

Behinderung und Dritte Welt

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Liebe Leserinnen und Leser!

Zufällige oder aus fanatischen Gründen heraus *Zugewollte* Ereignisse (Attentate) mit Folgen wie Tod, Verletzung und Behinderung, können jede/jeden von uns zu jeder Zeit treffen, auch in der westlichen Welt. Das haben die Attentate in London in der jüngeren Vergangenheit deutlich gezeigt. Unvorstellbar, dass solche Folgen für ihre Mitmenschen von den Tätern bewusst in Kauf genommen werden, gewollt werden. Dass solche Unvorstellbarkeiten fast jeden Tag in einem Land wie dem Irak geschehen und wir die Meldungen darüber wahrnehmen, gehört schon mehr oder weniger zur *Tagesordnung*. Diese Ereignisse sind auch beim Schreiben dieses Editorials wieder präsent.

Behinderung in armen Ländern und die Auswirkungen für die betroffenen Menschen und ihre Familien, nicht nur als Folge von Unfällen und Katastrophen, der Zusammenhang von Behinderung und Armut, damit beschäftigt sich die aktuelle Ausgabe unserer Zeitschrift in den Hauptbeiträgen.

Wir greifen damit unter anderem ein Thema auf, welches insbesondere im Dialog zwischen NGOs und politischen Ebenen (Weltbank, UN etc.) verstärkt zum Tragen kommt. Armutsreduzierung ist ein politisches Ziel, das vielfach bemüht wird.

Stefan Lorenzkowski geht in seinem übergreifenden Beitrag zunächst auf den Zusammenhang zwischen Armut und Behinderung ein, fokussiert dann auf Ansätze zur Armutsreduzierung verschiedener internationaler Organisationen und (Regierungs-)ebenen, sowie auf Kooperationen von NGOs und die Entwicklung politischer Strategien.

Aus Sicht einer international tätigen NGO für Menschen mit geistiger Behinderung – Inclusion International – stellt *Connie Laurin-Bowie* die Notwendigkeit dar, von einer spezifischen Behindertenpolitik zu einer inklusiven Politik zu wechseln, um so die Lage behinderter Menschen weltweit positiv verändern zu können. Inclusion International baut hierbei auf das Know-how ihrer Mitgliedsorganisationen in über 100 Ländern.

Bill Albert, Rob McBride und *David Seddon* stellen in ihrem Beitrag eine Beziehung zwischen Behinderung, Armut und Technologie in Entwicklungsländern her, sehen aber auch in der Armutsreduzierung einen möglichen positiven Einfluss auf den Umgang mit und die Folgen von Behinderung.

Tamsin Bradley kritisiert westliche Organisationen, die im Bereich Behinderung in Entwicklungsländern tätig sind, dergestalt, dass sie zu sehr westliche Modelle applizieren und zu wenig lokales (indigenes) Wissen und Unterstützungsstrategien wertschätzen. Diese Kritik stellt *Bradley* auch in den Zusammenhang von Armut und Behinderung und verdeutlicht seine Erfahrungen an einem konkreten Beispiel.

Majid Turmusani betrachtet die aktuelle Situation von Menschen mit Behinderung in Afghanistan aus verschiedenen Blickwinkeln. Hierbei wird nicht explizit auf Armut und Behinderung eingegangen, was aber diesen interessanten Beitrag in keins-ter Weise schmälert.

De Wet Swanepoel et al beschäftigt sich in seinem Artikel mit dem Zusammenhang von Hörschädigung und den Folgen für die betroffenen Menschen, für die Familien und die Gesellschaft am Beispiel einer Studie in einer Gemeinde in Südafrika. Dabei wird auf die Zusammenhänge zwischen regionaler (defizitärer) Entwicklung, Wohn- und Lebensverhältnissen unter Armutsbedingungen und deren Einfluss auf Hörschädigungen eingegangen.

Auch dieses Mal wieder bitten wir unsere Leserschaft um Rückmeldungen sowohl zu den Beiträgen der einzelnen Ausgaben als auch zu der Zeitschrift allgemein, um so Ihre Einschätzungen in folgende Ausgaben mit einfließen lassen zu können.

Bitte denken Sie auch daran, die Erstellung der Zeitschrift mit einer Spende ab 10 Euro pro Jahr finanziell zu unterstützen. Für Überweisungen aus dem Ausland sind die Angaben zur Bankverbindung entsprechend ergänzt worden.

