Behinderung und internationale Entwicklung

Disability and International Development

Diskriminierung überwinden/Overcoming Discrimination
# Table of Contents

## Editorial
- Schwerpunkt/Focus
  - Diskriminierung überwinden/Overcoming Discrimination
  - Inclusion from a Socio-Cultural Perspective – A Javanese Example
    - Joyce Dreezens-Fuhrke
  - Practices, Discrimination and Liberty Rights in the Mental Health Act of Ghana
    - Isaboke Moraa Wilmah
  - Interview: Frauen mit Behinderung werden beinahe überall ausgeschlossen
    - Dorothy Musakanya Mapulanga (Zambia)
  - Ich bin anders aber gleichberechtigt
    - Shafiq ur Rehman (Pakistan)
  - Disabled People and the Post-2015 Development Goal Agenda through a Disability Studies Lens
    - Gregor Wolbring/Rachel Mackay/Theresa Rybczinski/Jacqueline Noga
  - Governments are not Enough: Disability, Development, and the Role of Broad Based Planning
    - Stephen Meyers/Victor Pineda/Valerie Karr

## Kurzmeldungen/Notes
- Literatur/Reviews
- Veranstaltungen/Events

## Impressum/Masthead

**Behinderung und internationale Entwicklung**

**Disability and International Development**

**Anschrift/Address**
Wandastr. 9, 45136 Essen
Tel.: +49 (0)201/17 89 123
Fax: +49 (0)201/17 89 026
E-Mail: info@inie-inid.org
Internet: www.zbdw.de

Für blinde und sehbehinderte Menschen ist die Zeit¬schrift im Internet erhältlich./For persons with visual impairment, an electronic version of the journal is available at www.zbdw.de

**Redaktionsgruppe/Editorial Board**
Isabella Bertmann, Christine Brucker, Jana Offergeld, Prof. Dr. Sabine Schäper, Gabriele Weigt

**Schriftleitung/Editorship**
Gabriele Weigt

**Redaktionsassistent/Editorial Assistance**
Katharina Silter

**Gestaltung/Layout**
Amund Schmidt

**Druck/Print**
Druckerei Nolte, Iserlohn

**Bankverbindung/Bank Details**
Bank für Sozialwirtschaft
Konto-Nr./Account number: 80 40 702
BLZ/BIC: 370 205 00 / BFSWDE33
IBAN: DE19 3702 0500 0008 0407 02

Die Zeitschrift Behinderung und internationale Entwicklung wird vom Institut für inklusive Entwicklung herausgegeben.

Editor of the journal Disability and International Development is the Institute for Inclusive Development.

**Hinweis**: Für den Inhalt der Artikel sind die AutorInnen verantwortlich. Veröffentlichte Artikel stellen nicht unbedingt die Meinung der Redaktion dar. Die Veröffentlichung von Beiträgen aus der Zeitschrift in anderen Publikationen ist möglich, wenn dies unter vollständiger Quellenangabe geschieht und ein Belegexemplar über¬sandt wird.

**Please note** that the authors are responsible for the content of the articles. Published articles do not necessarily reflect the opinion of the editorial board. Papers published in the journal Disability and International Development may be reprinted in other publications if correctly cited and if a copy is forwarded to the contact provided above.

ISSN 2191-6888
Liebe Leserinnen und Leser,

in allen Ländern dieser Welt tragen negative gesellschaftliche Einstellungen gegenüber Menschen mit Behinderung zu sozialer Exklusion, Stigmatisierung und Diskriminierung bei. Die UN-BRK benennt daher in Art. 8 die Bewusstseinsbildung als zentrale Aufgabe in der Umsetzung von Menschenrechten. Im Auftakt unserer Schwerpunktreihe zu Barrieren gesellschaftlicher Teilhabe und deren Überwindung beschäftigen wir uns daher mit kulturell, religiös und spirituell geprägten Bildern von Behinderung sowie ihren Auswirkungen auf die Lebenssituation von Menschen mit Behinderung.


Wir wünschen Ihnen viel Vergnügen und interessante Denkanstöße bei der Lektüre,

Ihr Redaktionsteam

Dear Readers,

in countries all around the globe, negative social beliefs about persons with disabilities result in their exclusion, stigmatisation and discrimination. UNCRPD article 8 therefore calls for awareness raising as a vital strategy for the implementation of human rights. At the outset of our series on barriers to social participation and the overcoming of such barriers, we take a look at cultural, religious and spiritual images of disability and their implications on the lives of persons with disabilities.

Joyce Dreezens-Fuhrke provides examples of cultural beliefs about social roles of persons with disabilities in Java. Isaboke Wilmah elaborates on the integration of the traditional and spiritual healing systems into the care for persons with mental impairments in the scope of the new Mental Health Act and addresses the advantages and risks that come along with this measure. Afterwards, Dorothy Musakanya Mapulanya from Sambia and Shafiq ur Rehman from Pakistan report on prejudices and discrimination based on their own experiences.

The last two articles focus on the topic of disability in the context of international development: Gregor Wolbring et al. demonstrate how little persons with disabilities as a disadvantaged group are considered in the scope of the Post-2015 agenda and beyond. Last but not least, Viktor Pineda and his colleagues advocate for a stronger acknowledgement of the importance of the private and civil society sector in the efforts to improve the living conditions of persons with disabilities.

We hope this issue provides you with interesting and new ideas and ways of thinking,

Your editorial board
**Inclusion from a Socio-Cultural Perspective – A Javanese Example**

Joyce Dreezens-Fuhrke

The implementation of the legal framework for social inclusion of persons with disabilities in Indonesia is not yet satisfied, especially in rural areas (Irwanto/Rahmi Kasim et al. 2010). Deep-rooted social and cultural attitudes are sometimes difficult to identify, but still exist and have an impact on the lives of persons with disabilities. Based on qualitative data from my research on disability in rural Java, both negative and positive perceptions on persons with disabilities are illustrated by two examples of disabled women. It is shown how access to inclusion and interactions with the community are interrelated to the Javanese symbolic structure on the one hand and to the present socio-cultural factors on the other hand.

**Introduction**

Against the background of the ratification of the UN Convention on the Rights of Persons with Disabilities in 2011, Indonesia aims to achieve its implementation (UNESCO 2013). Through specific programmes and the National Plan of Action on persons with disability 2004-2013 in recent years, progress has been made regarding the improvement of their living conditions. However, services and facilities for people who live with a physical, intellectual, or psychiatric, mild or severe impairment are still insufficient. Big discrepancies not only exist between the different Indonesian provinces, but also between rural Javanese villages and larger cities. In general, the needs of individuals with disabilities are often not met and their quality of life is rather low (Irwanto/Rahmi Kasim et al. 2010). Moreover, they are neither included in society nor in the social development. The process of implementation of the UN Convention is facing different kinds of barriers.

In Indonesia, a country with diverse cultures, traditions and beliefs, different views on persons with disabilities exist. The underlying socio-cultural factors of discrimination and social exclusion as well as inclusion of persons with disabilities in a rural Javanese social setting will be exemplified by two case studies: one woman with a physical, and the other with a visual impairment. A closer look is taken at the social attitudes of community members towards one of the women who is fighting for her rights. Own observations over many years until now and descriptions from older and current literature (e.g. Byrne 2003; Irwanto/Rahmi Kasim et al. 2010; Minas/Diatri 2008) confirm that beliefs, attitudes, behaviour patterns and values perpetuate over decades.

**Persons with Disabilities in the Javanese Symbolic Structure and History**

To understand the social reactions towards persons with disabilities in rural Java, it is useful to have an idea of how this group was perceived in early Indonesia and to know about the values attached to Javanese symbolic structures to comprehend their cognitive classification.

Very little literature exists about the living conditions of persons with disabilities in ancient Indonesia. Only brief information is found in some anthropological monographs. More can be found in the context of symbolic structures. These data are very important, as they form the basis for the current attitudes towards this group. In Javanese symbolic structure, people with physical impairments are *trimala*. This means that they are viewed as “dirty”, “unclean” and “evil” (Juynboll 1023:430; Pigeaud 1938:253; Gericke/Roorda 1901, II:504). According to Van der Tuuk (1897-1912, II:615f.), not only persons with physical impairments are *trimala*, but also those who live with a visual or hearing impairment, further ‘dwarfs’, ‘hunchbacks’, ‘albinos’, ‘insane people’, ‘lepers’, ‘epileptics’, ‘lame’ and ‘crippled’ ones and those who are considered ugly. Thus *trimala* is an affliction of physical and mental impairments and diseases. This must be regarded in the light of the Javanese way of categorising all phenomena as *halus* and *kasar* and the Javanese notion of physical appearance in general. Benedict Anderson (1972:38) defined the meaning of these two terms:

“The meaning of the term *halus* (...) is to a certain extent covered by the idea of smoothness, the quality of not being disturbed, spotted, uneven, or discoloured. Smoothness of spirit means self-control; smoothness of behaviour means politeness and sensitivity. Conversely, the antithetical quality of being *kasar*..."
means lack of control, irregularity, imbalance, disharmony, ugliness, coarseness, and impurity.”

In Java, a tradition exists that palawija⁶, i.e. ‘dwarfs’, ‘hunchbacks’, ‘albinos’, and ‘petengan’, i.e. blind people are kept at the Javanese court. In general it was thought that these people were dangerous. Only a really powerful king was assumed to be able to neutralise the influences of these individuals afflicted by trimala and to be protected from harm. Due to the hierarchical Javanese society it was believed that ordinary people could not be safe in their presence (Pigeaud 1938:58; Gericke/Roorda 1901, II:298; Moertona 1968:67). These beliefs are characteristic for the Javanese society in the 19th and until the mid 20th century. As the kingdom is part of the country’s past, these beliefs might well be faded out, but could still exist in certain parts of the society in a modernised way. Associated to the symbolic classification described above, attitudes towards persons with disabilities are often rather negative.

**Barriers to Inclusion**

In rural villages, persons with disabilities may have different positions within the community, such as the role of the traditional healer, the ‘fool of the village’, or the position of the expelled individual (Dreezens-Führke 1996). Unlike the beliefs which were described above (cf. Pigeaud 1938; Gericke/Roorda 1901), I will now show the example of a person with a disability who is fighting for her rights and independence, which is a rather new phenomenon in a rural social context. The barriers to social inclusion and the discrimination these people often face are due to various socio-cultural aspects.

**The Impact of Explanation Models and Cultural Concepts of Behaviour**

As in many societies all over the globe, disability in Javanese culture entails shame and embarrassment for persons with disabilities and their families⁷. This feature is related to the explanation models that disability of children is the consequence of a social and/or cultural offence committed by the parents (mostly mother) or any ancestor, i.e. a punishment by spirits or God. Due to this belief, those parents feel very malu (ashamed) in general and often hide their child from the social public.

Besides, regardless of a disability, every individual in Java is taught since his/her childhood to behave malu as a cultural norm in order to become a real Javanese (Magnis-Suseno 1981:57ff). This behaviour is also expected from a person with impairment, no matter which type. In extreme cases, individuals who are not able to behave malu, e.g. due to mental health problems, are tied up at the back of the family’s house or at the edge of the village hidden from the rest of the community (Dreezens-Führke 1996; Byrne 2003). Fear for harm is frequently declared by the community as a reason for this treatment, because persons with mental-health problems are often believed to be possessed by a supernatural spirit with bad energies (ibid). All in all, the malu-concept has a huge impact on social attitudes towards persons with disabilities. The principle of non-discrimination is embodied in Indonesian policies at a legal and theoretical level. However, in practice the right to be treated as an equal member of society has not yet been realised and discrimination can be observed at different levels (Cheshire 2013; Irawanto/Rahmi Kasim et al. 2010; Sirait 2008).

In the case of 23 years old Ratna⁸, who lives with her parents in a small Javanese village, the first time she became aware of stigmatisation was when she entered school. She had to suffer from the insulting reactions from her schoolmates and was discriminated because of her different physical appearance (hyperkyphosis). The consequence was psychological stress:

“In the past when I went to primary school I stopped going to school for two times. The children laughed at me and were crying: There comes the hunchback again. I could not stand it anymore” (Ratna).⁹

The barriers of social inclusion can also be illustrated by Ratna’s efforts to integrate herself into the village community and to participate in different village organisations. This was often connected with a lot of obstacles or failure.

“The grown-ups consider me as minder¹⁰. They have never asked me, whether I would like to participate in PKK or Karang Taruna¹¹. Several times I have tried to be active in these organisations, but somehow they have never accepted me. I often have been mocked” (Ratna).

Further, her own initiative to participate in a training program in a rehabilitation centre in the city far away from the village was not understood and accepted by the community. Some relatives got very angry when they heard of her intention. They expected her to stay at home to help her mother and sisters and to accept her fate as a person with impairment. But Ratna did not belong to the type of people in the village that show a malu behaviour because of their
disability and are caught in their traditional thinking. She was not willing to accept the conventional role as an orang cacat (person with impairment) in the community that is mostly a stigmatised and dependent one. Contrary to the magic concepts of the villagers, she herself provided medical explanations for the cause of her physical impairment. She embodied a new type of energetic individuals who are trying to escape from their fate, showing ambitious behaviour and action to fight for an equal position among the persons without disabilities. However, this behaviour stands in contrast to the belief embedded in Javanese culture, to consider one’s place in the microcosm as fate that has to be accepted. In the traditional Javanese society, a person with disability carries the stigma of being a burden to other family members, although those who are able to work are given a special task in the household and usually enjoy the protection of the family. Yet characteristic for a recent development is the aspiration for equal education for all and independence of individuals with disabilities. Referring to the case of Ratna, it was her own idea and decision to finance her secondary school education by working as a housemaid, as her parents could not afford the school fee. Unfortunately, this longing for economic independence frequently bears the risk of exploitation by the employer, as Ratna stated:

“Once I was working as a housemaid. At the same time I went to the secondary school. But I could endure it with this family only for eight or nine months. I had to work impossibly hard for them. I had to get up every morning at 3:30 to clean the floor and to do the laundry as if I would be a normal human being (orang biasa), but I am a human being with a disability (orang cacat) and I am not strong”.

Persons with disabilities in rural areas are generally not encouraged to develop personally. Although many neighbours denied her ambitious attitude, she wanted to become a seamstress and an economically independent woman. With her high educational level, her certificate of a business course and work experience in the city, she was a significant phenomenon in the traditional village. The goal of the Association of Indonesian Women with Disabilities, one of the main Disabled People’s Organisations (DPOs), is to achieve welfare and to fight for equal rights of women with disabilities as well as to help women to live independently (Irwanto/Rahmi Kasim et al. 2010); Ratna sets a positive example in this regard.

However, the transformation to an innovative type of a woman with disability is connected with the search of a new identity. The human rights approach to disability in Indonesia is reflected by the increase of DPOs and self-help groups, which is mainly a trend in big cities. Usually persons with disabilities live quite isolated with their families. A lack of information on possibilities of service provision is one reason, a lack of power and will to detach from the family, and a lack of encouragement to express oneself are other ones. The fact that persons with disabilities prefer to be with their peers or equals is a more recent development. But Ratna was able to express her wish: “I would really like to go somewhere, where the people are like me. I don’t know why I don’t feel at home in the village”.

