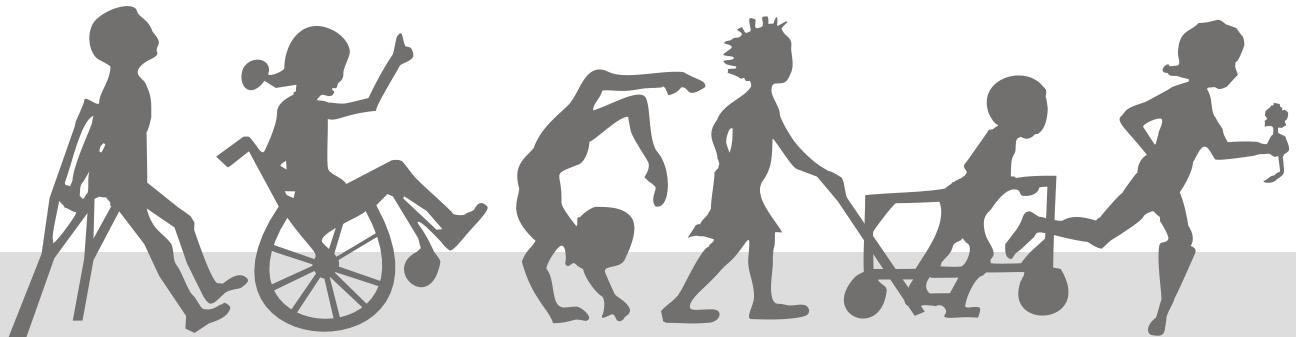


# Behinderung und internationale Entwicklung

Disability and  
International Development



Menschen mit kognitiver Behinderung/Lernschwierigkeiten  
in Entwicklungsprozessen  
Persons with Intellectual Disabilities in Development





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# Editorial

Liebe LeserInnen,

Menschen mit Behinderung stellen eine sehr heterogene Gruppe mit unterschiedlichen Behinderungen, Geschlechtern und Beeinträchtigungen und demzufolge auch unterschiedlichsten Bedürfnissen und Lebenserfahrungen dar. Zu ihnen gehören rund 130 Millionen Menschen mit kognitiver Behinderung/Lernschwierigkeiten\* und deren Familien, von denen rund 26 Millionen von weniger als 1,25 US Dollar pro Tag leben. Menschen mit kognitiver Behinderung/Lernschwierigkeiten zählen zu den am stärksten marginalisierten und verwundbaren Gruppen: Weitverbreitete Stereotype und negative Einstellungen ihnen gegenüber schränken ihren Zugang zu Basisdienstleistungen wie Gesundheitsversorgung und Bildung ein. Stigmatisierung, die oft die ganze Familie betrifft, setzt sie einer erhöhten Gefahr von Missbrauch und sozialem Ausschluss aus, vor allem in institutionalisierten Einrichtungen.

Der Mangel an Bildung erhöht ihr Risiko (tiefer) in Armut zu fallen und somit von ökonomischen Prozessen ausgeschlossen zu werden. Für Menschen mit kognitiver Behinderung/Lernschwierigkeiten gibt es nur wenige Möglichkeiten zur Selbstbestimmung und -vertretung. Gleichzeitig beschneidet der Mangel fördernder rechtlicher Rahmenbedingungen ihre rechtlichen Kapazitäten zur Teilhabe an Entscheidungen, die ihr eigenes Leben betreffen und in allgemeinen lokalen Entscheidungs- und Entwicklungsvorprozessen. Abgesehen von Einzelfallberichten gibt es vor allem in Entwicklungsländern kaum wissenschaftliche Erhebungen zur Situation von Menschen mit kognitiver Behinderung/Lernschwierigkeiten und ihren Familien und so bleiben sie weitgehend unsichtbar.

Die Konvention der Vereinten Nationen zur Stärkung der Rechte von Menschen mit Behinderung gab den Rechten vom Menschen mit Behinderung weltweit, einschließlich Menschen mit kognitiver Behinderung/Lernschwierigkeiten einen neuen Impuls. Die Umsetzung der Grundsätze der UN Konvention bietet Menschen mit kognitiver Behinderung/Lernschwierigkeiten entscheidende Möglichkeiten.

Diese Ausgabe unserer Zeitschrift untersucht, wie sich der rechtsbasierte Ansatz zu Behinderung und seine Umsetzung in der Praxis auf Menschen mit kognitiver Behinderung/Lernschwierigkeiten im Kontext nationaler und internationaler Entwicklungsprozesse sowie auf ihr Leben und das ihrer Familien auswirkt. Die Redaktionsgruppe bedankt sich bei Christin Lidzba für ihren Beitrag als Gasteditorin. Wir wünschen den Leserinnen und Lesern viel Spaß bei der Lektüre.

Ihre Redaktionsgruppe

Dear Reader,

persons with disabilities are a heterogeneous group of individuals, with different disabilities, genders and impairments, and thus different needs and experiences. Among them are about 130 million persons with intellectual disabilities and their families, out of which 26 million live on less than 1,25 US dollar per day. Persons with intellectual disabilities present one of the most marginalized and vulnerable groups: Widespread stereotypes and negative attitudes severely limit their access to basic services such as health or education. Stigmatization, often extending to their families, puts them at a high risk of abuse and social exclusion, in particular in institutional settings.

The lack of education increases their risk of falling (further) into poverty and increases their economic exclusion. There are only few expectations or opportunities for persons with intellectual disabilities to self-determination and -representation. At the same time, the lack of empowering frameworks often limits their (legal) capacities to participate in decisions about themselves, or in decision-making and development. Aside of anecdotal evidence, research evidence on the situation of persons with intellectual disabilities and their families, particularly in low-income countries, is scarce and they remain too often invisible in development.

The adoption of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) gave globally new impetus to the rights of persons with disabilities, including those with intellectual disabilities. The implementation of its imperative provides for vital opportunities from the perspective of persons with intellectual impairments.

This issue of our journal explores how the rights-based approach to disability and the adoption of new human rights provisions translate into practice for persons with intellectual disabilities in the context of national and international development processes as well as its impact on persons with intellectual disabilities and their families and the level of inclusion of their rights and needs in development. The editorial board would like to thank Christin Lidzba for her contribution as visiting editor. We hope that our readers enjoy reading our journal.

The Editorial Board

\* Wir benutzen den Begriff Menschen mit kognitiver Behinderung/Lernschwierigkeiten anstelle des Begriffes Geistige Behinderung, der im Laufe der letzten Jahre einen Wandel durchläuft.



# Junge Erwachsene mit geistiger Behinderung im ländlichen Raum Tansanias - Eine qualitative Studie zu ihrer Lebenssituation und ihren Zukunftsperspektiven

Anne Keiner

In dem folgenden Artikel werden die Ergebnisse einer qualitativen Befragung von jungen Erwachsenen mit geistiger Behinderung<sup>1</sup> und ihren Bezugspersonen in Tansania vorgestellt. An einer dortigen Sonderschule stellte sich fünf Jahre nach Gründung die Frage nach einer angemessenen pädagogischen Betreuung und Vorbereitung der ältesten Schüler und Schülerinnen auf ein Leben nach der Schule. Zur Ableitung pädagogischer Konsequenzen wurden die erhobenen Sichtweisen der Betroffenen auf ihre Lebenssituation und Zukunftsperspektiven als Basis genommen. Das Vorgehen zeigt exemplarisch den möglichen Beitrag partizipatorischer Forschung für ein Projektmanagement, das die soziokulturellen Gegebenheiten berücksichtigt.

## Einführung

Im Fokus der hier vorzustellenden Studie liegt eine Sonderschule im Nordosten Tansanias, an welcher ich ein siebenmonatiges Praktikum absolvierte. Fünf Jahre nach der Schulgründung stand man vor der Herausforderung, eine adäquate pädagogische Vorbereitung der ältesten Schüler und Schülerinnen auf ein Leben nach der Schule bereitzustellen. Die pädagogische Begleitung sollte die Perspektiven der Betroffenen selbst wie auch die kulturellen Gegebenheiten einbeziehen. Somit war das leitende Forschungsinteresse geprägt durch Fragen nach den Zusammenhängen von kulturspezifischer Entwicklung und Sozialisation in der Region - insbesondere von Kindern und jungen Erwachsenen mit geistiger Behinderung. Vor diesem Hintergrund wurden schließlich Konsequenzen für die pädagogische Begleitung der jungen Erwachsenen abgeleitet.

## Methodik

Einen angemessenen Zugang zu einer Situationsanalyse von jungen Erwachsenen mit geistiger Behinderung aus Betroffenensicht bietet die qualitative Sozialforschung. Sie nimmt „Lebenswelten ‚von innen heraus‘ aus der Sicht der handelnden Menschen“ (Flick/von Kardorff/Steinke 2004: 14) in den Fokus. Dieser Anspruch hat besondere Relevanz, werden doch die Wirklichkeitskonstruktionen von Menschen mit geistiger Behinderung häufig nur von außen (Eggert in Schuppener 2007: 112) betrachtet. Die Dominanz der Professionellen - welche Menschen mit Behinderung und ihre Familien nicht als Experten in eigener Sache anerkennen - ist auch im Rahmen der Entwicklungszusammenarbeit zu bemängeln (vgl. Kasonde-Ng'an-

dou 1999; Devlieger 1999).

Neben einer Erhebung der Sichtweisen der Menschen mit Behinderung selbst<sup>2</sup> erachtete ich eine problemzentrierte Befragung der Eltern oder anderer Bezugspersonen der Interviewpartner als bedeutsam. Es war davon auszugehen, dass die Erwartungshaltungen und Normvorstellungen des vom großfamiliären Bezug geprägten Umfeldes (vgl. Stone-MacDonald 2010) die Entwicklung der jungen Erwachsenen und ihrer Wirklichkeitskonstruktionen beeinflussten.

## Vorstellung der befragten Personen

Insgesamt befragte ich fünf Elternpaare bzw. -teile sowie vier Schüler und eine Schülerin auf Kiswahili - der *lingua franca* Tansanias (Stone-MacDonald 2010: 134). Die befragten SchülerInnen - Editha, Elija, Zepha, Abdul und Wilson<sup>3</sup> - waren zum Zeitpunkt der Befragung im Alter zwischen 17 und 28 Jahren. Ihre Biographien ähnelten sich dahingehend, dass sie alle aus dem regulären Schulsystem herausfielen. Meist wurde den Eltern nach Besuch des Kindergartens von einer Einschulung abgeraten oder aber es zeigten sich innerhalb eines kurzen Zeitraums an der Primarschule Lernschwierigkeiten. Erst mit Eröffnung der Sonderschule fand sich ein Lernort, wo die SchülerInnen - nach eigenen Aussagen und denen ihrer Eltern - adäquat gefördert werden konnten.

Die jeweiligen familiären Lebenssituationen zeichneten sich jedoch durch große Unterschiede aus und somit auch die Ausgangsbedingungen für die jungen Erwachsenen: Die verwitweten Mütter von Elija und Editha lebten zum Zeitpunkt der Befragung beide von Gelegenheitsarbeiten. Zepha wuchs zwar ebenfalls bei einer



alleinerziehenden Mutter auf, diese hatte jedoch eine hohe Bildung genossen und war nun als Buchhalterin und Ladenbesitzerin tätig. Auch Abduls und Mathayos Eltern waren sehr gebildete Personen und lebten mit ihren Familien in wohl situierten Verhältnissen.

## Darstellung der Studienergebnisse

### **Grundlegende Charakteristika der Situation von jungen Erwachsenen mit geistiger Behinderung in einem ländlichen Teil Tansanias**

Das Zusammenspiel von ökonomischer Situation und Gesellschaftsstruktur erwies sich als ein bedeutsamer Bezugsrahmen zum Verständnis der Schüler- und Elternaussagen. Wie ich bei der Annäherung an den sozioökonomischen Kontext der Studie bereits herausgearbeitet hatte, zeigte sich auch in den Interviews, dass v.a. die Ausrichtung auf Subsistenzwirtschaft und der großfamiliäre Zusammenhalt als soziales Absicherungssystem (vgl. Müller-Mbwilo 2008) tatsächlich charakteristisch für die Lebenssituationen der Befragten waren.

„Ok, [in] unsere[r] afrikanische[n] Gesellschaft, wenn (...) die Eltern sterben .. gibt es jene Familiengemeinschaft, jenen Familienclan, in welche das Kind hineinkommt.“ - Mathayos Vater

Hinsichtlich der Einstellungen gegenüber Menschen mit Behinderungen und dem Umgang mit ihnen berichteten die Eltern von gesellschaftlichen Isolierungstendenzen und fehlenden Teilhabemöglichkeiten. Diese traten auf, wenn ein Kind mit Behinderung nicht den gesellschaftlichen Konventionen oder den äußeren Normvorstellungen entsprach und wurden häufig religiös begründet (z.B. Behinderung als Fluch Gottes). Mangelnde Teilhabemöglichkeiten von Menschen mit geistiger Behinderung wurden u.a. sichtbar bei Erfahrungen fehlender Anerkennung ihrer Lernfähigkeit und ihres Rechts auf Schulbildung.

Zu den erfahrenen negativen Einstellungen und Umgangsformen standen die Ansichten der befragten Eltern selbst in einem starken Gegensatz. Sie gründeten sich meist ebenfalls in religiösen Überzeugungen, waren jedoch positiv konnotiert (z.B. ein Kind mit Behinderung als Geschöpf Gottes oder Teil in Gottes/Allahs Plan).

„Es gibt andere Eltern ... wenn sie ihre Kinder sehen, also, Gott hat sie beglückt. Dies ist Schicksal. Deshalb sage nicht, es sei eine Verdammnis. Nein! ... Dies ist Gottes Plan. (...) Ich glaube an Gott. Ich meine, dass (...) es ist kein böses Schicksal, dass

Gott mir diese Kinder gegeben hat. Ich sehe es als das, was Gott für mich vorbereitet hat.“ - Abduls Vater

Die Eltern selbst sahen Menschen mit geistiger Behinderung als lern- und Entwicklungsfähige Menschen an und betonen ihr Anrecht auf gesellschaftliche Teilhabe.

