handicap Research





Advantage Africa (<u>http://www.advantageafrica.org/</u>) supports people affected by poverty, disability and HIV to improve their education, health and incomes. Our work helps some of East Africa's most vulnerable people to overcome stigma, help themselves and build a better future for their families and communities.

Advantage Africa supports disabled children attend school for the first time, people living with HIV access life-saving medicines, single-parent families earn an income to meet their basic needs. These practical projects provide some of Africa's most vulnerable families with life-changing opportunities and real hope for the future.

Fondation Internationale de la Recherche Appliquée sur le Handicap

The mission of the Foundation of Applied Research on Disability (FIRAH, <u>http://www.firah.org/</u>) follows two main directions, which are complementary and merge: 1/ The call for projects: selection and funding of applied disability research projects,

2/ The Resource Center: sharing knowledge in applied disability research. The Resource Center Applied Research and Disability aims at creating connections and bonds between researchers and field stakeholders¹. It develops and disseminates research in order to promote an inclusive social transformation and to facilitate the full involvement of persons with disabilities.

CENTRE RESSOURCES RESOURCE CENTER Recherche Appliquée et Handicap Applied Research and Disability

¹ Field stakeholders

Persons with disabilities, their families, and their representative organisations. Any Human Rights organisation working with persons with disabilities. Service providers and other organisations working with Persons with disabilities. Service providers and other organisations working in mainstream that are required to meet the needs of persons with disabilities such as architects, teachers, companies, industries etc. Researchers and research institutes. Local, national and international decision makers.

This literature review concerns the achievements of a project which started in 2014 and will last three years. The aim of this project is the dissemination and promotion of applied research results and disability to researchers² and field stakeholders of the African continent (particularly to Disabled People Organizations), in order to increase knowledge on the situation of people with disabilities and the recommendations made to improve their social participation.³

The actions implemented during the three years of this project will enable us to conduct new research but also to gather major research for inclusion in the Resource Center, in order to promote exchanges between researchers and field stakeholders for mutual enrichment of their experiences and improve expertise and knowledge in the area of disability.

Do not hesitate to submit documents which will allows us to complement this work. To send us new identified research, you can contact us at the following address: <u>centre.ressources@firah.org</u>

Two other mappings of existing research conducted in close collaboration with universities had already been published: a general mapping, and a mapping on applied research in Maghreb and West Africa, you can consult the report on the Resource Center website⁴.

Next, from 2015 and 2016, a whole range of activities (study tours, creation of practical materials, and support to interventions in seminars or conferences, training sessions...) to supplement the Resource Centre of Applied Research and Disability contributions with direct interactions.

Close attention will be focused on the fact that all identified research and activities conducted will be available in open source, in an easily accessible format.

The present document was conducted as part of the Resource Center of Applied Research and Disability in partnership with FIRAH (International Foundation of Applied Disability Research) and Advantage Africa. The fulfilment of this work was entrusted to Mary Ann Waddell, research graduate of University College London with coordination by Advantage

² Research institutions and Researchers

An entity, such as a university or a research institute, or an department dedicated to research within a institution, or developed by a group of health institutions and affiliated with a university or a research institute, regardless of its legal status (public or private body) or the way it is funded, whose primary purpose is to carry out basic research or applied research or experimental development and to broadcast their findings by way of teaching, publication or technology transfer.

³ Social Participation

Social participation relates to the entire activities that a person must have to undertake to ensure a living, according to his /her lifestyle choices. It is measured against the fulfilment of activities of daily and domestic life as well as that of all social roles.

⁴ <u>http://www.firah.org/centre-ressources/revues-de-litterature.html</u>

Africa (Rob Aley). The full report was designed by FIRAH (Cécile Vallée / Resource Center Applied Research and Disability).

The goal of this literary review is to report on existing knowledge about applied research on East Africa, providing readers with access to a brief synthesis of knowledge written from selected documents, an initial list of documents submitted in an annotated bibliography and reading notes for those we consider a priority according to the selection criteria.

This work, which spans several thematic areas, does not intent to be comprehensive but to identify the results and knowledge generated by research that could be useful for field stakeholders in order to improve the quality of life and social participation for people with disabilities.

What FIRAH means by the very general terms of applied research is:

- First, it is proper research based on precision and methodologies which allow the implementation of a scientific approach involving teams of one or more researchers or lecturer researchers whose research is one of the statutory missions.
- Applied research differs from basic research. Its ultimate purpose is to increase independence and social participation of people with disabilities. It is not only aimed at producing theoretical knowledge but also tackling practical issues related to the needs and concerns of people with disabilities and their families. The collaboration between these people, professionals and researchers is a fundamental element to the achievement of this type of research.
- This type of research is designed to produce directly applicable results. In addition to
 usual publishing (scientific articles, research reports.) applied research is also
 designed to produce other materials called "means of application⁵" which can take
 various forms: development of good practices, methodological guides, training tools
 etc, and are destined to different field stakeholders (people with disabilities,
 professionals, policies makers).

Each title in the annotated bibliography contains a link with free or paying access to the work in question, and each reading note contains a link to the Resource Center database.

This document can be freely disseminated providing the source, author and relevant organisations involved are acknowledged.

⁵ Means of application

Shaping of the findings and knowledge gained from applied research into products, services and contents to meet the expectations and needs of people with disabilities. These application supports are adjusted to be used by field stakeholders.

Table of contents

Methodology	7
About the researcher	7
Inclusion Criteria	7
Search strategy	7
Search outcomes	8
Selection of the top 17 research papers	9

Synthesis	
Who is doing the research?	10
Subject matter	10
Accessibility and dissemination to audiences with disabilities	11
Steering the research agenda	11

Reading notes
The price of exclusion: the economic consequences of excluding people with disabilities from the world of work
How information is shared among CBR information service providers in Uganda 15
Disabled beggars in Addis Ababa. Current situation and prospects for change
User and researcher collaborations in mental health in low and middle income countries: a case study of the EMPOWER project
 « Using community / researcher partnerships to develop a culturally relevant intervention for children with communication disabilities in Kenya »
 « Home medication management practices and associated factors among patients with selected chronic diseases in a community pharmacy in Uganda »
Disability and urban agriculture – an innovative approach
 Young voices: Young people's views of inclusive education
 Linking CBR, disability and rehabilitation
 « Perspectives and concerns of clients at primary health care facilities involved in evaluation of a national mental health training programme for primary care in Kenya »26
 « Examining the trajectories of children providing care for adults in rural Kenya: implications for service delivery »

	« Resilience and successes of persons with disabilities in Ethiopia » in Disability in iopia: Issues, Insights and Implications
*	The lives of children with disabilities in Africa: a glimpse into a hidden world
	« Inappropriate enrolment of children in schools for the visually impaired in East ca »
	« Unravelling the spirits' message: a study of help-seeking and explanatory models ong patients suffering from spirit possession in Uganda »
	« Stakeholder consultations on community-based rehabilitation guidelines in Ghana Uganda »
	« A comparative analysis of institutional capacities for implementing disability policies ast African countries: functions of national councils for disability »

Annotated bibliography4	1
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Methodology

About the researcher

The researcher for this project, Mary Ann Waddell, is an experienced Occupational Therapist who has practiced in low resource settings of East Africa. She has a Master's degree in Global Health and Development from University College London. As an Occupational Therapist the researcher recognises material which relates to the experience of disability in everyday life. She is knowledgeable about physical disability, mental health and learning disabilities and in this research she gives equal consideration to aspects of daily living, health, education, livelihood and social engagement. Mary Ann was also alert to research which investigates key paradigms and approaches (such as CBR and the rights approach / UNCRPD) and of policy and relevant legislation.

Inclusion Criteria

At the start of the project a set of inclusion criteria was established to decide which applied research would be included in the study. FIRAH's definition of applied disability research was used. The countries included were Eritrea, Djibouti, Ethiopia, South Sudan, Kenya, Uganda, Rwanda, Burundi and Tanzania. Only publications more recent than 2005 were included (except pre-2005 publications if they were felt to be of high relevance to this project and not superseded).

Some other observations were made concerning the inclusion criteria:

- HIV&AIDS was regarded as a chronic illness rather than a disability. There is a great deal of literature about HIV/AIDS and this could overshadow attention on other disabilities. Studies which addressed specifically the disability aspects of HIV&AIDS were included.
- Mental ill health was considered a disability because it affects every aspect of an individual's ability to manage daily life.
- Studies available through subscription only were included as the majority of academic research papers fall into this category and are only available through subscription.
- Studies which are inaccessible because they do not have their full content available on the internet were excluded unless there was a very good reason for including them.

Search strategy

Searches were made using a university library database (allowing access to health and social science research databases and articles available through subscription only), and the open internet.

Searches were undertaken of:

- Health and social science databases (yielding mainly peer-reviewed research).
- The open internet especially international NGOs (yielding mainly grey literature i.e. non peer-reviewed, research).
- Snowballing (identifying new journals, authors or research teams from the references found through methods a) and b).

Key words were used to search for articles. The principal key words were "disability" AND "country name."

The key words were sought in the article title or abstract, not the main body of the text. This was because a country name may appear in passing in the text or even in the references when the country in question is not a principal focus of the research.

The selection criteria described above were then applied to articles identified.

Search outcomes

Initially articles were easy to find, for example, searching the journal Disability and Rehabilitation with "Uganda" as the key word, 31 articles were flagged up of which 5 met the inclusion criteria and were used. Searching the database Scopus using key words "disability" AND "Kenya" 104 articles were found from which 22 met the inclusion criteria and were used. As searching of the journals and databases continued the same articles were continually flagged up until searching for articles became the most time consuming part of the exercise. Searches of authors' names (mostly through their university websites) tended to identify repeat articles. Using this approach 175 articles were identified and written up in the table format agreed with FIRAH. Most of the articles catalogued were peer-reviewed academic studies or research produced by reputable international NGOs.

If future searches were to be undertaken in order to expand the number of relevant references the following approaches could be used:

- Inclusion of searching for key words in the full text (but if the country name did not appear in the title or abstract it was less likely that the article would refer substantially to the country).
- Using additional key words such as "deaf/ blind"

Selection of the top 17 research papers

Of the 175 articles catalogued in the literature review, 17 were chosen as being particularly relevant, or having immediate potential for practical application. More detailed information about these articles was written up in a separate document. The choice of the top 17 articles was influenced by the researcher's interpretation of FIRAH's core focus.

That is, on research which:

- has practical application at grassroots level,
- is by or for disabled person's organisations and CBR groups
- upholds the rights of persons with disabilities
- can be applied to improve policies and legislation.

Who is doing the research?

There is significant involvement of western research institutions, often working in partnership with African researchers. There is substantial involvement of people with disabilities as respondents (in other words, the perspectives of people with disabilities are sought). There is little indication of substantial involvement of people with disabilities in the design and implementation of research. It is possible that mention is not always made if research teams include people with disabilities, but there is little evidence that this is the case. Some NGO papers do indicate that CBR groups and disabled person's organisations have been substantially involved.

In terms of country representation – i.e. usually the research is about the country, or had a researcher from the country.

- Uganda
- Kenya
- Tanzania
- Ethiopia
- Rwanda
- South Sudan
- Burundi
- Eritrea
- Djibouti

Subject matter

It was found that the subject matter covered by applied disability research in the study countries is disparate, covering:

- physical disability, mental health and less on learning disabilities
- the concerns of people with disabilities and their carers'
- adults and children
- medical aspects of disability, identification of disability, experiences of disability, policy and policy implementation.

The research is mostly addressing useful questions such as practical ways to identify disability in resource-poor settings (Bower et. al., 2012); access to microfinance for livelihoods (De Klerk, 2008); effectiveness of training of frontline health workers in disability issues (Jenkins et. al., 2013) and analysis of policy implementation.

Accessibility and dissemination to audiences with disabilities

As a general rule academic papers, and even many of the NGO reports, do not indicate what initiatives are taken to share results with partners in the field. Those partners would include (a) individual people with disabilities and carers who contributed information (data) and (b) implementing organisations / service providers such as CBR groups or disabled persons' organisations whose practice may benefit from the research findings. However a few papers, such as CARD, 2008 and Gupta and Roberts, 2014 stood out as having been disseminated to persons with disabilities. This is not to say that participants are not included in feedback and that results are not being disseminated to grassroots level, but the literature is generally not stating how the research findings are being disseminated. The majority of academic papers are still only available through subscription. However it is possible to buy single articles (rather than have to subscribe to a journal).

Steering the research agenda

While papers describe the context and background to their studies they do not generally indicate what the original stimulus for the research was. That is, it is not clear whether the idea for a piece of research was initiated by academic researchers, practitioners, policymakers, NGOs or people with disabilities; or by people in the west or in East Africa. The literature itself does not indicate what the drivers are or who is setting the agenda for applied disability research.

It may be worth searching the literature to see what research, if any, has addressed the issue of which drivers are setting the agenda of applied disability research and how theses findings are being disseminated and utilised.

Reading notes

The seventeen (17) research papers presented below are identified from the main bibliography; each of them being summarized. These researches were identified as most relevant to the Resource Center.

The criteria are as follows:

- The connection between research results and the practical implementation of the principles of the UN Convention,
- The collaboration between researchers and field stakeholders,
- The identification of applied or applicable results to improve the quality of life of people with disabilities.
- The use of a rigorous research process.

Buckup S. The price of exclusion: the economic consequences of excluding people with disabilities from the world of work. Geneva: International Labour Organisation. 2009. 97p

Acces to the reading note and to complete documents into the documentary database of the Resource Center.

Key words

Employment. UN Convention and European and national legislations. Social protection.

Author's note

To contribute to the information base used by decision-makers in allocating resources to programmes relating to the employability and employment of people with disabilities, the ILO commissioned an exploratory study of the macro–economic costs of excluding people with disabilities from the world of work. Building on previous research, this study developed a new approach that takes two drivers of economic losses into account: the gap between the potential and the actual productivity of people with disabilities; and the difference between unemployment and inactivity rates of non-disabled people and people with disabilities. Together, these drivers yield the costs that society has to bear for excluding people with disabilities from the world of work. The approach was tested using data from a selection of ten countries in Asia (China, Thailand, and Viet Nam) and Africa (Ethiopia, Malawi, Namibia, South Africa, Tanzania, Zambia, and Zimbabwe). The overall losses and the relative importance of factors underlying these losses - disabling environment, unemployment and inactivity – are estimated for each country. The study shows that by combining reasonable assumptions and adequate modelling, it is possible to generate data on the costs of exclusion, even for countries where reliable primary data are generally scarce, and suggests that these data are more robust than those generated by a global extrapolation approach.