Sie helfen uns ebenfalls sehr, wenn Sie Änderungen Ihrer Bezugsadresse rechtzeitig an uns melden. Das erspart unnötige Kosten auf unserer Seite.

Vielen Dank, und gute Lektüre wünscht

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Armutsbekämpfung und Behinderung

Stefan Lorenzkowski

Menschen mit Behinderung werden bis heute in den internationalen Bemühungen zur Armutsbekämpfung nicht ausreichend berücksichtigt. Ein Beispiel hierfür sind die *Millennium Development Goals* (MDGs) der Vereinten Nationen, in denen behinderte Menschen keine Erwähnung finden. Seit dem Jahr 2000 sind allerdings in nationalen Entwicklungsministerien und internationalen Organisationen wie der Europäischen Union oder der Weltbank Initiativen entstanden, die auf eine Einbeziehung von Menschen mit Behinderung in die Strategien zur Armutsbekämpfung drängen. In Entwicklungsländern selbst sind Ansätze zur Reduzierung der Armut von behinderten Menschen in einzelnen Projekten bereits sichtbar. Der Artikel will einen Überblick über die gegenwärtig existierenden Initiativen geben, ohne den Anspruch zu erheben, vollständig zu sein.

Obwohl behinderte Menschen¹ in den letzten Jahren in der Arbeit von Nichtregierungsorganisationen (NROs) einen größeren Stellenwert eingenommen haben, ist Behinderung in der Entwicklungszusammenarbeit immer noch ein Randthema, das im Vergleich zu Fragen von HIV/Aids oder *Gender* wenig Aufmerksamkeit erhält. Eine Schwierigkeit in diesem Zusammenhang ist, dass Behinderung im Zusammenhang mit Armutsbekämpfung eine große Komplexität aufweist und die Berücksichtigung anderer Aspekte notwendig macht. Eine Reihe NROs, wie *Action in Disability and Development*, *Handicap International* oder *Oxfam* sehen Behinderung inzwischen als ein Querschnittsthema an, das im besten Fall alle Bereiche der Entwicklungskooperation einbezieht. Zwischen Behinderung und Armut besteht ein enger Zusammenhang, insbesondere wenn man den Begriff der Armut nicht ausschließlich wirtschaftlich definiert. Armut ist ein Zustand, in dem ein Zusammenspiel von Mangelzuständen zu einem sehr geringen Lebensstandard oder auch zu lebensbedrohlichen Zuständen führen kann. Schlechte Ausbildung, mangelnde Gesundheitsversorgung, fehlende politische Teilhabe und Diskriminierung sind für Armut ebenso charakteristisch wie ein geringes Einkommen. Für behinderte Menschen kommen weiterhin fehlende Rehabilitation und Hilfsmittel für den Alltag hinzu. Da sie mehr Aufmerksamkeit von anderen Familienmitgliedern benötigen, um den Alltag zu organisieren (z.B. tägliche Pflege, Gänge zum Arzt, Unterstützung im Transport etc.), kann es zudem dazu kommen, dass das Familieneinkommen beeinträchtigt wird.

Der gegenseitige Einfluss von Armut auf Behinderung und umgekehrt ist weltweit zu beobachten, am deutlichsten aber in Entwicklungsländern erkennbar. In Europa und Nordamerika bieten die sozialen Systeme zurzeit noch genügend Schutz für Behinderte und ihre Familien. Zudem werden behinderte Menschen dort durch Antidiskriminierungsgesetze – zum Beispiel auf dem Arbeitsmarkt – geschützt. Es wird aber auch deutlich, dass in Zeiten

wirtschaftlicher Krise der Staat nicht davor zurückschreckt, behinderten Menschen die Unterstützung zu beschneiden.

In Entwicklungsländern ist die Situation völlig anders. Hohe Arbeitslosigkeit, soziale Systeme mit wenig bis gar keinen Schutzmechanismen für gefährdete Bevölkerungsgruppen, unzureichende Grundversorgung mit Elektrizität oder Wasser und Korruption in den Behörden stellen für Behinderte eine existenzielle Bedrohung dar.

Die folgende Schilderung verdeutlicht, dass allgemeine Entwicklungsziele im Bereich Armutsbekämpfung Behinderung berücksichtigen müssen. Ohne dies wird es nicht möglich sein, gesteckte Ziele oder Strategien der Entwicklungskooperation (wie die MDGs oder die PRSPs) zu verwirklichen.