Im Rahmen einer entwicklungspsychologischen Annäherung an das junge Erwachsenenalter im tansanischen Kontext schienen sich insbesondere die sog. Entwicklungsaufgaben nach Havighurst anzubieten. Die Offenheit für kontextuelle Einflüsse und Wechselwirkungen zwischen Individuum und Umwelt sind charakteristisch für dieses Konzept (vgl. Lehr 1995; Montada 2008).

Anhand der Eltern- und Schüleraussagen konnten als Entwicklungsaufgaben, die das junge Erwachsenenalter im Allgemeinen prägen, Selbstständigkeit/Arbeit, Partnerschaft/Heirat, Elternschaft und Gründung eines eigenen Haushaltes herausgearbeitet werden.

„In unserer Tradition: Wenn ein Mensch erwachsen wird, (...) sollte er einen Weg finden, selbstständig zu werden. (...) Er sollte eine Arbeit finden, Gelegenheitsarbeiten, (...) damit er selbstständig ist .. besser als von mir weiter abhängig zu sein.“ - Elias Mutter

„Von einem Erwachsenen wird erwartet (...) wenn es eine Frau ist, dass sie geheiratet werde, mit ihrem Mann zusammen sei, dass sie Kinder bekomme, mit ihrer Familie zusammen sei, dass sie ihre täglichen Notwendigkeiten gesichert wisse.“ - Zephias Mutter

Diese genannten Aufgaben konstituieren die gesellschaftliche Erwartungshaltung, auf welche auch ein junger Erwachsener mit geistiger Behinderung trifft. Bei Havighurst spielen aber nicht nur diese gesellschaftlichen Normen eine Rolle sondern auch die individuellen, persönlichkeitsspezifischen Erwartungen und Wertvorstellungen (vgl. Lehr 1995). Die individuellen Wünsche und Bedürfnisse können in einem Spannungsverhältnis zu den individuellen Einschränkungen sowie den gesellschaftlichen Normen und sozioökonomischen Gegebenheiten stehen. Dies wurde besonders bei den Schilderungen von Zephias Mutter deutlich. Sie attestierte ihrem Sohn zwar sexuelle Bedürfnisse einerseits, andererseits konnte er diese aber nicht in der derzeitigen Gesellschaft ausleben.

„Es ist nicht leicht. Obwohl er diese Zeichen eines Erwachsenen hat: Er liebt .. er wird geliebt. Aber dieses Testen .. mit wem soll er es versuchen? (...) Ein Mädchen, wo bekommt er das? (...)



(Pause) Also, hier .. stecken wir ein wenig fest." - Zephas Mutter

Bezogen auf den Themenkomplex der Selbstständigkeit und Arbeit wurde deutlich, dass Schüler und Eltern in ihren Beschreibungen der Situation von jungen Erwachsenen mit geistiger Behinderung und den Zukunftsvorstellungen scheinbar bereits eine Angleichung der Diskrepanzverhältnisse geschaffen hatten: So entsprachen die von den SchülerInnen geäußerten Interessen der Erwartung, soweit wie möglich durch Hilfeleistung in Haushalt und Landwirtschaft einen Beitrag zur familiären Entlastung und zur Existenzsicherung zu leisten.

„Interviewer: Kannst Du mir erklären, wie es nach der Schule sein wird?

Editha: Es wird .. leicht werden.

Interviewer: Kannst Du mir das bitte noch etwas mehr erklären?

Editha: Und Spülen und Kochen und Waschen.“

Die Zukunftsvisionen der Eltern wie SchülerInnen entsprachen ihrem Erfahrungs- und kulturellen Kontext. Sie äußerten Ideen, welche meist der landwirtschaftlichen Orientierung Tribut zollten. Auch zogen die Eltern bei den Überlegungen zu zukünftigen Perspektiven ihrer Kinder deren individuelle Einschränkungen mit ein.

Ein einflussreicher Faktor war zudem die generelle familiäre Lebenssituation. Schwierigkeiten das Schulgeld zu zahlen, aber auch fehlende Beziehungen, um den Kindern berufliche Perspektiven zu eröffnen, wurden bereits in die Darstellung von Entwicklungsaufgaben und -möglichkeiten von jungen Erwachsenen mit geistiger Behinderung integriert.

### Zukunftsperspektiven der befragten jungen Erwachsenen

Die zukunftsbezogenen Interviewaussagen beinhalteten Ideen, die an der aktuellen Situation der Betroffenen ansetzen und relativ kurzfristige Zukunftsperspektiven eröffnen würden. Es wurden aber auch Faktoren genannt, von denen sich die Befragten einen langfristigen Wandel des Umgangs mit ihnen und damit auch der pädagogischen Begleitung erhofften.

Mathayos Vater entwickelte beispielsweise verschiedenste Ideen (finanzielle Absicherung durch Mieteinnahmen und kleine Einkommensprojekte, das Einsetzen eines Vormundes für seinen Sohn), mit welchen er für seinen Sohn Zukunftsperspektiven schaffen wollte.

„Dieser Betreuer .. seine Aufgabe ist nur, nach ihm zu schauen. Aber Mathayos Einkommen wird gesichert durch sein Vieh, seine Felder, sein Haus, wenn es vermietet

ist. Mathayo wird .. leben können, wie er mit seinen Eltern gelebt hat.“ - Mathayos Vater

Die Vorschläge des Vaters setzten am allgemeinen sozioökonomischen Kontext in Lushoto, der ökonomischen Lage der Familie und an den individuellen Fähigkeiten seines Sohnes an. Auf ähnliche Weise setzen andere der befragten Eltern v.a. an den praktischen Fähigkeiten ihrer Kinder an. Beispielsweise sehen sie im Schreinerhandwerk eine berufliche Perspektive für ihre Kinder. Edithas Mutter betont die hauswirtschaftlichen Fähigkeiten ihrer Tochter, mit denen sie als Haushaltshilfe bei einer Privatperson oder in einem Gästehausbetrieb tätig werden könnte. Jedoch äußert sie klar, dass sie angesichts ihres niedrigen sozialen Status nicht in der Lage sei, ihrer Tochter eine Anstellung zu verschaffen.

Auch an anderen Stellen wurde der Zusammenhang zwischen den Entwicklungs- und Zukunftsperspektiven der jungen Erwachsenen und der sozialen Ausgangssituation ihrer Familie deutlich. Genaue Untersuchungen der strukturellen Gegebenheiten scheinen demnach bei der Entwicklung von Projekten, die jungen Erwachsenen mit geistiger Behinderung Zukunftschancen eröffnen sollen, bedeutsam zu sein.

In den Überlegungen der befragten Personen hinsichtlich ihrer Zukunftsperspektiven bot die bereits bestehende schulische Struktur einen Anknüpfungspunkt zur Entwicklung von Zukunftsperspektiven. So äußerten die Eltern den klaren Wunsch, die berufliche Rehabilitation der jungen Erwachsenen mit geistiger Behinderung von der Schule ausgehend verstärkt zu fördern.

„Wegen der Tätigkeiten an der Schule, beginnt er/sie auch Zuhause zu arbeiten: Ackern, .. Gemüse verkaufen, auf einen Botengang geschickt werden. (...) Sie [die LehrerInnen der IRS, Anm.d.A.] sollten eine Abteilung eröffnen, wo diese Schüler angestellt werden können. Dass sie dann dort unter der Beaufsichtigung und Anleitung von Leitern sind. Und dann, beginnend von dort, könnten weitere Umfelder erschlossen werden.“ - Zephas Mutter

Aus meinen Kenntnissen der Schulabläufe sowie den Beobachtungen möglicher Beschäftigungsperspektiven in der Region scheint mir, dass die genannten Ideen der Eltern ohne großen finanziellen und personellen Aufwand in den derzeitigen Schulalltag integriert werden könnten: Beispielsweise könnte der sogenannte Club-day Anknüpfungspunkt für das langsame Heranführen der ältesten SchülerInnen an einkommensschaffende Tätigkeiten darstellen. Ein-



mal wöchentlich werden klassenübergreifende Projekte, beispielsweise in Musik, Kunst oder in praktischen Fertigkeiten, angeboten. Ohne dass eine organisatorische Umstellung notwendig wäre, könnte dieser Tag von den ältesten SchülerInnen auch intensiv zum Erlernen und Einüben berufsbezogener Fertigkeiten genutzt werden. In einem weiteren Schritt wäre es denkbar, kleine Beschäftigungs-Projekte außerhalb der Schule durchzuführen. An die gängige Tageslohn-Praxis anknüpfend könnten die SchülerInnen in den umliegenden Institutionen und Häusern Dienstleistungen wie Grasschneiden, kleine Bürodienste, Putzaktionen o.ä. erbringen. Das Lehrpersonal hätte die Aufgabe, die SchülerInnen bei ihren Tätigkeiten anzuleiten und zu begleiten. Wichtig wäre aber auch eine Sensibilisierung des Umfeldes, mögliche Vorurteile von Arbeitgebern und MitarbeiterInnen zu entschärfen sowie eine Einführung in den (pädagogischen) Umgang mit Menschen mit geistiger Behinderung zu geben.

Idealerweise könnten - ausgehend von einer solchen Sensibilisierung der Öffentlichkeit durch die Schule - für die jungen Erwachsenen mit geistiger Behinderung immer mehr Wege zur gesellschaftlichen und beruflichen Teilhabe eröffnet werden.

## Resümee

Anhand der Eltern- und SchülerInnenaussagen konnte ein plastisches Bild der Lebenssituation von jungen Erwachsenen mit geistiger Behinderung in der betrachteten Region gezeichnet und schwerpunktmaßige Entwicklungsaufgaben herausgearbeitet werden. Die Perspektiven der Betroffenen ermöglichen die Ableitung konkreter zukunftsbezogener Handlungsmöglichkeiten, die für die Begleitung der befragten SchülerInnen durch das Elternhaus und die Schule relevant sind.

Jegliche Projekte, die die Gestaltung von Zukunftsperspektiven von jungen Erwachsenen mit geistiger Behinderung zum Ziel haben, haben der Komplexität menschlicher Entwicklung und dem sozioökonomischen Kontext der Nutzer Rechnung zu tragen.

Die Relevanz der qualitativen Befragung für eine den kulturellen Gegebenheiten angepasste pädagogische Begleitung und die Planung und Gestaltung jeglicher programmatischer Interventionen und Projekte ist deutlich geworden. Das Einbeziehen der Betroffenenperspektiven hilft einen möglichen Zentrismus auf die eigene Kultur und die reine Außen-Perspektive von Professionellen auf einen Menschen mit sog. geistiger Behinderung zu vermeiden. Im

Kontext partizipativer Entwicklungsprozesse können konkrete Handlungsmöglichkeiten, die für Jugendliche mit geistiger Behinderung relevant sein können, identifiziert werden.

Dem versteckenden Anspruch der Heilpädagogik gerecht zu werden, bedeutet, sich stets der individuellen Wirklichkeitskonstruktionen und Lebenskonzepte des Gegenübers und der Komplexität menschlicher Entwicklung gewahr zu sein und diese in der pädagogischen Begleitung anzuerkennen. Ein Kiswahili-Sprichwort verdeutlicht treffend diesen Fokus auf die Individualität menschlicher Entwicklung sowie auf die Einzigartigkeit von Lebensentwürfen:

„Kila ndege huruka na mbawa zake.“<sup>4</sup> - Jeder Vogel fliegt mit seinen eigenen Flügeln.

## Anmerkungen

- 1 Der Begriff Geistige Behinderung kann nur im Bewusstsein seiner Begrenztheit verwendet werden. Die Problematik der damit verbundenen stigmatisierenden Klassifizierungs- und Zuweisungsprozesse muss stets mitberücksichtigt werden. Für den Rahmen der Studie ergab sich jedoch die Problematik, einerseits die Zielgruppe für den deutschen Sprachraum verständlich benennen zu müssen, andererseits ein offenes Behindernsverständnis zu wahren, um dem kulturübergreifenden Kontext Rechnung zu tragen.
- 2 Zu den Besonderheiten bei der Befragung von Menschen mit einer geistigen Behinderung, welche auch in der Durchführung meiner eigenen Befragung zum Tragen kamen, sei auf Hagen (2001), Kulig/Theunissen (2010) sowie Buchner (2008) verwiesen.
- 3 Die Namen aller Schüler wurden pseudonymisiert. Zusätzlich findet sich im Text das Pseudonym Mathayo. Dieser konnte auf Grund einer Erkrankung nicht befragt werden, jedoch seine Eltern.
- 4 Swahili proverbs. Abrufbar unter [www.mwambao.com/methali.htm](http://www.mwambao.com/methali.htm) [Stand 03.04.2010]

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**Abstract:** In the following article we present the results of a qualitative survey of young adults with intellectual disability and their contact persons in Tanzania. At a special needs school the question of appropriate educational support and

preparation for life after school for the older students is investigated. In order to draw educational consequences the views of those affected and their situation in life and future perspectives are used. The process shows a possible model for use of participative research for project management, that takes account of the socio cultural environment.

**Résumé:** Cet article présente les résultats d'un sondage qualitatif auprès de jeunes handicapés mentaux et de leurs proches en Tanzanie. Cinq ans après la création d'une école spécialisée s'est posée la question d'un accompagnement pédagogique approprié et d'une préparation des étudiants les plus âgés à leur vie après l'école. Les avis collectés auprès des intéressés ont servi de base pour tirer des conclusions pédagogiques. Cette expérience a démontré le bénéfice potentiel d'une recherche participative pour la gestion d'un projet qui prend en compte les données socio-culturelles environnantes.