Commentary

This paper was chosen because it draws attention to the economic loss to a country which results from under-employment of people with disabilities. The study used a new approach to estimating the economic cost of underemployment of people with disabilities. It looked at the gap between the actual and potential productivity of people with disabilities and at the difference between unemployment and inactivity rates of people with and without disabilities. A figure, given as percentage of gross domestic product, is arrived at for each country. The authors claim that reasonable estimates of exclusion can be obtained even where there is little primary data. The paper gives estimates for Ethiopia and Tanzania among eight other African and Asian countries. This paper is written for professional researchers but should be meaningful to others with tertiary level education. It is available in full by open access on the internet. This study may be useful to those advocating for fuller employment

of people with disabilities. It may also inform policymakers exploring employment and productivity matters.

Community Action Research on Disability in Uganda. How information is shared among CBR information service providers in Uganda. Community Action Research on Disability in Uganda. 2008. 2p

Access to the reading note and to complete documents into the documentary database of the Resource Center.

Key words

Accessibility. Services and care centers.

Author's note

CBR Service Providers in the course of their work acquire a wealth of knowledge and experience which, if shared is likely to benefit policy and practice. However, there are international concerns about whether information is being effectively shared and put to use. Within 19 organisations where the study was carriedout in Mbale, Mbarara, Masindi, Lira and Kampala districts, a total of 42 respondents were interviewed. A workshop using focus group discussions of these results developed ideas for improving information sharing.

Commentary

This study examined the extent and modes of communication between CBR organisations. Following interviews and focus group discussions some practical recommendations were made, particularly about the value of adapted and other non-literature based information sharing. This article was selected because it explores information exchange between CBR groups and has implications for dissemination of learning at the grass-roots level. Information was collected through interviews with 42 people working in CBR projects and a workshop. Documentation used by the CBR groups was also analysed. The study explored the methods used for the exchange of information among participating CBR teams. Barriers to information exchange were also explored. The findings address the barriers experienced at this grass-roots level and offer practical suggestions. The report of the study is available in full with open access on the internet. The style of writing aims at people with full primary education. The findings are useful for small CBR groups wanting to communicate with each other but also should provide guidance to larger organisations in improving access to information for small CBR groups. There may be benefit in exploring whether this report has been as widely read as it could be.

Groce N., Murray B., Kealy A. Disabled beggars in Addis Ababa. Current situation and prospects for change. Geneva: International Labour Organisation. 2014. 60p

Access to the reading note and to complete documents into the documentary database of the Resource Center.

Key words

Employment. UN Convention and European and national legislations. Social protection. Advocacy and self-advocacy. Social perception / Raising awareness.

Author's note

Worldwide, persons with disabilities who beg for part or all of their living are one of the most visible and least understood groups within the global disabled population. This exploratory study is intended to better understand what life is like for these individuals. It is a mixed methods study with an in-depth literature search followed by the presentation of data from a field study which collected and analyzed qualitative and quantitative data to provide an initial understanding of disabled beggars in one specific community – urban Addis Ababa. Persons with disabilities were asked how they came to beg, what their lives are on a daily basis and what they would like their futures to be. Particular attention was paid to identifying points where interventions to break the cycle of living with a disability and begging might be implemented, and to develop and validate a survey tool and appropriate set of open-ended qualitative questions that could be used for a larger, multi-country comparative study of disabled street beggars in the future. This Summary Paper presents key findings from the study. A more detailed discussion is contained in the ILO Working. Paper Disabled Beggars in Addis Ababa, Employment Working. Paper No. 141, ILO Geneva, 2013.

Commentary

This article was chosen because it draws attention to one of the "least understood" groups of people with disabilities.

Information was gathered through:

- a survey of people with disabilities who were begging for a living
- interviews with government and non-government organisations
- a literature review.

Recommendations are given regarding interventions by government and non-government agencies which could help individuals break the link between disability and begging.

The report is available in full, with open access online. The style of writing aims at people with secondary education. This study is of use to government and non-government services who could be drawing on the recommendations to help people with disabilities avoid begging.

Gupta, E. Roberts, B. User and researcher collaborations in mental health in low and middle income countries: a case study of the EMPOWER project. BMC Research Notes. 2014. 6p

Access to the reading note and to complete documents into the documentary database of the Resource Center.

Key words

Access to health services. Services and care centres. Advocacy and self-advocacy.

Author's note

Background. Increasing recognition has been given to the interaction of users and researchers in shaping the perspective and practice of mental health care. However, there remains very little evidence exploring how this interaction works, particularly in low and middle income countries. The aim of this study was to explore experiences of how users and researchers worked together to communicate research, using a case study of the EMPOWER project.

Methods. The study followed a case-study approach. EMPOWER was a project that sought to strengthen the capacity of user organizations in India, Kenya, Nepal and Zambia by encouraging user-researcher collaborations to communicate research findings in the four countries. A qualitative research method was applied for this study, with semi-structured interviews conducted with seven people: two researchers, one communications developer, and four user group members (one from each of the four countries). Data were analyzed using thematic analysis.

Results. The findings indicated positive perceptions of the collaboration between researchers and users. Key themes were partnership and support, the value of the personal experience of users and their knowledge of the target audiences, and empowerment. Key challenges related to differences in levels of education and technical knowledge and the lack of payments to users.

Conclusions. This exploratory study provides insight to help understand collaborative processes for communicating mental health research. It highlights many positive outcomes from the EMPOWER collaboration but also highlights the need for more in-depth research on this issue.

Commentary

This study was chosen because it explored the possibility of improving the communication of research findings about mental health to service-users by means of service-user / researcher partnerships. The study was conducted in four countries which were Kenya, Nepal, Zambia and India. Interviews were conducted with two researchers, one communications developer and one user group member in each country. The findings indicated positive perception of this approach and indicated some areas for improvement of the process. This is a small study

but it does show that this may be a fruitful approach. This is written for an academic readership but should be accessible to others with tertiary education. The full text is available online with open access. It might be useful to explore how widely this paper has been disseminated amongst non-government organisations who are considering conducting research in mental health. In addition, dissemination in a less-academic format amongst disabled persons' organisations and CBR groups may encourage them to feel able to suggest they take a more active role in the communication of research findings amongst service-users.

Hartley, S. Murira, G. Mwangoma, M. Carter, J. Newton, C.R.J. « Using community / researcher partnerships to develop a culturally relevant intervention for children with communication disabilities in Kenya ». Disability and Rehabilitation, 31 (6). 2009. p. 490-499

Access to the reading note and to complete documents into the documentary database of the Resource Center.

Key words

Accessibility. Culture. Autonomy. Child and teenager.

Author's note

Purpose. The objective of this study is to develop a culturally relevant community-based intervention for children with communication disabilities in Kenya through a community/researcher partnership. The resulting intervention is for use in a randomized control trial which will be reported at a later stage.

Method. Using a qualitative approach, initial data was collected through focus group discussions with women, disabled people and traditional dancers. The groups examined the needs, problems and challenges faced by disabled children and their families. This generated the content and structure for a series of participatory workshops with a further two women's groups. These workshops strove to generate a culturally relevant community-based intervention programme for children with communication disabilities and their families. The content and balance of the resulting intervention was observed to be different from existing programmes described in the literature. Notably it included many culturally appropriate strategies for increasing social integration and raising community awareness.

Results. The process of generating a locally relevant community-based rehabilitation intervention is potentially transferable and has particular relevance to the estimated 80% of the world where there are no formal rehabilitation services for children with disabilities and where women's groups are a strong element of local culture.

Conclusion

(i) Community/researcher partnerships can be used to develop interventions

(ii) such interventions are different from those imported from other cultures

(iii) this process is transferable and can be part of the preparations for a Randomized Control Trial.

Commentary

This study was selected because it describes research and intervention which was participatory and culturally appropriate and whose methodology is potentially transferrable. The aim of the study was to produce a culturally relevant, community-based intervention for children with communication difficulties. The children's needs were identified through participatory focus groups with women, people with disabilities and traditional dancers. This

led on to equally participatory workshops which developed a culturally relevant, communitybased intervention programme. The intervention was noted to be qualitatively different from those generated by more traditional research and service development methods. In particular it was felt to be appropriate to the culture of the community which developed the programme. In addition the intervention involved the whole community, rather than mainly parents, more than is usual. The authors feel that the highly participatory process was successful and should be transferrable. This is published in an academic journal. It is available online in full by open access. The authors intended this to act partly as a pilot for further research. It may be useful to search for subsequent papers by this group.

This paper is of interest to the research community. It may also be of interest to disabled people's organisations who may wish to advocate for more participatory research.

Kalyango, J.N. Hall, M. Karamagi, C. « Home medication management practices and associated factors among patients with selected chronic diseases in a community pharmacy in Uganda ». BMC Health Services Research, 12. 2012. p. 323.

Access to the reading note and to complete documents into the documentary database of the Resource Center.

Key words

Access to health services.

Author's note

Background. Chronic diseases are rapidly increasing and are currently the major cause of death and disability worldwide. Patients with chronic diseases experience many challenges including medicine-related problems. However, there is limited information about the home management of medicines among these patients. This study therefore was to determine home medication management practices and associated factors among patients with chronic diseases seeking care in a community pharmacy in Uganda.

Methods. A cross-sectional study was conducted in a community pharmacy in Kampala from June to July 2010. A total of 207 consenting chronic disease patients or caregivers of children with chronic disease were consecutively sampled. The patients were visited at home to evaluate their drug management practices and to check their medical forms for disease types and drugs prescribed. An interviewer-administered questionnaire and an observation checklist were used to collect the data.

Results. Overall home medication management was inappropriate for 70% (n = 145) of the participants (95% CI = 63.3-76.2) and was associated with perceived severity of disease (not severe OR = 0.40, moderately severe OR = 0.35), duration of disease >5 years (OR = 2.15), and health worker not assessing for response to treatment (OR = 2.53). About 52% (n = 107) had inappropriate storage which was associated with inadequate information about the disease (OR = 2.39) and distance to the health facility >5 kilometres (OR = 2.82). Fifteen percent (n = 31) had no drug administration schedule and this was associated with increasing age (OR = 0.97), inadequate information about the disease (OR = 2.96), and missing last appointment for medical review (OR = 6.55). About 9% (n = 18) had actual medication duplication; 1.4% (n = 3) had expired medicines; while 18.4% (n = 38) had drug hoarding associated with increasing number of prescribers (OR = 1.34) and duration of disease (OR = 2.06). About 51% (n = 105) had multiple prescribers associated with perceiving the disease to be non severe (OR = 0.27), and having more than one chronic disease (OR = 2.37).

Conclusions. Patients with chronic disease have poor home management of medicines. In order to limit the occurrence of poor outcomes of treatment or drug toxicity, health

providers need to strengthen the education of patients with chronic disease on how to handle their medicines at home.

Commentary

This paper was chosen because it considers an issue which in relative terms may not be too difficult to address and which could make a considerable difference. Chronic illness is a major cause of disability worldwide and is increasing. This study examined the medication management practices of patients with chronic illnesses. The researchers found inadequate practices in 70% of participants. These related to a number of factors such as inadequate information or monitoring from health workers, barriers to attending medical appointments, use of multiple prescribers and poor information about the diseases. The researchers recommend in particular strengthening of health workers' education of patients about managing medications. This paper is written for the research community. Its full content is available through open access on the internet. This subject may have potential for further exploration with respect to possible awareness raising among frontline health workers in tertiary and community settings, including pharmacists, and mid-level workers.

Leonard Cheshire Disability and Inclusive Development Centre. Disability and urban agriculture – an innovative approach. LCD and Inclusive Development Centre. London. 2013. 8p

Access to the reading note and to complete documents into the documentary database of the Resource Center.

Key words

Employement. Social protection. Autonomy. Accessibility. Independent living.

Author's note

Little is known about the extent to which persons with disabilities rely on agriculture in urban areas for livelihood support, or what - if any - opportunities persons with disabilities have to participate in urban agriculture. This pilot research project was an attempt at raising awareness and identifying gaps in access to urban agriculture for persons with disabilities through action based-research in Thika, Kenya. The results of the survey, the focus groups and interviews and the work undertaken in the demonstration gardens, has highlighted a need for expansion and training on innovative urban and peri-urban agriculture methods, such sack gardens, vermiculture, etc., which can be adapted for persons with disabilities. Much more research is needed on the links between disability-specific and disability-inclusive activities, focusing on what currently exists, and on where synergies can be fostered and promoted for improving food security and nutrition, as well as providing livelihoods and economic benefit through small-scale enterprise.

Commentary

This paper was chosen because it considers a possible very practical approach to improving livelihoods, nutrition and inclusion for people with disabilities living in urban settings. This was a participatory project. People with disabilities were interviewed. Methodologies for people with disabilities to practice small-scale urban agriculture were tried out in demonstration gardens. The paper considers the need for disability to be included in government and non-government urban agricultural initiatives which were taking place in Kenya at the time of this research. This paper is available in full by open access online. Its style addresses readers with secondary education. This study may be useful to disabled peoples' organisations to advocate for inclusion in urban agriculture initiatives.

Lewis, I. Young voices: Young people's views of inclusive education. Oslo: The Atlas Alliance. 2008. 52p

Access to the reading note and to complete documents into the documentary database of the Resource Center.

Key words

Education. Accessibility. Child and teenager

Author's note

The main aim of the Young Voices project was to create a book and a film, showcasing the views and photography of these young people. But we hope that it will also encourage other adults and young people to think about what makes their schools inclusive, to carry out similar projects, and to work together to solve any problems, so that their schools become more inclusive for everyone. "This booklet of students' photographs, drawings and opinions illustrates efforts to make inclusive education really happen. Issues raised by the young people range from policy, attitudes and behaviour, to resource allocation and environmental issues. The booklet showed me the need for collective responsibility and action from education policy-makers, managers, administrators, teachers, parents, caregivers and students in changing the perceptions of educational needs for children with and without disabilities."