Behinderung und Armut – Zahlen und Fakten

Im Laufe der letzten Dekade haben eine Reihe von Wissenschaftlern und Organisationen die Zusammenhänge von Behinderung und Armut untersucht. Die Forschungslage über behinderte Menschen in Armutslagen ist nach wie vor dürftig. Als positives Beispiel ist der Bericht des *Chronic Poverty Research Centres* hervorzuheben (2004), in dem ausführlich Bezug zum Thema Behinderung genommen wird. Auch die Weltbank (z.B. Elwan 1999) hat Studien veranlasst, die die Situation von armen Menschen mit Behinderung thematisieren.

Sowohl die Zahl von behinderten Menschen wie auch die Zahl von in Armut lebenden Menschen lassen sich schwer bestimmen. Die Weltgesundheitsorganisation (WHO) geht davon aus, dass weltweit ca. 10% der Bevölkerung eine Behinderung haben. In diesem Artikel werden diese Schätzungen als Grundlage genommen. Bei einer Weltbevölkerung von ca. 6 Milliarden Menschen haben demnach 600 Millionen Menschen eine Behinderung, von denen bis zu 480 Millionen in Entwicklungsländern leben. Ebenfalls nur Schätzungen gibt es über die Anzahl von Menschen, die unter Armut leiden. Die Welt-

bank vermutete 2001, dass 21% der Weltbevölkerung (ca. 1,26 Milliarden) in Armut (weniger als \$2 pro Person und Tag) oder absoluter Armut (weniger als \$1 pro Person und Tag) leben.

Die Zahl behinderter Menschen, die in Armut leben, ist schwer zu bestimmen. Elwan (1999) nimmt an, dass einer von fünf armen Menschen in Entwicklungsländern eine Behinderung hat (ca. 317 Millionen). Da wie bereits erwähnt, ein behindertes Familienmitglied mehr Aufmerksamkeit erfordert und die Familie als Einheit von Behinderung betroffen ist, dürfte die Zahl von Menschen, die von den Folgen einer Behinderung betroffen sind, noch viel höher liegen. Elwan hebt hervor, dass eine direkte Beziehung zwischen der Existenz einer Behinderung und dem Familieneinkommen besteht.

Ein Beispiel

In einer von der Weltbank geförderten Studie in Uganda (Hoogeveen 2004) wurden die Auswirkungen der Existenz von behinderten Familienmitgliedern auf die ökonomische Situation ihrer Familien herausgearbeitet. Basierend auf einer statistischen Erhebung aus dem Jahr 1991 stellt Hoogeveen fest, dass 5% aller Haushalte in Uganda einen behinderten Haushaltsführer haben. Diese Haushalte sind in der Regel größer als vergleichbare Haushalte ohne ein behindertes Familienoberhaupt. Außerdem haben die behinderten Familienoberhäupter eine geringere Ausbildung, sind häufiger Analphabeten und in vielen Fällen weiblich. Im Zusammenhang mit der sanitären Versorgung fiel auf, dass diese Haushalte weniger Zugang zu fließendem Wasser und Toiletten haben. Zudem ist mehr als die Hälfte von Haushalten mit behinderten Familienoberhäuptern darauf angewiesen, mit Kohle anstelle von Gas oder Benzin zu kochen. Bezüglich des Arbeitsmarktes befinden sich behinderte Menschen in Uganda in einer schlechteren Situation. Zusammenfassend lässt sich feststellen, dass Haushalte mit behinderten Familienmitgliedern besonders gefährdet sind, von Armut betroffen zu sein. Die daraus resultierenden Risiken betreffen das Familieneinkommen, die Ausbildungschancen für Kinder, medizinische und rehabilitative Versorgung und politische Partizipation. Diese Befunde verdeutlichen, dass Behinderung im Zusammenhang mit anderen Feldern der Entwicklungskooperation angegangen werden muss, um nachhaltige Erfolge zu erzielen.