**Resumen:** El artículo presenta resultados de una encuesta cualitativa realizado con jóvenes adultos con discapacidad mental y sus educadores en un centro especial en Tanzania. Después de cinco años de su fundación se plantearon la pregunta sobre la preparación adecuada para la vida después de la escuela. Para deducir consecuencias pedagógicas fueron investigados los puntos de vista de los alumnos y sus educadores sobre la situación de vida de los discapacitados y sus futuras perspectivas. El procedimiento enseña en forma ejemplar la contribución de la investigación participatoria para la gestión de proyecto, que considera la situación sociocultural de la gente.

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# Barriers and Possibilities for Participation by People with Intellectual Disabilities – Examples from Northern India

Kaaren Mathias and Jubin Varghese

The legislative and policy framework for participation of people with intellectual disabilities (PWID) in India has never been better. Yet opportunities and examples of participation for those with intellectual impairment remain very low. A review of Emmanuel Hospital Association's (EHA) three projects working among people with disabilities in three diverse locations in North India summarises some of the significant barriers to participation. We then provide signposts for a way forward, to a world where people with intellectual disabilities are able to participate in decisions. This participation is in every sphere, from decisions about activities of daily living, medical care and future care options as well as inclusion into relevant service provision planning and policy making, at community, state and national levels.

## Introduction

These are exciting times to be working with and beside people with disabilities. A range of international frameworks promote a paradigm shift from a charity-based approach to a focus on both the rights and inclusion of people with disabilities into all areas of society. Internationally, these rights include the United Nations Convention on the Rights of Persons with Disabilities while regionally, the Asia and Pacific decade of Disabled Persons and the Biwako Millennium Framework are focus areas.

India has a strong platform for people with intellectual disabilities (PWID) in both policy and legislation. Policies supporting rehabilitation for PWIDs were included in the 1992 Rehabilitation Council of India Act. The People with Disabilities Act in 1996 covers equal opportunity, protection of rights and participation, while the National Trust for welfare of persons with Autism, Cerebral Palsy, Mental retardation and Multiple disabilities Act, (1999) provides protection to people covered by the Act. India is also signatory to a number of United Nations resolutions for action towards an inclusive, barrier-free and right based society for persons with disabilities.

Policy and legislation thus provide many possibilities for inclusion and mainstreaming of PWIDs into all areas of community development. However despite this supportive policy environment, the opportunity for participation for the majority of PWID in India is very limited. Barriers to participation include aspects such as difficulties in even getting access to the arenas of decision making that can be financial, physical, technological and cognitive. PWID in India are highly unlikely to have received any formal education. The public perception of PWID is often prejudiced and they remain a highly mar-

ginalized sub-group in society and there are only a few examples of meaningful participation. People with intellectual disabilities are less well placed to gain from the momentum of the increased emphasis on inclusion than many other groups with disabilities.

Meaningful participation can be described at three levels

- At the most basic level, it includes the opportunity to make choices about the activities of daily living such as clothing, what food to eat and when. Decisions at this level give a level of respect and preparation for higher levels of decision making.
- A second level of participation allows participation in decisions with longer term impact such as care and schooling options and medical treatment.
- A third tier of decision making provides PWIDs participation in decisions about their community, and even at regional and national level policy making related to both themselves, the broader community of people with disability and other groups they are part of.

Experience and practice in decision making at the first two levels is important to build skills for participation at higher levels of participation. A review of community participation of PWIDs in developed countries found their participation in almost every sphere of life was significantly lower than non-disabled and even than other disabled groups. Levels of education, employment, social contact and community and civic activities were very low even among people with mild intellectual disability and were almost absent among people with severe intellectual disabilities. Verdonschot et al. describe the dearth of research around community participation of PWIDs, particularly for



those people with moderate or severe intellectual disability, underlining the importance of discussion and research in this area.

In this paper we consider both barriers and possibilities to participation for PWID based on our organisational experience working beside PWID in Northern and Eastern India. We provide a thumbnail sketch of our organisation and work with communities, before describing our specific projects with PWDs. Emmanuel Hospital Association (EHA) ([www.eha-health.org](http://www.eha-health.org)) is one of the largest not-for-profit health care and community health providers working in India. A faith-based organization, it employs over 1800 staff in 20 hospitals and 34 community health programmes across North, North-East and Central India. The organisation has been working with people with disabilities since 2001 in disability specific projects: In Herbertpur, Uttarakhand, in Raxual, Bihar and in Tezpur, Assam. These projects work with children with both physical and intellectual disabilities and their families. Each of these projects has a registered Parents' Association and is presently partnering with funders to mainstream disability in all 34 community and development projects in the Community Health and Development branch of EHA. EHA was a representative at the Community Based Rehabilitation (CBR) National Forum and is also a member of the National Association for the Promotion of Knowledge on Intellectual Disability (NAPKID).

As we seek to develop and expand our approach to include PWIDs in community health programme planning and implementation we see both exciting possibilities as well as barriers that will require innovation and persistence to surmount. We illustrate these in the following case study and suggest pathways forward to increase participation of PWIDs in all aspects of community health and development programmes.

EHA work at including people with intellectual disabilities into community development projects has proceeded along two levels: firstly we have worked with the wider community in promoting the visibility, presence and participation of PWID. Secondly, we have worked in capacity building of grass-root workers and community members in including and identifying PWIDs and their parents.

## Increasing Visibility

To make the voices of those with intellectual impairment and their families heard we have to first make them visible, promote their inclusion,

and ensure that PWIDs and their families have bargaining power. This work has included de-stigmatisation, building awareness of the needs and important contributions of PWDs. With many prejudices in all spheres of society, those with disabilities and their families often stay away from community celebrations and deliberations of the local governance.

The community development projects operating in EHA have focussed on empowering communities and building their bargaining power through self-help groups (groups that are self-governed and with self-determining objectives and actions) and through capacity building of the Village Health and Sanitation Committees (a unit of the local governance). Building awareness and capacities of these groups enables them to look at the inclusion and needs of PWDs. Deliberate inclusion of people with disabilities and their families into the membership of both village Self Help Groups and the Village Health and Sanitation Committees has helped in this process.

One of our most effective measures in promoting inclusion and participation of PWIDs has been in the formation of a Parents' Association. The Parents Association has helped to provide a platform for the parents to create awareness and to advocate for the rights of their children and is made up of parents of children with both physical and intellectual disabilities.

Services and the schemes for those with disabilities in India, can be availed only if the person with disability has a disability certificate issued by the Chief Medical Officer of the district. The process of obtaining a certificate is tedious, requiring repeated visits for assessment by various professionals and has associated costs as well as loss of income for caregivers. The Parents Association in one of our projects organised a disability camp with a multi-window approach. They networked with necessary government departments to get all the government professionals required to assess the children at one place and were able to get about 80 certificates issued within a day. This is an example of advocacy achieved by the Parents Association.

## Capacity Building

Our projects have worked on capacity building at a number of levels. The first has been to strengthen services to promote early identification and intervention. This has included training the government personnel who are the grass root presence of the national health care and education system. The three main groups we



have trained are Auxiliary Nurse Midwives (ANM), Accredited Social Health Activists (ASHA) and Early Childhood Centre Workers (AWW). We have taught a process for identifying children with delayed developmental milestones and refer them to community based centres for children with disabilities.

Secondly, we have established community based centres which are run by community members who we have selected and trained to work with the children with intellectual as well as physical disabilities. The centres provide support and special education to children with disabilities as well as their parents. We have used the WHO CBR matrix as the framework to plan for rehabilitation. As few professionals work in remote places, training the local people has been an effective strategy. Children with intellectual disabilities are a part of these centres and their parents are involved with planning for the centre and activity planning.

Thirdly, we work to increase awareness of normally-abled children in regular schools believing that children can challenge existing world views and prejudices. The primary vehicle we use is summer camps where normally non-disabled children spend one week with children with disabilities in our CBR centers. They participate in a daily programme of games, art activities, dramas etc. This has led to formation of children's clubs that meet together to play and plan activities with children with disabilities. This could be referred to as *reverse inclusion* and allows for children to interact with one another regardless of their abilities and aims to create a generation of children without the prejudices handed down by their parents.

## Discussion

Based on our experience across different community projects, we propose that programmes working to increase inclusion of PWIDs should include a realistic consideration of barriers so they can be surmounted, and also importantly increase participation of PWID at all levels of decision-making.

In the introduction we describe some generic barriers to participation for PWID anywhere. Further barriers we have observed in Northern India include lack of awareness in the community as well as among professionals about the needs and skills of PWIDs, low visibility of PWIDs, an absence of frameworks and examples of participation by PWIDs and perhaps most significantly, a lack of resources, facilities, trained professionals and services to support and develop participation of PWIDs.

Lack of public knowledge and understanding of the causes of intellectual disability are often because of myths surrounding intellectual disability. Two prevalent myths are that intellectual disability is caused by evil spirits and that intellectual disability is caused by pregnant women exiting their homes during a solar or lunar eclipse. Frequently the parents and family of PWIDs are held responsible for their condition, thus help is more often sought from witch doctors/traditional healers rather than professional Western health and rehabilitation service providers. The disability is perceived as of supernatural cause or the result of the *karma* (fate) of the parents. These beliefs often mean that parents receive minimal support with a child with intellectual disability and thus children are often not sent to school and are kept inside, with few social contacts or community participation outside of the immediate household. This keeps this group to a large extent invisible.

Another barrier is the lack of models and examples of participation of PWIDs in all aspects of life in Northern India. Family members and PWIDs in communities where we work have little concept of how or even why they should participate in all aspects of daily life. Their overall expectations are very low.

Lack of knowledge among professionals (both medical and educational) is a further barrier to visibility and participation of PWIDs. We have seen many instances where parents have taken their child to a doctor because of delayed developmental milestones and the parents are sent away with the doctor telling them that the child will get better as he grows older. Similarly teachers may blame a child with intellectual or learning disabilities with labels of *lazy* or *naughty*.

A further major barrier is the lack of opportunity for PWID to develop skills and knowledge with scant facilities and resources for diagnosis and intervention, particularly in the rural areas. Children with special educational and learning needs are rarely given the attention they need where under-resourced government schools have classes of 40-50 children. Throughout India there is a scarcity of therapists and special education professionals. In rural areas in particular there are no resources to support PWIDs for hundreds of kilometres at a stretch.

We need to notice and think about barriers to participation for PWID in order to supervene them. Most importantly, the extensive pro-disability policy and legislation in India needs to be supported with funding and a huge injection of human resources into rural and urban schools and government institutions as well as



awareness and skills building for health and education professionals. Inclusion of PWIDs should be modelled in arenas of decision making particularly in policy and service planning for PWDs by both government and non-governmental service providers.

We can also think through the possibilities of participation for PWIDs. Practical pathways ahead are exemplified in our examples described above. Increasing visibility of PWIDs into all arenas of community function is an important mechanism to build community awareness and understanding. Inviting participation in community-based advocacy groups for family members of PWIDs validates their roles, understanding and contributions. Increasing knowledge and awareness of disability among rural and urban communities is a first step to building meaningful participation. Changing attitudes in the new generation using reverse inclusion to bring a new and inclusive approach each demonstrate effective pathways to increase participation.

The following principles of good practice described by WHO ensure active and meaningful participation by individuals or groups of children with intellectual impairments:

- Training for caregivers to understand the importance of decision making and to facilitate the process in PWID right from the time they are children.
- Training and support for parents/carers to help them communicate with their children, including strategies for listening and communicating.
- Treating parents, care-workers and other adults as gate-keepers and a conduit to the child, rather than as a decision-maker for the child.
- Ensuring that national policies and service information are accessible for the individual in question. Examples include easy-read formats, in-person one-on-one communication, audio or video recordings.
- Ensuring that PWIDs and their parents are part of consultation for projects and policy making.
- Seek/Provide funding for direct and associated costs incurred by individuals, to ensure their ability to participate in any consultation process such as costs associated with transportation and physical or environmental adaptations needed.

## Conclusions

Despite the movement within the development sector in India to mainstream disability most programs focus on people with more easily visible physical disabilities. Without viable models or examples of participation, they do not include people with intellectual disability. For those of us already working with people with disabilities there is now a major responsibility to increase the visibility of people with intellectual disabilities, to build their skills and their families' capacity for self-advocacy and to provide platforms for them to be heard. For people with intellectual disabilities, an important part of our society who have hitherto had almost no voice, there really is a way forward!

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#### **Zusammenfassung:**

Die legislativen und politischen Rahmenbedingungen für die Beteiligung von Menschen mit kognitiven Behinderungen/Lernschwierigkeiten in Indien waren nie besser. Jedoch gibt es nach wie vor wenige Möglichkeiten und Beispiele für Beteiligungen für diejenigen mit kognitiven Behinderungen/Lernschwierigkeiten. Ein Rückblick auf drei Projekte der Emmanuel Hospital Association (EHA), die an drei verschiedenen Standorten in Nordindien mit Menschen mit Behinderungen arbeitet, fasst einige der signifikanten Barrieren bei der Beteiligung zusammen. Außerdem zeigen wir Wegweiser nach vorne auf, in eine Welt, wo es Menschen mit kognitiven Behinderungen/Lernschwierigkeiten möglich ist, sich an Entscheidungen zu beteiligen. Diese Beteiligung soll jede Sphäre umfassen, von Entscheidungen über Aktivitäten des alltäglichen Lebens, medizinische Versorgung und zukünftige Versorgungsmöglichkeiten sowie Inklusion in relevante Planungen von Dienstleistungen und politische Entscheidungsfindung auf Gemeinde-, Länder- und Nationalstaatsebene.

**Résumé:** Le cadre législatif et politique pour la participation des personnes handicapées mentales en Inde n'a jamais été meilleur. Malgré tout les opportunités et exemples de participation des personnes handicapées mentales restent très rares. Le passage en revue de nos trois projets dans trois localités différentes du Nord de l'Inde résume les obstacles principaux à la participation. Nous proposons dès lors des suggestions pour aller de l'avant, pour un monde

où les personnes handicapées mentales sont capables de prendre part aux décisions. Cette participation a lieu dans tous les domaines, que ce soient des décisions concernant la vie quotidienne, des soins médicaux ou des choix de soins futurs aussi bien que l'inclusion dans la planification des offres de services et la réalisation de politiques au niveau local, provincial ou national.