In spite of her physical impairment, she had the power and dared to complain. This behaviour is often seen as an offence against the cultural sabar-concept that prevails on Java. As sabar (patient) refers to a noble Javanese and is associated with a person of good character, not to be sabar is a non-Javanese behaviour and extremely condemned by the village community. This behaviour is in particular expected from persons with disabilities and is related to the shame and fate-concept. But in contrary to this traditional Javanese concept, Ratna was fighting for her rights and stated: “I feel at ease in the residence, although I am not happy in the shoe section where I was placed instead of the promised seamstress course. The administration constantly tries to console me and tell me to be sabar. I have been here for four months and they haven’t transferred me. But I really want to become a seamstress and a successful one. And I won’t stop asking until they place me in the right course”.

This unconventional behaviour of a woman with disability no longer necessarily corresponds to the ideal image of a typical patient Javanese woman, but may show repeatedly a behaviour which is considered to be non-Javanese from the perspective of Javanese ethical principals as described by Magnus-Suseno (1981), i.e. not being satisfied with the assigned place. “Unfortunately, the government didn’t provide me with a workplace after my training course, but only promised me a sewing machine, which I finally received after having made constant demands for many weeks” (Ratna).

Being aware of one’s rights and the achievement of substantial self-esteem, proactivity and perseverance as well as self-assertion go along with the development of a new identity (Goffman 1990). However, such a new identity is not easy to maintain in an environment of
discrimination. Even if a person with disability is able to become economically independent, inclusion in the sense of being a recognised member of the society often fails if the person tries to live independently in the city. Factors as personal attachment to traditional norms and values and strong family bonds have a strong impact on the process of developing a new identity. Ratna longed for her parents and especially her sister – for whom she intended to be responsible later. However, the essential factor for her decision to return to her village was the process she went through realising that she was neither accepted by persons without disabilities in the city, but at home she received support from her family. As her one year stay at the rehabilitation centre helped her to become aware that she was not alone with her problems of suffering from discrimination, she tried to find her identity by looking for peers in her own village to share her distress. However this endeavour was not very successful. Back to her village and family Ratna was hassled by her peers and faced further unequal treatment. As possibilities of service provision are not equal for the different groups of persons with disabilities, she felt less accepted than e.g. her blind girl-friend who had received a scholarship for the school for children with a visual impairment. Much more support for blind people is provided compared to other groups.

Ratna’s painful realisation that in spite of her efforts regarding self-integration, her educational status and her working experience in town, she was rejected, continuously lowered her self-esteem and led to further identity crises. “Sometimes I have doubts about myself and think what I have done wrong. The guy P. is treated differently than I am. They treat him well. I don’t know why” (Ratna).

Besides the type of disability, also gender aspects play a crucial role concerning the community attitude. While nobody cared that P., a young man who had a hearing impairment, was not yet married at the age of 25, Ratna was confronted with discriminating statements like: “Although she is already 23 years old, she is not yet married”, or, “Apparently she never will be married”. Nevertheless Ratna herself thought about marrying. Her self-awareness had been evidently increased, and also her self-esteem as a woman. She still felt malu to go out with a man who also has a disability, but marriage had become an alternative now in her mind. Though, the matron’s suggestion to marry a man without disability was unthinkable for her. She would have been afraid to become dependent, since she felt herself inferior to persons without disabilities.

Access and Inclusion

The classification of persons with disabilities as sages, wise or knowledgeable persons is a phenomenon we can find in different cultures (Clerkes 1985; Edgerton 1970). This reflects the association of disability with supernatural and magic power as well as with knowledge. Especially the relation of blindness and supernatural power is apparent in many regions of the world, and the ascribed ability of persons who are blind to heal is characteristic in particular (cf. Lowenfeld 1975; Monbeck 1973; Obele 1983).

In the Javanese symbolic classification persons living with blindness, are stigmatised and trimala, but at the same time they are believed to have pramana, the divine principle of human life that is of decisive significance for this type of disability. Blindness as punishment due to social or culture failure is a dominant perception among Javanese. However, this perception goes along with the belief of compensation through a special gift: the supernatural power. This is clearly reflected in the social reaction towards individuals whose eyeballs cannot be seen. Based on my case studies, it is interesting that from the emic perspective, such persons are not classified as disabled (orang cacat), and the blindness is only pointed out in connection with their supernatural power (Dreezens-Fuhrke 1996). In general, individuals with a visual impairment are not able to take over the tasks of people who are able to see, but this does not automatically lead to their rejection by the community. They often have access to niches and special roles that are blocked for other individuals and where they can acquire a high reputation. In case of the shamanic healer Mbah, an 80-year old woman, and the 70-year old traditional Gamelan musician Pak, in the village of my research, it is particularly their blindness that is related to a high position within the community. Two factors seem to be essential for their recognised social roles: the attribution of supernatural power and the use of this power for the beneficiary of the community, i.e. healing and playing music. As in many cultures, on Java a shaman with magic power has access to special rights in the community and represents a respected as well as feared person. However, persons with visual impairments like blindness are not per se assured such high and outstanding positions in society. Regarding the assessment of blindness various studies state a remarkable intracultural
variability (cf. Obele/Cloerkes 1985; Cloerkes/Neubert 1987). Compared to other individuals with disabilities in rural village life, the marital position, the number of children, and the socio-economic position have no great significance for the social reaction towards 'blind wise persons'. They are neither classified according to their impairment nor to their social behaviour, but according to their supernatural knowledge and power. Decisive for their social recognition is their special cultural position within the community.

These two cases illustrate that certain individuals with disabilities are included in the traditional Javanese social structure, and can develop and achieve a position where they are neither discriminated against nor stigmatised in the sense that the physical impairment is associated with bad energy (cf. Goffman 1990:9). Moreover, the role of a blind healer allows participation in the social life of the community (Dreezens-Fuhrke 1996, 1998) in terms of a "modified participation" (Neubert/Cloerkes 1984:54).

**Conclusion**

To put the UN-Convention on the Rights for Persons with Disabilities into practice, one has to overcome attitudinal barriers and stigmatisation within the society/community. We can see from Ratna’s example that the discriminating and deficit-oriented attitudes by society are based on socio-cultural perceptions still prevailing in the Javanese society and may have devastating effects on the individual's life. Fighting against one’s fate is damned as breaking the social norms. According to the Javanese concept of society, maintaining the social harmony within the community, i.e. accepting one’s place within the community, is more important than the inner individual will. From a psychological perspective, attributes as ambitious behaviour, intensive activity, increased self-esteem and self-image may be regarded as a personal success that simultaneously may diminish acceptance in the long-established social environment. Such social conflicts may further lead to an identity crisis. Hence, all these factors can be considered as barrier to social inclusion. Ratna’s case clearly demonstrates which socio-cultural, psychological and economical barriers a person with a physical impairment often encounters in regard to social inclusion. Although she has achieved a recognised educational and professional level, she is still perceived as a person with disability and therefore she maintains such an identity.

Yet, on Java also positive perceptions can be observed and not all persons with a disability experience discrimination. The case of Mbah Yu, who is not perceived as being a person with a disability, illustrates that disability is determined by the socio-cultural beliefs and not the physical impairment. But what will happen to her “modified participation” (Neubert/Cloerkes 1984:54) in the village when the shamanic healer is no longer requested due to social change? She might not have anymore a recognised position as before the social change. While in an achievement-oriented society she would be expected to have an employment and probably be considered as a woman with a disability, in a traditional Javanese village, these expectations don’t play any role. So, possible harmful implications of social change should always be taken into consideration.

As shown by the two examples, significant for the social inclusion of persons with disabilities on Java is their social behaviour and action according to the social norms prevailing and less their type of disability. Social and cultural attitudes may hamper the implementation of the UN Convention. However, they cannot be abolished by legal strategies and frameworks alone. Negative social and cultural perceptions need to change so that persons with disabilities can participate in social and community life. To improve the conditions for social inclusion of persons with disabilities much needs to be done at governmental and non-governmental level. Especially in rural areas on Java awareness raising on equality of persons with disabilities within the community should be enhanced through government and NGOs. Individuals with a disability should be empowered to fight for their rights by DPOs and human rights activists. With their support the combat against discrimination towards persons with disability in the employment and education sectors as well as better work place conditions could be promoted. As we have seen from Ratna’s example social potential and sources of families play an essential role and should therefore be strengthened. Whereas local communities should be supported by the government, providing social services for their members with disability.

**Notes**

1. This article is based on many years of living in Indonesia and medical-anthropological field research on Java in the 90ties (cf. Dreezens-Fuhrke 1996).

2. There is little comprehensive data regarding persons with disabilities in Indonesia. The Asia-Pacific Development Center on Disability estimated the number of persons with disabilities in Indonesia on the basis of
the International Classification of Functioning, Disability and Health (ICF) developed by WHO to be about 1.38 per cent of the total population recorded in 2006 (231 627 000). See http://www.apcdfoundation.org/?q=content/indonesia, retrieved 16.01.2013. However, recent World Health Organisation (WHO) figures showed that around 10-15 percent of the Indonesian population has a disability.

3 For example improvements refer to the welfare of women, education and workers with disability, access to public facilities and transport, and poverty alleviation.

4 The two case studies were part of my field research, using qualitative methods as narrative interviews and participant observation for data collection.

5 Symbolic structures underlie the culture of the people of a society and shape their apprehension of the world about them. They encompass knowledge, beliefs and representations and classify the world in terms of meaning through symbols.

6 The Javanese term for “secondary crop”, that is also used to refer to persons with a disability.

7 The shame-concept is not culture-specific, as I observed it also in Vietnam and Laos.

8 The name is a pseudonym. Ratna was one of my case studies.

9 All quotations are translated by the author.

10 From the Dutch word minder = inferior.

11 PKK: Pembinaan Kesahtera Keluarga (indon.) is a family welfare organisation on village level. Karang Taruna is a youth organisation.

12 This may be related to several factors, e.g. 1. Much support is given by foreign agencies referring persons with visual impairment. 2. Related to traditional beliefs they are often not perceived as “orang cacat”.

13 Towards deafness, often positive attitudes are observed in Indonesia. In a community in Bali, for example, hereditary deafness is common and both hearing and hearing impaired members of the community regularly use an ethnic sign language to communicate. Local cosmology and legend even incorporate devotion to a deaf god. Deafness is considered a part of diversity of nature in this region. And deaf members of the community are integral to the shared community culture and ritual (Byrne 2003).

14 Term of address for an old woman or man.

15 The name is a pseudonym.

16 Short term for mister.

17 These two persons were also part of my case studies.

18 Similar to this statement Cloerkes formulates that initially the social reaction “create” the disability (Cloerkes 2007:103).

References


PIGEAUD, TH. (1938): Javaansche Volkvertoning, Batavia.


Résumé: L’implémentation des conditions légales pour l’inclusion sociale des personnes handicapées en Indonésie, particulièrement dans les régions rurales, n’est pas encore satisfaite (Irwanto et al. 2010). Des attitudes sociales et culturelles profondément ancrées dans les sociétés sont parfois difficilement identifiables, elles existent pourtant et elles ont des répercussions sur les personnes handicapées. Sur la base des données qualitatives résultant de mes recherches sur le handicap dans les régions rurales de Java, les perceptions positives et négatives envers les personnes handicapées seront expliquées à partir de deux exemples. Le lien entre, de l’un coté, l’accès à l’inclusion et les interactions avec la communauté avec sa structure symbolique javanaise et, de l’autre côté, les facteurs socioculturels contemporains sera démontré dans l’article.


Contact: dreezens@web.de
Practices, Discrimination and Liberty Rights in the Mental Health Act of Ghana

Isaboke Moraa Wilmah

This article examines the impact and implication of recognising traditional and spiritual mental therapeutic services in the Mental Health Act of Ghana (2012) for persons with mental disabilities in respect of liberty rights and fight against stigmatisation and discrimination. The article propounds that it is profoundly imperative to legitimately acknowledge and utilize innocuous cultures in providing mental health services in Ghana. The proposition is grounded in the conviction that the inclusion is necessary towards fostering protection of rights, curtailing discrimination and arbitrariness of any nature. The author recommends that all relevant parties, government, healers associations, non-governmental organisations, conventional organisations of healing and human rights keep these contextual priorities in mind when developing and providing mental health services in the Ghanaian Society.

Introduction

The World Health Organisation (WHO) approximates that more than 80% of African populations call in on traditional and spiritual healers for health reason. Respectively, these estimates are attributable to practices in Ghana (WHO Aims-Report 2011). Ghana is a country with an estimated population of 21.6 million with three million approximated to be living with severe, mild to moderate mental impairments (WHO 2007:3). Furthermore with a treatment gap of 98% of those with mental impairments, 70-80% are believed to undertake mental health consultations with one of the 45,000 traditional healers and other spiritual healers (Healers) in the country for health related complications (WHO 2007:28). Even though the efficacy of these methods and outcomes are constantly challenged comparatively with western medicine (Ministry of Health 2005:22), they nonetheless continue to be the first line of intervention in issues of health for the majority of the natives (Waldram 2000:603-604). This evidently indicates the relevant role of healers within the respective communities. However, recent documentation of abuse in traditional and spiritual healing centres in some African countries such as Kenya, Somalia, South Africa, Uganda, Tanzania and Ghana among jurisdictions have indeed elevated and fortified arguments against the effectiveness of their interventions (Human Rights Watch 2012:1-84; Hooper 2013). From the social, medical and human rights perspectives their validity have essentially been weakened.

In spite of this, the 2012 Mental Health Act of Ghana (MHA) which has replaced the antiquated Mental Health Decree of 1972 (Decree) recognises the therapeutic nature of traditional and spiritual services. It includes them among the authorised institutions to provide mental health care services to the people of Ghana on condition that the services are legally accredited. In addition, the enforcement of the new Act is timely, as the country is in dire need of reforms in the mental health sector and in the fight against discrimination. The MHA emphatically dictates the application and protection of basic human rights principles of all voluntary and involuntary patients (section 54, 55). It proscribes all forms of discrimination, cruelty, torture and other inhuman treatment through various procedural safeguards and judicial institutional mechanisms (section 54, 57, 62).

Thus, the article starts by highlighting the patronage towards traditional and spiritual mental health therapeutic processes and continues to examine their accordance with liberty rights of persons with mental disabilities. Finally, it provides a general overview of the MHA implications in the combat against stigmatisation and discrimination of persons with mental disabilities.

Ghana and Traditional Practices

In Ghana, therapeutic systems for mental health are multicultural with both traditional and conventional methods. The exercise of cultural healing has significantly been recognised from the time of independence and by different sequential Ghanaian governments showing an understanding in the country's traditional medicine and its practitioners. As early as 1962, the Nkrumah regime sought to recognise the valuable contribution of indigenous healers and enhance their professional status by promoting the creation of the Ghana Psychic and Traditional Healing Association (Wyllie 1983:46). Subsequently, in 1999 the Government joined
the traditional medicine associations into one organisation, the Ghana Federation of Traditional Medicine Practitioners Associations regulated by the Traditional Medicine Practice Act (TMPA 2000, Owoahene-Acheampong/Vasconi:1-2). The TMPA established a council to standardise the practice of traditional medicine, record practitioners, license them to practice, regulate the preparation and trade of herbal medicines. The limitation of the TMPA is that it neither regulates nor contains mechanisms for traditional mental health treatment and care.