Zusammenhänge zwischen Armut und Behinderung

Rebecca Yeo (2001) unternahm mit ihrer Studie den Versuch, die Zusammenhänge zwischen Behinderung und Armut darzustellen. Sie arbeitete deut-

lich die Verflechtungen der verschiedenen Ebenen Beeinträchtigung, Gesundheit, Umwelt, Diskriminierung, wirtschaftliche Aspekte und Menschenrechte heraus. Es wird immer wieder betont, dass Beeinträchtigungen einerseits durch Armut ausgelöst werden können. So kann z.B. Mangelernährung einer schwangeren Frau direkt eine Behinderung des neugeborenen Kindes bewirken. Andererseits kann Behinderung umgekehrt auch Armut hervorrufen, wenn sie nämlich zum Beispiel zur Folge hat, dass die behinderte Person keine Arbeitsstelle erhält. Es ist nicht immer klar, welches die primäre Ursache einer Behinderung oder der Armut ist, sondern Behinderung und Armut müssen in einem wechselseitigen Wirkungsgeflecht gesehen werden.

Die Gefahr dieser Darstellung liegt allerdings darin, dass die Zusammenhänge zwischen Behinderung und Armut durch Zirkelschlüsse vereinfacht werden (Nohlen 1996) und so die Erschließung der direkten Ursachen im Rahmen der lokalen Gegebenheiten schwierig gemacht wird. Im Alltag der Entwicklungsarbeit kann diese Vereinfachung der Zusammenhänge zu Schwierigkeiten führen und Projektziele plausibel erscheinen lassen, die langfristig nicht zu einer wesentlichen Verbesserung der Armutssituation führen können.

An dieser Stelle soll kein Alternativmodell vorgestellt werden, sondern der Stellenwert holistischer Modellen hervorgehoben werden, die es ermöglichen, die Wechselwirkungen zwischen einzelnen Teilbereichen zu erkennen, die auf den ersten Blick außerhalb der direkten Ursachen liegen.

Ansätze zur Armutsbekämpfung bei Menschen mit Behinderung

Twin Track Approach

Im Rahmen der Entwicklungszusammenarbeit gibt es eine Reihe von Ansätzen, die Armut unter behinderten Menschen zu reduzieren. Der populärste Ansatz ist der *Twin Track Approach*, der von der *Europäischen Kommission* und vom britischen *Department for International Development* (DFID) vertreten wird. Durch diesen Ansatz sollen Menschen mit Behinderung einerseits in allgemeine Projekte und Programme der Entwicklungskooperation einbezogen werden, andererseits aber auch direkt gefördert werden. Die Einbeziehung behinderter Menschen in allgemeine Projekte betrifft sowohl die Zielgruppenorientierung als auch die Teilhabe an Planungsprozessen. Dies soll die Ungleichheiten zwischen behinderten und nicht behinderten Menschen ausgleichen. Die Förderung der Fähigkeiten behinderter Menschen in speziellen Projekten soll diesen ermöglichen, sich selbständiger in das Leben

der Gemeinschaft einbringen zu können.

Community Based Rehabilitation

Ein weiterer Ansatz zur Reduzierung von Armut behinderter Menschen sind gemeinwesenorientierte Ansätze wie *Community-Based Rehabilitation* (CBR) oder *Community Approaches to Handicap in Development* (CAHD). In der Neuauflage des *Joint Position Papers* aus dem Jahr 2004 von WHO, ILO und UNESCO wird deutlich hervorgehoben, dass CBR als partizipativer Ansatz im Rahmen der lokalen Entwicklungsarbeit angewendet werden kann, um behinderte Menschen aus Armutslagen herauszuführen. Durch lokale, in der Gemeinschaft verwurzelte Aktivitäten im Bereich der Rehabilitation, Ausbildung und Beschäftigung werden behinderte Menschen direkt in Maßnahmen der Armutsbekämpfung mit einbezogen.

Beide hier erwähnten Ansätze sehen sowohl Armut als auch Behinderung als soziale Phänomene, die durch verschiedene Schritte und Aktivitäten zwar nicht komplett beseitigt werden können, denen aber doch entgegengewirkt werden kann.

Initiativen internationaler Institutionen

Global Partnership for Disability and Development (GPDD)

Für die meisten internationalen Organisationen, die im Bereich der Armutsbekämpfung aktiv sind, hat das Thema Behinderung keine hohe Bedeutung. Behinderung sei ein Thema für Spezialisten wie Therapeuten oder Mediziner, hört man hier des Öfteren. Häufig wird argumentiert, dass Behinderung keine Priorität in der Armutsbekämpfung sei, da sich die allgemeinen Strategien zur Armutsreduzierung automatisch auf behinderte Menschen auswirken würden. In fast allen multinationalen Geberorganisationen werden die engen Zusammenhänge zwischen Behinderung und Armut vernachlässigt.