Commentary

This paper was included because it reminds us that we may miss important considerations if we do not consult service-users. In this case the service-users are children with and without disabilities commenting on an inclusive education environment. The study also explains what factors made the participating children feel included in the school environment. This project sought the views of pupils with and without disabilities, in an inclusive education setting, about the inclusiveness of their school environment. The children used drawing, drama, filming, photography and discussions to express their views. The product is a book which conveys the children's views. The study illustrates the importance of seeking the children's views. The study also sets out some of the factors which made them, those with and those without disabilities feel included. The author concludes that the exercise showed her the need for collaboration between a wide range of stakeholders from policymakers to teachers, the children and others in order to achieve inclusiveness in the education environment. The full text is available through open access online. The book is presented in a style accessible to anyone including upper primary pupils. This study will be of interest to policymakers and educators striving towards inclusive education and to parents and disabled peoples' organisations.

Musoke, G. Geiser, P., eds. Linking CBR, disability and rehabilitation. Bangalore: CBR Africa Network. 2013. 121p

Access to the reading note and to complete documents into the documentary database of the Resource Center.

Key words

Access to health services. Autonomy. Services and care center. International Development. Independent living.

Author's note

Excerpts from the foreword and editorial

This book is a recollection of the highlights from the 4th CBR Africa Conference 2010 held in Abuja, Nigeria on 26th -29th October, 2010. The conference also provided an opportunity to explore key features of CBR and how they are enacted in African contexts. Held under the theme "Linking CBR, Disability and Rehabilitation", it placed a deliberate emphasis on partnerships, between community stakeholders, within and between sectors of services, as well as across different perspectives and disciplines (including the need for measurement, research and training capacities in CBR). This book examines how services and support to people with disabilities in Africa are best delivered by multi-disciplinary teams and through mobilizing a wide range of stakeholders, including persons with disabilities themselves and their families. The book seeks to address such questions as: who are the stakeholders if CBR is to be meaningful to people with disabilities? How can linkages be made across sectors to ensure that people with disabilities are at the centre in implementing CBR? How can the capacity of key stakeholders be built to support the development of CBR? How are health and rehabilitation linked to CBR? And how can evidence that CBR is effective be strengthened?

Commentary

This book was chosen because it addresses CBR fairly comprehensively. This book is a recollection of the highlights from the 4th CBR Africa conference in 2010. The book is divided into chapters, each of which addresses a key issue in CBR, such as, "The role of the community in CBR," and "Learning to do CBR". This is not a basic introduction to CBR but more a critical reflection. It will therefore be useful to actors already involved in CBR who wish to critically appraise the approaches being taken by their organisations and communities and who are seeking ideas from the experiences of others. The style is suitable for people with secondary education. Its content is available in full online with open access.

Othieno, C. Jenkins, R. Okeyo, S. Aruwa, J. Wallcraft, J. Jenkins, B. « Perspectives and concerns of clients at primary health care facilities involved in evaluation of a national mental health training programme for primary care in Kenya ». International Journal of Mental Health Systems, 7:5. 2013. 7p

Access to the reading note and to complete documents into the documentary database of the Resource Center.

Key words

Access to health services. . Services and care center

Author's note

Background. A cluster randomised controlled trial (RCT) of a national Kenyan mental health primary care training programme demonstrated a significant impact on the health, disability and quality of life of clients, despite a severe shortage of medicines in the clinics (Jenkins et al. Submitted 2012). As focus group methodology has been found to be a useful method of obtaining a detailed understanding of client and health worker perspectives within health systems (Sharfritz and Roberts. Health Transit Rev 4:81–85, 1994), the experiences of the participating clients were explored through qualitative focus group discussions in order to better understand the potential reasons for the improved outcomes in the intervention group.

Methods. Two ninety minute focus groups were conducted in Nyanza province, a poor agricultural region of Kenya, with 10 clients from the intervention group clinics where staff had received the training programme, and 10 clients from the control group where staff had not received the training during the earlier randomised controlled trial.

Results. These focus group discussions suggest that the clients in the intervention group noticed and appreciated enhanced communication, diagnostic and counselling skills in their respective health workers, whereas clients in the control group were aware of the lack of these skills. Confidentiality emerged from the discussions as a significant client concern in relation to the volunteer cadre of community health workers, whose only training comes from their respective primary care health workers.

Conclusion. Enhanced health worker skills conferred by the mental health training programme may be responsible for the significant improvement in outcomes for clients in the intervention clinics found in the randomised controlled trial, despite the general shortage of medicines and other health system weaknesses. These findings suggest that strengthening mental health training for primary care staff is worthwhile even where health systems are not strong and where the medicine supply cannot be guaranteed.

Commentary

This paper was chosen because it describes positive results from a programme which gave training on mental health to primary healthcare workers. This approach has potential to improve mental health services with relatively modest investment. Primary healthcare workers in Kenya were given training on mental health interventions. A cluster randomised controlled trial demonstrated that the programme had had a significant impact on the health, disability and quality of life of clients. This paper reports service-users' views of the programme as derived from focus group meetings. Feedback from the service-users was positive. The researchers conclude that the training programme for mental health workers in primary care was effective. The content of this paper is available in full by open access on the internet. It is written in academic style. This paper will support health workers who feel that they, and their service-users would benefit if they were to have further training in mental health. This will also be of interest to disabled person's organisations and policymakers.

Skovdal, M. « Examining the trajectories of children providing care for adults in rural Kenya: implications for service delivery ». Children and Youth Services Review, 33 (2011). 2011. p. 1262-1269

Access to the reading note and to complete documents into the documentary database of the Resource Center.

Key words

Indepedent living. Service and care centers. Child and teenagers.

Author's note

Research on caregiving children tends to be limited to children's caregiving experiences of parents with a specific disease or disability. This has led to a common perception that children's caregiving is a single, uniform and often long-term experience. Whilst this is most certainly the case for many children in economically more advanced countries, this may not hold true in rural Africa, where poverty and AIDS can have significant knock-on effects on entire families and communities. This paper seeks to develop a more complex understanding of children's caring experiences by asking children whom they have cared for over time and explore the different pathways that lead to their caregiving at different stages of their lives.

The study reports on qualitative data collected from 48 caregiving children and 10 adults in the Bondo district of western Kenya in 2007. A multi-method approach was adapted, with historical profiles, Photovoice and draw and-write essays complementing 34 individual interviews and 2 group discussions. A thematic network analysis revealed that children's caregiving was not confined to a single experience. Children were observed to provide care for a number of different family and community members for varying periods of time and intensities. Although their living arrangements and life circumstances often gave them little choice but to care, a social recognition of children's capacity to provide care for fragile adults, helped the children construct an identity, which both children and adults drew on to rationalise children's continued and multiple caring experiences. The study concludes that agencies and community members looking to support caregiving children need to consider their care trajectories — including whom they care for as well as the order, intensity, location and duration of their past and likely future caring responsibilities.

Commentary

This study was chosen because of its capacity to remind community workers to support children who are caring for adult service-users. This research examined the pattern of care giving by children towards adults with illness or disability. A variety of methods were used to elicit the children's experiences. These included photovoice, draw-and-write essays, interviews and group discussions. It was found that children tended to care for a number of different family and community members at different times, for different lengths of time and at different levels of intensity. The pattern of a child caring for a single adult for extended periods was not standard. This finding may be of value to community workers whose understanding of the nature of children's roles will help them support the children appropriately. The full content of this paper is available through open access online. The paper is written in academic format. This paper might be useful to trainers of CBR workers, though it may need to be interpreted before being presented.

Teferra, T. « Resilience and successes of persons with disabilities in Ethiopia » in Disability in Ethiopia: Issues, Insights and Implications. Addis Ababa: Addis Ababa Printing Press. 2005.

Access to the reading note and to complete documents into the documentary database of the Resource Center.

Key words

UN Convention and european and national legislations. Advocacy and self advocacy. Service and care centers. Family. Child and teenager

Author's note

Excerpts from the introduction and the summary

This is an empirical cross-disability study among successful persons with hearing, visual and motor impairments. It tries to explore the threads of resilience which may be attributed to personal as well as environmental factors within the Ethiopian context. As it is the first attempt in the country, it is presumed to bring a fresh insight in the field and serve as a basis future intervention and research endeavour. The scope of the study was limited to three groups of persons with hearing, visual and motor impairments. A questionnaire consisting of structured and semi-structured items, and focus-group discussion schedules were developed and employed for collecting data. This study has attempted to examine the nature of specific personal qualities of selected persons with disabilities of high achievement or success in Ethiopia. In this endeavour, the study has brought to light the importance of : a) caring and supportive family in promoting self-esteem, self-efficacy and resilience, and contextualizing the coping styles employed at a personal and social level. The findings of this study have shown a great deal of imilarity with the studies conducted in the other parts of the world. The data generated may serve as a learning experience not only for children and young persons with disabilities but also for their parents, caregivers, teachers and practitioners in the field of rehabilitation as well as researchers.

Commentary

This study was chosen because it focuses on positive expectations for people with disabilities and identifies significant factors which contribute towards their success. Ninety people with visual, hearing and motor disabilities who were considered to be relatively high achievers were interviewed. The principal factors contributing towards their success were identified as caring and supportive family and community in promoting self-esteem and ability to apply coping strategies. This is not a ground-breaking study; the authors say that the findings are consistent with research from other parts of the world. Nonetheless the findings are evidence of effective interventions. This study would be useful in the training of frontline health workers as it demonstrates the benefits of working with whole families and communities, rather than focusing entirely on people with disabilities. It would also be useful in teacher training in showing teachers the benefits of encouraging peer-support in schools.

The African Child Policy Forum. The lives of children with disabilities in Africa: a glimpse into a hidden world. Addis Ababa: The African Child Policy Forum. 2011. 86p

Access to the reading note and to complete documents into the documentary database of the Resource Center.

Key words

UN Convention - national legislations - equality and non-discrimination. Advocacy. Child

Author's summary

"The lives of children with disabilities in Africa: a glimpse into a hidden world," is a multiple country study conducted by the African Child Policy Forum (ACPF). The study took place in Ethiopia, South Africa, Senegal and Uganda – all countries that have ratified the UN Convention on the Rights of Persons with Disabilities. In Ethiopia, Senegal and Uganda, approximately 1,339 children with disabilities and 1,473 primary caregivers were interviewed. In South Africa, a desk review was conducted of the situation for children with disabilities. This project looked at various aspects of the realities facing children with disabilities in selected countries in Africa, including the following: a review of policies and legislation and their implementation; service delivery; the impact of poverty on wellbeing; health care, education and employment; knowledge, attitudes and practices; and social integration. Findings suggested that while all four countries in the study have the necessary policies and legislation in place to protect the rights of children with disabilities, these are rarely implemented effectively.

Commentary

This study was chosen because it gives a broad overview of life for children with disabilities in Africa, including East Africa. The study made the connections which are crucial if circumstances are to improve for children with disabilities, namely the connections between the lived experience of disability, policy and implementation. The children's voices were heard. Over 1,300 children were interviewed. The voices of primary caregivers were heard.

Over 1,400 primary caregivers were interviewed. Policy and legislation and their implementation were reviewed. The writing style is aimed at people with good secondary education but not necessarily tertiary education. The full text is available openly (without subscription) on the internet. This study should be useful to those needing an introduction to the field and to those needing a broad overview. It is likely to be useful to policymakers, academics and to NGOs exploring the field of children with disabilities such as development NGOs who are exploring the field of disability for the first time.

Tumwesigye, C. Msukwa, G. Njuguna, M. Shilio, B. Courtright, P. Lewallen, S. « Inappropriate enrolment of children in schools for the visually impaired in East Africa ». Annals of Tropical Paediatrics, 29 (2). 2009. p. 135-139.

Access to the reading note and to complete documents into the documentary database of the Resource Center.

Key words

Education. Child and Teenager

Author's note

Background. Many visually impaired children can learn to read print with appropriate training and simple visual aids. This may allow them to attend normal schools and to be integrated into society, which has lifelong benefits. Yet, in Africa, many visually impaired children are enrolled in special schools and taught only Braille. The purpose of this analysis was to document the extent of inappropriate enrolment of visually impaired children in special schools and annexes for the blind in four African countries.

Methods. Schools were selected through a population-proportional-to-size method so that they would represent all children attending special schools in Kenya, Malawi, Tanzania and Uganda. Children were examined by ophthalmologists trained in standardised methods to determine visual acuity and the cause of decreased acuity.

Results. Of 1062 children examined in special schools and annexes for the blind, 361 (34%, 95% CI 31.2, 36.8) had visual acuity >6/60; the most common cause of visual impairment was retinal disease. Of the 120 children with normal vision (>6/18), 69 (57.5%) had two normal eyes, 21 (17.5%) had an obvious ocular disfigurement in the fellow eye and 10 (8.4%) had had successful cataract surgery.

Commentary

This study was chosen because it demonstrates that a proportion of children who have nearnormal, or even normal, vision are attending schools for the visually impaired.

Children in special schools, or special annexes for the visually impaired, were assessed by ophthalmologists. It was found that a proportion of the children had near-normal, or even normal vision. The authors contend that children with a certain degree of visual impairment can learn to read print with low-key interventions and do not need to be in special settings where they are taught only Braille. The authors say that full elucidation for the reasons for inappropriate school admissions was beyond the scope of the study. However they point to some possibilities such as, non-assessment of children's vision, albino children enrolled because special schools are perceived to be shelters from stigma, schools benefitting from funding from pupil numbers, parents benefitting from lower boarding and uniform fees, people not understanding that cataract surgery in fact restores vision.

Implications:

a. Children's vision should be assessed if they are being considered for special schools or special annexes for the visually impaired.

b. Education of communities about visual impairment and of families of children who have cataract surgery.

Preventative measures (a, and b) may not require high levels of resources.

c. Further research to understand the prevalence and causes of this situation.

This paper is available in full on the internet by subscription only. It is written in academic / research format and may need to be presented differently for user groups such as disabled people's organisations. This study will be of interest to education authorities and to those providing services for visual impairment.

Van Duijl, M. Kleijn, W. DeJong, J. « Unravelling the spirits' message: a study of help-seeking and explanatory models among patients suffering from spirit possession in Uganda ». International Journal of Mental Health Systems. 2014. 13p

Access to the reading note and to complete documents into the documentary database of the Resource Center.

Key words

Culture. Access to health services.