In principle, the power legitimising the exercise of traditional practices stems from Article 26 of the constitution (1972). When read together with the above legislations (TMPA/MHA), it ensures the protection and perpetuity of the innocuous diverse cultures in Ghana in all aspects of life. The Article stipulates that

1. Every person is entitled to enjoy, practice, profess, maintain and promote any culture, language, tradition or religion subject to the provisions of this Constitution.
2. All customary practices which dehumanise or are injurious to the physical and mental well-being of a person are prohibited.

Conversely, these legislative measures have not prevented the exercise of offensive practices (BasicNeeds 2011:1-44). Moreover and as highlighted in the following section, the cultural stigmatisation and discrimination that are associated with or emanate from traditional beliefs and methods continue to tremendously affect the lives of persons with disabilities. On the other hand, patronage to the abilities of healers continues fervently. Before ascertaining the implications of the MHA in this context, it is pertinent to understand the reasons for the resilient allegiance to customary and spiritual methods of healing.

The Patronage

As aforementioned, the usage of these methods is greatly linked to the cultural beliefs of the inhabitants of Ghana. This aspect should not be overlooked because culture, the intricate relationships of the family and the community in general influence Ghanaians understanding and approach to matters of mental illness and treatment (Kofi 1981). Ghana is constituted of various ethnic groups with an interesting range of belief and support system that influences their lifestyles (Neil 2007:177-178). For example, the majority culturally perceive sickness as a “state of disharmony in the body-and in the person or even in the society- as a whole”, mostly caused by evil spirits or breaking of a social taboo (Manda 2008:126).

When an individual becomes sick, and he/she is incapable of maintaining him/herself, the family be accountable for others as part of a bigger community (Neil 2007:53), this failure to execute a societal function makes the sick individual including those with mental disability vulnerable to being treated just like a child (Read/Adiibokah/Nyame 2009:13). Hence, the stripping of an individual’s right to autonomy, and subsequent taking of the individual to a prayer camp or traditional healer’s centre where treatment is administered through detention and without consent. Furthermore, since culturally causes of illness including mental impairment is attributed to divine punishment, possession of evil juju or the work of an evil eye, the only place that can offer a remedy are these healing centres (Aindanbila/Thompson 2011).

Stigmatisation, discrimination and exclusion from family and community life may transpire if there is a desire to protect the status of the family in the society and guarding that status from the stigma associated with mental illnesses (Neil 2007:182-186). The same may occur as an outcome of the impact of the behaviour of the person with mental impairment that might be considered embarrassing and damaging to the concerned families particularly in family or community gatherings (Neil 2007:86). In addition, discrimination may happen from distancing from the person considered to have been bewitched for the fear of receiving the same (McKenzie/Formanek 2011). Contextually, it may result from the imperativeness of ascertaining the cause of such an illness which can only be understood by the healers (Kofi 1981:12-14). The cumulative effect of all these factors together with the confidence in the expertise of the healers at fixing the social disharmony caused, pilots the families or individuals concerned to the first line of intervention in the community, the healers shrine (Danquah 1988).

It should be noted, however, poverty and other social issues have been pointed out as the push factors to these methods of healing which often leads to neglect and abuse.

Adequate evidence exists of the efficacy and social outcomes of African traditional or indigenous diagnosis of psychotic illness and other lesser forms of mental illnesses though critically disputed by various experts and researchers (Bartlet 2010; Sodi 1996; Waldram 2000:603-604). Nonetheless, the healers strongly believe in their abilities to heal various forms of mental disorders and so do the communities they serve. Research undertaken in various African countries points towards the fact that communi-
ties have different ethnic names referring to psychoses such as mania, schizophrenia and psychotic depression with manifold elucidatory models and methods of healing (Abbo 2011; Osei 2001; WHO 2002). The methods used normally depend on the diagnosis of the ailment and the powers so bequeathed to the healer. The common method of divination is used in diagnosis particularly with the inexplicable and often takes place in enigmatic ceremonial healing sessions (Atindanbila/Thompson 2011). This process involves the diviner, believed to have supernatural abilities giving foreknowledge as to the cause of illnesses or misfortunes. Other approaches could include – but are not limited to – confessions, chants, exorcisms, prescription of healing herbs, sacrifices, fasting to beating away of spirits from the individual whose mental illness is considered to be caused by witchcraft (Jocelyn 2014:1-2). Patronage to the healer’s methods and powers notwithstanding is very resilient.

The benefaction to the methods, powers and healing nature of the healers is situated in the healer’s capacity to correct an unacceptable social conduct and bring about social harmony (Kofi 1981). The capacity emerges from the conviction of being chosen by supernatural agents like the ancestors, deities and Supreme Being as believed by the Akan’s in religious healing (Mufamadi/Sodi 1999). Furthermore, the allegiance and widespread use of these methods resonates therapeutic outcomes when compared with the western approach to medicine (Madu 1997). In essence, healers communicate with their clients on an unconscious emotive and emblematic level rather than knowledgably (Kakar 1982). They control signs which align with the desires of those in their communities. The traditional thinking practiced by users follows a layout equivalent to that of healers. Generally, practitioners carry out astounding actions and participants subconsciously assent or heighten their belief in a specific healing dogma. Faith is not constructed considerably on a body of systematic information, but on the empirical confirmations the user gains from discerning the rite. This conviction influences the vicissitudes in attitudinal and physiological conditions that coincide with healing.

However, in our contemporary world governed by international human rights standards and norms, exercise of certain traditional and spiritual methods of healing stand to violate a considerable number of human rights standards. Flogging, chaining and seclusions in deplorable conditions for lengthy durations shred every bit of any individual’s human dignity, autonomy, equality, protection from torture, ill treatment, liberty and security of persons (Selby 2008). Moreover, in situations where legislative frameworks do not exist, the right to equal recognition before the law and right to justice are extremely breached.

Traditions and Liberty Rights

From above, it is ostensible that certain supposedly therapeutic methods may in essence amount to serious violations of human rights. Equally, in particular situations and when certain circumstances are not fulfilled, voluntary or involuntary treatment of individuals in traditional healing facilities may amount to arbitrary deprivation of liberty and security of persons. Deprivation of liberty in a lawful manner without arbitrariness is a fundamental guarantee of contemporary liberal nations, with confinement of citizens only undertaken in accordance with a due process of law. It is also dependent on lawful challenge, periodic review and proper conditions of detention (E/CN.4/2005/6:para 66). This principle regulates not only criminal incarceration, but all other lawfully permissible deprivations of liberty attributable to the state. In some cases the positive obligation of a State is engaged where it involves private parties (Jacobs/White/Ovey 2010:210-211). States ought to establish legislative and other measures to protect citizens vertically and horizontally.

Prohibition of arbitrary deprivation of liberty or detention is also an internationally recognised principle. Numerous international treaties sanction arbitrariness and emphatically prescribe guarantees of procedural protections and restrictions on detention. For example Ghana has ratified some of these instruments such as the Universal Declaration of Human Rights (Article 9 UDHR), International Convention on Civil and Political Rights (Article 9, ICCPR, Communication No. 702/1996) and Convention on the Rights of Persons with Disabilities (Article 14 CRPD), the African Charter on Human and Peoples Rights (Article 6, ACHR/Communication No. 241/2001(2003)).

Therefore, Ghana as a party to the above mentioned human rights documents is required to implement its obligations legislatively and through the establishment of enforcement mechanisms. Essentially, article 15 of the constitution (1972) emphasises the inviolability of human dignity of every person “whether arrested, restricted or retained, proscribes torture or other cruel, inhuman or degrading treatment or punishment and any other condition that de-
tracts or is likely to detract from his dignity and worth as a human being”. Consequently, in all conduct associated with restrictions on liberty human dignity has to be respected. The constitution also provides the framework for mental health access through involuntary detention and treatment under article 14. In spite of its archaic and deficit oriented reference to persons with mental disability, it recognises the deprivation of liberty of persons with mental disorders for the purpose of care, treatment or protection of the community by declaring inter alia,

“(1) Every person shall be entitled to his personal liberty and no person shall be deprived of his personal liberty except in the following cases and in accordance with procedure permitted by law (d) in the case of a person suffering from an infectious or contagious disease, a person of unsound mind, a person addicted to drugs or alcohol or a vagrant, for the purpose of his care or treatment or the protection of the community;

(2) A person who is arrested, restricted or detained shall be informed immediately, in a language that he understands, of the reasons for his arrest, restriction or detention and of his right to a lawyer of his choice.”

Notwithstanding the proscriptive nature of the constitutional provisos, experiences of ill treatment and arbitrariness in detention of persons with mental disabilities is a constantly happening phenomenon in Ghana’s psychiatric hospitals, traditional and spiritual centres of healing (Human Rights Watch 2012; Robert 2001). Individuals are greatly coerced to these centres and dumped there by relatives. Restriction of movement is enforced through the chaining of legs around trees or in tree stumps and in unhygienic surroundings for extensive durations (BasicNeeds 2011). These actions taken in totality amount to arbitrary deprivation of liberty and security of persons with mental disorders.

With the enactment of the MHA, it is anticipated that it shall guarantee the strengthening of the legal framework regulating mental health. In this manner, it optimises the fighting and elimination of arbitrariness through the procedural safeguards within the legislations. For example, the MHA promotes principles of autonomy, humane treatment and observance of human rights norms for all voluntary and involuntary patients. Admissions into a mental health care facility can be induced with or without referrals if in the opinion of the head or psychiatrist the patient’s mental disorder warrants an admission and depending on the availability of adequate facilities to treat the patient. At the centre of admission the MHA categorically requires the consent of the patient, personal representative and family. In circumstances where the patient or the personal representative is unable to give consent, the courts and tribunals are empowered to act in the best interest of the patient. Additionally, the patient is to be provided with relevant information pertaining to treatment and discharge.

Involuntary patient rights in the MHA are safeguarded through detailed procedural safeguards highlighting the reasons for admission, detaining durations and discharging conditions. Equality before the law and the protection of the law is guaranteed by the functions of the mental health tribunal and courts with the power of determining certain admission decisions, discharge, appeal and review of detentions. Admissions under involuntary detention may arise from emergency situations, through temporary treatment orders and from admissions that converse from voluntary to involuntary during treatment process. The duration of holding patients under the mentioned arrangements are within a period of 48 hours, 72 hours and according to the court order which shall not be more than month. Finally, warrant admission, sufficient evidence indicating that an individual is (a) suffering from a severe mental disorder, (b) patient’s health is deteriorating and (c) possess a risk to the public safety of others has to be presented.

Hitherto these provisions are effective and practical in a systemised psychiatric or mental health hospital and where there are strong judicial processes in place. Presently, the same situation cannot be maintained for Ghana. Moreover, the operation and practicability of such a structure within the traditional and spiritual healing systems is unknown. A report by WHO (2012) expresses factually that in Ghana expenditure on mental health is truncated with the majority of services concentrated on the heavily inhabited capital city of Accra, thus leaving a great part of the country with only scarce provisions. In addition, there is a lack of regional and district administration structures for mental health with numerous adverse concerns including very insufficient systems for designing and monitoring service and quality development. Furthermore, there is no use of legislation to regulate detention of patients within traditional healing centres. Traditional practitioners exercise unchecked powers of admission, treatment and detention of individuals with mental disorders. Needless to mention, that these powers are perpetuated by government for non-supervision on the one hand, and fami-
lies and relatives on the other for dumping and forgetting their persons at these centres. It is therefore not surprising that the majority of patients are sequestered and confined when not formally detained, thus resulting in the prevalent breach of human rights.

**Tradition and Spiritual Services in the MHA: The Perks and Perils of Inclusion**

It is strongly maintained that in the application and promotion of human rights, the culture of ethnic people must be given due considerations. This is in order to guarantee that human rights initiatives do not weaken the customary therapeutic processes of ethnic people (General comment E/C.12/2000/4: Para 27). In view of the complex connection between mental health and human rights, there is a persistent necessity to intensify the degree of discussion and reinforce an inclusive review of this needed connection (Dudley/Silove/Gale 2012). Progressive and inclusive mental health laws may promote the safety of people with mental disorders in a globalised yet culturally diverse world (Dudley/Silove/Gale 2012). It is crucial that in constructing assimilated mental health and human rights structures that advance and support rights based practices in mental health, proofs of efficiency of clinical, traditional and human rights interventions are acquired.

Accordingly, the recognition of traditional healing services in the MHA is substantially positively and negatively manifold. The positive side includes: promotion of mental health patient’s rights through undertaking consultancies and receiving treatments in accredited and accountable health institutions. Giving protection through the requirements of review, inspections and monitoring of these establishments. Also, providing standardised affordable and accessible alternative therapeutic treatments, treatments whose efficacy is supported by empirical research and data collection. This is imperative because it reduces the costs of pharmaceuticals consequentially providing accessible medicine for many poor families in Ghana. Furthermore the recognition implies inclusion of these services in the overall mental health system, imperative for the promotion of collaborations for effective service delivery, assessing the quality of service delivery, improvements and future planning. It has duly been noted that in Ghana, there is a prevalence of scarcity and sparsity of mental health services for persons in the rural areas. Thus, traditional and spiritual healers continue to be the primary care giver of mental health services albeit many repercussions.

The downside of recognition may entail the lack of regulations and mechanisms providing legal authority and safeguards in regards to treatment of involuntary mental health patients in the healing centres. There is a nonexistence of a policy and directive regarding the practice of psychiatry by faith-based practitioners and referrals systems between psychiatric hospitals and healing centres (WHO 2012). It is important to annotate that there have been cases where referrals have been made though in limited numbers. Furthermore, the tensions as to the efficacy of traditional medicine still looms. All in all, it is a belief that the inclusion will do more good than harm. Above and beyond it is not an easily eradicable system. Tenacity in curbing arbitrariness and prosecuting the offenders in cases where traditional interventions lead to abuse or mistreatment of a patient is imperative.

**Conclusion**

It is a deep-seated opinion of this discourse that Ghana through the MHA is in a position to effectively guarantee individuals with mental disabilities respect of their rights and access to mental health services without discrimination. However, in order to be in alignment with international human rights standards, procedural and institutional changes have to be put in place to overcome challenges that manifest. Similarly, it reckons that traditional and spiritual service can be tailored to uphold and respect human rights guarantees if proper structures and procedural safeguards are put in place. It underscores that traditional beliefs should be acknowledged and taken into reason by conventional trained doctors, human rights activists in their advocacies and policy makers, because these beliefs have a meaning within the socio-cultural and environmental context of Ghanaian people. Furthermore, it is important to concede that traditional healers and spiritual healers take into account the world view of the culture within which they work and that their misadministrations are for that reason consonant with the prevailing beliefs of their communities.