Eine der wichtigsten und am meisten kritisierten Organisationen im Bereich der Entwicklungszusammenarbeit ist die Weltbank. In den letzten fünf Jahren hat hier ein Umdenken stattgefunden. Die Ernennung von Judy Heuman zum *World Bank Advisor on Disability and Development* führte zu einer langsamen Sensibilisierung für die Bedürfnisse von behinderten Menschen in der Weltbank. Mitarbeiter von Judy Heuman bemängeln allerdings, dass Behinderung von einem Großteil der Weltbank-MitarbeiterInnen immer noch nicht ernst genommen wird.

Ein wesentliches Ergebnis der Aktivitäten der Weltbank im Bereich Behinderung ist die *Global Partnership for Disability and Development*

(GPDD). Die Zielsetzung von GPDD ist, der wirtschaftlichen und sozialen Entwicklungskooperation eine Behinderungskomponente hinzuzufügen. Durch die Bekämpfung ihrer Ausgrenzung soll der Verarmung von behinderten Menschen entgegen gewirkt werden. GPDD basiert auf drei Schwerpunkten:

- einer offenen und informellen Allianz aller beteiligten Organisationen und Staaten;
- einer finanziellen Unterstützung, die von verschiedenen Geldgebern geleistet wird, und
- einer Leitungsgruppe, die die Arbeit von GPDD koordiniert.

GPDD ist so angelegt, dass verschiedene Teilhaber einbezogen werden können, wie z.B. NROs, Regierungen, bi- und multilaterale Geldgeber, DPOs und auch Unternehmen. Das Wesentliche an diesem Ansatz ist, dass keine neuen Strukturen geschaffen werden, sondern Behinderung in existierende Ansätze einbezogen wird. Inwieweit sich das GPDD auf Menschen mit Behinderung auswirken wird, ist noch nicht absehbar.

Poverty Reduction Strategy Papers (PRSPs)

Die zusammen von einzelnen Regierungen und der Weltbank koordinierten *Poverty Reduction Strategy Papers* (PRSPs) sind ein weiteres Beispiel, an dem die Schwierigkeiten des *Mainstreaming* von Behinderung deutlich werden. In den meisten Fällen haben die PRSPs keinen speziellen Bezug zu Behinderung. Behinderung wird meistens nur im Zusammenhang von sozialer Sicherung gesehen und nicht unter den Aspekten von *Empowerment* oder *Inclusion*.

Eine positive Ausnahme ist in diesem Zusammenhang das PRSP für Malawi.² Behinderte Menschen werden darin als eine Zielgruppe erwähnt, die besonders von Armut betroffen ist. Dies ermöglicht die gezielte Einbeziehung von behinderten Menschen in die einzelnen armutsrelevanten Bereiche wie Bildung, Gesundheit, soziale Absicherung und allgemeine Lebensqualität. Im offiziellen Fortschrittsbericht vom Februar 2005 werden allerdings nur die Verbesserungen im Bereich der höheren Bildung erwähnt. Dies zeigt die Notwendigkeit, Behinderung gezielt in PRSPs anzusprechen, um damit einerseits ein Bewusstsein für Behinderung und andererseits Verpflichtungen für Staaten zu schaffen, die erfüllt werden müssen.

Millennium Development Goals (MDGs)

Auf dem Millenniumsgipfel im Jahr 2000 haben sich die Staats- und Regierungschefs mit den *Millennium Development Goals* (MDGs) die Halbierung der Armut bis 2015 als Ziel gesetzt. Hier, wie auch im Falle der meisten PRSPs der Weltbank,

wird nicht gesondert Bezug auf Behinderung genommen. *Inclusion International* nahm dies als Anlass, behindertenspezifische MDGs aufzustellen, um die Forderungen von Behindertenorganisationen nachvollziehbar zu machen.