Author's note

As in many cultures, also in Uganda spirit possession is a common idiom of distress associated with traumatic experiences. In the DSM-IV and -5, possession trance disorders can be classified as dissociative disorders. Dissociation in Western countries is associated with complicated, time-consuming and costly therapies. Patients with spirit possession in SW Uganda, however, often report partial or full recovery after treatment by traditional healers. The aim of this study is to explore how the development of symptoms, concomitant helpseeking steps, and explanatory models (EM) eventually contributed to healing of patients with spirit possession in SW Uganda. Illness narratives of 119 patients with spirit possession referred by traditional healers were analysed using a mixed-method approach. Treatments of two-thirds of the patients were unsuccessful when first seeking help in the medical sector. Their initially physical symptoms subsequently developed into dissociative possession symptoms. After an average of two help-seeking steps, patients reached a healing place where 99% of them found satisfactory EM and effective healing. During healing sessions, possessing agents were summoned to identify themselves and underlying problems were addressed. Often-mentioned explanations were the following: neglect of rituals and of responsibilities towards relatives and inheritance, the call to become a healer, witchcraft, grief, and land conflicts. The results demonstrate that traditional healing processes of spirit possession can play a role in restoring connections with the supra-, inter-, intra-, and extrahuman worlds. It does not always seem necessary to address individual traumatic experiences per se, which is in line with other research in this field. The study leads to additional perspectives on treatment of trauma-related dissociation in Western countries and on developing effective mental health services in low -and middle-income countries.

Commentary

This study was chosen because it suggests that traditional healing methods for spirit possession / dissociative disorders may be effective and less resource intensive than western treatment methods. This study looked at traditional healing methods for spirit possession which are classified as dissociation disorders in western medicine.

Illness narratives of over a hundred patients who had been treated by traditional healers were analysed. The researchers found that traditional healing methods appeared to sometimes be effective for this type of illness, even after an average of two sessions. Western therapies for dissociation disorders are time-consuming and costly. These findings have implications for the development of effective treatments for spirit possession / dissociative disorders in the region. This paper is written in an academic / research style. It is available in full on the internet by open access. This research is of interest to those involved in the development and delivery of mental health services in the region.

Wickenden, M. Mulligan, D. Fefoame, G.O. Katende, P. « Stakeholder consultations on community-based rehabilitation guidelines in Ghana and Uganda ». African Journal of Disability 1(1). 2012.

Access to the reading note and to complete documents into the documentary database of the Resource Center.

Key words

Access to health services. Autnomy. UN Convention and european and national legislations. Advocacy and self advocacy. International Development.

Author's note

Background. The focus of this paper is the new broadened conceptualisation of communitybased rehabilitation (CBR), which promotes the empowerment and inclusion of people with disabilities (PWDs) in diverse ways within their communities. New guidelines for CBR were launched in October 2010 by WHO/ILO/UNESCO/IDDC, and this paper describes part of the process by which these were produced using participatory approaches involving International Non-Government Organisations (INGOs) and local partners. The paper reviews the evolution of CBR and describes how grassroots consultation by INGOs working with key stakeholders in the disability arena can influence policy on disability issues, and reciprocally how policy change can inform organisations' practice and research activities. This ongoing bidirectional influence is illustrated with data from the participatory consultation process about the new CBR guidelines carried out by Sightsavers in Uganda and Ghana.

Objective. To consult with key stakeholders in the disability arena in Uganda and Ghana, in order to gain their opinions and suggestions for improvements to the then draft CBR guidelines, as part of a wider global participatory process of consultation on the document.

Methods. The INGO Sightsavers gathered qualitative data through focus group discussions and questionnaires in both countries.

Results. The participants' critiques of the draft guidelines carried out in multiagency participatory processes were analysed thematically and fed back to the CBR guidelines editorial team.

Conclusion. The paper concludes that stakeholders in diverse communities can actively contribute to shaping policy and practice through participatory consultations. Local and national government and non-government organisations and other key informants can inform the development of national and international guidelines and policies. This participatory approach can be successfully facilitated by INGOs. In turn, these processes have prompted organisations to adapt their own policies and programmes in order to be more responsive to the local needs and concerns of PWDs.

Commentary

This paper was chosen because it illustrates the effectiveness and value of consultation between grassroots actors and international organisations in influencing policy and practice. This study examines the participatory consultation process which took place between international organisations, local partners and other key stakeholders as part of the development of the international 2010 CBR guidelines. The authors observe how the contributions of grassroots stakeholders influenced policy change and how policy change influences organisations' practices. The authors observe that "stakeholders in diverse communities can actively contribute to shaping policy and practice through participatory consultations." A process such as this has the potential to focus the relevance of research, policy and practice. A process such as this includes the voices of people with disabilities in shaping policies and practices which affect them. This paper is available in full online through open access. It is written in an academic format but should be accessible to those with full secondary education. This paper may be useful to students of disability studies, to international development organisations beginning to include disability, to policymakers and to disabled people's organisations.

Yokoyama, A. « A comparative analysis of institutional capacities for implementing disability policies in East African countries: functions of national councils for disability ». Disability, CBR and Inclusive Development (DCID), 23 (2).2012.

Access to the reading note and to complete documents into the documentary database of the Resource Center.

Key words

UN Convention and european and national legislations.

Author's note

During the "African Decade of Persons with Disabilities (2000-2009)", East African countries witnessed significant achievements, especially in the development of law, collection of statistics and in funding. However, many persons with disability are still marginalised from opportunities in education, healthcare and employment.

Purpose. With the pre-supposition that the lack of institutional capacities for implementing disability policies is the one major stumbling-block which hinders widespread delivery of social services to persons with disabilities in low-income countries, this study makes a comparative analysis of institutional capacities in the disability sectors of Uganda, Kenya and Tanzania.

Method. The research methods adopted were a literature survey and a field survey. The framework for analysis consists of: 1) capacities and functions of disability units in central governments, 2) relationships between central and local governments in the disability sector, and 3) relationships between governments and organisations of persons with disability (DPOs). Special attention is paid to the status, roles and functions of national councils for disability (NCDs), the independent statutory bodies recently established in each of the three countries, with clear authority and duties for the implementation of disability policies. The NCDs enable multi-sectoral stakeholders to be involved in the implementation of disability policies; therefore, positive relationships between the governments and DPOs are essential for the smooth functioning of the NCDs.

Results. While the result of the field survey in Tanzania reveals several effective approaches for the smooth operation of the NCD, further study is needed to verify whether these approaches would be applicable to other East African countries such as Kenya and Uganda.

Commentary

This study was chosen because it examines the methods and effectiveness of collaboration of multiple stakeholders in effecting change for persons with disabilities.

The study examined relationships between stakeholders in central government, local government and disabled people's organisations, and in particular at the National Councils for Disability. The study also examined the processes of collaboration between these

stakeholders. The researchers observed different approaches to communication and collaboration between central government, local government and disabled people's organisations in the four countries of the study. The study examines the effectiveness of these different approaches to collaboration. This paper is available in full through open access on the internet. This is an academic paper whose style should be accessible to an informed reader with tertiary education. This paper is of interest to actors at different levels of government and to disabled people's organisations because it illustrates and appraises different approaches to collaboration between central government, local government and people with disabilities.

Annotated bibliography

The bibliography contains the 175 researches that have been identified during the mapping on applied research in East Africa. These references were selected for their relevance to the Resource Center criteria. However, flexibility had to be adopted in the application of the criteria in order to better report on the needs in terms of research.

A link to each research is available by clicking on the title (the majority of them are on free access).

The link leads to the full notice into the Resource Center documentary databse for the references presented in reading notes.

Abera M., Tesfaye M., Belachew T., Hanlon. C. « <u>Perceived challenges and opportunities arising from integration of mental health into primary care: a cross-sectional survey of primary health care workers in south-west Ethiopia</u>. » BMC Health Services Research. 2014. 10.p.

This research considered delivery of mental health support of the healthcare system in Ethiopia. It was found that health workers at the community level were keen to deliver care but lacked the training to be able to do so. It also found that the health service systems for mental health need strengthening. This study will support health workers at all levels in the health service, including mid-level workers, in advocating for training in mental health and for facilities to support this work.

Abubakar A., Holding P., Van Baar A., Newton C.R., Van de Vijver F.J. « Monitoring psychomotor development in a resource limited setting: an evaluation of the Kilifi <u>Developmental Inventory</u>. » Annals of Tropical Paediatrics, 28. 2008. p. 217-226 (paying access)

This study assesses a tool designed to identify psychomotor disabilities in infants for its accuracy and suitability for resource poor settings.

Abubakar A., Alonso-Arbiol I., Van de Vijver F.J., Murugami M., Mazrui L., Arasa J. « <u>Attachment and psychological well-being among adolescents with and without</u> <u>disabilities in Kenya: the mediating role of identity formation</u>. » Journal of Adolescence, 36 (5). 2013. p.849-857. (paying access)

This study examined factors contributing towards the psychological wellbeing of adolescents with and without disabilities in Kenya. In particular the roles of attachment and identity development.

The African Child Policy Forum. <u>Children with disabilities in Ethiopia: the hidden reality</u>. Addis Ababa: The African Child Policy Forum. 2011. 96 p.

This detailed study reviews the general situation in Ethiopia for children with disabilities, it draws on interviews with children with disabilities and their carers and examines the policy and implementation contexts.

The African Child Policy Forum. <u>Violence against children with disabilities in Africa:</u> <u>field studies from Cameroon, Ethiopia, Senegal, Uganda and Zambia</u>. Addis Ababa: The African Child Policy Forum. 2011. 72 p.

This research explored the issue of violence against children with disabilities in the five named countries. It included interviews with more than (nine hundred) 900 people with disabilities and other key informants.

The African Child Policy Forum. <u>Educating children with disabilities in Africa:</u> <u>towards a policy of inclusion</u>. Addis Ababa: The African Child Policy Forum. 2011. 106 p.

This report explores the legal and policy framework and the realities on the ground around the inclusion of children with disabilities in education in Africa by drawing particularly on desk-based and primary research in Ethiopia, the Central African Republic, Sierra Leone, South Africa and Zambia. The report is intended to set out for governments, and others concerned with providing education, the rights of children with disabilities to education and other issues associated with providing them with education.

The African Child Policy Forum. <u>The lives of children with disabilities in Africa: a glimpse into a hidden world</u>. Addis Ababa: The African Child Policy Forum. 2011. 67 p.

This study examined the situation for children with disabilities in Ethiopia, South Africa, Senegal and Uganda. It combined primary research with desk-based research. The study looks at the legal and policy frameworks and the lived experiences of children with disabilities and their caregivers.

 Adeoye A., Seeley J., Hartley S. « <u>Developing a tool for evaluating community-based</u> <u>rehabilitation in Uganda</u> ». Disability and Rehabilitation, 33 (13-14). 2011. p. 1110-1124 (paying access)

About CBR.

Aderemi. T.J., Mac-Seing M., Woreta S.A., Mati K.A. <u>Predictors of voluntary HIV</u> <u>counselling and testing services utilization among people with disabilities in Addis</u> <u>Ababa, Ethiopia</u>. AIDS Care. 2014. 6 p (paying access)

This article looks at factors affecting the uptake of HIV testing and counselling by people with disabilities.

Albu M. Economic empowerment of disabled people: lessons from northern Uganda about developing the market for enterprise-based skills development services. Moreton-in-Marsh: APT Enterprise Development. 2005. 15 p.

This paper describes an action research project which explored factors around inclusion of people with disabilities in employment. It looks at this from the point of view of how markets can operate to work for marginalised groups.

 Aldersey H.M., Rutherford Turnbull H. « <u>The United Republic of Tanzania's national</u> policy on disability: A policy analysis. » Journal of Disability Policy Studies, 22(3).
 2011. p. 160-169. (paying access)

This article is about implementation of government commitment to inclusion of people with disabilities in Tanzania.

Aldersey H.M. « Family perceptions of intellectual disability: Understanding and support in Dar es Salaam ». African Journal of Disability. 1(1). 2012. 12 p.

This study explores the perceptions of family members of people with intellectual disabilities about how they understand intellectual disability and around support within families.

Amosun S.L., Mutimura E., Frantz J.M. «<u>Health promotion needs of physically</u> <u>disabled individuals with lower limb amputation in Rwanda</u>». Disability and Rehabilitation, 27 (14). 2005. p. 837-847 (paying access).

This research studied the health and health-seeking behaviours of people in Rwanda with lower limb amputations

Aniyamuzaala J.R. « <u>Raising our voices for an inclusive society: Challenges and opportunities for the disability rights movement in Uganda</u>». Journal of Human Rights Practice, 4(2). 2012. p. 280-287 (paying access)

This article is about advocacy for people with disabilities.

Ayazi T., Lien L., Henning Eide A., Jenkins R., Amok Alvino R., Hauff E. « <u>Disability</u> <u>associated with exposure to traumatic events: results from a cross-sectional</u> <u>community survey in South Sudan</u> » BMC Public Health, 13. 2013. p. 469.

This research used a standardised method for assessing the prevalence of disability. It identifies the prevalence of disability in South Sudan and some of the major contributory factors.

Ayazi T., Lien L., Eide A., Shadar E.J., Hauff E. « <u>Community attitudes and social</u> <u>distance towards the mentally illin South Sudan: a survey from a post-conflict</u> <u>setting with no mental health services</u> ». Social Psychiatry and Psychiatric <u>Epidemiology</u>, 49 (5). 2014. p. 771-780. (paying access)

This study examined what factors in people's beliefs affected the extent to which they will associate with or distance themselves from people with mental illness. The research calls for social beliefs to be addressed as part of programmes to develop mental health services.

Baptiste S.J., Malachie T., Struthers P. « <u>Physical environmental barriers to school</u> <u>attendance among children with disabilities in two community based rehabilitation</u> centres in Rwanda » Rwanda Journal of Health Sciences, 2 (1). 2013. p. 10-15.

This research investigated physical, environmental barriers to school attendance by children with disabilities within community based rehabilitation centres in Rwanda. It found that the physical environment presents barriers to access to education for these children.

Barrett H., Marshall J. « Implementation of the World Report on Disability: developing human resource capacity to meet the needs of people with communication disability in Uganda ». International Journal of Speech-Language Pathology, 15 (1). 2013. p. 48-52. (paying access)

This paper describes a programme to train speech and language professionals for Uganda. It also considers the broader issues of developing new cadres of health professionals in a low-income country context.

Beisland L.A., Mersland R. « Income characteristics and the use of microfinance services: evidence from economically active persons with disabilities ». Disability and Society, 29 (3). 2014 p. 417-430. (paying access)

This study examines income levels and sources, and access to microfinance for people with disabilities in Uganda.