**Resumen:** El marco de acción legislativo y político para la participación de personas con discapacidad en India nunca ha sido mejor. Sin embargo, en la realidad existen pocos ejemplos y oportunidades concretas. Un estudio sobre tres proyectos en tres diferentes localidades en el norte de India resume barreras significativas de la participación. Por otro lado el estudio da una impresión sobre el camino hacia la participación: Ella está presente en cada esfera, comenzando con decisiones sobre actividades diarias, tratamiento médico, inclusión en servicios sociales hasta el diseño de políticas, y todo a nivel comunitario, estatal y nacional.

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# From the Mountains in the Sky – the Wales Lesotho Link

## Supporting Disabled People in Wales make to Contributions to Development in Lesotho

Wayne Crocker

For the last ten years Mencap Cymru has engaged in a link with a developing country to support the aspirations of people with a learning disability. The involvement in the link has grown the impact disabled people have in their communities in Wales as a result of their work in communities overseas.

### How It All Began

In a rather undistinguished office belonging to the then Secretary of State for Wales, a memorandum of understanding was signed between the representatives from the UK Government and the Lesotho High Commission.

The MOU initiated a country to country twinning that was to be the first in the world focusing on the fields of education, health, governance and civil society. In both countries, civil society organisations grasped the opportunities the link provided to develop friendships, understanding, and shared development projects which have lasted for over 25 years. The Wales-Lesotho link is managed by Dolen Cymru (meaning Wales Link), an independent charity, whose patron is Prince Harry, the grandson of Queen Elizabeth II.

The link first came to the attention of Mencap Cymru (an organisation of people with a learning disability and their families in Wales) in 1999 during an informal meeting between the then director of Mencap Cymru Mr. Howard Sinclair and the Education Officer of Dolen Cymru (the charity established to manage the Lesotho-Wales link in Wales) Mr. Delyth Lloyd.

Following this discussion, a formal link was proposed between Mencap Cymru and the Lesotho Society for Mentally Handicapped Persons (LSMHP) and was formally launched by veteran Disability Rights Campaigner and Member of Parliament and member of the National Assembly for Wales, the Rt. Hon. Dafydd Wigley a year later.

### So Why a Link and What Were the Benefits to People with a Learning Disability?

Mencap Cymru is an organisation established to support people with a learning disability and their families in Wales. Its remit did (and does) not allow international work. However, the

premise of its link with the LSMHP was twofold:

Firstly, it allowed people with a learning disability access to a Wales-wide stage that many of their peers were actively involved with. Over 200 schools, churches, civil society organisations have formed mutually beneficial links with similar organisations in Lesotho, and it was believed that to support people with a learning disability to develop their own link was a suitable medium for challenging the misconceptions that many people had about the ability to make a difference that people with a learning disability could have.

Secondly, it was felt that such exposure to life chances and experiences of people with a learning disability in a very different culture some 5000 miles away would help develop a greater sense of awareness and self belief among Mencap members with a learning disability in Wales.

With the link formally established, a delegation of members with and without a learning disability set off to meet their counterparts in Lesotho in March 2001.

Stephen Rose, a 28 year old man from Cardiff with Down's Syndrome was joined by Jackie Jones, a 43 year old woman with a learning disability from Llandudno in North Wales. They were supported by a volunteer Mary Oliver (a specialist in Special Educational Needs) and two staff members.

The ten day visit set the tone of the impact the link was to have on people with a learning disability and those who care for and work with them in both Wales and Lesotho.

Lesotho is a country of extreme poverty. With the third highest adult HIV prevalence rate in the world at over 23% (UNAIDS 2010) the needs of people with an intellectual disability were not high on the list of consideration for those in Government, and the formal linking of LSMHP and Mencap Cymru under the auspices of the Wales - Lesotho link gave strength to the



voices of disabled people in Lesotho.

The visit was taken up with formal and informal information sharing and visits to a range of inclusive schools to see how parent empowerment projects supported parents to aspire for more for their sons and daughters. The two delegates with a learning disability spoke about their lives in Wales, the support structures (formal and informal) that help them live as independent lives as they choose to. The schools were interesting places to visit for the Welsh delegation as teachers taught pupils with a learning disability in the same classes as their peers and there was evidence of peer support. However, the need for formal training for teaching staff on how to support disabled pupils was obvious.

During the visit, the British High Commissioner in Lesotho hosted a reception which launched the link from the Lesotho end, but more importantly provided staff, trustees and members of the LSMHP with their first opportunity to meet with government officials within the departments of health and education, a side effect of the visits which the two organisations were keen to exploit over the next ten years.



Sandro Cairns with HM Queen Maserate of Lesotho

The LSMHP is a young organisation and keen to learn from others with longer experiences of campaigning and lobbying. For the LSMHP, the benefits of the link have been simple: The link has facilitated meetings with key officials within the government, allowing the

LSMHP to lobby for the needs and aspirations of their members. High profile meetings have been arranged with civil servants within the department of rehabilitation, including a successful meeting with the Minister of Health and Social Services, resulting in the Lesotho government agreeing to increase the funding for the work of LSMHP.

Other meetings included a reception hosted by Her Majesty Queen Maserate at the Palace in Maseru for LSMHP parents and members with a learning disability. These meetings helped to strengthen the lobbying and political skills of the LSMHP and their members, and experienced campaigners with a learning disability from Wales have been able to teach new skills to their colleagues from Lesotho.

The LSMHP has also been able to develop new aspirations for their members with a learning disability through hearing and learning about the services provided in the UK. Aspirations for a better life have been developed through hearing of what life chances people with a learning disability can expect in Wales.

One unplanned benefit of the link for both sides of the partnership was that the LSMHP has gained an influential patron. His Royal

Highness Prince Seeiso Bereng Seeiso is the younger brother of the King of Lesotho, King Letsie III. For most of the history of the Mencap Cymru - LSMHP link, he has been Lesotho's High Commissioner to London and has been a good friend of the link.

In 2008, Prince Seeiso agreed to take on the role of LSMHP's first Patron and has been an invaluable support to the organisation, especially with his other role as co-founder of the charity Sentebale, an organisation he founded with the UK's Prince Harry

to support orphans and vulnerable children in Lesotho (many of whom have a learning disability).

Those are some of the benefits of the link to the LSMHP. From the Welsh side, the link has allowed a range of people with a learning dis-



ability from different parts of Wales and with very different socio-economic background to learn more about the lives of people with a learning disability in a very different culture, and also to feel valued as an ambassador, not only for an organisation but also a country.

To date, nine members with a learning disability have been to Lesotho. They have undertaken various roles from trainer, ambassador, role model to political campaigner. But for all, it has been a journey of self awareness through experiencing life through the eyes of people that are less fortunate and less able to make changes in their lives.

One of the most profound aspects of the visits and volunteer projects undertaken by the link have been the changes in the way those involved see themselves when they return to the UK. One comment you will hear from all those who have visited Lesotho is about their experience of being accepted without prejudice or pity. Tony Sheavills, Mencap Cymru's co-chair, summed up that feeling on returning from a visit to Lesotho in November 2010.

*"The thing I will remember most, are the children at the orphanage. They just came up to me and asked me to help them put on their jumpers. In Wales, children don't come up to me, they just shout names or throw things at me. I really liked spending time there."*

There have been changes seen by those who live with the returning ambassadors. Sandro Cairns, a man with Down's Syndrome from Aberystwyth in Mid Wales, visited Lesotho in March 2007. His family is quite open about the changes they have seen in him since his return. Sandro like many people with a learning disability had a small world, focusing his thoughts around his day service, gateway club and his music. His mother is most certain that since returning to Wales from Lesotho, he is more socially aware and thinks about those less fortunate than himself.

Sandro's visit to Lesotho has provided him with many new opportunities including the opportunities to meet Prince Harry at a conference in Lesotho and to speak at a conference in Berlin as part of Inclusion International's Congress in 2010.



Sandro Cairns with HRH Prince Harry, Patron of the Wales Lesotho Link

## Outlook

So what is left for the link? Times are difficult and organisations are struggling to fund the key parts of their work. Projects like the Lesotho link have always been at the margins of what Mencap was established to do, funding pressures in Lesotho also make it more difficult for the LSMHP to play a full role in the link. But Wayne Crocker, Mencap's Director in Wales is sure of one thing: The link has provided experiences in Lesotho that not only change the people who go but also the communities to which they return to. Mencap Cymru is about to submit a funding proposal to UK funders to support the development of advocacy programmes in Lesotho delivered by staff and volunteers with a learning disability from Wales. In Wales, over 20% of staff in Mencap Cymru have a learning disability.

*"I have seen nine individuals with a learning disability come back from Lesotho different people, better people, better citizens of Wales and the world. I am incredibly proud of the opportunities we have been able to give people who are excluded to be included and I know from talking to*



*colleagues in other organisations with links with Lesotho how envious they are of the commitment staff and volunteers have put into keeping the link alive."*

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## Zusammenfassung:

*In den vergangenen zehn Jahren hat Mencap Cymru durch eine Verbindung mit einem Entwicklungsland die Bestrebungen von Menschen mit Lernschwierigkeiten unterstützt. Die Einbindung in diese Partnerschaft hat den Einfluss der Menschen mit Behinderungen in ihren Gemeinden in Wales aufgrund ihrer Arbeit in Gemeinden in Übersee vergrößert.*

**Résumé:** *Au cours des dix dernières années Mencap Cymru a développé un lien avec un pays en développement pour soutenir les aspirations des personnes handicapées*

*mentales. Le développement de ce partenariat a augmenté l'impact des personnes handicapées dans leurs communautés au Pays de Galles comme résultat de leur travail dans les communautés outre-mer.*

**Resumen:** *En los últimos 10 años Mencap Cymru se ha comprometido en una conexión con un país en vías de desarrollo para apoyar las aspiraciones de personas con problemas de aprendizaje. Con este trabajo en comunidades en el exterior ha crecido el impacto que tienen las personas discapacitadas de Gales en sus propias comunidades.*

**Author:** Wayne Crocker is the Director of Mencap Cymru. He has worked with people with a learning disability and their families for close to 20 years. Wayne is based at the Mencap Cymru HQ in Wales at 31 Lambourne Crescent, Cardiff CF14 5GF, E-Mail: [Wayne.crocker@mencap.org.uk](mailto:Wayne.crocker@mencap.org.uk)

Information about the Wales - Lesotho twinning can be found at [www.dolencymru.org](http://www.dolencymru.org).



# Full Inclusion in Development Aid for People with Intellectual Disabilities and their Families

Petra Letavayova

People with intellectual disabilities face a significantly higher risk of poverty and social exclusion than other groups of the population in developing countries. The international community often fails to take this fact on board in the design of development policies and projects. The UN Convention on the Rights of Persons with Disabilities, ratified by the European Union in December 2010, calls for international development cooperation to be inclusive of all people with disabilities. Along these lines, the project *Full Inclusion in Development Aid for People with Intellectual Disabilities* aims to mobilise local intellectual disability NGOs in the European Union and encourage them to get involved in development cooperation projects around the globe.

Inclusion International estimates that around 26 million people with intellectual disabilities live on less than \$ 1 a day. In fact, people with intellectual disabilities are disproportionately overrepresented amongst the poor, regardless of economic wealth of the country they live in (Inclusion International 2006). The structural link between disability and poverty has been generally acknowledged (Elwan 1999). Additional costs associated with a disability are rarely sufficiently reimbursed by the state. The capacity of people with intellectual disabilities to meet the general and additional costs of living is often very low as they are largely excluded from employment opportunities. Moreover, in the case of children with intellectual disabilities or people with complex needs, a family member often has to give up paid employment in order to care for the disabled person, which may have a dramatic impact on the family income.

In developing countries, extreme poverty combines with deeply-rooted social stigma caused by prejudice, superstitions and negative attitudes, particularly strong towards intellectual disability. As a result, the needs of people with intellectual disabilities are neglected by the community and public authorities and often whole families become excluded from the life of the community. In addition, the situation of people with intellectual disabilities is further exacerbated by the alarming lack or even absence of support services, attributed to lacking expertise and resources. Many times, the needs of people with disabilities, particularly those with intellectual impairment, are simply overlooked and neglected due to negative social perception. Moreover, analysis show that extreme poverty may lead to disability, as often preventable conditions become disabling due to the lack of appropriate health care and treat-

ment. Malnutrition is another important factor. Its effect on health and intellectual development and disability has been examined (Elwan 1999).

Even though it may seem that disability has been receiving increased attention in the development cooperation field over the past years, with several development agencies such as the Norwegian Agency for Development Cooperation (NORAD) or the Italian General Directorate for Development Cooperation (GDCC) establishing frameworks for including disability in development aid; the specific situation of people with (intellectual) disabilities is rarely addressed in a truly coherent and systematic manner. In the context of a more general package of disability-related development action, the human rights of people with intellectual disabilities are rarely explicitly referenced or addressed by a systematic strategy that would take into account specific needs associated with intellectual disability. The support usually takes form of financial backing for individual projects carried out predominantly by civil society organisations. In this respect, collaboration of government agencies and disability NGOs has once again proved to be crucial since organizations of and for people with intellectual disabilities are best placed to provide expertise on the needs of people with intellectual disabilities. On the other hand governments possess the relevant financial resources required for the implementation of such projects. The Canadian International Development Agency (CIDA), for example, channels its support for people with intellectual disabilities through funding for the Canadian Association for Community Living (CACL) and its project is designed to "raise awareness and engage with Canadians and Canadian-based development NGOs on the need to combat global poverty and exclusion of



people with intellectual disabilities, and to ensure that international development efforts - including poverty reduction strategies and the MDGs - are inclusive of people with intellectual disabilities" (CACL website). However, there is no specific disability policy statement in CIDA's policy suite.