Conversely, the healers and their associations have the burden of providing quality and human rights oriented mental health services to individuals. Communities and their leaders have the task of seeking and receiving information for the best interests of their peoples. In addition, they have a duty of fighting stigmatisation and discrimination within their societies. Power tussles between methods of healing, ig-
nornance, lack of information and sensitisation should not stand in the way of individuals with mental disability living a normal life like any other individual without impairment. Partnerships with tertiary mental health providers need to be pursued to effectively provide a high standard of mental health for individuals in the Ghanaian society.

References


GHANA MENTAL HEALTH DECREE, (1972).


Résumé: Cet article examine les effets et implications du Mental Health Act of Ghana (2012) pour la reconnaissance des services psychothérapeutiques traditionnelles et spirituelles pour les personnes avec un handicap mental tout en le mettant en lien avec leurs libertés individuelles et la lutte contre leurs stigmatisation et discrimination. Cet article démontre l’extrême urgence de reconnaître comme légitime l’utilisation d’institutions anodines de soins médicaux pour la santé psychique au Ghana. Cette thèse est fondée sur la conviction que l’inclusion est nécessaire pour la promotion de la protection des droits et la réduction de la discrimination et de l’arbitraire de toute forme. L’auteur recommande que tous les acteurs concernés, gouvernements, associations de guérisseurs, organisations non-gouvernementales, organisations conventionnelles de guérisseurs et groupements des droits de l’homme prennent en compte ces priorités dans le développement et l’approvisionnement des services médicaux dans le domaine de la santé psychique dans la société ghanéenne.

Resumen: En este artículo se examinan los efectos e implicaciones de la Ley de Salud Mental de Ghana (2012) para el reconocimiento de los servicios de psicoterapia tradicionales y espirituales para las personas con discapacidades mentales en términos de sus derechos de libertad y la lucha contra el estigma y la discriminación. El artículo demuestra que es sumamente urgente reconocer el uso de instituciones inofensivas para el suministro de servicios de la salud mental. La tesis se basa en la convicción de la necesidad de la inclusión para fortalecer la protección de los derechos y disminuir la discriminación y la arbitrariedad de cualquier tipo. El autor recomienda que todas las partes interesadas, los gobiernos, las asociaciones de curanderos, organizaciones no gubernamentales, las organizaciones de derechos humanos, tengan en cuenta estas prioridades en el desarrollo y suministro de servicios en el campo de la salud mental en la sociedad ghanesa.

Author: Isaboke Moraa Wilmah is of Kenyan descent and a Human Rights Advocate. She is currently a PHD candidate in Central European University-Hungary. Her PHD research conducted under the supervision of Professor Károly Bárd, is focused on the challenges posed by accessing mental health care and treatment for persons with mental disabilities Vis a Vis liberty rights and other interconnected rights
Contact: Isaboke_Wilmah@ceu-budapest.edu

Author: Isaboke Moraa Wilmah is of Kenyan descent and a Human Rights Advocate. She is currently a PHD candidate in Central European University-Hungary. Her PHD research conducted under the supervision of Professor Károly Bárd, is focused on the challenges posed by accessing mental health care and treatment for persons with mental disabilities Vis a Vis liberty rights and other interconnected rights
Contact: Isaboke_Wilmah@ceu-budapest.edu
Interview: Frauen mit Behinderung werden beinahe überall ausgeschlossen

Dorothy Musakanya Mapulanga (Zambia)

Was bedeutet es konkret für einen Menschen in einem Entwicklungsland mit einer Behinderung aufzuzwachsen? Im folgenden Interview stellt Dorothy Musakanya Mapulanga ihr Leben als Frau mit einer körperlichen Beeinträchtigung in Zambia vor.

Bitte stellen Sie sich kurz vor: Wo und wie leben Sie?

Wann haben Sie zum ersten Mal festgestellt, dass es Barrieren in ihrem Alltag gibt? Was waren das für Barrieren? Wie hat sich das ausgewirkt?

Würden Sie kurz ihre Kindheitserlebnisse bis zur Schule schildern, bitte?
Während meiner Kindheit riefen mir die Kinder Namen zu wie „Chatyoka“, was soviel heißt wie „etwas ist kaputt“. Andere nannten mich „Akaloshi kailowa akakulu“, was übersetzt bedeutet „die Hexe, die ihr eigenes Bein verhext hat“. Niemand wollte mit mir zu tun haben, noch nicht einmal Bücher tauschen oder am selben Tisch sitzen. Als einziges von acht Kindern mit einer Behinderung hatte ich in meiner Familie viele Einschränkungen und Verboten durchzustehen. Zuerst kamen immer die anderen an die Reihe, ich war die letzte.

War es für Sie möglich eine Schule zu besuchen? Wenn ja, was haben Sie für einen Abschluss?

Sind Sie derzeit berufstätig? Wenn nein, bekommen Sie eine Unterstützung (materiell oder immateriell) vom Staat?

Haben Sie das Gefühl, als Frau anders behandelt zu werden als ein Mann?

Welche Erfahrungen haben Sie als Mutter mit einer Behinderung gemacht?

Was müsste sich Ihrer Meinung nach ändern, um die Situation von Menschen mit Behinderungen in Ihrem Land zu verbessern?

Die größte Sünde der Welt ist es, den Menschen zu kategorisieren. Normalerweise diskutieren wir untereinander und versuchen die Realität zu verstehen, versuchen das Beste zu geben, aber aufgrund unserer beschränkten Fähigkeiten klappt das leider nicht immer. Was ist die Wirklichkeit? Wer weiß das schon?


Wir können die Welt ändern, wenn wir wollen. Es scheint so, als ob wir Diskriminierungen akzeptiert haben, sonst würden wir unsere Stimme viel stärker erheben. Wir wollen ein Teil der Gesellschaft werden und nicht außen vor stehen. Wann immer ein Unglück passiert, wie
Ich bin gleichberechtigt, weil ich anders bin.

Disabled People and the Post-2015 Development Goal Agenda through a Disability Studies Lens

Gregor Wolbring/Rachel Mackay¹/Theresa Rybchinski¹/Jacqueline Noga¹

The purpose of the study Disabled People and the Post-2015 Development Goal Agenda through a Disability Studies Lens was to examine the role and visibility of disabled people in global policy processes related to various sustainable development (SD) discourses such as social sustainability, sustainable consumption, Rio+20 and the Post-2015 development. The study found that disabled people were barely visible to invisible in the SD literature covered, that the goals and actions proposed in the SD discourses are of high relevance to disabled people, but that these discussions have generally not been explicitly linked to disabled people. It found further that disabled people have clear ideas why they are invisible, what the problems with development policies are and what needs to happen to rectify the problems. It found also that there was a lack of visibility of various SD areas such as social sustainability and goals such as energy security within the discussion of SD in the disability community. Our quantitative data also highlights other forms of social group visibility unevenness in the literature and as such we argue that the data we present in this paper is also of use for other stakeholders such as young persons, women and indigenous people and also for NGO’s and policy makers. The paper presented here is a two-third shorter version of the original (Wolbring/Mackay et al. 2013)².

Introduction

Sustainable development (SD) has been discussed for quite some time (DSD n.d.) and increasingly since SD was defined in the Brundtland Report (WCED 1987) as development that meets the needs of the present without compromising the ability of future generations to meet their own needs. One of the outcomes of the SD discourse was the generation of the Millennium Development Goals (MDGs) in 2000. Efforts are underway to link sustainable development goals with the Post-2015 development agenda. It is well documented that disabled people are missing from the MDG discourse (Groce 2011; Godziek 2009; IDA n.d.; DPI n.d.) despite the facts that
a) article 32 of the UN Convention on the Rights of Persons with Disabilities covers the demand that international co-operation, including international development programs have to be inclusive of and accessible to persons with disabilities (UN-CRPD n.d.);
b) the United Nations General Assembly had numerous resolutions on the topic of the MDGs and disabled people since 2007 (UN Enable The MDGs and Disability n.d.);
c) that numerous reports from the Secretary General of the United Nations covered the topic (UN Enable The MDGs and Disability n.d.) and

d) that the Secretary General report, Keeping the Promise: Realising MDGs for Persons with Disabilities Towards 2015 and Beyond (UN 2010) had many recommendations as to how to solve the problem.

The online consultation for a disability inclusive development agenda towards 2015 and beyond moderated by a member of the International Disability Alliance that took place between March 8th-April 5th, 2013³, which is analysed as a part of this paper, is just one effort to ensure a higher visibility of disabled people than before.

The original full length paper provides missing but needed qualitative and quantitative data highlighting the situation of disabled people in the social sustainability, sustainable consumption, Rio+20 and Post-2015 development agenda proposals and the Post-2015 development discourses. It provides furthermore data on the views of disabled people on their situation related to development discourses. We also provide quantitative data related to other social groups and in general, we submit that the data we report is of use to NGO’s, INGO’s, policy makers, academics and others involved in SD discourses whether they work on disability issues or focus on other social groups.

Methods

Data Sources
To investigate the academic sustainability consumption and social sustainability discourse, we searched the following databases: Scopus (full text), EBSCO (All) (full text), Web of Science (topic) and JSTOR (full text) for the keywords ‘social sustainability’ or ‘sustainable consumption’ (no time frame limit beside what is covered by the databases). We ended up with
1909 abstracts covering social sustainability and 1122 abstracts covering sustainable consumption. To investigate the Rio+20 Discourse, we searched academic literature (articles from peer-reviewed journals n=99), non-academic sources (International Institute for Sustainable Development (IISD) reporting service n=79 article) and newspapers (New York Times and n= 300 newspapers from the Canadian Newsstand, n=312 article) and the Rio+20 (n.d.) outcome document The Future we Want. To analyse the discussion forum of disability and the Post-2015 development goal agenda discourse, we downloaded on April 7th all the comments of the online consultation for a disability inclusive development agenda towards 2015 & beyond3. To gain information as to goals envisioned for the Post-2015 development agenda, we downloaded on March 12th all the Post-2015 development proposals collected by Post2015.org5. We searched Google Scholar (on March 20, 2013) for the phrase “sustainable consumption of”, which yielded 848 results of which 656 were usable (English and covering the topic) in order to generate quantitative data on what is seen in need of being sustainable consumed.

Results

Section 3 of the original paper is organised into three sections covering the three research questions. Section 3.1. provides quantitative data on who is mentioned as a stakeholder in our data sources, including academic coverage of social sustainability and sustainable consumption, the Rio+20 outcome document, the Post-2015 development agenda proposals and the views of participants of the discussion forum of disability and the Post 2015 development goal agenda5. Section 3.1 provides furthermore qualitative data on the views of participants of the disability and the Post 2015 development goal agenda on their own visibility in the development discourses and how it should be rectified. Section 3.2 provides qualitative data on what participants of the disability and the Post 2015 development goal agenda view as the attitude toward them and the problems it causes and what is needed to fix it. Section 3.3 provides quantitative data on what goals and actions are seen in need of being tackled as evident in the academic coverage of social sustainability and sustainable consumption, the Post-2015 development agenda proposals and the views of participants of the discussion forum of disability and the Post 2015 development goal agenda5. It provides also qualitative data on goals evident in the Rio+20 outcome document The Future we Want (n.d)6.

Discussion

Stakeholders

Visibility of disabled people

Our study provides quantitative and qualitative evidence for the lack of visibility of disabled people and their topics within many SD discourses. Our results show that disabled people are not a topic which academics working on SD topics pursue to understand, nor do they analyse the relationship between disabled people and social sustainability, sustainable consumption, the Rio+20 outcome document, the Future we Want (n.d)6.

Our study provides quantitative evidence for the lack of visibility of disabled people and their topics within many SD discourses. Our results show that disabled people are not part of the energy discourse and are rarely visible in the climate change discourse (Wolbring 2009) or the education for sustainable development discourse (Wolbring/Burke 2013). Disabled people are also invisible in many water related discourses including sanitation and hygiene (Noga/Wolbring 2012). None of the World Water Reports (a collaboration between various UN agencies) cover disabled people (ibid.). As to the water discourse, the invisibility could be linked to certain ability expectations and utilities one expects stakeholders to have (Wolbring 2011). Another reason could be linked to how disabled people are perceived. Indeed participants of the discussion forum disability and the Post 2015 development goal agenda7 highlighted that the stereotypical understanding of disabled people within a medical framework precludes them from being part of certain discourses as the focus towards them is about preventing disability as in ill health not about decreasing their low social health. Indeed if one searches for the term disability within the World Water reports one only finds medical references, including terms such as disability adjusted life years and terms that look at disability as something to be prevented (Noga/ Wolbring 2012). However, although this finding is not surprising we posit that there are no practical reasons why disabled people could not be part of SD discourses. Numerous recommendations are in existence that highlight what should be done in general to increase the inclusion of people with disabilities (see for example World Report on Disability, WHO 2011).

Or recommendations in the 2011 United Nations report Disability and the Millennium Development Goals: A Review of the MDG Process and Strategies for Inclusion of Disability Is-
sues in Millennium Development Goal Efforts (Groce 2011) and the latest Secretary General report, Keeping the Promise: Realising MDGs for Persons with Disabilities Towards 2015 and Beyond (UN 2010).

Furthermore the participants of the discussion forum disability and the Post 2015 development goal agenda voiced many ideas as to what worked and what prevents the improvement of the development agenda for disabled people. We posit that the problem is not one of lack of knowledge of what should and could be done. Many participants of the discussion forum disability and the Post 2015 development goal agenda stated the problem is a lack of political and societal will to better the situation of persons with disabilities and to implement existing legal documents such as the UN Convention on the Rights of Persons with Disabilities (UN CRPD).

Many strategies exist for achieving participatory realities. For example, within the design field participatory design processes are employed (Millen/Cobb/Patel 2011; Alper/Hourcade/Gilutz 2012) where co-designing of products are explored as possible avenue to perform participatory design (Hussain/Sanders 2012). Participatory action research is developed to generate research that is informed from the start by non-academics (Fals-Borda/Rahman 1991; Stoudt/Fox/Fine 2012). Participatory policy development is employed in various SD related discourses (Majdzadeh/Forouzan et al. 2009; Bijlsma/Bots/Wolters 2011). It is just not often applied to increase the inclusion of disabled people. The lessons learned within other discourses around participatory policy development should be applicable to disabled people and SD discourses.

We posit that the invisibility often exists because certain topics are simply not associated as being topics of concerns to disabled people. This is especially true on a local level. Many small scale initiatives often do not think about disabled people when they start, because the members were never exposed to disabled people who point out how the topic impacts them. Furthermore even if a group would look for input from disabled people they might not get useful answers. If we look at all the issues disabled people face its evident that many basic issues such as employment and education or access to transportation still are far from achieved by disabled people. This makes it hard for many disabled people to formulate their opinions and voice their concerns especially on new topics. Indeed the participants of the discussion forum disability and the Post 2015 development goal agenda stated clearly that capacity building of disabled people is also needed so they could hold their own in other discourses when they want to voice their opinions. We posit that capacity building of disabled people should be a main focus of the education part of various SD fields (Wolbring/Burke 2013).