Beisland L.A., Mersland R. « <u>Staff characteristics and the exclusion of persons with disabilities: evidence from the microfinance industry in Uganda</u> ». Disability and Society, 29 (7). 2014. p. 1061-1075. (paying access)

This research examines factors regarding access to microfinance for people with disabilities in Uganda.

Boersma M. <u>Violence against Ethiopian children with disabilities</u>. The stories and perspectives of children. Masters. University of Amsterdam. 2010. 60 p

This is a thesis for a Masters in Medical Sociology and Anthropology about violence suffered by children with disabilities in Ethiopia (the studies were conducted in 2007/8). It includes a literature review about violence towards children with disabilities and interviews with Ethiopian children with disabilities. The author considers the children's stories in the context of the extent to which they are included amongst community members and the way they are viewed by family and community. The research questions were: What are the experiences of violence against children with disabilities, of Ethiopian children with disabilities, their family and community? How does the organisation of Ethiopian society influence violence against their children with disabilities?

Botokro Beguin R. « <u>An overview of occupational therapy in Africa</u> ». WFOT Bulletin, 68. 2013. p. 51-58. (summary available)

This article is an overview of occupational therapy in Africa. It contents several examples or experiences in this field. This document may be useful for developing rehabilitation services in the East Africa region.

Bouchard M., Kohler J.C., Orbinski J., Howard A. « <u>Corruption in the health care sector: a barrier to access of orthopaedic care and medical devices in Uganda</u>». BMC International Health and Human Rights, 12:5. 2012. 9.p.

This research looked at elements of corruption as barriers to access to orthopaedic care and medical devices. This research may be useful for policy markers, managers of health services and Users of orthopaedic services.

Boyce W., Cote L. 2009. « <u>The influence of HIV/AIDS on community-based</u> <u>rehabilitation in Dar es Salaam, Tanzania</u>». Asia Pacific Disability Rehabilitation Journal, 20 (1). 2009

This study identifies the effect of a diagnosis of HIV in a family on both carer and CBR workers' ability to support a family member with disability.

Bruce S.M., Venkatesh K. « <u>Special education disproportionality in the United</u> <u>States, Germany, Kenya, and India</u>». Disability and Society, 29 (6). 2014. p. 908-921. (Paying access)

This research explored the impacts of gender, economic status, ethnicity and culture on the likelihood of a child with a disability being enrolled in school in Kenya, India, Germany and the United States.

Buckup, S., 2009. The price of exclusion: the economic consequences of excluding people with disabilities from the world of work. Geneva: International Labour Organisation. 2009. 85p.

This research used a new approach to exploring the economic costs of under employment of people with disabilities. It takes into account the relative levels of employment of people with disabilities compared with the general population and the difference between the potential and actual productivity of people with disabilities which are factors of their physical and socio-cultural environment.

Bunning K., Gona J.K., Buell S., Newton C.R., Hartley S. « <u>Investigation of practices</u> to support the complex communication needs of children with hearing impairment and cerebral palsy in a rural district of Kenya: a case series ». International Journal of Language and Communication Disorders, 48 (6). 2013. p. 689-702. (Paying access)

This research explores how cadres other than fully qualified speech and language therapists manage in assisting children with complex communication needs. It is of interest to those concerned with communication. It is also of interest to those concerned with sharing the roles of professional therapists with others such as teachers and CBR workers. The paper is rather technical to read.

Bunning K., Gona J.K., Odera-Mung'ala V., Newton C.R., Geere J-A., Swee Hong C., Hartley S. « <u>Survey of rehabilitation support for children 0–15 years in a rural part</u> <u>of Kenya</u> ». Disability and Rehabilitation, 36 (12). 2014. p. 1033-1041.

This research surveys the extent and appropriateness of services for children with disabilities in rural Kenya.

Community Action Research on Disability in Uganda. <u>How information is shared</u> <u>among CBR service providers in Uganda</u>. Town not stated: Community Action Research on Disability in Uganda. 2008.

This study examined the extent and modes of communication between CBR organisations. Following interviews and focus group discussions some practical recommendations were made, particularly about the value of adapted and other non-literature based information sharing.

Comprehensive Community Based Rehabilitation in Tanzania. <u>The participation of persons with disabilities in Tanzania's 2010 general election. A report on the observations and recommendations made by voters with disabilities</u>. Comprehensive Community Based Rehabilitation in Tanzania. 47 p.

This report describes the experiences and evaluations of people with disabilities in Tanzania participating in a general election in which the government had made adjustments to support their participation.

 Chataika T., Moses M., Mji G., MacLachlan M. Did what? <u>Research brief: A-PODD in</u> <u>Uganda</u>. Dublin: Global Health Press. 2011. 12 p.

This paper reports findings from primary research conducted in Uganda with people with disabilities and other concerned organisations. It looks at how disability can be included in national development agendas and how disability research can be utilised.

Chernet T. W., Opdal L.R. <u>Raising a child with intellectual disabilities in Ethiopia:</u> what do parents say? 2007. 15 p.

This paper draws on primary research to explore the experiences of families bringing up children with intellectual disabilities in Ethiopia.

Chibuga E., Massae P., Geneau R., Mahande M., Lewallen S., Courtright P. « <u>Acceptance of cataract surgery in a cohort of Tanzanians with operable</u> <u>cataract</u> ». Eye, 22 (6). 2008. p. 830-833.

This study examined factors influencing people to take up cataract surgery. There was higher uptake among those with less severe vision loss who stood to gain more from avoidance of disability. Older people with more severe visual loss face other barriers in accessing surgery. The study has implications for encouraging different sectors of the community to consider surgery. Chireshe R., Rutondoki EN., Ojwang P. <u>« Perceptions of the availability and effectiveness of HIV/AIDS awareness and intervention programmes by people with disabilities in Uganda</u> ». Journal of Social Aspects of HIV/AIDS, 7 (4). 2010. p. 17-32.

This study looked at the accessibility of HIV/AIDS services for people with disabilities in Uganda.

Ndoleriie C., Turitwenka E., Bakeera-Kitaaka S., Nyabigambo A. <u>The prevalence of hearing impairment in the 6 months – 5 years HIV/AIDS-positive patients attending paediatric infectious disease clinic at Mulago Hospital</u>. International Journal of Paediatric Otorhinolaryngology, 77. 2013. p. 262-265. (Paying access)

This study researched the incidence of hearing loss among infants with HIV in Uganda.

Cleaver S., Nixon S. « <u>A scoping review of 10 years of published literature on community-based rehabilitation</u> ». Disability and Rehabilitation. 2013. p.10. (paying access)

This study scopes research on CBR.

Cobley D.S. « <u>Towards economic empowerment: segregation versus inclusion in the</u> Kenyan context ». Disability and Society, 27 (3). 2012. p. 371-384. (paying access)

This study compares the inclusive and segregated approaches to inclusion regarding economic empowerment.

Courtright P., Williams T., Gilbert C., Kishiki E., Shirima S., Bowman R., Lewallen S.
 « <u>Measuring cataract surgical services in children: an example from Tanzania</u> ».
 British Journal of Opthalmology, 92 (8). 2008. p. 1031-1034 (Paying access)

This study contributes towards reduction of childhood blindness through cataracts. The researchers surveyed the level of provision of cataract surgery and found regional differences; they also found disparity between the numbers of girls and boys receiving surgery. The study demonstrates the need to survey service delivery in order that disparities are identified.

Crawford J.L., Stodolska M. « <u>Constraints experienced by elite athletes with disabilities in Kenya, with implications for the development of a new hierarchical model of constraints at the societal level</u>. » Journal of Leisure Research, 40 (1). 2008. p. 128-155.

This article looks at access and barriers to access to facilities and opportunities for elite athletes in a resource poor country.

 De Klerk T. « <u>Funding for self-employment of people with disabilities. Grants, loans,</u> <u>revolving funds or linkage with microfinance programmes</u>. » Leprosy Review, 79 (1). 2008. p. 92-109

This study examines options for access to finance for self-employment for people with disabilities.

Deleu M. <u>Strengthening communities to integrate persons with disabilities in the HIV & AIDS response in Rwanda</u>. Lyon: Handicap International. 2013. 74p.

This report documents analysis of a programme to include people with disabilities in HIV/AIDS services in Uganda, and subsequently to include them also in sexual violence services. The analysis examined how change occurred and has led to recommendations for good practice regarding inclusion of people with disabilities in HIV/AIDS and sexual violence services.

Dewhurst F., Dewhurst M.J., Gray W.K., Orega G., Howlett W., Chaote P., Dotchin C., Longdon A.R., Paddick S-M., Walker R.W. « <u>The prevalence of disability in older people in Hai, Tanzania</u>. » Age and Ageing, 41. 2012. p. 517-523.

This research examines the incidence of disability among older people in Tanzania. Although the incidence was lower than in higher income countries the authors anticipate that the incidence of disability in the older populations of lower income countries is likely to rise as longevity increases.

 Disability and Development Partners. <u>Deaf children in Burundi – their education</u> <u>and communications needs</u>. London: Disability and Development Partners. 2011. 52 p.

This study examines the experiences of young people in Burundi who have hearing disabilities and of services available to them. It finds that services need strengthening and makes recommendations for this.

Dube A.K. <u>Participation of disabled people in the PRSP/PEAP process in Uganda</u>. Disability Knowledge and Research. 2005. 50 p.

This study examines the participation of people with disabilities in the Uganda Poverty Reduction Strategy Plan. It is based on a literature review and interviews with stakeholders.

Eichler M., Burke M.A. « <u>The BIAS FREE Framework. A new analytical tool for global</u> <u>health research</u>. » Canadian Journal of Public Health, 97 (1). 2006 p. 63-68.

This article looks at a framework which can identify bias with respect to disability (and other marginalising parameters) in public health research, policy and programmes.

Eide A. H., Ingstad B. <u>Disability and poverty: a global challenge.</u> [e-book] Policy Press Scholarship, online. 2011. (registration)

This book has chapters which address living with disability in Kenya, Uganda, other African countries and other continents.

Ekwan F., Lassman R. <u>The vision for occupational therapy in mental health in</u> <u>Uganda. Celebrating the unique contribution of occupational therapy</u>. A research project and position paper. 2012.

This paper explores the role of occupational therapy in providing mental health services in Uganda.

Erhard L., Degabriele J., Naughton.D., Freeman M.C. « <u>Policy and provision of WASH</u> <u>in schools for children with disabilities: a case study in Malawi and Uganda</u> ». Global Public Health, 8 (9). 2013. p.1000-1013 (paying access)

This study examined access to water and sanitation facilities for school children with disabilities in Uganda and Malawi.

Evans R., Atim A. « <u>Care, Disability and HIV in Africa: diverging or interconnected</u> <u>concepts and practices?</u> » Third World Quarterly, 32 (8). 2011. p. 1437-1454 (paying access)

This study considers the dependence of people living with HIV on carers, the relationships between carers, carers' needs for support and possible community support mechanisms for people living with HIV and for their carers.

Federal Democratic Republic of Ethiopia Ministry of Health. <u>National mental health</u> <u>strategy 2012/13- 2015/16.</u> Federal Democratic Republic of Ethiopia Ministry of Health. [2012]. 55 p.

This is an evidence-based national strategy for supporting Ethiopians with psychological difficulties. Apart from supporting service users it will support health personnel at all levels, including the community level, to access training and provision of facilities for treating mental health conditions.

 Feinstein S. « <u>A research study on individuals with disabilities in the Maasai tribe of</u> <u>Tanzania</u> ». Review of Disability Studies, 5 (4). 2009. p. 3-9.

This research investigated the situation for people with disabilities living in the Maasai tribe of Tanzania.

Fekadu A., Hanlon C., Gebre-Eyesus E., Agedew M., Solomon H., Teferra S., Gebre-Eyesus T., Baheretibeb Y., Medhin G., Shibre T., Workneh A., Tegen T., Ketema A., Timms P., Thornicroft G., Prince M. « <u>Burden of mental disorders and unmet needs</u> <u>among street homeless people in Addis Ababa, Ethiopia</u> ». BMC Medicine, 12:138. 2014. 12 p.

This study provides evidence of very high levels of mental illness and mental distress among people who are homeless in Addis Ababa. The authors propose that this is evidence for the need for advocacy for provision of mental health services for people who are homeless in this city and probably other similar cities in low-income settings.

Fitaw Y., Boersma J.M. <u>Prevalence and impact of disability in north-western</u> Ethiopia. Disability and Rehabilitation, 28 (15). 2006. p. 949-953 (paying access)

This article describes use of a standardised survey method to determine the prevalence of disability in given location and to identify what the main difficulties people with disabilities experience are.

Frantz J., Phillips J.S., Matheri J.M., Kibet J.J. « <u>Physical activity and sport as a tool</u> to include disabled children in Kenyan schools ». Sport in Society: Cultures, Commerce, Media, Politics, 14 (9). 2011. p. 1227-1236 (paying access)

This study examines the level of engagement of children with disabilities in physical activities at school.

Geere J.L., Gona J., Omondi F.O., Kifalu M.K., Newton C.R., Hartley S.« <u>Caring for children with physical disability in Kenya: potential links between caregiving and carers' physical health</u>». Child: care, health and development, (39) 3. 2013. p.381-392.

This article is about the need for provision of support to carers of people with disabilities.

Geneau R., Lewallen S., Bronsard A., Paul I., Courtright P. 2005. « <u>The social and family dynamics behind the uptake of cataract surgery: findings from Kilimanjaro Region, Tanzania</u> ». British Journal of Opthalmology, 89 (11). 2005. p. 1399-1402.

This study found that not everyone regards the need for sight in the same way, that this affects the level of support family members give to elders with visual disabilities and whether people seek cataract surgery. The authors conclude that the benefits of eye care services need to be presented to all family members, not just those with visual loss. They also consider how cost sharing affects people in seeking treatment.

Gona J.K., Xiong T., Muhit M.A., Newton C.R., Hartley S. «<u>Identification of people</u> <u>with disabilities using participatory rural appraisal and key informants: a pragmatic</u> <u>approach with action potential promoting validity and low cost</u>». Disability and <u>Rehabilitation, 32 (1). 2010. p. 79-85 (paying access)</u>

This study compares different methods for identifying people in the community who have disabilities.