"Nothing about us without us". For development aid to be truly inclusive, people with (intellectual) disabilities need to be included also in the design, implementation and evaluation of development policies. And this is where the organisations of people with (intellectual) disabilities have a crucial role to play. The project *Full Inclusion in Development Aid for People with Intellectual Disabilities and their Families* aims to facilitate better support for people with intellectual disabilities and their families in mainstream development aid programs by mobilizing local and regional NGOs in Europe and encouraging their involvement in developing countries. The project is based on the recognition that local disability NGOs in Europe have managed to develop high-quality support services for people with intellectual disabilities. This, together with their expertise in the development of inclusive local policies, is a precious know-how that could be of great use in the developing world.

Inclusion Europe, the European Association of Societies of Persons with Intellectual Disabilities and their Families, has prepared this project together with its member associations the Royal Mencap Society from the United Kingdom and Lebenshilfe Germany. Both of them are national intellectual disability NGOs comprising around 500 local and regional member associations each, thus reaching out to more than 250,000 people with intellectual disabilities and many more family members. Both associations have been involved in development cooperation activities either directly or through their members. Their collaboration on this project started in December 2009 after the project proposal was awarded funding from the European Commission under the program *Non-State Actors and Local Authorities in International Development* and runs until the end of March 2011.

Some European disability NGOs have already reached out to their counterparts in developing countries and become involved in development cooperation activities on the ground. Lebenshilfe Germany and Mencap report a number of member associations that are internationally active in the transfer of professional knowledge in developing countries and Central and Eastern Europe. Mencap Wales, for example, has been working with a Lesotho organisa-

tion for people with learning disabilities (LSMHP) for 10 years, collecting money for LSMHP and organising exchange visits for volunteers with a learning disability from Wales to Lesotho and vice-versa.

Still, significant potential remains undiscovered. The reasons for a relatively low involvement of European disability NGOs in development projects have been analysed in depth prior to the commencement of the project. Lacking knowledge of development cooperation issues and policies had been identified as a major barrier. As a result, the NGOs either do not at all consider engaging in development cooperation activities or they simply copy practices from Europe, disregarding the cultural and other specificities of the particular developing country. At the same time, disability NGOs lack contacts with development cooperation stakeholders that could stimulate their activity. In addition, without such contacts, mainstream development aid can never become inclusive. And finally, it is essential to ensure promotion and exchange of good practices in including people with intellectual disabilities and their families in mainstream development cooperation projects.

Hence, the ultimate goal of the project has been to tackle these barriers and mobilise European disability NGOs by providing easy access to all the necessary information about including support for people with intellectual disabilities in mainstream development aid programs and by promoting exchange of contacts and networking among European disability NGOs, as well as with development cooperation stakeholders.

To this end, an online toolkit on the inclusion of support for people with intellectual disabilities in mainstream development aid programs has been developed. This toolkit aims to support development cooperation activities to the benefit of people with intellectual disabilities by providing local disability organisations and authorities in Europe with a selection of useful and practical information: An overview of relevant development cooperation policies and programs from the UK, Germany and the European Union, guidelines on how to initiate and manage development cooperation partnerships, a guide on funding opportunities for such projects, a list of relevant websites and organisations etc. All this material, together with examples of relevant good practices and success stories about including people with intellectual disabilities in mainstream development aid programs, is available on the website [www.inclusive-development.eu](http://www.inclusive-development.eu) in English, German and French.



In order to encourage cooperation between local disability organisations, local authorities and national mainstream development aid organisations as well as to provide input for the toolkit, three national networking meetings were organised both in the UK and Germany over the course of 2010. For a European and international outreach, the European Networking Conference, organized in June 2010 in Berlin on the margins of the World Congress of Inclusion International, gathered more than 50 stakeholders from both developed and developing countries to discuss possibilities for better support for people with intellectual disabilities and their families in mainstream development aid programs. The conference identified success factors for inclusive development as well as challenges for practical projects. Questions of transferability, necessary policy support and ways to encourage instrumental networking were also addressed. The outputs of the gathering are equally available on the [www.inclusive-development.eu](http://www.inclusive-development.eu) website.

Finally, three awareness-raising publications have been elaborated, each of them targeting different audience with one common objective: Ensure that extreme poverty and exclusion of people with intellectual disabilities in the developing countries is no longer an *invisible* issue of development cooperation. The publications explain the substance of this problem to families, professionals, aid organisations and, most importantly, in easy to read language to people with intellectual disabilities; and offer actions that could be taken by each of them to alleviate the hardship of people with intellectual disabilities living under the poverty line.

The project *Full Inclusion in Development Aid for People with Intellectual Disabilities and their Families* thus directly addresses the implementation of article 32 of the UN Convention on the Rights of Persons with Disabilities (UN CRPD), focusing on making development cooperation inclusive and accessible for and with people with intellectual disabilities. This initiative has been undertaken in a timely manner, as the European Union ratified the UN CRPD in December 2010. The deliverables of this project will be distributed through the project partners and the network of Inclusion Europe, reaching out to more than 10,000 local disability NGOs in Europe.

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**Zusammenfassung:** Menschen mit kognitiven Behinderungen/Lernschwierigkeiten sind einem signifikant höherem Risiko von Armut und sozialer Exklusion ausgesetzt als andere Bevölkerungsgruppen in Entwicklungsländern. Die internationale Gemeinschaft übersieht diese Tatsache oftmals bei der Gestaltung von Entwicklungspolitiken und -projekten. Die UN-Behindertenrechtskonvention, von der Europäischen Union 2010 ratifiziert, verlangt von der internationalen Entwicklungszusammenarbeit die Inklusion aller Menschen mit Behinderungen. Auch in diese Richtung zielt das Projekt „Umfassende Inklusion in der Entwicklungszusammenarbeit für Menschen mit kognitiven Behinderungen/Lernschwierigkeiten“, welches lokale Nichtregierungsorganisationen im Bereich der kognitiven Behinderung/Lernschwierigkeiten in der Europäischen Union mobilisieren will und sie dazu ermutigen möchte, sich in Projekte der Entwicklungszusammenarbeit auf der ganzen Welt einzubringen.

**Résumé:** Les personnes handicapées mentales sont exposées à un risqué de pauvreté et d'exclusion sociale significativement plus élevé que les autres groupes de population dans les pays en développement. La communauté internationale néglige souvent de prendre en compte ce facteur dans la conception des politiques et projets de développement. La Convention des Nations Unies pour les droits des personnes handicapées, ratifiée par l'Union Européenne en décembre 2010, demande que la coopération internationale au développement soit inclusive de toutes les personnes handicapées. Dans cet esprit, le projet "Inclusion totale dans l'aide au développement pour les personnes handicapées mentales et leurs familles" vise à mobiliser les ONG locales de personnes handicapées mentales dans l'Union Européenne et les encourage à participer à des projets de coopération au développement à travers le monde.

**Resumen:** Personas con discapacidades intelectuales tienen un riesgo significativo más alto de pobreza y exclusión social que otros grupos de la población en países en vías



de desarrollo. Este hecho es tomado en cuenta pocas veces por la comunidad internacional y sus proyectos. La Convención de las Naciones Unidas sobre los Derechos Humanos de Personas con Discapacidad, ratificado por la Comunidad Europea en Diciembre 2010, exige que la cooperación al desarrollo tiene que ser inclusiva para todas personas con discapacidad. Como consecuencia, el proyecto 'Full Inclusion in Development Aid for People with Intellectual Disabilities' intenta movilizar ONGs de la Comunidad Europea para incluirse en proyectos mundiales de la cooperación al desarrollo.

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# People with Intellectual Disabilities – Opening Pathways to Training and Employment

Barbara Murray and Jeannette Sanchez

In many developing countries millions of people with intellectual disabilities and their families are inordinately affected by poverty and social and economic exclusion. The United Nation's International Labour Organization (ILO)<sup>1</sup> and Irish Aid, the Government of Ireland's programme of assistance to developing countries, have worked to focus attention on the issue and discuss ways of promoting training and employment opportunities for people with intellectual disabilities alongside non-disabled workers in Africa.

## Background

There are 130 million people with intellectual disabilities and their families around the world, according to Inclusion International. In Africa, some 10 to 15 million people - from a population of over 800 million - have an intellectual disability.<sup>2</sup> Many are living in isolation and social exclusion, with little access to services in health, education and employment.

Although programmes aimed at the development of work skills, sheltered employment and employment with job support for people with intellectual disabilities exist in most African countries, they are fewer than in countries with higher levels of income. Many non-governmental organizations play a central role in delivering these programmes in place of public authorities.

Yet, people with intellectual disabilities want to be included in the same life experiences as non-disabled persons or people with other types of disabilities.

Across the world in recent years, they have demonstrated their ability to learn and to be valued employees, provided they receive the appropriate training and work in jobs suited to their skills and interests, with support as required. These opportunities have significantly improved their quality of life.

However, getting access to the workplace, in particular, poses a challenge to people with intellectual disabilities. Fear, negative attitudes and mistaken assumptions about their capabilities among employers and others continue to present barriers to their full participation at all levels of society.

Slowly, things are changing and momentum is being established. International human rights standards such as the *United Nations Convention on the Rights of Persons with Disabilities* (CRPD), adopted in 2008, give renewed emphasis to efforts to overcome discrimination and exclusion. Most significantly, Article 27 on Work and Employment highlights the need for

people with disabilities to work on an equal basis with others. It requires States to move away from an approach that caters to people with disabilities in separate facilities towards an inclusive approach that opens doors to training opportunities in general training centres and employment opportunities in the open labour market alongside non-disabled people.

People with intellectual disabilities are entitled to gain from the provisions of the CRPD as well as people with other kinds of disabilities. Yet, they are frequently not well placed to benefit from this changed emphasis on inclusion. In many developing countries, in particular, they are often deprived of the opportunity to attend school or to acquire relevant vocational skills. This leaves them at a disadvantage when it comes to seeking jobs.

Challenging exclusion of persons with disabilities is increasingly becoming an aim of the international donor community, many of whom already have a written commitment to include disability concerns in their overseas development assistance projects. For example, the Government of Australia's aid programme (AusAID) for 2009-2014 provided Samoa with \$1.3 million in 2009-10 to support the transition of children with hearing impairment and intellectual disability from primary to secondary school. AusAID also supports Samoa's Ministry of Education, Sports and Culture work in developing inclusive education policies and programmes<sup>3</sup>.

At ILO, the Disability Team collaborates with ILO's Partnership and Development Cooperation Department to ensure a disability perspective across a broad range of donor-supported projects. Towards that aim, the team has put in place a Disability Checklist as a guide in the development of project proposals. This is combined with an advisory service regarding project proposals when they are draft stage.

And there are further grounds for optimism. A number of African countries have either ratified or signed<sup>4</sup> the CRPD. Many have also rati-



fied ILO conventions, such as the ILO Vocational Rehabilitation and Employment (Disabled Persons) Convention, 1983 (No. 159), and committed to supporting other international, regional and national initiatives to bring about meaningful improvement in the lives of people with intellectual disabilities and their families.

It was within this context that the ILO-Irish Aid Partnership Programme decided to gather together representatives of governments, employers, trade unions and civil society from East African countries, Australia and the United Kingdom to discuss shared issues and draw on a number of perspectives to explore what could be done to provide more equitable access to vocational training to people with intellectual disabilities in Africa and prepare them for work. A key element of the conference was the participation of people with intellectual disabilities and their families, which gave them the opportunity to tell their stories.

The three-day conference, organized in 2010, was the first of its kind organized by the ILO in the promotion of decent and productive work for persons with intellectual disabilities. Since 2001, the ILO-Irish Aid Partnership Programme has worked in select countries of East and Southern Africa and the Asia Pacific region to promote the inclusion of people with all forms of disabilities in the world of work by: Creating a positive environment for the employment of people with disabilities through support for effective disability-sensitive policies and legislation; and providing practical support and advice on promoting inclusive workplaces, including access to small enterprise development activities, vocational training and micro-finance.

## ILO and Disability

Productive and freely-chosen employment for all is at the core of ILO's mandate, and it is under this directive that the organization addresses issues related to work and disability.

ILO's concern with disability issues first became explicit six years after the founding of the Organization, when the first international instrument containing provisions relating to the vocational rehabilitation of disabled workers was adopted by the International Labour Conference (ILC) in 1925. Since then, the specific concern of ILO for workers with disabilities continues to run like a thread through its Conventions and Recommendations, with all International Labour Standards implicitly applying to them, and some protecting their rights in particular.

ILO's disability-specific standards include the Vocational Rehabilitation and Employment (Disabled Persons) Convention, 1983 (No. 159), its associated Recommendation (No. 168), the Human Resources Development Recommendation, 2004 (No. 195) and the ILO Code of practice on managing disability in the workplace, (2002). Together, these instruments provide the framework for ILO's response to requests for support for this target group, emphasizing the inclusion of disabled persons in general training and employment-related programmes and in the open labour market. These are actively promoted through meetings, seminars and training programmes, both general and disability-specific.

## Conference Outcomes

The conference provided representatives from each country with an opportunity to highlight current practices in their countries and difficulties experienced in ensuring that children and adults with intellectual disabilities are able to enjoy their rights.

Most stressed that educational attainment was still hit and miss for many children with intellectual disabilities, with a majority never attending school at all. In Zambia, for example, if children don't pass a certain exam in grade 7, they will not be allowed to go on to secondary school. This requirement effectively excludes intellectually disabled children from secondary education and employment training.

Shared views on requirements needed to support the successful integration of people with intellectual disabilities in open employment included: Access to education and a well-planned transition from school to work, beginning in secondary school; some work experience opportunities while in school to enable the individual to make a choice about what they enjoy doing and to get a sense of the world of work; and, access to vocational training opportunities when the individual leaves school.