UN-Konvention für die Rechte behinderter Menschen

Das *Department for Economic and Social Affairs* (DESA) der Vereinten Nationen ist eine weitere UN-Institution, die im Bereich Behinderung nicht übersehen werden darf, da sie mit der Aufgabe betraut ist, zusammen mit dem *UN Menschenrechtskommissariat* die Konvention für die Rechte behinderter Menschen voran zu treiben. Armutsbekämpfung ist nicht als spezieller Artikel in dieser Menschenrechtskonvention vorgesehen. Dennoch gibt es verschiedene Punkte, an denen Armutsbekämpfung verhandelt wird. So sind die in der Konvention repräsentierten Konzepte der Nichtdiskriminierung (Artikel 7), Teilhabe (Artikel 4 und 18) und Repräsentierung (Artikel 2 und 4) wichtige Elemente, die eine effektive Armutsbekämpfung bei behinderten Menschen ermöglichen können. Durch die Verpflichtung zur Internationalen Kooperation bietet auch Artikel 24bis ein Potenzial für Armutsbekämpfung. Er stellt die Grundlage für *Inclusive Development* und die Stärkung lokaler Strukturen.

Die Allianz von Behindertenorganisationen (*International Disability Caucus*, IDC) forderte beim fünften Ad-Hoc-Meeting im Februar 2005, zum einen in der Entwicklungszusammenarbeit keine nicht zugänglichen Infrastrukturprojekte mehr zu finanzieren, zum anderen mehr Ressourcen für behinderte Menschen bereit zu stellen. Inwieweit diese Forderungen in die endgültige Version des Konventionstextes eingehen werden, wird sich während der nächsten Treffen in New York zeigen.

BIWAKO Millennium Framework

Ein positives Beispiel für die direkte Einbeziehung von behinderten Menschen in regionale Strategien zur Armutsbekämpfung ist das *Asien- und Pazifik-Referat der Vereinten Nationen* (UN ESCAP). Im Rahmen der *Asiatischen und Pazifischen Dekade für behinderte Menschen* wurde das so genannte BIWAKO Millennium Framework für die Schaffung einer inklusiven, zugänglichen und rechtsbasierten Gesellschaft für behinderte Menschen verabschiedet. In dieser Richtlinie werden die wesentlichen Aspekte für die Einbeziehung behinderter Menschen genannt und die asiatischen und pazifischen Staaten aufgefordert, diese in ihre Gesetzgebung aufzunehmen. Armutsbekämpfung soll vor allem durch Kapazitätsaufbau, soziale

Sicherheit und nachhaltige Entwicklung erfolgen. UN ESCAP kooperiert aktiv mit den verschiedenen regionalen und nationalen Behindertenorganisationen (DPOs) und erreicht somit einen enormen Einfluss auch auf die nationalen Strategien zur Armutsbekämpfung. Die Aktivitäten in Indien oder Bangladesch sind erfolgreiche Beispiele.

Guidance Note on Disability and Development und Länderstrategiepapiere der EU

Eine andere internationale Ebene, die sich mehr und mehr auch mit Behinderung beschäftigt, ist die Europäische Union. 2003 wurde die *Guidance Note on Disability and Development for EU Delegations and Services* verabschiedet, die den Delegationen der *Direktion Entwicklung* Richtlinien vorgibt, wie behinderte Menschen in ihre Arbeit einbezogen werden können. Trotz der ambitionierten Ziele hat sich dieses Dokument in den verschiedenen Ländern nicht durchgesetzt. Vielfach ist nicht einmal seine Existenz bei den Delegationen der Europäischen Kommission bekannt.

Eine weitere Möglichkeit, Behinderung in die allgemeine Entwicklungszusammenarbeit einzubeziehen, bieten die Länderstrategiepapiere (LSP) der EU. In 19 dieser LSP werden behinderte Menschen immerhin erwähnt, aber nur in vier von ihnen werden direkte Hilfen für Menschen mit Behinderung vorgeschlagen.

Disability Knowledge and Research

Neben den internationalen Organisationen haben auch einige nationale Entwicklungsministerien im Laufe der letzten Jahre Behinderung in ihre Arbeit einbezogen. An erster Stelle ist hier DFID in Großbritannien hervorzuheben. Im Jahr 2000 veröffentlichte das DFID das Strategiepapier *Behinderung, Armut und Entwicklung*, das als eines der ersten Dokumente den *Twin Track Approach* erwähnte. Seit diesem Zeitpunkt finanziert DFID das Forschungsprogramm *Disability Knowledge and Research*, das den Zusammenhängen von Armut, Behinderung und Technologie nachgeht. Unter anderem wurden durch dieses Programm Forschungsprojekte in Auftrag gegeben, die einerseits Behinderung in einigen Entwicklungsländern untersuchen und andererseits die globale Strategie von DFID im Hinblick auf Behinderung auf den Prüfstand stellen. Hier zeigte sich, dass es erfolgreiche Kooperationen zwischen den DFID-Länderbüros und DPOs auf dem Balkan, in Russland und Indien gibt. Außerdem gibt es eine verstärkte Zusammenarbeit mit NROs wie *Action on Disability and Development*, die langfristig und projektunabhängig unterstützt werden. Auf der anderen Seite ist zu beklagen, dass auch im