Gona J.K., Mung'ala-Odera V, Newton C.R., Hartley S. « <u>Caring for children with</u> <u>disabilities in Kilifi, Kenya: what is the carer's experience?</u> » Child: Care, Health and Development, 37 (2). 2010 .p. 175-183.

This study considers the challenges faced by carers of children with disabilities and the need for services to understand and support carers.

Groce N., Kett M., Lang R., Trani J-F. <u>Disability and poverty: the need for a more nuanced understanding of implications for development policy and practice</u>. Third World Quarterly, 32 (8). 2011. p. 1493-1513 (paying access)

This article is about the relationship between disability and poverty in low-income countries, including in particular Asia and Africa.

Groce N., Murray B., Loeb M., Tramontano C., Trani J.F., Mekonnen A. « <u>Disabled</u> <u>beggars in Addis Ababa, Ethiopia</u> ». ILO Employment Sector Working Paper, no.141. Geneva: ILO. 2013. 107 p.

This paper reports primary research regarding the interrelationship between disability and begging as a means of livelihood

Groce N., Murray B., Kealy A. <u>« Disabled beggars in Addis Ababa. Current situation</u> and prospects for change ». Geneva: International Labour Organisation. 2014. 58 p.

This report presents research about the lives of people with disabilities living as beggars in Addis Ababa. It describes the research findings and considers possible options for breaking the link between disability and begging.

Gronlund A., Lim N., Larsson H. « <u>Effective use of assistive technologies for inclusive</u> <u>education in developing countries: issues and challenges from two case studies</u>. » International Journal of Education and Development Using Information and Communication Technology, 6 (4). 2010. p. 5-26.

This research examined the use of assistive technology in inclusive education in resourcepoor settings. Using a literature review and interviews with stakeholders. It identifies coordination as a primary strategy for making the most of limited resources. Grut L., Ingstad B. <u>Using qualitative methods in studying the link between disability</u> <u>and poverty</u>. Developing a methodology and pilot testing in Kenya. Oslo: SINTEF Health Research. 2006. 46 p.

This paper describes a methodology for researching the relationship between disability and poverty in a resource-poor setting.

Grut L., Hjort P., Eide A.H. More of the same and try something new. <u>Evaluation of</u> <u>the community based rehabilitation programme in Eritrea</u>. Oslo: SINTEF. 2004. 86 p.

This report describes an evaluation of a CBR programme. It is an example of CBR evaluation and also gives some information about the lived experiences of people with disabilities in Eritrea.

Gupta E., Roberts B. <u>User and researcher collaborations in mental health in low and middle income countries: a case study of the EMPOWER project</u>. BMC Research Notes. 2014. 6 p.

This study looks at collaborative partnerships between researchers and mental health service user groups to disseminate mental health research findings. It analyses and evaluates the collaborative process.

Hammond R. <u>Condemned</u>. Heidelberg Press, Ofset Yapimavi, Istanbul. 2013.

This book of photos and comments by subjects powerfully depicts what life is like for many people with mental illness in resource poor countries.

The book is only available for purchase but some of the pictures and captions can be seen on the website.

Hanass-Hancock J., Grant C., Strode A. « <u>Disability rights in the context of HIV and AIDS: a critical review of nineteen Eastern and Southern Africa (ESA) countries</u>». Disability and Rehabilitation, 34 (25). 2012. p. 2184-2191 (Paying access)

This study looks at access to services for people who have HIV and disabilities. It also looks at the inclusion of provision for people with disabilities in HIV programmes.

Hanass-Hancock J., Strode A., Grant C. « <u>Inclusion of disability within national</u> <u>strategic responses to HIV and AIDS in Eastern and Southern Africa</u>. » Disability and Rehabilitation, 33 (23-24). 2011 p. 2389-2396 (Paying access)

This paper examines the provision of HIV services for people with disabilities. It takes a rights based approach.

Handicap International, Christoffel-Blindenmission. <u>Making PRSP inclusive</u>. Munich. 2006. 134 p.

This handbook provides information and guidance regarding the inclusion of people with disabilities in poverty reduction strategies. It includes a 4 page case study from Tanzania which illustrates how disabled people's organisations worked for and achieved the inclusion people with disabilities in the PRSP process.

Handicap International. <u>As It Is. Research findings on the knowledge, attitude, practice and access to HIV and AIDS information and services amongst persons with disability</u>. 2009. 19 p.

This study used both primary and secondary research to investigate the perceptions and contextual factors around the vulnerability of people with disabilities in Kenya to HIV/AIDS, and any differences when compared to the general population.

The study is intended to guide the planning and implementation of HIV prevention and management services for people who have disabilities.

Handicap International. <u>Supporting persons living with trauma by rebuilding social</u> <u>and community links</u>. Handicap International. 2010. 70 p.

This paper describes and evaluates psychosocial support projects, at community level, with people affected by the 1994 genocide in Rwanda. It should help readers learn about interventions which were effective.

Handicap International. <u>Diabetes prevention and control projects in countries with</u> <u>limited resources. Lessons from experience: know-how analysis</u>. Lyon: Handicap International. 2009. 37 p.

This paper reports on a workshop in which project managers and local partners in Burundi, Kenya, the Philippines, Nicaragua and Mali shared their experiences of implementing diabetes interventions. It sets out learning outcomes from the sharing and may give useful pointers to others running diabetes programmes in low-resource settings.

Hansen A.M., Chaki A.P., Mlay R. « Occupational therapy synergy between Comprehensive Community Based Rehabilitation Tanzania and Heifer International to reduce poverty ». African Journal of Disability. 2(1). 2012. 7 p.

This study looks at a partnership between an income generating organisation and a community based rehabilitation service which led to improved wellbeing for families caring for children who have disabilities.

Hartley S., Ojwang P., Baguwemu A., Ddamulira M., Chavuta A. « <u>How do carers of</u> <u>disabled children cope? The Ugandan perspective</u> ». Child: Care, Health and Development, 31 (2). 2005. p. 167-180 (paying access)

This research examines how carers for children with disabilities cope and proposes practical approaches which could be incorporated within CBR.

Hartley S., Murira G., Mwangoma M., Carter J., Newton C.R.J. <u>« Using community/researcher partnerships to develop a culturally relevant intervention for children with communication disabilities in Kenya »</u>. Disability and Rehabilitation, 31 (6). 2009. p. 490-499.

This paper is about developing a culturally appropriate intervention for children with disabilities in Kenya. The intervention was developed through a partnership between researchers and members of the community.

Hollander T., Gill B. « Every day the war continues in my body: examining the marked body in postconflict northern Uganda ». The International Journal of Transnational Justice, 8. 2014. p. 217-234 (paying access)

This study considers the long term disability and marginalisation of people who have been deliberately disfigured as an act of war.

Hoogeveen J.G. « <u>Measuring welfare for small but vulnerable groups: poverty and disability in Uganda</u> ». Journal of African Economies ,14 (4). 2005. p. 603-631 (paying access)

This paper is about measuring poverty and gives information about the population of people with disabilities in Uganda.

 Howitt S.C., Jones M.P., Jusabani A., Gray W.K., Aris E., Mugusi F., Swai M., Walker R.W. « <u>A cross-sectional study of quality of life in incident stroke survivors in rural</u> <u>northern Tanzania</u> ». Journal of Neurology, 258. 2011. p. 1422-1430 (Paying access)

This study explored the impact of strokes on quality of life.

 Idro R., Newton C., Kiguli S., Kakooza-Mwesige A. « <u>Child neurology practice and</u> <u>neurological disorders in East Africa</u> ». Journal of Child Neurololgy, 25 (4). 2010. p. 518-524 (paying access)

This paper sets out the extent of disabling neurological disorders in the East Africa region.

Idro R., Musubire K.A., Byamah Mutamba B., Namusoke H., Muron J., Abbo C., Oriyabuzu R., Ssekyewa J., Okot C., Mwaka D., Ssebadduka P., Makumbi I., Opar B., Aceng J.R., Mbonye A.K. « <u>Proposed guidelines for the management of nodding</u> <u>syndrome</u> ». African Health Sciences, 13 (2). 2013. p. 219-232.

This paper introduces nodding syndrome which can cause a variety of disabling symptoms. It outlines recommendations for management of the condition and support for people who have the condition.

 International Labour Organisation. <u>Moving towards disability inclusion</u>. Geneva: International Labour Organisation. 2011. 61 p.

Drawing on case studies this report sets out lessons learned from experience and examples of good practice regarding the inclusion of people with disabilities in employment. It takes two perspectives: firstly approaches to effective legislation and secondly at the project level of sensitisation of employers, support for entrepreneurship in individuals with disabilities and employment support such as micro-finance. The lessons learned are drawn from case studies in four countries, including Ethiopia, whose projects are described over 22 pages.

Jenkins R., Othieno C., Okeyo S., Aruwa J., Wallcraft J., Jenkins B. « Exploring the perspectives and experiences of health workers at primary health facilities in Kenya following training ». International Journal of Mental Health Systems, 7:6. 2013. 8p.

This study found positive impact of training of mental health primary care personnel as perceived by both the health personnel and their clients.

Johnstone C., Corce H. «<u>I have been given the power to teach. The children understand me very well. A preliminary study of the social and academic impact of deaf teacher training in Kenya</u>». International Review of Education, 56. 2010p. 149-165 (paying access)

This study considers the value of hearing impaired teachers and teachers who have sign language for children with hearing disabilities.

Jones M.P., Howitt S.C., Jusabani A., Gray W.K., Aris E., Mugusi F., Swai M., Walker R.W. <u>« Anxiety and depression in incident stroke survivors and their carers in rural</u> <u>Tanzania: a case-control follow-up study over five years</u> ». Neurology, Psychiatry and Brain Research, 18. 2012. p. 122-128. 2012 (paying access)

This study draws attention to the issues of depression and anxiety among stroke survivors and their carers.

 Jones I., Marshall J., Lawthom R., Read J. « <u>Involving people with communication</u> <u>disability in research in Uganda: a response to the World Report on Disability</u> ». International Journal of Speech-Language Pathology, 15 (1). 2013. p. 75-78. (paying access)

This paper considers the importance, benefits and challenges of inclusion of people with communication difficulties in research.

Kakooza-Mwesige A., Ssebyala K., Karamagi C., Kiguli S., Smith K., Anderson M.C., Croen L.A., Trevathan E., Hansen R., Smith D. Grether J.K. «<u>Adaptation of the "ten</u> <u>questions" to screen for autism and other neurodevelopmental disorders in</u> <u>Uganda</u> ». Autism, 18 (4). 2014. p. 447-457.

This research tested the validity of two methods of screening for autism and other neurodevelopmental conditions in Uganda.

Kalyango J.N., Hall M., Karamagi C. <u>« Home medication management practices and associated factors among patients with selected chronic diseases in a community pharmacy in Uganda</u> ». BMC Health Services Research, 12. 2012. p. 323.

This study found that many people with long-term conditions do not manage their medication well, which has implications for their long-term health. This also has implications for the way medications are prescribed and the advice given to patients collecting their medications from the pharmacy.

Karangwa E., Miles S., Lewis I. « <u>Community-level responses to disability and</u> <u>education in Rwanda</u>». International Journal of Disability, Development and Education, 57 (3). 2010 p. 267-278 (paying access)

This research compared the policy aspiration of education for children with disabilities and the reality in Rwanda.

Katsui H., Kumpuvuori J. « <u>Human rights based approach to disability in development in Uganda: a way to fill the gap between political and social spaces?</u> » Scandinavian Journal of Disability Research, 10 (4). 2008. p. 227-236.

This article is about the rights based approach to disability.

Kuper H., Polack S., Limburg H. « <u>Rapid assessment of avoidable blindness</u> ». Community Eye Health Journal, 19 (60). 2006. p. 68-69.

This paper describes a simple and rapid method for assessing prevalence and causes of visual impairment which form a basis for planning services. It has been used successfully in Kenya and Rwanda.

Kweka J. Employment of persons with disabilities in Dar es Salaam, Tanzania. <u>An assessment of the proportion of persons with disabilities in the workplace. Dar es Salaam: Comprehensive Community Based Rehabilitation in Tanzania (CCBRT)</u>. 2010. 37 p.

This report describes a survey of the level of employment of people with disabilities in local mainstream companies. It looks at the level of employment of people with disabilities and perceived barriers to their employment in these companies.

Lang R., Murangira A. <u>Disability scoping study for DFID Uganda</u>. 2009. 61 p.

This is a comprehensive review of the situation for people with disabilities in Uganda in 2009. It critically examines policy and implementation. In particular it focuses on and makes recommendations for the role of the UK Department for International Development who commissioned the study.

Leonard Cheshire Disability and Inclusive Development Centre. <u>Undoing inequality:</u> <u>inclusive water, sanitation and hygiene programmes that deliver for all: Uganda</u> <u>and Zambia.</u> 10 p.

This paper reports primary research which explored the access for people with disabilities to water and sanitation facilities. It found that there are many access barriers which affect the lives of people with disabilities and the carers who assist them. Policy implications are considered.

 Leonard Cheshire Disability and Inclusive Development Centre. <u>Disability and urban</u> <u>agriculture – an innovative approach</u>. 8 p.

This report describes a participatory action project which explored access to and participation in low-cost, urban agriculture for people with disabilities, an activity which addresses livelihoods and food security.

Lehtomaki E., Tuomi M.T., Matonya M. « <u>Educational research from Tanzania 1998–</u> <u>2008 concerning persons with disabilities: what can we learn?</u> » International Journal of Educational Research, 64 (2014). 2013. p. 32-39 (paying access)

This paper raises and summarises the main issues surrounding the education of people with disabilities in Tanzania during the period of the study.

Lewis I. <u>Young voices. Young people's views of inclusive education</u>. Oslo: The Atlas Alliance. 2008. 45 p.

This report presents the views of children with and without disability about the inclusive education programmes they have experienced.

Lewis I. <u>Education for disabled people in Ethiopia and Rwanda</u>. Paper commissioned for the EFA Global Monitoring Report 2010, Reaching the marginalised. 2009. 55 p.

This paper sets out and discusses key issues around the education of children with disabilities in Ethiopia and Rwanda.

Lewallen S. «<u>Inappropriate enrolment of children in schools for the visually</u> <u>impaired in east Africa</u>». Annals of Tropical Paediatrics, 29 (2). 2009. p. 135-139 (Paying access)

This research found that a proportion of children in special schools for children with visual disabilities had enough sight to be able to enrol in mainstream school, or even had normal vision. There is brief discussion about the reasons for this and recommendation for avoiding the situation.