A short film entitled *A Day in the Life of Jacqueline Minchin*, showing a young woman with Down's syndrome and her daily routine at the school where she works, proved to be a powerful testimony for how positive work environments allow people with intellectual disabilities to contribute to the world of work. Since its debut, the film has been promoted by several non-governmental organizations in the United Kingdom (UK), among them are the UK Down Syndrome Association and DASH (Disabilities And Self Help) of Wales, a parents' association that works towards promoting of the rights of persons with intellectual disabilities.



An important outcome of the conference was the *Lusaka Declaration on People with Intellectual Disabilities: Achieving Full Participation in Training and Employment*. Developed jointly, the Declaration is a compilation of ideas and suggestions from conference participants and disability advocates to collectively affirm the vision and values for people with intellectual disabilities, while recognizing key challenges and providing recommendations for implementation. The set of recommendations spells out concrete actions to be undertaken by government, employers and their organizations, trade unions, and non-governmental organizations and parents groups in the disability field. The Declaration provides a framework for action in this area in the years to come.

Since its adoption, the Declaration has been widely distributed among the 80 conference participants, with several referencing it as part of their advocacy and outreach efforts to governments in their home countries. It is hoped that this Declaration will inspire the sponsorship of new development cooperation projects specifically designed to improve opportunities for persons with intellectual disabilities, to enable them to overcome the multiple disadvantages they face in seeking to earn a decent living and take part more broadly in their communities.

A video (see reference at the end of article) highlighting the barriers to inclusion, and which examines what is possible for persons with intellectual disabilities so that they are able to obtain decent work and a better life, was prepared following the conference. In it, persons with intellectual disabilities also describe how valuable work is to them.

## Voices from the conference

Conference participants with intellectual disabilities expressed their thoughts on the conference and described what work means to them:

**Mr. Quincy Mwija, 34, Zambia**

Vice-Secretary General of the Zambia Association of Children and Adults with Learning Disabilities (ZACALD); Council Member, Inclusion International

*"People with intellectual disabilities are highly marginalized in many African countries. In the past, meetings of this nature have never involved the participation of person with intellectual disabilities. Involvement of persons with intellectual disabilities is critical - we also know what our needs are and we have feelings like anybody else."*

*What do I expect from this conference? I*

*hope that working together, we can have a positive impact on the lives of persons with disabilities."*

**Ms. Jacqueline Minchin, 33, United Kingdom (UK) - Wales**

Clerical Assistant, Penglais Comprehensive School in Aberystwyth, Wales; Special Olympics Champion

*"I love going to work. I wouldn't miss a day. It makes me feel good that I have different jobs to do and that I do them well."*

**Ms. Anne Mary Kanyange, Uganda**

Office Worker, Uganda Parents of Children with Learning Disabilities (UPACLED)

*"I'm very happy. I know what I am doing. I love my work. I count books, newsletters. I know how to write the names of the months and weeks. So, I know how to do my best in UPACLED of Uganda."*

**Dr. Ann Minchin, Parent and Activist, United Kingdom (UK) - Wales**

Parent of person with intellectual disabilities shares her views

*"It is important that this conference will help bring to the notice of decision-makers what is possible for people with intellectual disabilities, so that they are able to go forward to improve the lives of these individuals in all countries. My experience with my daughter is relevant to all people here at the conference. She has an intellectual disability and she has managed to have a job. This has made such a big difference to her life. I think that when others see what is possible it will encourage them to do more for their own people in their own countries."*

**Disclaimer:** The views expressed herein are those of the authors and do not necessarily reflect the views of the International Labour Organization.

## Notes

- 1 The International Labour Organization (ILO) is a specialized agency of the United Nations (UN) responsible for drawing up and overseeing international labour standards. It is the only tripartite UN agency that brings together representatives of governments, employers and workers to jointly shape policies and programmes. This unique arrangement gives the ILO an edge in incorporating real world knowledge about employment and work.
- 2 Inclusion International, Hear our voices: a global report. People with an intellectual disability and their families speak out on poverty and exclusion, 2006, p. 2.
- 3 Australian Government, AusAID, Development for All:



Towards a disability-inclusive Australian aid program 2009-2014, Achievement highlights – the first two years, [www.ausaid.gov.au/publications/pubout.cfm?ID=8879\\_935\\_304\\_1644\\_2484&Type=/](http://www.ausaid.gov.au/publications/pubout.cfm?ID=8879_935_304_1644_2484&Type=/) (accessed 10.03.2011).

- 4 When a country signs a convention, this indicates its general intention to abide by the principles of the convention as the convention does not become legally binding until a country ratifies the convention by depositing an instrument of ratification (usually a letter of accession, acceptance, or approval) with the relevant international organization. Once a country ratifies a convention, it may take several months (depending on the terms of the convention) before the convention enters into force; at this point the country is bound by the articles of the convention and must conform to its principles under international law.

Further information can be found at ILO Programme on Disability, Department of Skills and Employability. Available at [www.ilo.org/disability](http://www.ilo.org/disability)

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Video: Opening Pathways to Training and Employment for People with Intellectual Disabilities, ILO TV hosted on YouTube. Available at [www.youtube.com/watch?v=\\_xcZAqOajaE](https://www.youtube.com/watch?v=_xcZAqOajaE)

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Ms. Jeannette Sanchez currently works for the International Labour Organization in Geneva, Switzerland, as a Senior Communications and Public Information Officer. She is an experienced professional in managing international, national and local public information and advocacy campaigns and projects. She has consulted for major overseas development and United Nations agencies including the US Agency for International Development, the World Bank, the International Labour Office and the World Health Organization.

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## International Development Partners Forum: Promoting Inclusive Development through Increased Donor Coordination

While the United Nations Convention on the Rights of Persons with Disabilities (CRPD) marks a new paradigm shift from viewing disability as a medical or social welfare concern to recognizing it as a human rights issue, Article 32 of the CRPD also signifies a shift from conducting separate and often isolated disability programs to implementing international development co-operation and humanitarian assistance in a manner which is fully inclusive of all people with disabilities. As a result, many governmental donor agencies, United Nations agencies, multilateral organizations as well as private foundations are seeking innovative ways to ensure that their current and future programs, activities and operations are mainstreamed and inclusive. The ability to learn from other donors, or development partners, is an essential component in order to promote the issue of disability and development and reduce incidences of duplication of efforts and/or resources. Though some coordination amongst donors has already taken place, the majority of these interactions has been based upon individual relationships and took place sporadically. There is a clear need for the establishment of a systematic approach to donor coordination in the field of disability and development. Recognizing this need, the World Bank and the Global Partnership on Disability and Development (GPDD) organized the *International Development Partners Forum on Disability and Development* that took place in Brussels, Belgium on September 15-16, 2010.

Representatives and disability focal points from 22 government donor agencies, United Nations agencies, multilateral organizations, and private foundations participated in the meeting with the goals of increasing donor coordination and collaboration in the area of disability and inclusive development through sharing information and knowledge and to establishing a systematic method to promote sustained coordination among development partner organizations and agencies. The first part of the two-day meeting focused on presentations from each of the participants on the situation of disability and inclusive development within their respective agencies. Specifically, presentations provided information on: 1) framework: Information on policies, guidelines, structure/disability focal points or disability teams, and strategic plans; 2) programs and funding: Information on support to disability programs and to

inclusive programming, funding priorities and monitoring and evaluations systems for disability and inclusive development; 3) training: Internal training for organization/agency staff on disability and training materials; and, 4) resources, tools and research: Information provided internally to staff on disability and development and published and proposed studies related to technical issues on disability and development.

While it was evident from the presentations that there is a clear commitment to promote disability issues and support inclusive development, it was also clear that much work remains to be done in order for Article 32 of the CRPD to be realized and for programs to be fully inclusive. There were also several similarities and trends that emerged during the meeting. For example, the vast majority of the organizations have specific policies or guidelines related to disability and inclusive development; though many of the participants stated that their guidelines may need to be reviewed and updated to ensure that their policies are consistent with CRPD. In addition, there was also a trend, especially those representing government donor agencies, to establish a disability team or unit within their agency that provides expertise and technical support to their respective agencies on inclusive development. Many organizations, through their disability teams or through outside consultants, have developed or are in the process of developing trainings for staff on disability and inclusive development.

In regards to funding, there seems to be a general trend in which more money is being allocated towards not only disability specific programs but also for research as well as for pilot programs to demonstrate how mainstreaming can be achieved in the various sectors of development. Moreover, most donors seem to be looking for ways to support and build the capacity of disabled persons organization (DPOs) by providing grants or subgrants directly to DPOs in developing nations. Other organizations, especially private foundations, are focusing their funding support on issues related to the implementation of the CRPD, such as developing policies or awareness raising activities.

During the forum, there were several discussions concerning common challenges. One of the main challenges voiced by many of the participants is the difficulty of implementing fully inclusive programs and the lack of resources



and tools to show how inclusive programming can be achieved in all sectors in an effective manner. There was also an expressed need to build a demand for disability and inclusive programming within the countries in which the participants are working as well as build incentive amongst the respective organization's and agencies' staff. Others mentioned the need to establish better mechanisms for consulting with DPOs in the design, implementation and evaluation of all of their programs and the need in general to strengthen DPOs' capacity to design and implement programs. There also seemed to be common consensus that there is a need to develop monitoring and evaluation systems for inclusive programming such as developing indicators to measure inclusion. All participants stated that there is also a clear need for improved and continued collaboration amongst all development partners in order to share experiences and avoid duplication of efforts.

The final day of the meeting focused on future endeavors and the need for sustained collaboration amongst donors and other development partners. Upon discussion, it was decided to establish an informal network among the participants that will also be open to other invited government donor agencies, UN agencies, multilateral organizations and private foundations. Though the Development Partners Forum may meet periodically, the primary means of communication will be via a list serve as well as through the development of a web

portal in order to share documents, information, best practices and lessons learned. The GPDD, a global initiative developed to strengthen international cooperation in order to advance the inclusion of disability issues and considerations into mainstream social and economic development efforts, will serve as the moderator for the list serve and portal.

The meeting in Brussels marked the first time that the various stakeholders providing support for disability and the implementation of the CRPD had the opportunity to meet as a group to share experiences, knowledge, and lessons learned. However, subsequent discussions and interactions as well as the involvement of other government donor agencies, United Nations agencies, multilateral organizations, and private foundations is essential to effectively learn from each other and build best practices. In addition, though the first meeting was held only with donors in order to provide them with a confidential space to discuss issues, it will be key to also find future platforms that allows for meaningful interaction with civil society, in particular, disabled persons organizations. Donor coordination alone will not be enough to make the implementation of Article 32 a reality. It is, however, an important component and a positive step in the right direction

Anne Hayes  
Global Partnership on Disability and Development (GPDD)



# The 4<sup>th</sup> CBR Conference: Linking Disability, Rehabilitation and CBR

## Introduction

The CBR conference hosted every three years by CBR Africa Network (CAN) in different countries was held in October 2010 at the Nicon Luxury Hotel<sup>1</sup> in Abuja, Nigeria. The conference attracted 381 delegates from 52 countries in the Africa region, the Middle East, Asia, Latin America and Europe.

The conference also served as the Africa launch for the WHO/ILO/UNESCO/IDDC CBR Guidelines for community-based inclusive development.

## Background

Participants at the first CBR Africa conference held in Uganda in 2001 agreed that there was need for more documented evidence on CBR. Due to the oral tradition that dominates the communication process in Africa, there was very minimal evidence of documentation and sharing of CBR experiences. Besides relying on oral tradition, lack of resources and difficulties in communication between countries remained a very real barrier to communication in Africa. More so CBR practitioners often lacked the time, skills and will needed to be able to share their experiences and therefore rarely pursued activities that would promote documentation and sharing of these experiences. This further undermined the progress of CBR in the rehabilitation of disabled people as good practices were not shared and programmes remained unevaluated. This was a threat, especially in African countries which have embraced the CBR approach and yet lack the documented evidence to eloquently defend the strategy.

CAN (CBR Africa Network) as an organisation was set up in July 2002 as a result of the resolutions of participants at this conference targeting four areas of action. These were: (a) To initiate the formation of national CBR Associations; (b) To improve the capacity for sharing information about good CBR practice (c) To review CBR training programmes in order to promote their synchronisation; and (d) To organise regular CBR conferences in Africa starting with one in 2004. Through the formation of CAN it was hoped that CBR workers and beneficiaries would have a chance to share, and learn from each other's experiences of both good and bad practices. Encouraged interaction amongst those involved in CBR and the sharing of experiences and information would also lead to the

development of better CBR practices with the end result of improved human rights and quality of life for disabled people in Africa.

## Conference Highlights

The Nigerian government support of the conference was evident in the official opening, which was presided over by the Nigerian First Lady Dame Patience Goodluck Jonathan. A welcome address was also delivered by the Minister for Women Affairs and Social Development, Ms. Iyom Josephine Anenih, and included the participation of high-level Nigerian government officials.

Topics of the keynote presentations included:

- CBR Multi-Sectoral Approach and Role of UN Agencies
- CBR and Partnership - Role of International NGOs & Civil Societies
- Linking Research Programmes of Disability Studies, CBR, and Rehabilitation
- The Changing Face of CBR
- Collaborative Inter-Professional Community-Based Rehabilitation for People with Disabilities in Disadvantaged Communities
- Working Partnerships between CBR and other Rehabilitation Services

## Who, How & Why?: CBR capacity building in Africa

The presentations were delivered by representatives from World Health Organisation; Christian Blind Mission - UK; Dept. of Social Work University of Botswana; Community and Health Services at the University of Western Cape - South Africa; Sight Savers International - Ghana; and Centre for Global Health & School of Psychology, Trinity College Dublin - Ireland.

## Key Conference Recommendations:

They are available in English, French and Portuguese and can be downloaded from the CAN website, [www.afri-can.org](http://www.afri-can.org).

## Linking Disability, Rehabilitation, and CBR

### 1. Guidelines

The guidelines provide a framework for development of CBR and should be used in a way that fits the local context.