**Role of Academics**

Finally we would like to draw the attention to the triangle of role of academics in SD, academics and their relationship to disabled people and disabled people being involved in academic and other SD discourses. Academics are mentioned in all SD discourses, however we want to engage with what participants of the discussion forum disability and the Post 2015 development goal agenda felt academics and its institutions should do related to disabled people. As a disability studies scholar, one has to think about who one serves and how (Wolbring 2012). The view of the participants of the discussion forum disability and the Post 2015 development goal agenda on the role of academics and academic institutions can be summed up to reflect that academics have the duty to perform participatory action research that ensures relevance of the research for disabled people. It is expected that research performed fills the gaps identified regarding data and evidence and that it contributes to decreasing barriers of all type disabled people experience. It is also expected that researchers perform outreach and be instrumental in decreasing the negative perception of disabled people and in decreasing barriers. Moreover, it also is expected that the material of the research reaches disabled people. These expectations pose numerous problems for academics including disability studies scholars (for a discussion around problems regarding disability studies scholars which is linked to many of the here recorded expectations see (Wolbring 2012)).

**Challenges for Academia**

We posit that the expectations of academia exhibited by participants of the discussion forum disability and the Post 2015 development goal agenda also pose challenges to the academic system. The reality is that a disability studies angle is still vastly under-represented in academia in general (Wolbring 1012) and that the key analytical lens used within disability studies (ableism) is not broadly used within other academic fields (ibid.). It is stated elsewhere (Wolbring/Burke 2013) that ableism is a useful angle for the education for sustainable development discourse and we submit an ableism lens...
is useful for all SD discourses covered in this paper. The highlighted expectations also pose challenges for academia given the low level of disabled people within academia and the problematic sentiment toward disabled students (Hutcheon/Wolbring 2012) and to the output academics generate (open access or not or both; academic language or lay language or both) (Wolbring 2012). To be more concrete, the expectations pose challenges for academics involved in SD discourses and academic degrees covering SD topics to include a disability studies lens within their programs, to educate their students on the disability angle of the topic, looking at disability beyond the medical label and to find ways to build capacity of disabled people to be involved in SD discourses. The suggestions also pose challenges to funders and their priorities of academic funding in general and in regards to disabled people (social or medical nature of question investigated) as well as to what governments see as important to support within academic institutions.

**Need for capacity building of disabled people**

Finally the vision poses challenges for disabled people because if participatory action research is to be the norm that means there have to be disabled people who want to be part of it, either as people willing to give their opinion or people who want to be involved in research projects. The question is which research projects disabled people do feel competent to be involved in. Especially if one looks at emerging issues of relevance to disabled people, do enough disabled people exist to answer emerging research questions? We posit that capacity building on emerging topics of relevance to disabled people is needed beside the increase of knowledge of disabled people in general. This has to happen through the use of academic institutions but it also has to happen through means developed outside of academia through informal learning, learning by doing and lifelong learning. This entails the need for NGO’s to be involved to provide some form of capacity building of disabled people. We submit the use of knowledge brokers (Meyer 2010) could be expanded who would provide disability NGO’s with knowledge needed to train their staff and board members and to increase capacity of their membership to be involved in SD discourses, especially on local levels. Indeed what is needed is a strategy that allows disabled people to constantly build their knowledge on topics in order to be able to influence as acknowledged experts a given discourse – a difficult tasks acknowledged by others (UN 2013a).

If we look at the stakeholder visibility numbers outside of the disability studies lens one can question also other invisibilities such as the invisibility of indigenous people. However this goes beyond the scope of this article but the authors hope that others use the data to look at it through other lenses.

**Attitude Toward Disabled People**

Problems related to the imagery of disabled people is not a new one but is seen for a long time a pervasive issue (Wolbring/Burke 2013; Yumakulov/Yergens/Wolbring 2012; Billawala/Gregor 2014) whether on the one hand the tragedy imagery the participants of the discussion forum disability and the Post 2015 development goal agenda [12] questioned a lot or the ‘supercrip’ image where disabled people are portrait as heroically overcoming ‘their limitation’ (Shear 1986; Harnett 2000; Myers Hardin/Hardin 2004; Kama 2004; Booher 2010; Silva/Howe 2012; Tyndal/Wolbring 2013). These imageries are detrimental to disabled people taking part in SD discourses as normal citizens. Indeed they were seen as one cause of the lack of political and societal will to increase the social health of disabled people by the participants of the discussion forum disability and the Post 2015 development goal agenda. We posit exclusionary language has to be abolished so that disabled people are not seen as “special need” anymore which is often used to not involve them (as special is often not seen as something particular deserving but something that requires additional actions and allows for other-ism to take hold).

**Goals, Themes and Action Issues Evident in the Discourses Covered**

In this section we discuss how the goals and actions identified are linked to and influenced by disabled people or not and how they and the discussion around them could impact disabled people for example in their endeavour to participate in SD and Post 2015 development discourses and their ability to increase their quality of life.

**Comparison of goals and action items mentioned in the disability and non-disability related sources**

There were many challenges voiced in the disability consultation which are also seen as action items for SD/MDG/Post-2015 development goals such as education, health, poverty/income, employment, infrastructure, transportation, water, sanitation, food and basic needs. This makes it paramount that disabled people...
be part of the discourses so they can ensure that remedies developed would also be of use to them. There were many issues mentioned as targets in the discussion forum disability and the Post 2015 development goal agenda\(^3\) that did not show up in the other sources. This is an indicator of a lack of diffusion of issues faced by disabled people into other discourses.

Finally certain terms such as social sustainability and sustainable consumption were not mentioned once in the discussion forum disability and the Post 2015 development goal agenda\(^3\). We submit this is also problematic, suggesting a total disconnect between the discourses and disabled people, not only from the SD discourse end as covered before but also from the end of disabled people not being familiar with the social sustainability and sustainable consumption discourses and the impact they have on disabled people. In this case, disabled people do not seem to even know the terms enough to identify the lack of visibility in these discourses as a problem.

Furthermore certain issues seen as action items in need of being fixed in the SD discourses were not mentioned in the disability consultation, such as energy insecurity and biodiversity. That biodiversity was not mentioned might be understandable as the biodiversity discourse is about non-human biological structures such as animals and plants but not about human biological diversity. However we posit it being a problem as human biological diversity is an area of engagement of disabled people for example in their discourse of questioning the medical model of disability and they should link it to the term biodiversity. The lack of mentioning of energy as an issue of concern is surprising and troubling given that many of the adaptation solutions for disabled people need energy whether fuel (special transportation of disabled people) or electricity (e.g. buttons to doors, or batteries for electric wheelchairs) and that in general disabled people have higher than average energy needs (House of Parliament 2009). This lack of highlighting certain areas of problems and the lack of mentioning key SD discourse terms suggests a need for drastic capacity building increase among disabled people. We posit there has to be a greater integration and cross-fertilisation between the disability and non-disability development discourses.

Disability as a cross-cutting theme
The topics for actions mentioned in the social sustainability, sustainable consumption, Rio+20 outcome document and the Post-2015 development goal proposals nearly all impact disabled people. For example, how we deal with topics such as sustainable consumption of food and food security impacts disabled people greatly. Indeed food was mentioned (n=267) in the discussion forum of disability and the Post 2015 development goal agenda. To give one quote:

“In a time of insecurity for food, water, jobs, and public monies the general social preference toward ‘us’ and people like us/versus ‘others’ becomes more intense. There are more people without visible disability and therefore the ‘without’ disability/group/has a louder voice in the social struggle for resources. Even in places with comparative wealth there is a remarkable outcry against ‘entitlement’ of people who seek public monies or even civil right legislation for the less numerous ‘other’, while ignoring the public monies and legislation that continue to give preference to their own group”\(^3\).

This quote highlights that food insecurity does not only impact the access of disabled people to food but that it increases the division within society making it even more difficult for disabled people to achieve all kind of other inclusion related goals. The quote highlights similar dynamics for other shortages and insecurities felt by disabled people. The quote suggests that disabled people might be best served by being a cross-cutting theme in SD discourses to be incorporated into all goals although other options may be possible. The cross-cutting option is supported by the latest United Nations Secretary General report of July 26, 2013, A Life of Dignity for All: Accelerating Progress Towards the Millennium Development Goals and Advancing the United Nations Development Agenda Beyond 2015 which indicates that cross-cutting is seen as the preferred option:

“111. Goals and targets should take into account cross-cutting issues such as gender, disability, age and other factors leading to inequality, human rights, demographics, migration and partnerships” (UN 2013b, 45).

This wording suggests that cross cutting should also be employed for youth and indigenous people two other social groups we found underrepresented as stakeholders in our data sources.

Universal design is pushed by the disability community for some time (Audirac 2008; Ellis 2008; Design 2010; Udo/Fels 2010; Darcy/Cameron/Pegg 2010; Ruiz/Pajoares/Utray et al. 2011; Sanford 2012; Street/Fields et al. 2012) as a means to fix their special status and the special status of their problems by designing for more holistic needs in mind so one does not have to do it special for ‘the disabled’. Universal design could be seen as one tool to main-
stream disabled people concerns as well as making disability a cross-cutting topic.

The importance of evidence
All discourses perceive indicators, measurements, frameworks and standards as important. They are seen to provide means to generate usable evidence. We submit it is essential for disabled people to be part of the development of such indicators, measurements, frameworks and standards as disabled people do not necessarily have the same needs and problems and solutions to a given problem might be different for disabled people. The Rio+ 20 outcome document *The Future We Want* (UN n.d.) for example acknowledges the necessity of measures of sustainable development which are universal, unified, and grounded in scientific knowledge. We posit for it to be universal it has to be able to and to actually measure the reality of disabled people.

Given that there is an increasing push for evidence based actions, the reasoning that lack of data leads to invisibility as mentioned in the sources we covered seems to be sound because if there is no evidence, it cannot be discussed; to take the example of water and sanitation various datasets exist as to GDP lost and employment lost due to lack of access to clean water and sanitation but these datasets do not indicate disabled people and as such one cannot point for example the finger at the magnitude of the problem for disabled people (Noga/Wolbring 2012). Lack of data is a well-known problem which is flagged as an issue to be solved in various MDG related documents and in the WHO World report on disability (WHO 2011). However so far no cohesive strategy has been implemented to generate the data needed in a consistent and methodological accepted way. One problem with data generation is that no consistent use of the term disability is evident meaning that often different groups of people are covered under the term disability. Also not every person with a disability is encountering the same problem or needs the same solution. Someone with arthritis is differently situated than a wheelchair user or a blind or deaf person or a person with autism or Down Syndrome. Furthermore, data reported under the header disability often does not report data based on the severity of the disability which is problematic as people with less ‘severe’ disabilities have less problems such as obtaining employment than people with more severe disabilities (Buckup 2009). Given the importance of evidence we posit that more evidence based data has to be produced related to disabled people and that this data has to be stratified for different disabilities based on severity with a clear indication what severity scales are used (for discussion on severity scale see for example ibid.) with the mentioning of examples of abilities for better understanding by the public as to which disabilities might fall into which severity category. So far there is no global standard on severity scales or even whether to use them. This makes it very hard to compare disability data generated by different sources.

Conclusions
Our study highlights that disabled people are still underrepresented in SD discourses and that disabled people have clear ideas as to what the problems are and what the solutions should be. We posit there is an urgent need for more visibility of disabled people; better imagery of disabled people; cross fertilisation between the disability and non-disability SD and Post-2015 development discourses; involvement of disabled people in the design of SD and Post-2015 development indicators, measures and frameworks and generation of disability data linked to SD and Post-2015 development topics to inform SD and Post-2015 development policies. Our data suggest that there is a need for the academic system (the academic institutions, academics, funding systems....) to be much more relevant to disabled people and that there is a need for capacity building of disabled people through formal and informal education in order for them to be able to contribute in a broader way to SD discourses. We posit that the knowledge of what should be done exists and it is an issue of implementation and monitoring of the numerous recommendations of various UN and other documents and of making use of the knowledge of disabled people.

However there are challenges to overcome to achieve the goal of establishing disability as a cross-cutting theme and increasing the visibility of disabled people and their use as experts. Numerous challenges were identified within the disability inclusive development agenda towards 2015 & beyond3 such as attitudes towards disabled people and their needs, stigma related to disabled people, lack of political will, the lack of awareness of the needs of disabled people, their rights and the non-medical models of disability. Lack of capacity of disabled people was also mentioned as a barrier as was lack of data. We submit these are all areas in need of action from academics and academia, governments, funding agencies, policy makers and NGO’s if the goal of inclusion of disabled
people in SD and Post-2015 development is to become a reality. We further submit that decreasing invisibility of disabled people requires a fundamental shift in how we perceive and treat disabled people and how they are engaged and empowered to self-advocate on local to global level of all segments of society.

Acknowledgments
We would like to express our gratitude that the organisers of the online consultation for a disability inclusive development agenda towards 2015 & beyond that took place March 8th-April 5th, 2013 allowed us to analyse the data and use it in our study.

Notes
1. The students contributed equally to the study.
2. We cover in the here presented piece only some selected areas from the original publication with the understanding that the reader goes to the full open access original article available at http://www.mdpi.com/2071-1050/5/10/4152/pdf.
4. Please go to the online full length article version at http://www.mdpi.com/2071-1050/5/10/4152/pdf for the full description of how the study was performed.
6. For results such as all the tables of data see full paper at http://www.mdpi.com/2071-1050/5/10/4152/pdf.

References
HUTCHEON, E. J./WOLBRING, G. (2012): Voices of “disa-


**Zusammenfassung:** Die Absicht der Studie Disabled People and the Post-2015 Development Goal Agenda through a Disability Studies Lens war, die Rolle und Sichtbarkeit von Menschen mit Behinderung in globalen politischen Prozessen in Bezug auf unterschiedliche nachhaltige Entwicklungs- (sustainable development, SD) Diskurse, wie zum Beispiel die soziale Nachhaltigkeit, nachhaltigen Konsum, Rio+20 und die Post-2015 Entwicklung zu untersuchen. In der Studie wurde festgestellt, dass Menschen mit Behinderung kaum sichtbar bis unsichtbar in der untersuchten SD Literatur waren, dass die vorgeschlagenen Ziele und Maßnahmen im SD Diskurs von hoher Relevanz für Menschen mit Behinderung sind, aber dass diese Diskussionen generell nicht explizit mit Menschen mit Behinderung verknüpft wurden. Es wurde außerdem herausgefunden, dass Menschen mit Behinderung klare Ideen davon haben warum sie unsichtbar sind, was die Probleme in der Entwicklungspolitik sind und was passieren muss um diese Probleme zu korrigieren. Es wurde auch herausgefunden, dass ein Mangel an Sichtbarkeit von unterschiedlichen SD Bereichen in der Behindertengemeinschaft herrscht, wie zum Beispiel Themenserien der sozialen Nachhaltigkeit und Ziele wie die Energie sicherheit in der Diskussion um SD. Unsere quantitativen Daten heben außerdem Ungleichgewichte in der Sichtbarkeit anderer Formen sozialer Gruppen in der Literatur hervor und damit vertreten wir die Auffassung, dass die Daten, die wir in diesem Beitrag vorstellen, auch für andere Stakeholder, wie zum Beispiel für junge Menschen, Frauen und Indigene, als auch für NGO’s und politische Entscheidungsträger von Nutzen sein können. Der hier dargestellte Beitrag ist eine zwei drittel kürzere Version der Originalversion (Wolbring/Mackay et al. 2013)².