Luyirika E., Kikule E., Kamba M., Buyondo F., Batamwita R., Featherstone A., Mills E.J. « <u>Meeting the challenges of disability and HIV in East Africa</u> ». Journal of Acquired Immune Deficiency Syndromes, 57 (3). 2011. p. e68-e69.

This article sets out which disabilities are associated with HIV/AIDS in Uganda and calls for appropriate services.

Lynch P., McCall S., Douglas G., McLinden M., Mogesa B., Mwaura M., Muga J., Njoroge M. « Inclusive educational practices in Kenya: evidencing practice of itinerant teachers who work with children with visual impairment in local mainstream schools ». International Journal of Educational Development, 31 (2011). 2011. p. 478-488 (paying access)

This study informs about issues around the education of children with visual disabilities in Kenya and the role of special teachers.

Mathewson P., (ed). <u>Different and the same. Towards equal access, education and solidarity in WASH</u>. WaterAid. 2008. 10 p.

This report sets out the main findings from research on access to water and sanitation for people with disabilities in Ethiopia. It is a short document which serves largely to sensitise readers to the particular issues for people with disabilities and indicates key approaches to solutions. The research is more fully documented in two more detailed reports which are referenced on the last page, for those who need more detail.

Mbwilo G.S., Smide B., Aarts C. « Family perceptions in caring for children and adolescents with mental disabilities: a qualitative study from Tanzania ». Tanzania Journal of Health Research, 12 (2). 2010. 12 p.

This research explores what support is available for families who have a member with intellectual disability and factors around access to services.

McElroy T., Konde-Lule J., Neema S., Gitta S. <u>The Uganda Sustainable Clubfoot Care</u> <u>Project. Understanding the barriers to clubfoot treatment adherence in Uganda: A</u> <u>rapid ethnographic study</u>. Disability and Rehabilitation, 29 (11-12). 2007. p. 845-855 (paying access)

This research examined the barriers to compliance with treatment for clubfoot in Uganda.

McGeown J. « Out of the shadows: A qualitative study of parents' and professionals' attitudes and beliefs about children with communication disability in Uganda and how best to help them ». M.Sc. University College London, Institute of Child Health. 2012.

This study explored the communication strategies parents, teachers and classroom assistants use with children who have communication difficulties. In terms of its findings it points towards the education of society regarding disability, training for parents, teachers and classroom assistants including the provision of resources to support this training.

Mckenzie J.A., McConkey R., Adnams C. « <u>Intellectual disability in Africa:</u> <u>implications for research and service development</u>». Disability and Rehabilitation, 35 (20). 2013 p. 1750-1755 (paying access)

This article looks at the access to support for people with intellectual disabilities in Africa (including East African countries).

McNally A., Mannan H. « <u>Perceptions of caring for children with disabilities:</u> experiences from Moshi, Tanzania ». African Journal of Disability. 2 (1). 2013.

This paper examines the experiences of carers for children with disabilities in a resourcepoor setting.

Mendenhall E., De Silva M.J., Hanlon C., Petersen I., Shidhaye R., Jordans M., Luitel N., Ssebunnya J., Fekadu A., Patel V., Tomlinson M., Lund C. <u>« Acceptability and feasibility of using non-specialist health workers to deliver mental health care: Stakeholder perceptions from the PRIME district sites in Ethiopia, India, Nepal, South Africa, and Uganda</u> ». Social Science and Medicine. 2014.

This research explores the feasibility of non-specialists providing mental health support at primary care level in resource-poor countries. It found that this is perceived to be acceptable and feasible in these settings as long as key conditions around systems support and training and support to the non-specialists are met.

Miles S. « Exploring understandings of inclusion in schools in Zambia and Tanzania using reflective writing and photography ». International Journal of Inclusive education, 15 (10). 2011 p. 1087-1102 (paying access)

This piece looks at barriers to education for children with disabilities.

Miles S., Wapling L., Beart J. « <u>Including deaf children in primary schools in</u> <u>Bushenyi, Uganda: a community-based initiative</u> ». Third World Quarterly, 32 (8). 2011. p.1515-1525 (paying access)

This paper discusses a project which has augmented access to education for children with hearing disabilities by drawing on government funding and community involvement.

M'kumbuzi V.R., Sagahutu J.-B., Kagwiza J., Urimubenshi G., Mostert-Wentzel K.
 « <u>The emerging pattern of disability in Rwanda</u> ». Disability and Rehabilitation, 36 (6). 2014. p. 472-478 (paying access)

This research explored the prevalence of disability in Rwanda.

Monk J., Wee J. « Factors shaping attitudes towards physical disability and availability of rehabilitative support systems for disabled persons in rural Kenya ». Asia Pacific Disability Rehabilitation Journal, 19 (1). 2008. p. 93-113.

This study looks at factors in the social and physical environment which facilitate or hinder access to services for people with disabilities, and a possible role for community based rehabilitation.

Montgomery M.A., Desai M.M., Groce N.E., Elimelech M. « <u>Relationship between</u> <u>distance to social gathering facilities and risk of trachoma for households in rural</u> <u>Tanzanian communities</u> ». Social Science and Medicine. 2011.73 (1)p. 1-5. (paying access)

This study states that trachoma is a leading cause of preventable blindness. The research finds that there is a higher risk of contracting trachoma for residents whose houses are further from social facilities. This has implications for the design of trachoma prevention programmes.

Mousley E., Deribe K., Tamiru A., Davey G. <u>The impact of podoconiosis on quality of life in Northern Ethiopia</u>. Health and Quality of Life Outcomes. 2013. 11 p.

This article examines the effects of podoconiosis on quality of life

Moyi P. « <u>Primary school attendance and completion among lower secondary</u> <u>school age children in Uganda</u> ». Current Issues in Education, 16 (2).2013. 17 p.

This study looks at many factors which influence children's school attendance, in Uganda, such as poverty, ethnicity and conflict; it also gives substantial attention to disability as a factor in school exclusion.

Mshana G., Dotchin C.L., Walker R.W. « <u>"We call it the shaking illness": perceptions</u> <u>and experiences of Parkinson's disease in rural northern Tanzania</u> ». BMC Public Health, 11 : 219. 2011. 8 p.

This study draws attention to the disabling effects of Parkinson's Disease, its effects on the quality of life of people who have the condition and their carers and the lack of services available to them in an East African context.

Mugo J. K., Oranga J., Singal N. <u>Testing youth transitions in Kenya: are young people</u> <u>with disabilities falling through the cracks?</u> Research Consortium on Educational Outcomes and Poverty.2010. 16 p.

This paper examines the opportunities for young people with disabilities in Kenya, especially in relation to education, employment and social participation.

Murray Cramm J., Paauwe M., Finkenflugel H. Facilitators and hindrances in the experiences of Ugandans with and without disabilities when seeking access to microcredit schemes. Disability and Rehabilitation, 34 (25). 2012. p. 2166-2176 (paying access)

This study explores access to microcredit for people with disabilities.

Mushi D., Burton K., Mtuya C., Gona J.K., Walker R., Newton C.R. <u>Perceptions, social life, treatment and education gap of Tanzanian children with epilepsy: a community-based study.</u> Epilepsy and Behavior, 23 (3). p. 224-229. 2012 (Paying access)

This study looked at how epilepsy in children affects their social inclusion and education and the difficulties they have in accessing medical treatment.

Musoke G., Geiser P., eds. <u>Linking CBR, disability and rehabilitation</u>. Bangalore: CBR Africa Network. 119 p.2013.

This book collates the experiences of many CBR experts, including many from Africa, and addresses in particular key questions around stakeholder partnerships in CBR and about the effective delivery of services for people with disabilities at community level.

Mwende J., Bronsard A., Mosha M., Bowman R., Geneau R., Courtright P. « <u>Delay</u> in presentation to hospital for surgery for congenital and developmental cataract in <u>Tanzania</u> ». British Journal of Opthalmology, 89 (11). 2005. p. 1478-1482.

This study found that there are sometimes significant delays in children with cataracts getting to hospital for surgery. Delay was associated sometimes with the distance families live from hospitals, the mother's socioeducational status and whether there is an older sibling. These findings have implications for community workers who may be able to support earlier presentation for surgery if they are aware of these factors.

 National Bureau of Statistics Office of the chief Government Statistician, Zanzibar. <u>Tanzania Disability Survey Report</u>. Dar es Salaam: National Bureau of Statistics. 2008. 231 p.

This reports the first national survey to determine the prevalence of disability in the country. The survey collected information at household level by means of questionnaire.

 Njelesani J., Couto S., Cameron D. « <u>Disability and rehabilitation in Tanzania: a</u> <u>review of the literature</u> ». Disability and Rehabilitation, 33 (23-24). 2011. p. 2196-2207. (paying access)

This review draws on recent academic and other literature to explore what knowledge there is about disability in Tanzania and what services are available in the country.

Njeri Mbugua M., Kuria M.W., Ndetei D.M. « <u>The prevalence of depression among</u> <u>family caregivers of children with intellectual disability in a rural setting in Kenya</u> ». International Journal of Family Medicine, (2011) Article ID 534513. 2011. 4 p.

This article is about depression among carers of people with intellectual disabilities in Kenya.

Njoroge Mwendwa T., Murangira A., Lang R. « <u>Mainstreaming the rights of persons</u> <u>with disabilities in national development frameworks</u> ». Journal of International Development, 21 (5). 2009. p. 662-672. (paying access)

This article is about the inclusion of people with disabilities in policy implementation.

Ochien'g M.A., Onyango G.M. Wagah, G.G. « <u>Accessibility of students with physical disability to washrooms in Bungoma bus terminus, Kenya</u>». Disability, CBR and Inclusive Development (DCID), 24 (1). 2013. p. 143-149.

This study looked at accessibility of a public facility for people with disabilities.

Omar M.A., Green A.T., Bird P.K., Mirzoev T., Fisher A.J., Kigozi F., Lund C., Mwanza J., Ofori-Atta A.L., Mental Health and Poverty Research Programme Consortium (MHaPP). « Mental health policy process: a comparative study of Ghana, South Africa, Uganda and Zambia ». International Journal of Mental Health Systems, 4 (24). 2010. 10 p.

This study examines progress with development and implementation of mental health policies in Ghana, South Africa, Uganda and Zambia.

Omondi D., Ogol C., Otieno S., Macharia I. « <u>Parental awareness of hearing impairment in their school-going children and healthcare seeking behaviour in Kisumu district, Kenya</u>. » International Journal of Pediatric Otorhinolaryngology, 71 (3), 2007. p. 415–423 (paying access)

This research highlights underuse of services for young children with hearing disabilities despite parental awareness of their children's hearing difficulties.

Opini B.M. « <u>A review of the participation of disabled persons in the labour force:</u> <u>the Kenyan context</u> ». Disability and Society, 25 (3). 2010. p. 271-287 (Paying access)

This is about access to employment for people with disabilities and about implementation of disability rights in Kenya.

Opini B.M. « Examining the motivations of women students with disabilities' participation in university education in Kenya ». Scandinavian Journal of Disability Research, 14 (1). 2012. p. 74-91 (paying access)

This paper is about the rights of people with disabilities in Kenya and in particular about the right to education.

Othieno C., Jenkins R., Okeyo S., Aruwa J., Wallcraft J., Jenkins.B. <u>« Perspectives</u> and concerns of clients at primary health care facilities involved in evaluation of a national mental health training programme for primary care in Kenya ». International Journal of Mental Health Systems, 7:5. 2013. [online]. 7 p.

This study found positive impact of training of mental health primary care personnel as perceived by service users.

Ovuga E, Oyok T.O., Moro E.B. « <u>Post traumatic stress disorder among former child</u> <u>soldiers attending a rehabilitative service and primary school education in northern</u> <u>Uganda</u> ». African Health Sciences, 8 (3). 2008p. 136-141.

This study examines psychological effects on children abducted as soldiers. In particular it looks at the pattern of ongoing symptoms in relation to the different treatments which children had received. This has the potential to assist evaluation of various approaches to resettlement and various types of psychological treatment for child soldiers.

 Penny N., Zulianello R., Dreise M., Steenbeek M. « <u>Community-based rehabilitation</u> and orthopaedic surgery for children with motor impairment in an African <u>context</u> ». Disability and Rehabilitation, 29 (11-12). 2007. p. 839-843 (paying access)
 This is a study of the use of a range of services, in particular CBR, to support children with motor impairment in Uganda. Petroze R.T., Joharifard S., Groen R.S., Niyonkuru F., Ntaganda E., Kushner A.L., Guterbock T.M., Kayamanywa P., Calland J.F. «<u>Injury, disability and access to care</u> <u>in Rwanda: results of a nationwide cross-sectional population study</u>». World Journal of Surgery. 2014. (paying access).

This study investigated the level of injury related surgical conditions and associated disability and death rates. It found that 38% of injury-related surgical conditions were perceived to have led to disability. Over 30% of household deaths over the previous year may have been surgically treatable. This draws attention to the need for identification of people with disabling injuries, surgically treatable cases and provision for surgical services.

Plan International. <u>Include us! A study of disability among Plan International's</u> <u>sponsored children</u>. Woking: Plan International. 2013. 271 p.

This report presents an analysis of the life circumstances of children around the world sponsored by Plan International. It finds that children with disabilities have less opportunity for schooling and overall poorer health than their non-disabled peers. It goes on to consider the implications of these findings.

Polat F. « <u>Inclusion in education: a step towards social justice</u> ». International Journal of Educational Development, 31 (1). 2011. p. 50-58.

This study considers inclusion of children with disabilities in education in a social justice framework. It also looks at primary research concerning inclusion. (paying access)

Ramos J.M., Reyes F., Lemma D., Tesfamariam A., Belinchon I., Gorgolas M. « <u>The burden of leprosy in children and adolescents in rural southern Ethiopia</u> ». Paediatrics and International Child Health, 34 (1). 2014. p. 24-28.

This study looks at the prevalence of leprosy among children and adolescents in Ethiopia and includes data on disabilities and completion of treatment.

Ransom B. <u>Missing Voices: children with disabilities in Africa</u>. Addis Ababa: The African Child Policy Forum. 2009. 73 p.

This report uses analysis of research, policy and other documents to explore and describe the living conditions of children with disabilities in Africa.