### 2. CBR Matrix

This provides a helpful structure but care must



be taken not to build walls around the boxes of the CBR matrix, but reach out and partner with people in other boxes.

### **3. Research**

A research network should be set up in the African region to promote evidence based practices and develop an evidence base for CBR.

### **4. Training**

CBR training should be included in mainstream training of workers across sectors, e.g. agriculture, education, law.

### **5. Training**

People with disabilities should be at the centre of all CBR training initiatives.

### **6. Families**

The family needs to be at the heart of CBR planning and practice.

### **7. Activism**

The expertise of people with disabilities is the core of any CBR programme.

### **8. Activism**

Children with disabilities should be supported to advocate for themselves.

### **9. Policies**

Disability should be put on the mainstream development agenda through the UN Development Assistance Framework-UNDAF (incl. MDGs, PRSPs).

The CAN website also has available for download the resolutions from past CBR conferences.

### **New CBR Guidelines:**

The Conference was also chosen as the occasion for the global launch of the CBR Guidelines and each participant was given a copy after the First Lady launched the guidelines and received the first copy. The guidelines, under development since 2004, were produced by the World Health Organization (WHO), the International Labour Office (ILO), the United Nations Educational, Scientific and Cultural Organisation (UNESCO) and International Disability and Development Consortium (IDDC), in close consultation with other key stakeholders on disability and development globally. The supplemen-

tary chapter of the Guidelines includes a section on CBR and leprosy<sup>2</sup>.

The guidelines are expected to impact on millions of people with disabilities, many of whom now live in poverty and exclusion. They

- provide guidelines on how to develop and strengthen CBR programmes;
- promote CBR as a strategy for community-based inclusive development;
- support stakeholders to meet the basic needs and enhance the quality of life of disabled people and their families; and
- encourage the empowerment of disabled people and their families.

The guidelines are available on both the WHO website, [www.who.int/disabilities/cbr/en/](http://www.who.int/disabilities/cbr/en/), and the CAN website, [www.afri-can.org](http://www.afri-can.org).

### **Conclusion**

In the spirit of information sharing, documentation and dissemination, the main outputs of the CBR conferences are the key recommendations and a post conference publication. Currently available are three publications from the previous conferences of the same theme: CBR A participatory strategy for Africa (Uganda, 2001); CBR as part of Community Development (Malawi, 2004), and CBR inclusive policy development and implementation, (South Africa, 2007). They are available at [www.talcuk.org](http://www.talcuk.org).

Availability of the CBR book of the 2010 conference shall be announced once it is published.

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### **Notes**

- 1 The conference received funding from World Health Organisation (WHO), International Labour Organisation (ILO), Christian Blind Mission (CBM) and funds from the registration fees.
- 2 The conference choose to highlight the disabling effects of leprosy. Even though leprosy is curable, many people continue to be affected and thus need to be included in CBR programmes. Furthermore, much emphasis has been put on the incurable (and hard to prevent) diseases that often lead to disability.

Grace J. Musoike  
CBR Africa Network



## Internationale Tagung: Inklusive frühkindliche Entwicklung - ein unterschätzter Baustein der Armutsbekämpfung

Über 90 Teilnehmerinnen und Teilnehmer trafen sich vom 3. - 4.2.2011 in Bonn, um über die Bedeutung der ersten Lebensjahre für die menschliche Entwicklung und Armutsbekämpfung zu diskutieren. Die Tagung *Inklusive frühkindliche Entwicklung – ein unterschätzter Baustein der Armutsbekämpfung* wurde gemeinsam veranstaltet von Behinderung und Entwicklungszusammenarbeit (bezev), Caritas international, dem Kindermissionswerk Die Sternsinger und der Kindernothilfe\*.

Die Tagung befasste sich in zwei Schwerpunkten mit den Auswirkungen von Armut auf die frühkindliche Entwicklung und die Inklusion von Kindern mit Behinderung in entsprechenden Programmen. Die frühe Kindheit des Menschen wurde als Tagungsthema gewählt, da dieser Zeitraum eine wichtige Rolle spielt für das Entwicklungspotenzial der Kinder, der heranwachsenden Generation und damit der Gesellschaft als Ganzes. Sie trägt entscheidend zum Erreichen des Millenniumsentwicklungsziels der Armutsreduzierung sowie zu den Entwicklungszielen Gesundheit und Bildung bei.

Die Weltbank hat deshalb die frühkindliche Entwicklung als einen wichtigen Bereich der Armutsbekämpfung erkannt und widmet sich dieser mit einem eigenen Programmreich. Interventionen in den ersten Lebensjahren - vor allem im sensiblen Alter von 0 bis 3 Jahren - haben für die geistige und körperliche Entwicklung des Menschen eine größere Wirkung als in späteren Lebensjahren. Investitionen in die frühkindliche Entwicklung sind effizienter als zu einem späteren Zeitpunkt. Dies gilt in besonderem Maße für Entwicklungsländer, wie Emiliana Vegas von der Weltbank erläuterte. Für ein Vorschul- und Ernährungsprogramm in Bolivien schätzt die Weltbank, dass jedem Dollar Projektkosten ein volkswirtschaftlicher Nutzen von 1,8 bis 3,66 Dollar entgegensteht.

### Die Auswirkungen von Armut auf die frühkindliche Entwicklung

Neben den grundsätzlichen Zusammenhängen zwischen Armut und frühkindlicher Entwicklung ging es zunächst im Wesentlichen um die Frage, welche Armutsfaktoren diese nachhaltig beeinflussen können. Als besondere Risikofaktoren wurden die Folgen von Mangelernährung, armutsbedingten Krankheiten und die soziale Situation von Kindern und ihren Familien näher beleuchtet, da diese in der Entstehung von vermeidbaren Beeinträchtigungen eine wichtige

Rolle spielen. Besonders gefährdet sind Kinder und Mütter, die in absoluter Armut oder in Kriegs- und Konfliktregionen leben oder an HIV/Aids erkrankt sind.

Insbesondere Mangel- oder Unterernährung wirken sich negativ auf die frühkindliche Entwicklung aus. Dabei ist nicht nur eine Protein-Energie-Mangelernährung von Bedeutung. Auch eine unzureichende Versorgung mit Spurelementen (wie z.B. Jod) oder Vitaminen können Kinder langfristig schädigen. Jodmangel während der Schwangerschaft kann beim Kind zu irreversiblen intellektuellen, körperlichen und sensorischen Beeinträchtigungen führen, Vitamin A-Mangel ist eine bedeutende Ursache für Blindheit und Sehbeeinträchtigungen bei Kindern.

Unter den armutsbedingten Erkrankungen stellen die Durchfallerkrankungen ein wesentliches Risiko dar. Sie stellen allein schon ein Gesundheitsrisiko dar und führen außerdem dazu, wie andere Infektionskrankheiten auch, dass sich der Gesundheitszustand eines von Mangelernährung betroffenen Kindes weiter verschlechtert. Unterernährte Neugeborene und Kleinkinder haben insgesamt ein viermal höheres Risiko an weiteren, i.d.R. relativ leicht behandelbaren Infektionskrankheiten zu sterben. Nach Angaben von UNICEF erreichen weltweit 200 Millionen Kinder unter fünf Jahren nicht ihr kognitives und sozial-emotionales Potenzial. Die eingeschränkte intellektuelle und kognitive Leistungsfähigkeit des Kindes hat Auswirkungen auf seine Schulleistungen, verringert seine späteren Chancen den Lebensunterhalt zu sichern und erhöht somit das Risiko in Armut zu leben.

Die Tagung richtete aber nicht nur den Blick auf Entwicklungsländer, sondern auch auf die Situation in Deutschland, wo etwa jedes sechste Kind von Armut betroffen ist. Auch in einem Land mit überdurchschnittlichem Bruttoinlandsprodukt können armutsbedingte, deprivierende Lebensbedingungen die soziale und emotionale, unter Umständen auch die kognitive Entwicklung der Kinder entscheidend negativ beeinflussen.

### Inklusive frühkindliche Entwicklung

Der zweite Schwerpunkt der Tagung widmete sich der Frage, wie gute inklusive frühkindliche Programme und Angebote aussehen sollten. Mit Bezug auf frühkindliche Programme wurde deutlich, dass diese ganzheitlich ausgerichtet sein müssen, d.h. sie sollten Gesundheit, Er-



nährung, Bildung und die soziale und emotionale Situation berücksichtigen. Nach der UN-Konvention über die Rechte von Menschen mit Behinderung haben Kinder mit Behinderung das Recht, gleichberechtigt mit einzbezogen zu werden. Dies bedeutet, dass frühkindliche Programme inklusiv sein müssen.

Dass neben der menschenrechtlichen Verpflichtung auch ein großer Bedarf besteht, verdeutlichte Carissa Gottlieb von der University of Wisconsin. Studien aus 18 Ländern zeigen deutliche Zusammenhänge zwischen dem Ernährungszustand, frühen Fördermaßnahmen und dem Risiko einer Beeinträchtigung auf. Diesen Ergebnissen zufolge wiesen 23 % der untersuchten Kinder ein erhöhtes Risiko für eine Beeinträchtigung bzw. Behinderung auf.

Damit Kinder mit Behinderung in frühkindlichen Programmen berücksichtigt werden können, ist die Früherkennung von entscheidender Bedeutung, stellt in Entwicklungsländern aber eine große Herausforderung dar. UNICEF hat in Zusammenarbeit mit der University of Wisconsin einen einfachen 10-Fragen-Katalog entwickelt, der dies ermöglichen soll.

Zur Inklusion von Kindern mit Behinderung in frühkindlichen Programmen stellt der von der Weltgesundheitsorganisation entwickelte Ansatz der gemeindenahen Rehabilitation (CBR) eine gute Grundlage dar, der in allen wesentlichen Bereichen Möglichkeiten aufzeigt, wie Kinder mit Behinderung in allgemeinen Maßnahmen und im Rahmen der Gemeinwesenentwicklung berücksichtigt werden können.

Mit Praxisbeispielen aus Indien, Südafrika, Kambodscha und Chile wurde konkret aufgezeigt, wie inklusive frühkindliche Programme aussehen können. Usha Ramakrishnan aus Indien und Sandy Padayachee aus Südafrika stellten aus ihrer praktischen Arbeit heraus ent-

standene einfache Handbücher vor, zum Beispiel in Form eines Kalenders. Diese erklären die unterschiedlichen Entwicklungsstadien von Kindern im Alter von 0-6 Jahren und zählen Anzeichen auf, die auf eine mögliche Behinderung hinweisen. Gleichzeitig erfahren die Eltern, wie sie die kognitiven und emotional-sozialen Fähigkeiten ihres Kindes fördern können.

Am Beispiel Chile wurde ein staatliches Programm vorgestellt, das die Inklusion von Kindern mit Behinderung auf nationaler Ebene im vor-schulischen Bereich erfolgreich umgesetzt hat und damit weiter ist, als die inklusive vor-schulische Bildung in Deutschland, die diesen Umsetzungsgrad noch nicht erreicht hat.

### **Resümee**

In der abschließenden Podiumsdiskussion wurde noch einmal die Bedeutung der frühkindlichen Entwicklung für die Entwicklungszusammenarbeit hervorgehoben. Einig war man sich darin, dass dieser Bereich insgesamt noch zu wenig Beachtung findet. Insgesamt bedarf der frühkindliche Bereich im staatlichen und nicht-staatlichen Bereich einer stärkeren Aufmerksamkeit, wobei frühkindliche Programme ganzheitlich und inklusiv angelegt sein sollten.

Die Präsentationen der Tagung sowie weitere Informationen zur inklusiven frühkindlichen Entwicklung sind unter [www.bezev.de](http://www.bezev.de) abrufbar. Voraussichtlich im Sommer 2011 wird die Tagungsdokumentation erscheinen.

Benedikt Nerger  
Behinderung und Entwicklungs-zusammenarbeit (bezev)

\* Die Tagung wurde zusätzlich gefördert durch den Evangelischen Entwicklungsdienst, Gesellschaft für Internationale Zusammenarbeit, Misereor und Stiftung Umwelt und Entwicklung Nordrhein-Westfalen.



## Kurzmeldungen/Announcements

### New European Disability Strategy for 2010-2020

The European Commission has just adopted the European Disability Strategy 2010-2020 to break down barriers with a view to tackling inequalities and social exclusion. The overall aim of this Strategy entitled *A Renewed Commitment to a Barrier-Free Europe* is to empower persons with disabilities, so that they can enjoy their full rights and benefit fully from participating in society, as well as in the European economy, notably through the Single Market. Achieving this and ensuring effective implementation of the CRPD across the EU calls for consistency. This Strategy identifies actions at the EU level to supplement national initiatives, it determines the mechanisms needed to implement the CRPD at the EU level, including at EU institutions, and takes into account the international articles of CRPD.

For further information see [www.cedefop.europa.eu/EN/news/17121.aspx](http://www.cedefop.europa.eu/EN/news/17121.aspx)

### Abuja Conference Launched New CBR Guidelines

The 4th CBR Africa Network Conference (CAN), held from 27 to 29 October 2010 in Abuja/Nigeria, launched new guidelines designed to empower persons with disabilities by supporting their inclusion in health, education, employment, social, skills training and other community services.

The Community-based Rehabilitation (CBR) guidelines resulted from the joint efforts of four U.N. and international organizations are expected to impact on millions of people with disabilities in Africa, many of whom now live in poverty and exclusion.

Nigerian government support for the landmark conference came in the wake of its recent ratification of the UN Convention on the Rights of Persons with Disabilities (CRPD) and its Optional Protocol and ILO Convention No. 159 on Vocational Rehabilitation and Employment (Disabled Persons) Convention which aim to ensure that people with disabilities enjoy their rights on an equal basis with all others.

IDDC and its partners across Africa, Asia and Latin America, having contributed to the development of the Guidelines, are expected to put into practice this fundamental shift toward a multi-sectoral approach involving all parts of government in partnership with people with disabilities, their families and communities.