**Résumé:** L'étude « Disabled People and the Post-2015 Development Goal Agenda through a Disability Studies Lens » visait d’analyser le rôle et la visibilité des personnes handicapées dans les processus politiques globaux en relation avec les discours divers sur le développement durable (sustainable development, SD), comme par exemple la durabilité sociale, la consommation durable, Rio+20 et le développement post-2015. L'étude a démontré que les personnes handicapées étaient guère visibles voire invisibles dans la littérature SD et que les résultats et actions recommandés dans le discours SD sont d’une grande importance pour les personnes handicapées, mais que ces mêmes discussions ne sont pourtant pas explicitement mis en lien avec les personnes handicapées. L'étude a également révélé que les personnes handicapées ont des idées claires sur les raisons pour leur propre invisibilité, les problèmes dans la politique de développement et les actions et mesures nécessaires pour corriger ces problèmes. De plus, on a découvert qu’il existe, auprès de la communauté des handicapés, un manque de visibilité dans les différents domaines du SD, comme par exemple dans la durabilité sociale ou dans les objectifs au sein de la discussion SD tels que la sécurité énergétique. De surcroît, nos données quantitatives soulignent d’autres formes de déséquilibre en ce qui concerne la visibilité des groupes sociaux dans la littérature. Pour cela, nous argumentons que les données présentées dans ce rapport peuvent être également utiles pour les organisations non-gouvernementales (ONGs) et les décideurs politiques.

**Authors:** Gregor Wolbring is an Associate Professor in the Faculty of Medicine, Dept. Community Health Sciences, stream of Community Rehabilitation and Disability Studies, University of Calgary. He is also a Visiting Professor of Ability Expectation and Ableism Studies at American University of Sovereign Nations (AUSN); scientific staff at the Institute for Technology Assessment and Systems Analysis in Karlsruhe, Germany; a Fellow at the Institute for Science, Policy and Society at the University of Ottawa, Canada; adjunct faculty in Critical Disability Studies at York University, Toronto, Canada; and Affiliated Scholar at the Center for Nanotechnology and Society at Arizona State Uni-
versity. He serves on a number of boards, including the Society for Disability Studies and the Council of Canadians with Disabilities. He is past-President of the Canadian Disability Studies Association, and has served on a variety of boards such as the Canadian Commission for UNESCO.

Rachel Mackay, Theresa Rybchinski and Jacqueline Noga are undergraduate students in the Bachelor of Health Sciences Program, Faculty of Medicine, University of Calgary. More information about the work of the students can be found at http://www.crds.org/research/faculty/Gregor_Wolbring.shtml

Contact: E-Mail:
Gregor Wolbring: gwolbrin@ucalgary.ca,
Rachel Mackay: ramackay@ucalgary.ca;
Theresa Rybchinski: tkrybchi@ucalgary.ca;
Jacqueline Noga: jmnoga@ucalgary.ca.
Governments are not Enough: Disability, Development, and the Role of Broad Based Planning

Stephen Meyers/Victor Pineda/Valerie Karr

Disability inclusive development requires that states, civil society organisation, and the private sector work together to actively engage persons with disabilities in larger development processes. This paper reviews core features of development and how they affect the nearly 1 billion persons with disabilities worldwide. The paper recommends that disability inclusive development must be continuously re-examined, refined, measured, and linked to tangible outcomes. Comprehensive national and international development strategies must not only focus on creating rights but also tangible opportunities and resources.

Redefining Empowerment and Participation

In many countries where civil society organisations are more robust, new political spaces are opening up for large segments of the population that have been historically marginalised, such as persons with disabilities. These political spaces allow for new forms of engagement and open up venues for the individual and collective aspirations of too often invisible constituents to be seen. But it is not enough for disability advocates to mobilise in the streets, nor is it enough to only look at political action, if they are to enter the halls of power. Truly empowered individuals are citizens that enjoy an equitable distribution of political, economic, and social power. This power allows empowered citizens to take part in deciding how states, markets, and civil society function.

Empowerment is a notoriously difficult word to define, often described as a “process rather than an event” (Chamberlin 1997:3) and given as many as twenty dimensions (Bolton/Brookings 1996). Amongst those many dimensions, participation, voice, and choice are by far the most common. This paper, however, argues that at the centre of any definition of empowerment must be a concept of power (Page/Czuba 1999) by which secondary concepts such as participation, voice, and choice must be evaluated. The underlying principles of the CRPD embrace a framework for inclusive development. Such a framework is predicated upon the notion of participatory governance and is based on the disability rights motto, “Nothing about us, without us”. This does not simply mean persons with disabilities have a voice, but also have a vote and a veto over every aspect of the way political, social, and corporate power affects their everyday life.

Despite the almost ubiquity of participation in public discourse regarding governance and development, what it means in practice and how it can be measured and assessed is poorly understood. Some academics and practitioners have argued that a focus on participation means a shift from focusing on development outcomes and the concrete what of service delivery, to the whom and how in regards to the way in which impoverished or marginalised persons are included in programming (Chapman 2009) and the political knowledge they have gained (Williams 2004). This is a process based understanding of participation, which usually focuses on measures such as the number of people who participated in a public event or attended workshops or, perhaps, whether civil society leaders were able to meet with government officials or otherwise be politically recognised. Process based understandings do not focus on concrete outcomes. One reason for a focus on participative processes rather than outcomes is based upon a recent shift, among many social scientists and political philosophers, to discourse analysis wherein the way people, problems, and phenomena are described and seen as enactments of power (Foucault 1994, 2002). Related is the ethical imperative popularised by Jurgen Habermas that everyone is given voice in the public sphere (Habermas 1991). When these views are related to development, agency amongst the beneficiaries of development is defined as their ability to participate, speak, or otherwise express views publically (Everett 1997). Thus, development and empowerment are linked. Both advance individual and collective capacity to participate in shaping ideas, values, and outcomes.

While language and culture are assuredly powerful, these views are called Post-Structuralist for a reason: they no longer concern themselves with the hard, concrete institutions that populate our political, economic, and social structures. As demonstrated by the recent uprisings in Madrid, Sao Paolo, Istanbul, and Cairo,
language and culture is key to shaping political outcomes (Tejerina/Perugorria et al. 2013). Furthermore, persons with disabilities form part of each movement and are in some degree working with others to shape a more equitable and accountable public sphere.

Proactively Engaging with Equity

Protecting and promoting the rights of persons with disabilities through inclusive development is everyone’s responsibility. Traditionally, ministries of health and social welfare have had the responsibility for developing and implementing national disability policies, of which the primary focus was service provision, reflecting a health and welfare perspective on disability. More recently, as disability rights advocates have become successful in advocating for the right to participate in their communities on an equal basis with others. Ministries of education, labour, and transportation have begun to play significant roles in developing disability policies that increase access for persons with disabilities to education, work, and public transportation, respectively. Equally, ministries of justice have begun adjudicating more cases protecting persons with disabilities from discriminatory treatment. Ministries of health, social welfare, education, labour, transportation, and justice will remain central in their role of promoting and protecting many of the rights specified in the CRPD. At the same time, every ministry must be held accountable for developing disability inclusive policies.

For example, the G8 announced the Deauville Partnership and released a Declaration on the Arab Spring in May 2011. The partnership outlines a donor and development strategy focused on Egypt, Tunisia, and other countries for private sector development and job creation. As donors, the G8 members who are state parties to the CRPD have the responsibility (under Article 32) to ensure that persons with disabilities are included in international cooperation agreements, including international development programs. Many of the promises made by the G8 are for trade agreements. Ministries of finance, trade, and/or commerce must be engaged to ensure that provisions within trade treaties are made requiring that products and services provided by international firms are disability inclusive. Ministries of commerce should be engaged to include protections for the rights of persons with disabilities in commercial law and develop the capacity to monitor both national and international businesses active within countries not furthering discrimination. In addition to engaging donor countries and ministries of trade and commerce, businesses should also be engaged with disability rights advocates directly. Private corporations should not be seen as secondary actors in the realisation of human rights. In March 2011, John Ruggie, Special Representative of the Secretary-General on the issue of human rights and transnational corporations and other business enterprises, submitted a landmark report to the United Nations Human Rights Council outlining Guiding Principles on Business and Human Rights (field notes 2013). In addition to reiterating the state’s duty to protect human rights through policies, legislation, regulation, and adjudication focused on preventing human rights abuses perpetrated by private businesses or committed by state-owned businesses, the report also promotes the norm that businesses should respect human rights and must develop and maintain appropriate policies and processes to promote human rights. This norm, advanced by the international community, parallels private corporations’ voluntary efforts at corporate social responsibility and diversity, often fulfilled through partnerships with civil society organisations or through commitments to corporate social responsibility networks such as the UN Global Compact (field notes 2013). In addition, as was evidenced during the High-level meeting of the General Assembly on the realisation of the Millennium Development Goals and other internationally agreed development goals for persons with disabilities (HLMDD), governments are increasingly aware that the Post-2015 Development deliberations needs to include a wider set of metrics and must incorporate the needs of persons with disabilities (United Nations 2013).

All corporations doing business in a country should be educated and engaged on the rights of persons with disabilities, encouraged to develop disability inclusion policies, and monitored and held accountable to them. Additionally, DPOs should partner with businesses to train and assist them in providing reasonable accommodation and connecting them to qualified job candidates with disabilities. The International Labour Organisation has taken a lead in engaging the private sector, oftentimes putting it in touch with civil society organisations in order to promote the right to decent work for persons with disabilities. In 2012, the ILO Better Work Project in Nicaragua found that 95% of garment manufacturers in Nicaragua were not achieving their obligations to include persons with disabilities in the workplace under Nicaraguan Labour Law (ILO/IFC 2013). Rather than simply advocate for more legislation or simply
report those companies to the Ministry of Labour, the Better Work country office got to the root of the problem: even when companies wanted to hire persons with disabilities, they were unable to recruit them nor find local expertise in accessibility and workplace accommodation. As a result, the Better Work office partnered with a local CSO that had more than a decade experience working with the private sector on disability inclusion to begin educating manufacturers on best practice in disability inclusion and helping human resources offices connect with DPOs in order to identify potential employees (ILO/IFC 2012). The ILO has also begun engaging multinational corporations at the global level, such as IBM, PepsiCo, and Volvo, by supporting the ILO Global Business and Disability Network, which connects businesses to one another to share knowledge on disability inclusion and helps them identify DPO partners on the ground to help them implement disability inclusion down the supply chain (ILO 2014). In each case, the central development actors providing the opportunities are private enterprises who, when supported, willingly hire persons with disabilities, thus helping them achieve their right to employment.

Lastly, CSOs across the world not only provide important goods and services to members of the community, but are also involved in shaping or reforming social policies. Goods and services provided by CSOs need to work harder on training and providing services to persons with disabilities on an equal basis with others. A 2009 study (Bwire 2009) on the economic inclusion of persons with disabilities in developing countries, unfortunately, found that amongst microfinance institutions, many of which were civil society organisations, the percentage of clients with disabilities who were provided access to microloans ranged between 0-0.5% of the majority of microfinance organisations’ clientele, well below the average percent of PWDs (10%) in the general population. CSOs provide important goods and services, as well as other opportunities to improve education, health, and employment outcomes. If persons with disabilities are to benefit from the activities of all civil society organisations, CSOs must be educated about the rights of persons with disabilities, encouraged to develop disability inclusion policies and practices, and held accountable to involving persons with disabilities in their project planning and implementation. Ministries of foreign affairs that certify or license international civil society organisations should require CSOs to develop disability inclusion policies. Ministries of social affairs and local governments working with grassroots CSOs should likewise require disability inclusion policies. In many places, mainstream development NGOs and local social movements are not inclusive, as was found in a recent study in Cambodia and Indonesia (Meyers/Karr/Pineda 2014), despite the fact that these civil society actors are major providers of opportunities and have mission statements oriented towards social justice or the common good. In many cases, these organisations had not received outreach from the disability community, which was focuses all of their efforts on educating and advocating towards the state. Examples of engaging with equity across all three actors in development can be illustrated most simply in a table (Figure 1). Each actor provides a range of specific resources and services. Each actor also engages in transactions on different scales, that of the individual and the society.

<table>
<thead>
<tr>
<th>Level</th>
<th>State Resources &amp; Services</th>
<th>Private Market Resources &amp; Services</th>
<th>Civil Society Resources &amp; Services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individual</td>
<td>Individuals control how personal rehabilitation services &amp; benefits are spent (as opposed to doctors &amp; social workers deciding who provides services)</td>
<td>Individuals are participants as employees and business owners in the labor market and as consumers in the private market</td>
<td>Individuals are equally included as volunteers and staff in mainstream CSOs &amp; all of the services and products are equally accessible.</td>
</tr>
<tr>
<td>Social Level</td>
<td>DPOs have a vote and veto in how communities and states spend tax money</td>
<td>DPOs are involved in businesses creating human resource policies and regulating products and services sold (i.e. to ensure accessible resources exist)</td>
<td>DPOs are part of CSO networks and all CSOs are regulated to ensure equal access to goods and services provided</td>
</tr>
</tbody>
</table>

Figure 1: Engaging with Equity in Development
Need for New Approaches

While participation in public discourse is an important aspect of citizenship, this paper argues that these process-based measures can and should never be separated from concretely measurable outcomes regarding access to and control over the distribution of goods and services through a given country’s institutions. Politics, by definition, means social relations involving authority or power normally thought of in terms of government, but equally true in the spheres of civil society and the market. Thus, if the political participation of persons with disabilities is to be more than symbolic, policies, projects, campaigns, and institutions must be assessed from the perspective of power, especially the power to have true access to competitive employment and public schools, for example. As such persons with disabilities should have real influence over the ways in which both goods and services are regulated and distributed in all social spheres. In order to have true access and influence institutions, all development actors have an obligation to positively include persons with disabilities and their representative organisations (DPOs). Inclusive democracy involves more than the formal equality of all individuals and groups to enter the political process, but entails taking special measures to compensate for the social and economic inequalities of unjust social structures. Such special measures may require forms of group representation, so that the particular social perspective of group members gains voice (Young 1990). For example, disability networks should be represented on National Disability Boards that go beyond advisory status to propose legislation, make budget decisions, and write policy.

In addition, mainstream CSOs should do more than simply take persons with disabilities into account in their needs assessments, but rather actively engage persons with disabilities in significant roles during the proposal and budget-writing process, project implementation, and monitoring and evaluation of development projects. Likewise, corporations should not only be held accountable to core labour standards regarding non-discrimination and Corporate Social Responsibility norms, but actively be working with persons with disabilities to develop effective human resources and consumer-access strategies that ensure persons with disabilities can both benefit from the products and services they sell, but also gain employment and advance within the firms. It is important that the advancement of the rights of PWDs in developing countries be carried out holistically, through a synchronised engagement of these three key actors: governments, private enterprises, and civil society organisations (including DPOs). Under this holistic approach, those individuals and organisations that are advocating for change understand that states are still the primary guarantors of rights, while corporations offer opportunities for innovation and employment.