Redley M., Maina E., Keeling A., Pattni P. « <u>The voting rights of adults with intellectual disabilities: reflections on the arguments, and situation in Kenya and England and Wales</u> ». Journal of Intellectual Disability Research, 56 (II). 2012 p. 1026-1035 (paying access)

This paper addresses the issues around the rights of people with intellectual disabilities to vote and how this is approached in Kenya, England and Wales.

 Rochester L., Rafferty D., Dotchin C., Msuya O., Minde V., Walker R.W. « <u>The effect</u> of cueing therapy on single and dual-task gait in a drug naïve population of people with Parkinson's disease in northern Tanzania ». Movement Disorders, 25 (7). 2010. p. 906-911.

This study researched the effectiveness of a therapist administered, behaviour based treatment to improve walking in people with Parkinson's disease who do not have medication. The approach appeared promising. (paying access)

Sariah A.E., Outwater A.H., Malima K.I. « <u>Risk and protective factors for relapse</u> <u>among individuals with schizophrenia: a qualitative study in Dar es Salaam,</u> <u>Tanzani</u> ». BMC Psychiatry. 14:240. 2014.

This study identified a number of factors which contribute towards relapse of people with schizophrenia. It also identifies provision of appropriate information and support to patients and carers during hospital admissions and when they are at home as contributing towards reducing the risks of relapse. The paper focuses on the role of mental health nurses and enhanced training for them, but one may consider the possibilities of other community health personnel being trained to provide information and support to patients and their caregivers to possibly reduce risk of relapse.

Schiemer M., Proyer M. « <u>Teaching children with disabilities: ICTs in Bangkok and Addis Ababa</u> ». Multicultural Education and Technology Journal, 7 (2/3). 2013. p. 99-112 (paying access)

This paper examines access to information technologies for the education of children with disabilities.

Schneider M., Waliuya W., Munsanje J., Swartz L. « <u>Reflections on including</u> <u>disability in social protection programmes</u> ». IDS Bulletin, 42 (6). 2011. p. 38-44 (paying access)

This paper examines concerns around targeted inclusion of people with disabilities in social protection programmes.

Scorza P., Stevenson A., Canio G., Mushashi C., Kanyanganzi F., Munyanah M., Betancourt T. «<u>Validation of the "World Health Organization disability assessment</u> <u>schedule for children, WHODAS-Child" in Rwanda</u>». PLOS One [online] 8 (3). 2013. 8 p.

This study tested a standardised assessment for establishing the prevalence of disability among children in Rwanda.

Shirima S., Lewallen S., Kabona G., Habiyakare C., Massae P., Courtright P. « Estimating numbers of blind children for planning services: findings in Kilimanjaro, Tanzania ». British Journal of Opthalmology, 93 (12). 2009. p. 1560-1562 (paying access)

This paper reports a survey to identify children with blindness in one area of Tanzania. It found the incidence of childhood blindness to be low and suggests that efforts to reduce blindness in the region are working, that therefore the service provision priority should be to support children with low vision and that the assessment methods used in this study worked effectively.

Sisay Belete S. <u>Electoral participation as a fundamental political right of persons</u> <u>with disabilities in Ethiopia; critical examination of the law and the practice.</u> Master of Laws. Addis Ababa University. 2011. 128 p.

This thesis, based on a literature review and interviews with stakeholders, examines the participation of people with disabilities in the electoral processes of Ethiopia. It looks at the rights of people with disabilities to vote and to stand for office, and at the attitudinal and legal environment.

Skovdal M., Ogutu V.O. «<u>I washed and fed my mother before going to school:</u> <u>Understanding the psychosocial well-being of children providing chronic care for</u> <u>adults affected by HIV/AIDS in Western Kenya</u>». LSE research online [online]. 2009. 10 p.

This study explores the experiences of children caring for parents affected by HIV/AIDS and the children's thoughts about the meanings of their responsibilities. It sheds light on how children perceive and cope with the role of carer for someone with HIV/AIDS. It should stimulate thought also to what support these children need, such as for their psychosocial wellbeing and access to education.

Skovdal M. <u>« Examining the trajectories of children providing care for adults in rural Kenya: implications for service delivery »</u>. Children and Youth Services Review, 33 (2011). 2011. p. 1262-1269. (Paying access)

This study looks at children who are carers of family members who have disabilities. It identifies the children's caring role as multifaceted.

Ssewamala F.M., Wang J.S-H., Karimli L., Nabunya P. « <u>Strengthening universal</u> <u>primary education in Uganda: the potential role of an asset-based development</u> <u>policy</u> ». International Journal of Educational Development, 31 (2011). 2011. p. 472-477 (paying access)

This study examines the potential of the asset-based development approach to facilitate schooling for children with disabilities in Uganda.

Stone-MacDonald A. « <u>Cultural beliefs about disability in practice: experiences at a special school in Tanzania</u> ». International Journal of Disability, Development and Education, 59 (4). 2012. p. 393-407 (paying access)

This article is about cultural beliefs about disability in the context of a school in Tanzania

Sayed A., Polack S., Eusebio C., Mathenge W., Wadud Z., Mamunur A.K., Foster A., Kuper H. « <u>Predictors of attendance and barriers to cataract surgery in Kenya,</u> <u>Bangladesh and the Philippines</u> ». Disability and Rehabilitation, 35 (19). 2013. p. 1660-1667. (Registration).

This research examines the barriers to access to cataract surgery for people in low-income countries.

Sym N., Rouger T. Sexual violence against children with disabilities in Burundi, Madagascar, Mozambique and Tanzania. Lyon: Handicap International. 2011. 142 p. This paper reports on a study of sexual violence against children with disabilities in Burundi, Tanzania, Madagascar and Mozambique. "Out from the Shadows" also reports on this study. The paper described here aims to provide more detail on the individual findings of the study. Save the Children & Handicap International 2011. Out From the Shadows. Sexual Violence Against Children with Disabilities. London: Save the Children UK.

http://www.savethechildren.org.uk/sites/default/files/docs/out_of_the_shadows_5.pdf

Taegtmeyer M., Hightower A., Opiyo W., Mwachiro L., Henderson K., Angala P., Ngare C., Marum E. <u>A peer-led HIV counselling and testing programme for the deaf</u> in Kenya. Disability and Rehabilitation, 31 (6). 2009. p. 508-514 (Paying access)

This article concerns the risk of HIV among people with hearing disabilities in Kenya and their access to HIV services.

The Tanzania Commission for AIDS. <u>The forgotten.</u> <u>HIV and disability in Tanzania</u>. Dar es Salaam: Tanzania Commission for AIDS. Year not stated. 34 p.

This study scoped the extent to which people with disabilities in Tanzania are affected by HIV and the level of their access to HIV/AIDS services. It found that they have reduced access to HIV services and makes recommendations.

Teferra S., Shibre T., Fekadu A., Medhin G., Wakwoya A., Alem A., Kullgren G., Jacobsson L. « <u>Five year mortality in a cohort of people with schizophrenia in</u> <u>Ethiopia</u> ». BMC Psychiatry. 2011. 9 p.

Schizophrenia is a disabling condition and one associated with premature death. The researchers found the mortality rate in the study population as "alarmingly high" and say that much of it was from treatable causes. The authors call for improved care for this population in rural Ethiopia

Teferra T. <u>Resilience and successes of persons with disabilities in Ethiopia</u>. An article extracted from the book entitled "Disability in Ethiopia: Issues, Insights and Implications". Addis Ababa: Addis Ababa Printing Press. 2005. 31.p.

This study looked at successful people who have disabilities and what factors enabled them to be successful.

Tesfu M. Leave no one out. Reaching people with disabilities and leprosy with water, sanitation and hygiene: WaterAid Ethiopia's experience. WaterAid. 2013. 8 p.

This briefing note describes the links between access to water and sanitation for people with leprosy and in addition examines the particular issues around safe water for people with leprosy.

Tumwesigye, C., Msukwa, G., Njuguna, M., Shilio, B., Courtright, P., Lewallen, S., 2009. <u>Inappropriate enrolment of children in schools for the visually impaired in</u> <u>east Africa</u>. Annals of Tropical Paediatrics, 29 (2). 2009. p. 135-139 (Paying access)

This research found that a proportion of children in special schools for children with visual disabilities had enough sight to be able to enrol in mainstream school, or even had normal vision. There is brief discussion about the reasons for this and recommendation for avoiding the situation.

Tungaraza F.D. « <u>Who sinned? Parents' knowledge of the causes of disability in</u> Tanzania ». International Journal of Special Education, 27 (2). 2012. p. 215-223.

This article looks at parents' beliefs about the causes of their children's disabilities, in Tanzania, and at the relationship between poverty and disability.

Urimubenshi G., Rhoda A. «<u>Environmental barriers experienced by stroke patients</u> <u>in Musanze district in Rwanda: a descriptive qualitative study</u>». African Health Sciences, 11(3). 2011. p. 398 -406.

This study looks at barriers faced by people who have had strokes in the Musanze district of Rwanda. IT found that they experience physical and attitudinal barriers and difficulties with access to physiotherapy services.

Van Duijl M., Kleijn W., deJong J. <u>«Unravelling the spirits' message: a study of help-seeking and explanatory models among patients suffering from spirit possession in Uganda»</u>. International Journal of Mental Health Systems 2014.[online]

This study explored approaches to treatment of spirit possession and dissociative disorders through traditional healing and church healing approaches. The authors conclude that these approaches may benefit mental health service provision in low and middle income countries.

Van Veen N.H., Meima A., Richardus J.H. «<u>The relationship between detection</u> <u>delay and impairment in leprosy control: a comparison of patient cohorts from</u> <u>Bangladesh and Ethiopia</u>». Leprosy Review, 77 (4). 2006. p.356-365.

This study confirms that delay in diagnosis increases the risk of acquiring impairment from leprosy. The relationship between length of delay and development of impairment varied between population groups. However, minimising the delay to diagnosis remains important in preventing disability from leprosy.

 Visser B.J., Korevaar D.A., van der Zee J. « <u>A 24-year-old Ethiopian farmer with</u> <u>burning feet</u> ». American Journal of Tropical Medicine and Hygiene, 87 (4). 2012. p. 583.

This article highlights podoconiosis as preventable and a cause of disability and poverty.

Wagithunu M.N. « <u>Teachers' attitudes as a factor in the Realization Inclusive</u> <u>Education Practice in primary schools in Nyeri Central District</u> ». Mediterranean Journal of Social Sciences, 5 (5). 2014. p. 117-134.

This article describes a primary research project on the matter of inclusion of children with learning disabilities into education.

Wamocho F.I., Karugu G.K., Nwoye A. « <u>Development of a guidance programme for</u> <u>students with special educational needs in Kenya: a study on personal</u> <u>orientation</u> ». British Journal of Special Education, 35 (4). 2008. p. 221-229 (Paying access)

This study looks at psychological factors around the personal development of secondary education students with disabilities and possible support mechanisms for them.

Wazakili M., Wakeni D., Mji G., MacLachlan M. <u>Did What? The African Policy on</u> <u>Disability & Development (A-PODD) project in Ethiopia.</u> Dublin: A Global Health Press. 2011. 13 p.

This paper reports findings from primary research conducted in Ethiopia. It looks at how disability can be included in national development agendas and how disability research can be utilised.

 Water Engineering and Development Centre. <u>Why the water and sanitation sector</u> <u>in East Africa should consider disabled people.</u> Loughborough University: WEDC. 2006.

This short paper summarises the issues around access to water for people with disabilities, the difficulties they face and it points towards solutions. It is a useful introduction to the subject.

Wee J. « Examining factors impacting community based rehabilitation in a refugee camp – an exploratory case study ». Asia Pacific Disability Rehabilitation Journal, 21 (2). 2010.

This study identifies barriers to access to services for people with disabilities in a refugee camp and considers the role of CBR.

Wickenden M., Mulligan D., Fefoame G.O., Katende P. <u>« Stakeholder consultations</u> <u>on community-based rehabilitation guidelines in Ghana and Uganda »</u>. African Journal of Disability 1(1). 2012. 10 p

By examining a stakeholder consultation exercise this paper examines and reflects upon the influence of grassroots stakeholder consultation in shaping policy and reciprocally how policy change can inform organisational practice.

Wilbur J., Jones H. "<u>Disability: making CLTS fully inclusive,</u>" Frontiers of CLTS: <u>Innovations and insights</u>. 3. Brighton: Institute of Development Studies. 2014. 2014.

CLTS is Community Led Total Sanitation. This report is based on research from Uganda and Zambia. It looks at barriers to sanitation facilities for people with disabilities and gives recommendations for the inclusion of people with disabilities in improvement planning process at community level.

Wilbur J. <u>Principles and practices for the inclusion of disabled people in access to safe sanitation. A case study from Ethiopia.</u> London: WaterAid. 2010. 20 p.

While this report addresses some issues around access to water and sanitation it is particularly valuable in that it generously describes approaches attempted which were not successful, especially in relation to the empowerment of people with disabilities, and considers why they did not work.

Wormnaes S., Sellaeg N. « <u>Audio-described educational materials: Ugandan</u> <u>teachers' experiences</u> ». The British Journal of Visual Impairment, 31 (2). 2013. p. 164-171 (paying access)

This study examines the usefulness of audio support to visual media training materials for trainee teachers with visual impairments in Uganda.

Yokoyama A. <u>« A comparative analysis of institutional capacities for implementing disability policies in East African countries: functions of national councils for disability »</u>. Disability, CBR and Inclusive Development (DCID), 23 (2). 2012. p. 22-40.

This study looks at the relationship between policy and implementation at national and regional levels.

The present document was conducted as part of the Resource Center of Applied Research and Disability in partnership with FIRAH (International Foundation of Applied Disability Research) and Advantage Africa. The fulfilment of this work was entrusted to Mary Ann Waddell, research graduate of University College London with coordination by Advantage Africa (Rob Aley). The full report was designed by FIRAH (Cécile Vallée / Resource Center Applied Research and Disability).

The goal of this literary review is to report on existing knowledge about applied research on East Africa, providing readers with access to a brief synthesis of knowledge written from selected documents, an initial list of documents submitted in an annotated bibliography and reading notes for those we consider a priority according to the selection criteria.

This work, which spans several thematic areas, does not intent to be comprehensive but to identify the results and knowledge generated by research that could be useful for field stakeholders in order to improve the quality of life and social participation for people with disabilities.