The new guidelines provide guidance on using CBR programmes to implement the CRPD in low and middle income countries; promote a strategy for community-based inclusive development; shift away from the old approach which separated people with disabilities from the

mainstream of society to a new approach that seeks to empower and include them in decision making; and, promote dignity and rights for all.

To access the guidelines see [www.who.int/disabilities/cbr/en/](http://www.who.int/disabilities/cbr/en/)

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### ILO – Promoting Opportunities for Persons with Intellectual Disabilities

Persons with intellectual disabilities represent nearly two per cent of the world's population, or some 130 million people. Because of stigma and discrimination, a majority are excluded from education, training and employment. In this short film, the International Labour Organization (ILO) examines what is possible for persons with intellectual disabilities, so that they are able to access opportunities to obtain decent work and a better life.

See the video at [www.youtube.com/ilotv#p/u/5/\\_xcZAqOajaE](http://www.youtube.com/ilotv#p/u/5/_xcZAqOajaE)

### Conrad N. Hilton Humanitarian Prize 2011 geht an Handicap International

Am 13. April 2011 verlieh die Hilton Stiftung in Kalifornien den Conrad N. Hilton Humanitarian Prize 2011 an die Organisation Handicap International - für ihren Einsatz in der Unterstützung von Menschen mit Behinderung in Situationen von Armut, Ausgrenzung, Konflikten oder Katastrophen. Der mit 1,5 Millionen US-\$ dotierte Preis wird seit 1996 jährlich an humanitäre Organisationen für außergewöhnliche Beiträge zur Linderung menschlichen Leidens übergeben. In diesem Jahr waren ca. 200 Organisationen für den Preis nominiert.

### bezev-Preis verliehen

Seit 2002 verleiht Behindern und Entwicklungszusammenarbeit den bezev-Preis für herausragende wissenschaftliche Arbeiten im Bereich Behindern und Entwicklung. Der bezev-Preis 2011 wurde im Rahmen der Internationalen Tagung *Inklusive frühkindliche Entwicklung* –



ein unterschätzter Baustein der Armutsbekämpfung am 3. Februar 2011 in Bonn an Anne Keiner von der Katholischen Hochschule NRW in Münster verliehen. Frau Keiner



hat sich in ihrer Arbeit auf der Basis einer mehrmonatigen Forschungsreise nach Tansania mit der besonderen Lebenssituation und Zukunftsperspektive von jungen Menschen mit geistiger Behinderung befasst und dazu Interviews mit ihnen selbst und ihren Eltern durchgeführt. Sie hat damit einen wichtigen Beitrag zu Erfassung der subjektiven Perspektive von Menschen mit Behinderungen in Armutskontexten und unter erschwerten Lebensbedingungen geleistet. Die Laudatio von Prof. Dr. Sabine Schäper hob u.a. das hohe Maß an Kultursensibilität insbesondere im Blick auf die eigenen Wahrnehmungsweisen hin. „Jeder Vogel fliegt mit seinen eigenen Flügeln“, hatte Frau Keiner ein Sprichwort aus Tansania zitiert, das darauf hindeutet, dass die eigenen Wünsche und Lebensperspekti-

ven von Menschen mit Behinderungen – auch in unseren wohlfahrtsstaatlichen Kontexten – noch immer viel zu wenig wahrgenommen und zum Ausgangspunkt der Gestaltung von Unterstützungsnetzwerken gemacht werden.

Die Diplomarbeit mit dem Titel *Zur Situation junger Erwachsener mit geistiger Behinderung im ländlichen Raum Tansanias: Grundlagen und mögliche Perspektiven* ist über die bezev-Website abrufbar: [www.bezev.de](http://www.bezev.de).

### weltwärts mit bezev

bezev entsendet seit Anfang 2008 junge Erwachsene mit dem Freiwilligenprogramm *weltwärts* in Projekte mit Menschen mit Behinderung in Afrika, Asien und Lateinamerika.

Die Einsatzgebiete sind so vielfältig wie die Profile der Freiwilligen, zum Beispiel unterstützen Lehramtsanwärterinnen als Schulassistentinnen Förderschulen in Ghana, eine Studierende der Sozialen Arbeit kommt bei einer Selbstvertretungsorganisation in Kamerun zum Einsatz, ein Heilerziehungspfleger hilft in einer Ausbildungswerkstatt für Jugendliche mit einer Behinderung in Tansania mit, ein Orthopädiemechaniker unterstützt in Bangladesch eine Orthopädiewerkstatt.

Im Sommer 2011 werden voraussichtlich 15 Freiwillige über das *weltwärts*-Programm entsendet. Der Bewerbungsschluss für eine Ausreise im Sommer 2012 endet Mitte September 2011. Mehr Informationen zum Auswahlverfahren und zu den Einsatzstellen unter [www.bezev.de](http://www.bezev.de) im Bereich *Freiwilligendienst*.



## Literatur/Reviews

UNESCAP

### **Disability at a Glance 2010: A Profile of 36 Countries and Areas in Asia and the Pacific**

November 2010; 138 pages

The publication provides a snapshot of disability statistics and information in the region, particularly with regards to the population of persons with disabilities, the definition of disability, and national policy, programmes and institutional mechanisms on disability matters. The compilation serves as a point of reference whereby Governments, researchers, organizations of persons with disabilities, and other stakeholders are encouraged to take further action to enhance their data collection efforts and create an inclusive, barrier-free, and rights-based society.

**Bezug:** [www.unescap.org/sdd/publications/Disability/Disability-at-a-Glance-2010.pdf](http://www.unescap.org/sdd/publications/Disability/Disability-at-a-Glance-2010.pdf)

law analysis then highlights the diverse approaches adopted in the EU Member States. In a majority of these, persons who have lost their legal capacity are automatically deprived of their right to political participation.

The European Court of Human Rights, however, clearly stated that such an automatic deprivation contravenes the European Convention on Human Rights, to which all EU Member States are party. In other EU Member States, the practice is to organise an individualised assessment of the actual ability to vote of the individuals in question.

Finally, a third group of EU Member States have moved towards full participation of persons with disabilities in the electoral process. The report provides some way forward to make sure that the standards in this area are applied in practice.

**Bezug:** [http://fra.europa.eu/fraWebsite/attachments/Report-vote-disability\\_EN.pdf](http://fra.europa.eu/fraWebsite/attachments/Report-vote-disability_EN.pdf) und <http://fra.europa.eu/fraWebsite/attachments/Factsheet-disability-nov2010.pdf>

UNESCAP

### **Regional Workshop on the Empowerment of Persons with Intellectual Disabilities and their Families in Asia and the Pacific: We Gathered Talked Decided & Proposed**

June 2009, 28 pages, ISBN: 978-92-1-120555-8

The Economic and Social Commission for Asia and the Pacific (ESCAP) has been promoting a rights-based approach to disability in Asia and the Pacific for the last 15 years. ESCAP and its long-time partner, the China Disabled Persons' Federation (CDPF) organized possible solutions. The report summarizes the discussions and activities undertaken during the Workshop and places special emphasis on the personal stories of participants with intellectual disabilities.

**Bezug:** [http://www.unescap.org/esid/psis/disability/publications/ShanghaiReport\\_.pdf](http://www.unescap.org/esid/psis/disability/publications/ShanghaiReport_.pdf)

### **WHO Regional Office for South-East Asia Regional Programme Review Group (RPRG) for Elimination of Lymphatic Filariasis in the South-East Asia Region**

Report of the seventh meeting, Jakarta, Indonesia, 19-20 April 2010

Lymphatic filariasis (LF) is one of the leading causes of permanent disability and a major impediment to socioeconomic development. The South-East Asia Region accounts for the highest burden of LF with 65% of the global population at risk and 50% of the infected people living in 9 of the 11 Member States. The seventh meeting of the Regional Programme Review Group (RPRG) for Elimination of Lymphatic Filariasis in the South-East Asia Region, held on 19-20 April 2010, in Jakarta, Indonesia, reviewed the progress of LF elimination in the Region, identified problems and made technical and operational recommendations to scale up mass drug Administration (MDA) and disability management by endemic countries. This report synthesizes the deliberations at the meeting and its recommendations.

**Bezug:** [http://203.90.70.117/PDS\\_DOCS/B4621.pdf](http://203.90.70.117/PDS_DOCS/B4621.pdf)

### **European Union Agency for Fundamental Rights The Right to Political Participation of Persons with Mental Health Problems and Persons with Intellectual Disabilities**

November 2010

This report provides the first results from a legal study carried out by the European Union Agency for Fundamental Rights (FRA) in the context of its project on the Fundamental Rights of Persons with Intellectual Disabilities and Persons with Mental Health Problems.

The report sets out by recalling the international and European standards favouring the full participation of persons with intellectual disabilities and persons with mental health problems in the electoral process. The comparative

ILO

### **People with Intellectual Disabilities: Opening Pathways to Training and Employment in the African Region**

Lusaka, Zambia, 9-11 March 2010, 94 pages

The report examines experiences, from African countries and the world at large, in vocational training, preparation for work and employment of persons with intellectual disabilities. It explores policy frameworks that seem most



conducive to promoting training and employment opportunities for this group. The report identifies steps that might be taken and measures that might be adopted by governments, social partners and civil society to promote the economic and social inclusion of people with intellectual disabilities.

**Bezug:** [www.ilo.org/public/libdoc/ilo/2010/110B09\\_115\\_engl.pdf](http://www.ilo.org/public/libdoc/ilo/2010/110B09_115_engl.pdf)

## ILO

### Promoting Opportunities for Persons with Intellectual Disabilities

Persons with intellectual disabilities represent nearly two per cent of the world's population, or some 130 million people. Because of stigma and discrimination, a majority are excluded from education, training and employment. In this short film, the International Labour Organization (ILO) examines what is possible for persons with intellectual disabilities, so that they are able to access opportunities to obtain decent work and a better life.

**Bezug:** [www.youtube.com/ilotv#p/u/5/\\_xcZAqOajaE](http://www.youtube.com/ilotv#p/u/5/_xcZAqOajaE)



„Was tust du als Erstes, wenn du wieder sehen kannst, Joyce?“

Die Antwort auf:  
[www.10-millionen-wunder.de](http://www.10-millionen-wunder.de)

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# VERANSTALTUNGEN EVENTS

- 13.04.-20.04.2011      Include2011 - International conference on Inclusive Design in London, UK  
**Information:** The Royal College of Art Helen Hamlyn Centre, Kensington Gore, London SW7 2EU, UK, Tel.: +44 20 7590 4242, Fax: +44 20 7590 4244, E-mail: [hhc@rca.ac.uk](mailto:hhc@rca.ac.uk), [www.hhc.rca.ac.uk/2968/all/1/include-2011.aspx](http://www.hhc.rca.ac.uk/2968/all/1/include-2011.aspx)
- 05.06.-08.06.2011      Festival of International Conferences on Caregiving, Disability, Ageing and Technology in Toronto, Canada  
**Information:** [www.confmanager.com/main.cfm?cid=1559](http://www.confmanager.com/main.cfm?cid=1559)
- 30.05.-31.05.2011      Oslo Conference on Disability in Conflicts and Emergencies *Reaching the most vulnerable*  
 Thon Hotel Opera, Oslo, Norway  
**Information:** [www.oslodisability2011.org](http://www.oslodisability2011.org)
- 29.06.-01.07.2011      3rd International Conference Education for All in Warsaw, Poland  
**Information:** Office for Persons with Disabilities, University of Warsaw, Office for Persons with Disabilities, Krakowskie Przedmiescie St. 26/28, 00-927 Warsaw, Tel: +48 22 55 24 228, Fax: +48 22 55 20 224, E-mail: [disability@uw.edu.pl](mailto:disability@uw.edu.pl), [www.disability.uw.edu.pl/index.php?lang=english](http://www.disability.uw.edu.pl/index.php?lang=english)
- 03.07.-08.07.2011      Access Africa, 5th Institutional Development Program (IDP) Africa Forum in Accra, Ghana  
**Information:** [www.perkins.org/idp/africa-forum](http://www.perkins.org/idp/africa-forum)
- 07.07.-08.07.2011      Disability and the Majority World: Towards a Global Disability Studies: The 1st Annual International Conference in Manchester, UK  
**Information:** Elizabeth Gaskell Campus, Manchester Metropolitan University, Hathersage Road, Manchester, M13 OJA, UK, E-Mail: [shaungrech@gmail.com](mailto:shaungrech@gmail.com), <http://disabilityworld.wordpress.com>
- 17.10.-21.10.2011      World Mental Health Congress in Cape Town, South Africa  
**Information:** E-Mail: [info@wmhc2011.com](mailto:info@wmhc2011.com), [www.wmhc2011.com](http://www.wmhc2011.com)



## STELLENAUSSCHREIBUNG

Die Zeitschrift Behinderung und internationale Entwicklung - Disability and International Development - erscheint dreimal jährlich. Ihr Anspruch ist einerseits, ein Medium für einen grenzüberschreitenden Informationsaustausch darzustellen und andererseits, die fachliche Diskussion zu pädagogischen, sozial- und entwicklungspolitischen sowie interkulturellen Fragen im Zusammenhang mit Behinderung im globalen Süden weiter zu entwickeln.

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## Schwerpunktthemen kommender Ausgaben der Zeitschrift Focal Topics of Upcoming Issues

- 2/2011 Kinder mit Behinderung im Licht der UN-Konvention über die Rechte von Menschen mit Behinderung/Children with Disabilities and the UN Convention on the Rights of Persons with Disabilities (verantwortlich/responsible: Christiane Noe, christiane.noe@hotmail.de)
- 3/2011 Terminologie/Terminology (verantwortlich/responsible: Stefan Lorenzkowski Stefan.Lorenzkowski@web.de)

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 [gabi.weigt@t-online.de](mailto:gabi.weigt@t-online.de).

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