As such, these actors in development each have a role in removing unnecessary barriers that exclude persons with disabilities. The international community has publicly stated its commitment to nations that are democratic, transparent and responsive to the aspirations of their people. Inevitably, different sectors may be at the forefront of change and reform depending on the specific country, but it is always important for the individuals, corporations, or government agencies advocating for the inclusion of persons with disabilities to establish and maintain an inclusive and comprehensive agenda that engages all three actors. For persons with disabilities to fully share in the benefits of reform and development, meaningful participation, access, and social inclusion must crosscut all sectors of society.

Notes
1 This article was the result of substantial collaborative efforts of the three authors. During the final revision process however Stephen Meyers’ writings now constitute a larger portion of this final piece.

References
HABERMAS, J. (1991): The structural transformation of


Résumé: Le développement inclusif exige la collaboration d’États, d’organisations de société civile et du secteur privé dans l’engagement actif pour les personnes handicapées dans les divers processus de développement. Cet article examine les points fondamentaux du développement et comment ils affectent presque 1 milliard de personnes autour du monde. L’article recommande que le développement inclusif soit régulièrement contrôlé, mesuré et lié aux résultats concrets. Des stratégies de développement compréhensibles nationales et internationales ne devraient pas seulement se focaliser sur la création des droits, mais aussi sur les possibilités concrètes et les ressources.

Resumen: El desarrollo inclusivo requiere que los estados, las organizaciones de la sociedad civil y el sector privado trabajen juntos para cooperar activamente a favor de las personas con discapacidad en los procesos más amplios del desarrollo. Este artículo analiza los temas claves del desarrollo y cómo éstos afectan a casi un billón de personas en todo el mundo. El artículo recomienda que el desarrollo inclusivo incluya que se sea revisado constantemente, refinado, medido y conectado con resultados concretos. Estrategias nacionales e internacionales de desarrollo comprensibles deben centrarse no solo en el diseño de los derechos, sino también en las oportunidades y recursos específicos.

Authors: Victor Santiago Pineda, PhD, Chancellor’s Research Fellow at the University of California Berkeley, Department of City and Regional Planning. He is also a Adjunct Professor at American University's Institute for Disability and Public Policy.

Stephen Meyers, PhD Candidate in Sociology at the University of California, San Diego. He has worked with a landmine survivors assistance NGO and with the International Labour Organisations' Disability Inclusion Project. At present, he is an Associate with World ENABLED.

Valerie Karr, Ph.D. Adjunct Professor, University of New Hampshire, and Director, World ENABLED, the only youth-focused international disability rights organisation. She authored a UNICEF’s human rights education manual for youth with disabilities based on the UN Convention on the Rights of Persons with Disabilities and co-authored several papers in the field of education curricula for children with disabilities.

Contact: E-Mail: Victor Santiago Pineda: vsp@berkeley.edu; Stephen Meyers: stephen@worldenabled.org; Valerie Karr: valerie.karr@unh.edu.
**Eighth Session of the UN Open Working Group on Sustainable Development Goals**

At the eighth session of the UN Open Working Group (OWG) on Sustainable Development Goals (SDGs) in New York (6th February 2014), a post-2015 sustainable development agenda that is inclusive of persons with disabilities was discussed.

IDA (International Disability Alliance) members stated the importance of mainstreaming the rights of persons with disabilities across the sustainable development agenda. The theme of the session was Promoting Equality, Including Social Equity, Gender Equality and Women’s Empowerment and the participants demanded that the Sustainable Development Goals must be based on a human rights framework incorporating non-discrimination and equality, in compliance with the UN Convention on the Rights of Persons with Disabilities (UN CRPD).

OWG Member States, including co-chair Hungary, the Republic of Korea, Israel, Switzerland, Nicaragua, Brazil, Egypt, Japan, Poland, Cuba and Palau voiced their support for the inclusion of persons with disabilities in the SDGs. In particular, the Republic of Korea emphasised the importance of recognising disability as a cross-cutting issue in the post-2015 process, while the United States and Israel supported the inclusion of disability status in disaggregated data as a priority area for the OWG to address.

In the afternoon, IDA, in cooperation with the International Disability and Development Consortium (IDDC), the Permanent Mission of Greece to the UN, and the European Union Delegation to the UN held a panel discussion on the inclusion of persons with disabilities in the sustainable development agenda. Representatives from Member States, UN agencies and civil society, discussed the importance of targets and indicators inclusive of persons with disabilities, to be included in all goals.

**Global Campaign for Education Launches Send All My Friends to School Project 2014**

The Global Campaign for Education (GCE) launched a campaign called “Equal Right, Equal Opportunity. Education and Disability” that focuses on inclusive education for the 2014 Global Action Week to raise the awareness of issues around disability. The Global Action Week is one of the major focal points for the education movement. Created and led by the Global Campaign for Education, Global Action Week provides everyone campaigning for the right to education with an opportunity to highlight a core area of the Education For All agenda and make targeted efforts to achieve change on the ground, with the added support of millions of members of the public worldwide joining together for the same cause. Teachers, students, education campaigners and members of the public are asked to take part in the Global Action Week events happening all around the world, 4th to 10th May 2014.

In most low- and middle-income countries, children with disabilities are more likely to be out of school than any other group of children; even if they do attend school, children living with disabilities are often more likely to drop out and leave school early. In some countries, having a disability can more than double the chance of a child who actually manage to enter classrooms, the quality and form of schooling received – often in segregated schools – can act to powerfully compound exclusion from the mainstream and confirm pre-existing societal notions about disability.

The Global Campaign for Education (GCE) issued a report calling for inclusive education for children with disabilities urging national governments to adopt appropri-
ate legislative frameworks and set out national plans for inclusive education. The report on education and disability summarises current evidence of exclusion from education faced by children with disabilities as well as the obstacles to quality education in developed and developing countries. It sets out the recommendations for national governments to create inclusive educational systems which can help bring down the barriers in quality learning. The report points out that disability is a major reason for dropping out school for children in developing countries. Another problem is the segregated schools systems. In many countries children with disabilities are obliged to receive education in segregated classes, which limits their contact with non-disabled peers. Moreover, quality of this education is often inferior to the mainstream one and restricts the possibilities of children with disabilities to continue learning at secondary and higher education institutions.

The report calls on all countries to ratify the Convention on the Rights of Persons with Disabilities (CRPD) and implement this commitment in national plans for inclusive educational policies. Properly trained teachers, accessible classrooms and supporting facilities must be put in place to sustain inclusive learning. Raising awareness and data evidence must ensure that rights of children with disabilities are promoted to receive quality education.

Furthermore, the report provides also policy recommendations for bi-lateral donors and international community to enhance inclusive education building. Countries should allocate at least 10% of aid budgets to basic education. Measurable global targets for inclusive education and disability must be set into the post 2015 agenda (http://www.campaignforeducation.org/docs/reports/EqualRight,EqualOpportunity_WEB.pdf).

The campaign invites UK school pupils to remind world leaders that children with disabilities are missing out most on education. In 2000, world leaders promised to get all children a primary education by 2015. A lot has been achieved: the number of children out of school has actually halved. That still leaves 57 million children without an education and more than one in three have a disability. Last year, over half a million pupils from 5,000 UK schools took part in the campaign. This year, the campaign is asking young people to get creative and raise awareness of the right of every child everywhere, regardless of disabilities, to have an education.


Access to Justice for Crime Victims with Disabilities Set as a Priority in Eastern Africa

More than 30 representatives of human rights and development NGOs, families of persons with intellectual impairments, self-advocates and human rights lawyers came together at a roundtable discussion on access to justices for persons with disabilities who were victims of a crime. The event was held on 11th September 2013 in Nairobi in Kenya and was hosted by Inclusion Africa and Inclusion International together with the Open Society Initiative for Eastern Africa (OSIEA). Lack of knowledge, inability to report an abuse, outdated laws and failure to provide proper procedure in a case were highlighted as the main obstacles encountered by persons with intellectual disabilities in Eastern Africa when seeking justice. Participants in the consultation shared their experience of these difficulties and expressed their concern about violence and impunity.

Based on the evidence and examples from participants, the roundtable brainstormed on the options for persons with disabilities to effectively respond to situations of abuse or crime and preventing such violations on persons with intellectual impairments to happen. Moreover, participants expressed that this discussion was only a first step in the process on how to equip organisations in the region with tools to protect persons with intellectual disabilities from violence and reinforce effective justice system. The Eastern African coalition will set up its agenda on the discussions’ outcomes to assure the continuation of activities on access to justice for persons with intellectual disabilities.


Celebrating the International Day of Persons with Disabilities

The International Day of Persons with Disabilities was celebrated worldwide on 3rd December. Break Barriers, Open Doors: for an Inclusive Society and Development for All was a featured topic of last year’s International Day, stressing the importance of inclusion of persons with disabilities in the post-2015 development framework. Ban Ki-moon, the UN Secretary General addressed a speech to all countries celebrating this occasion, emphasising the UN engagement for a disability inclusive development agenda in 2015.

There are over one billion persons with disabilities worldwide. More than 80% of them are living in developing countries, overrepresented among those living in absolute poverty. Despite this fact, persons with disabilities as a vulnerable social group were excluded from the Millennium Development Goals, the United Nations development agenda 2000-2015. The worlds’ celebration of last year’s International Day of Persons with Disabilities was therefore an opportunity to raise awareness of disability and accessibility as a cross-cutting development issue and further the global efforts to promote accessibility, to realise the full and equal participation of persons with disabilities in society.

Various events around the world took place on 3rd December to commemorate the International Day of Persons with Disabilities. Governments, organisations of persons


Information: www.bezev.de.

Menschenrechts-Tagung Armut und Behinderung weltweit - Ein vernachlässigtes Problem?


The first regional conference for the establishment of the Arab Office for Disabled People’s International (DPI) was held in Beirut, between 12th to 14th December 2013, under the slogan of Towards Strategies of Revival - A Movement of Empowerment, Partnership, and Inclusion. The conference was held following discussions between Disabled People’s Organisations (DPOs) and several experts on the rights of persons with disabilities in the Arab world. It is based on an initiative by the Lebanese Physically Handicapped Union (LPHU) and Disabled People’s International (DPI) in partnership with Diakonia World Federation. Participants from various Arab countries came together on one platform where voices from the Arab Region were heard. The conference led to the establishment of a new DPI Arab region, the office of which will be based out of Beirut, Lebanon.

Sixteen Arab countries have signed and ratified the CRPD since 2007. Nevertheless, attending representatives from DPOs stated that there has not been any noted progress in the field of enacting and implementing the CRPD in the Arab World, nor in the areas of national and regional coordination mechanisms. Persons with disabilities in the Arab world still suffer from ongoing exclusion and isolation; according to World Bank estimates, 20% of the poor are disabled persons. They still suffer from high unemployment and illiteracy rates, weak inclusive mechanisms, and a total absence of some disability sectors including issues related to persons with psychosocial disabilities and short people.

The conference aimed to set up a positive and efficient regional civil society framework reviving the Arab disability movement in favor of a qualitative transformation and the institutionalisation of a new regional rights-based movement. Decisions that where taken during the conference are summarised in an outcome document.


Resolution on the Inclusion of Persons with Disabilities in Ethiopia

On 24th November 2013 the International Disability and Development Consortium (IDDC) organised an event on the rights of persons with disabilities and the role of international cooperation in advancing these rights in Addis Ababa, Ethiopia. This event took place in the margins of a major parliamentary gathering between Parliamentarians of African, Caribbean and Pacific (ACP) countries and the European Union (EU), which is called the ACP - EU Joint Parliamentary Assembly (JPA). The objective of this side event was to offer JPA Members an insight into the reality of persons with disabilities in Ethiopia. Parliamentarians visited different health and educational projects followed by a debate during which Ethiopian Disabled People’s Organisations shared their main hopes, aspirations and concerns with JPA Members.

The Ethiopian hosts underlined the favourable policy framework which their country has put in place in crucial areas such as employment and education. However, those policies often lack follow-up and implementation. Accessibility was also identified as an obstacle to including persons with disabilities in Ethiopian society. This was assumed to be true for all aspects of accessibility. As another challenge, data collection was mentioned. The discussion revealed that there is a huge discrepancy between the official statistics that estimate the percentage of persons with disabilities at 1% of the population, and other sources believing this percentage close to the 15% figure as contained in the World Disability Report. On a positive note, the Ethiopian authorities stated to wish to address this matter in the upcoming census, in order to get more accurate data.

During the debate, Parliamentarians highlighted the importance of existing international mechanisms to promote the rights of persons with disabilities. Since the event took place in the context of the ACP-EU Joint Parliamentary Assembly, the 2011 Resolution on the Inclusion of Persons with Disabilities in Developing Countries was mentioned. The upcoming progress report of that resolution was highlighted as an important opportunity to share with the international community good examples, but also to address remaining challenges in countries such as Ethiopia. There was also agreement amongst panelists to showcase role models that could inspire many more persons with disabilities, but also help to remove the many barriers that still exist.

**VENRO: Stellungnahme zum Koalitionsvertrag veröffentlicht**


**WHO MiNDbank: More Inclusiveness Needed in Disability and Development**

The WHO launches a database, called the WHO MiND­ bank that is an online platform which brings together a range of country and international resources, covering mental health, substance abuse, disability, general health, human rights and development. These include policies, strategies, laws, and service standards. MiNDbank aims to facilitate debate, dialogue, advocacy and research in or­ der to promote national reform in these areas, in line with international human rights standards and best practice. MiNDbank has been made possible thanks to the collecti­ ve efforts of WHO Member States in sharing their national resources, with a view to achieving better health and hu­ man rights outcomes for all.

*Information: [http://www.mindbank.info](http://www.mindbank.info)*

**UNESCO-Gipfel: Bonner Erklärung zur Inklusiven Bildung in Deutschland verabschiedet**


schen Bundestag, die Bundesregierung, Länder, Kommun­ nen, die Wirtschaft, Zivilgesellschaft, Wissenschaft und Ak­ teure der Bildungspraxis auf, systematische Anstrengun­ gen zu unternehmen, um Exklusion im deutschen Bil­ dungswesen zu überwinden und Inklusion als Leitbild für Bildungspolitik und -praxis zu etablieren.


Deutschland hat sich insbesondere seit der Ratifikation der UN-Behindertenrechtskonvention auf den Weg zu ei­ nem inklusiven Bildungssystem gemacht. Es wurde ange­ merkt, dass die Rahmenbedingungen, die gesetzlichen Re­ gelungen und der Stand der Umsetzung in den einzelnen Ländern in Deutschland jedoch noch weit auseinanderge­ henen. Im Vergleich mit vielen seiner europäischen Nach­ barn habe Deutschland einen erheblichen Nachholbedarf bei der Schaffung inklusiver Bildungsangebote. Es wurden systematische Anstrengungen gefordert, um Exklusion im deutschen Bildungswesen zu überwinden und Inklusion als Leitbild für Bildungspolitik und -praxis zu etablieren. Bar­ rieren müssten zügig abgebaut und die erforderlichen Strukturen eines inklusiven Bildungssystems weiter aufge­ baut werden, um Inklusion umfassend in allen Bildungs­ bereichen zu ermöglichen und die Teilhabe aller am allge­ meinen Bildungswesen sicherzustellen. Es wurde betont, dass dies eine Aufgabe der Gesamtgesellschaft sei.

Die Teilnehmenden des Gipfels *Inklusion – Die Zukunft der Bildung* forderten alle an der Umsetzung inklusiver Bil­ dung Beteiligten zu einer Schaffung eines öffentlichen Be­ wusstseins für inklusive Bildung, zum Abbau von Vorurtei­ len und zum Wissensaustausch über inklusive Bildungs­ praxis, sowie zur Gewährleistung von Barrierefreiheit im Bildungssystem auf. Außerdem müssten professionelle


United Nations Development Programme

**Humanity Divided: Confronting Inequality in Developing Countries**

The report was presented on the 29th January 2014 and analyses global inequality trends around the world. It identifies their causes, their impact, and the ways in which they can be reduced. It clearly shows that, although we are living in a much richer world overall, the inequalities within and between countries are sharper and more extreme, and potentially form a threat to long-term social and economic development. As reported in this article by the United Nations Development Programme, women in rural areas are still up to three times more likely to die while giving birth than women living in urban centres. Women are also participating more in the work force, but remain disproportionately overrepresented in vulnerable and informal employment and underrepresented among political decision makers, while continuing to earn significantly less than men. Furthermore, children in the lowest wealth quintiles were up to three times more likely to die before their fifth birthday than children born in the highest wealth quintiles in some regions.

The report shows that persons with disabilities are up to five times more likely than average to incur catastrophic health expenditures.

**Bezug:**

**Behinderung und Entwicklungszusammenarbeit e.V. (bezev)**

**Dokumentation inklusiver Klima-Projekte zum Globalen Lernen im Rahmen des Projekts Jugend inklusiv – global engagiert**


**Bezug:**

**World Bank**

**Inclusive Mobility: Improving the Accessibility of Road Infrastructure Through Public Participation - East Asia and Pacific Region Transport**

This working paper describes a number of innovations taken by some Chinese cities, in particular Jinzhou, Liaoning province, to ensure that urban transport systems are more accessible for mobility-challenged persons. Public participation by residents with disabilities in Liaoning province in northeast China has increased awareness and consideration for special needs in the design and implementation of road infrastructure. Jinzhou has convened a series of meetings inviting public participation on the issue of improving traffic infrastructure for use by persons with disabilities. With the introduction of some low or no-cost features, the principle of people first for urban transport has been put into practice.

**Bezug:**
- [http://www-wds.worldbank.org/external/default/WDSContentServer/WDSP/IB/2014/01/24/000442464_20140124115129/Rendered/PDF/WDSContentServer/WDSP/IB/2014/01/24/000442464_20140124115129/Rendered/PDF/841770WP0inclu0Box0382094B00PUBLIC0.pdf](http://www-wds.worldbank.org/external/default/WDSContentServer/WDSP/IB/2014/01/24/000442464_20140124115129/Rendered/PDF/WDSContentServer/WDSP/IB/2014/01/24/000442464_20140124115129/Rendered/PDF/841770WP0inclu0Box0382094B00PUBLIC0.pdf)

**Plan International**

**Include Us! – A study of Disability Among Plan International’s Sponsored Children**

This report, produced in collaboration with the London School of Hygiene & Tropical Medicine, reveals that children with disabilities in developing countries are being held back from an education. Based upon Plan’s dataset of 1.4 million sponsored children, the report compares sponsored children with disabilities to those without, from 30 countries worldwide. Key findings show that children with disabilities are 10 times more likely not to attend school. When they do attend school, their level of schooling is below that of their peers; children with disabilities are much more likely to have had a serious illness in the last 12 months, including malaria and malnutrition. The findings should help to improve responses to the needs of children with disabilities, particularly regarding their health and education.

**Bezug:**

**IKV Pax Christi**

**Worldwide Investments in Cluster Munitions: A Shared Responsibility**


Jody Heymann/Michael Ashley Stein/Gonzalo Morena

**Disability and Equity at Work**

Despite international and national guarantees of equal rights, there remains a great deal to be done to achieve global employment equality for individuals with disabilities. In OECD countries, the employment rate of persons with disabilities was just over 40%, compared to 75% for persons without disabilities; in many low- and middle-income countries, the employment rates are even lower. There are numerous reasons why persons with disabilities fare poorly in the labor market; Disability and Equity at Work is a book to document what can be done to improve this imbalance.


Center for Election Access of Citizens with Disabilities/General Election Network for Disability Access

**Accessible Elections for Persons with Disabilities in Five Southeast Asian Countries**

This report is the first systematic attempt to gather data on election access from Cambodia, Indonesia, Laos, the Philippines and Vietnam. The report reviews, for persons with disabilities, existing legal frameworks, challenges and barriers in exercising political rights and participation; best practices and innovations; and examples of how disabled persons organisations have been involved in electoral issues.


AusAid

**Triple Jeopardy: Violence Against Women with Disabilities in Cambodia**

This policy brief paper presents an overview of a participatory research project developed collaboratively between Australian and Cambodian partners that sought to provide comparative information about the lives of women with disabilities and those without in Cambodia. Information is provided about the experience of violence, barriers to disclosure and services, policy directions, and policy and program recommendations.


Handicap International

**Sport and Play for All: A Manual for Including Children and Youth with Disabilities**

This training manual Sport and Play for All provides tips, guidance and advice on disability and inclusion, with the primary aim of enhancing users’ knowledge and practice on inclusion. It brings together many training materials used during the Sports for All Project in Sri Lanka, including materials on disability, social inclusion and models of inclusive sport. It features many games and sports which have been field tested and adapted to enable children with disabilities to participate.


Leonard Cheshire Disability and Inclusive Development Centre

**Maternal and New-Born Care Practices among Disabled Women, and Their Attendance in Community Groups in Rural Makwanpur, Nepal**

This paper presents qualitative and quantitative research that describes the type and severity of disability of married women in the study area, describes their participation in community groups and analyses associations between maternal and new-born care behaviours and disability. Health workers and field researchers were also interviewed about their experience with disabled women in rural Makwanpur.


Jo Sanson/Michael Felix

**Disability, Poverty, and Livelihoods Guide: Guidance from Trickle Up**

This guide is intended to encourage and assist organisations seeking to include persons with disabilities in their economic strengthening and livelihood programs. It contains lessons for organisations that aim to move households out of poverty, and those that seek to economically and socially empower particularly vulnerable members of poor household.

Help-Seeking Behaviour, Barriers to Care and Experiences of Care Among Persons with Depression in Eastern Cape, South Africa

Little is known about the help-seeking behaviour and barriers to care among people with depression in poor resource settings in Sub-Saharan Africa. This is a cross-sectional population-based study including 977 persons aged 18-40 living in the Eastern Cape Province in South Africa. The prevalence of depression was investigated with the help of a questionnaire (the Mini International Neuropsychiatric Interview). Several socio-economic variables, statements on help-seeking and perceptions of earlier mental health care were included. Data collection was performed from March to July 2012. The prevalence of depression was 31.4%. People aged 18-29 and those with no or low incomes were less likely to seek help. Promotive factors for help-seeking included having social support and tuberculosis comorbidity. Of all people with depression in this sample, 57% did not seek health care at all even though they felt they needed it. Of the variety of barriers identified, those of most significance were related to stigma, lack of knowledge of their own illness and its treatability as well as financial constraints. Recall bias may be present and the people identified with depression were asked if they ever felt so emotionally troubled that they felt they should seek help; however, we do not know if they had depression at the time they referred to. Depression is highly prevalent among young adults in the Eastern Cape Province, South Africa; however, many do not seek help. Health planners should increase mental health literacy in the communities and improve the competence of the health staff.

VERANSTALTUNGEN/EVENTS

**Information:** http://www.worldeducationcenter.eu/new/index.php/H-SCI2014/H-SCI2014; Kontakt: Zeynep Sentido Hotel Convention Center, Belek, Antalya, Turkey; E-mail: h­sci.editor@globalcenter.info.

06.05. - 08.05.2014 1st Global Conference: Sexuality and Disability, Lisbon, Portugal. 
**Information:** http://www.inter-disciplinary.net/critical-issues/gender-and-sexuality/sexuality-and-disability/call-for-presentations/; Kontakt: Inter-Disciplinary.net, Priory House, 1498 Wroslyn Road, Freeland, Oxfordshire OX29 8HR, United Kingdom; Tel.: +44 1993 8820 87; Fax: 0044 870 4601 132; E-mail: Colette Balmain: cb@inter-disciplinary.net, Rob Fisher: sd1@inter-disciplinary.net.

14.05. - 17.05.2014 Annual International Conference of Cognitive, Social, and Behavioural Sciences (icCSBs), Mersin, Turkey. 
**Information:** http://iccsbs.c-crcs.org ; Kontakt: Cognitive, Counselling, Research & Conference Services, Post Box 24333, Post Code 1703, Nicosia – Cyprus.

**Information:** http://pacrim.hawaii.edu/; Kontakt: Tel.: 808 956 7539; E-mail: prin­fo@hawaii.edu.

19.05. - 20.05.2014 30th Pacific Rim International Conference on Disability and Diversity, Honolulu, Hawaii. 
**Information:** http://pacrim.hawaii.edu/; Kontakt: Tel.: 808 956 7539; E-mail: prin­fo@hawaii.edu.

10.06. - 13.06.2014 16th Inclusion International World Congress: A Better World for All- No One Left Behind, Nairobi; Kenya. 
**Information:** http://inclusion-international.org/world-congress/; Kontakt: Inclusion International, KD.2.03, 4 -6 University Way, London E16 2RD, United Kingdom; Kontakt: Tel: +44 (0)208 223 7709; Fax: +44 (0) 208 223 6081; E-mail: info@inclusion-international.org.

10.06. - 13.06.2014 12th Global Conference on Ageing: Be Healthy, Be Safe, Become a Community, Hyderabad, India. 
**Information:** http://www.ifo2014.in/; Kontakt: Heritage Foundation, 37 Kamalapuri Colony Phase-III, Hyderabad, AP, India; Tel: +91-40-6516-2846; Fax: +91-40-23-114-421; E-mail: secretariat@ifo2014.in.

**Information:** http://www.ud2014.se; Kontakt: E-mail: ud2014@design.lth.se.

**Information:** http://www.health3000.org/; Kontakt: #858/6, Kaduwela Road,Thalangama North, Sri Lanka.; Tel: +94 777 799915; E-mail: info@theicrd.org.

**Information:** www.tomorrowpeople.org; http://www.publichealth-conference.org; Kontakt: Dusana Vukasovic 73, 11000 Belgrade, Serbia; Tel: + 381 62 680 683; E-mail: contact@tomorrowpeople.org.

**Information:** https://www.isaac-online.org/english/conference-2014/; Kontakt: E-mail: conference2014@isaac-online.org.
Schwerpunktthemen kommender Ausgaben der Zeitschrift
Focal Topics of Upcoming Issues

2/2014: Barrierefreiheit in den Bereichen Information und Kommunikation/Information and Communication without Barriers (verantwortlich/responsible: Christine Bruker/Isabella Bertmann)

3/2014: Physische Barrierefreiheit/Physical Access without Barriers (verantwortlich/responsible: Christine Bruker/Isabella Bertmann)

1/2015: Inklusion in der Humanitäten Hilfe und Katastrophenvorsorge/Inclusion in Humanitarian Aid and Disaster Risk Reduction (verantwortlich/responsible: Gabriele Weigt)

Interessierte Autorinnen und Autoren mögen sich für nähere Informationen und unseren Leitfaden für Autorinnen bitte an die oben genannten Verantwortlichen wenden. Darüber hinaus sind Vorschläge für weitere Schwerpunktthemen willkommen unter info@inie-inid.org.

If you are interested in contributing, please contact the respective member of the editorial board mentioned above for more information and our Guidelines for Submissions. Moreover, we welcome ideas and suggestions for future focal topics which you can submit to our editorship at info@inie-inid.org.

Declarations for the upcoming issues:

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Kurzbeiträge/Other contributions</td>
<td>21.03.2014</td>
<td>25.07.2014</td>
<td>15.10.2014</td>
</tr>
</tbody>
</table>

Liebe Leserinnen und Leser,
bitte informieren Sie uns unter info@inie-inid.org über eine Adressänderung bzw. wenn Sie die Zeitschrift nicht mehr beziehen möchten oder falls Ihnen die Zeitschrift nicht zugestellt worden ist.

Dear Reader!
Please notify any changes of address, if you wish to end your subscription or have not received the print edition to info@inie-inid.org.
Die Zeitschrift **Behinderung und internationale Entwicklung** erscheint seit 1990 dreimal jährlich mit Beiträgen sowohl in deutscher als auch englischer Sprache. Ihr Anspruch ist es, ein Medium für einen grenzüberschreitenden Informationsaustausch zur Thematik zu bieten sowie die fachliche Diskussion zu pädagogischen, sozial- und entwicklungspolitischen sowie interkulturellen Fragen im Zusammenhang mit Behinderung in Entwicklungsländern weiterzuentwickeln. Jede Ausgabe ist einem Schwerpunktthema gewidmet, das durch Einzelbeiträge und einen aktuellen Informationsteil ergänzt wird.

**Bezugsmöglichkeiten:**
- Kostenfreier Versand der Ausgabe im pdf-Format per E-Mail (für die Aufnahme in den Verleger: info@inie-inid.org)
- Kostenpflichtiger Bezug der Printausgaben für 18 EUR/Jahr (3 Ausgaben) innerhalb Deutschlands und 27 EUR im europäischen Ausland (info@inie-inid.org)

Darüber hinaus kostenlos im Internet unter www.zbdw.de.

The journal **Disability and International Development** is published three times a year since 1990, featuring contributions in both English and German. Its objective is the scholarly and practice-oriented discourse on disability in low-income countries. The journal aims at providing a platform for a cross-border dialogue and promoting the professional discussion of related development policy, pedagogical/educational, socio-political and intercultural questions. Each issue is dedicated to a focal topic, complemented by single contributions on other subjects and up-to-date information.

**Subscription:**
- Free pdf version via e-mail (info@inie-inid.org for subscription)
- Print version at a rate of 18 EUR/year (3 issues) within Germany and 27 EUR to other European countries (info@inie-inid.org for subscription)

In addition, a free online version is available at www.zbdw.de.

Institut für inklusive Entwicklung
Wandastr. 9, 45136 Essen, Germany
Tel.: +49-(0)201/17 89 123, Fax: +49-(0)201/17 89 026
E-Mail: info@inie-inid.org
Internet: www.inie-inid.org/

**Die Zeitschrift **Behinderung und internationale Entwicklung** wird unterstützt durch/The journal *Disability and International Development* is supported by:**

- Kindernothilfe
- Caritas International
- Christoffel-Blindenmission

- Misereor
- Handicap International
- Behinderung und Entwicklungs-zusammenarbeit e.V.