DFID Behinderung nicht ein zentraler Aspekt der Arbeit ist, wie z.B. Gender oder HIV/Aids, sondern in die Abteilung Menschenrechte integriert ist.

Fazit

Die Reduzierung der Armut unter behinderten Menschen setzt Kooperationen auf verschiedenen Ebenen voraus. Einerseits müssen internationale und nationale Entscheidungsträger ein Umfeld schaffen, in dem Behinderung mitgedacht wird. So können Aspekte von Behinderung in allgemeine Programme und Richtlinien einfließen. Ohne die Unterstützung auf der internationalen und nationalen Ebene wird es schwer für Interessengruppen behinderter Menschen, ihre Anliegen durchzusetzen.

Andererseits müssen lokale und regionale Behörden direkt mit lokalen NROs und DPOs zusammenarbeiten, damit die Richtlinien sinnvoll umgesetzt werden können. Dies beinhaltet die volle Einbeziehung von behinderten Menschen und Behindertenorganisationen auf lokaler Ebene.

Daneben müssen nicht behinderte Menschen für das Thema Behinderung sensibilisiert werden. Dies kann durch die Menschen mit Behinderung in ihren lokalen Kontexten erfolgen, durch spezielles Training für Angestellte verschiedener Behörden und Institutionen, aber auch durch breit angelegte regionale Kampagnen wie im Rahmen der asiatischen und pazifischen Dekade der Menschen mit Behinderung.

Anmerkungen

- 1 In diesem Artikel wird vorwiegend der Begriff *behinderte Menschen* verwendet. Dadurch soll deutlich gemacht werden, dass diese Bevölkerungsgruppe durch äußere Umstände behindert wird und Behinderung kein individuelles Merkmal ist (wie es z.B. in dem Ausdruck *Menschen mit Behinderung* den Anschein hat).
- 2 http://povlibrary.worldbank.org/files/Malawi_PRSP.pdf

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Summary: *Disabled people have not been considered sufficiently within the context of international cooperation. One example are the Millennium Development Goals, that do not take disability into consideration. Since 2000 a number of international initiatives try to include disability into their poverty reduction strategies. This article summarizes the current situation without claiming to consider all existing initiatives.*

Résumé: *Les personnes handicapées ne sont pas, jusqu'à présent, suffisamment prises en considération dans les efforts internationaux pour la lutte contre la pauvreté. Un exemple de cela sont les Millenium Developments Goals (MDGs) des Nations Unies dans lesquelles les personnes handicapées ne sont pas mentionnées. Depuis l'année 2000, cependant, des initiatives ont vu le jour dans les ministères nationaux du développement et les organisations internationales telles que l'Union Européenne ou la Banque Mondiale. Ces initiatives exigent l'intégration des personnes handicapées dans les stratégies de la lutte contre la pauvreté. Même dans les pays en voie de développement de légères améliorations concernant la réduction de pauvreté de personnes handicapées sont visibles. L'article veut donner un aperçu des initiatives existantes à l'heure actuelle sans pour cela prétendre être intégral.*

Resumen: *Las actividades internacionales de la lucha contra la pobreza todavía no toman en cuenta adecuadamente a las Personas con Discapacidad. Sin embargo, desde el año 2000, en diferentes ministerios nacionales de desarrollo y organizaciones internacionales como la Comunidad Europea y el Banco Mundial se desarrollaron iniciativas para la inclusión de este grupo en las estrategias de la lucha contra la pobreza. En los países en vias de desarrollo ya son notables los primeros programas para reducir la pobreza de Personas Discapacitadas.*

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Poverty, Disability and Social Exclusion: New Strategies for Achieving Inclusive Development

Connie Laurin-Bowie

Despite international investments in development initiatives targeted to people who have a disability – investments by domestic governments in support to people who have a disability and commitments by governments to international and domestic human rights commitments – little if any progress has been made in improving the economic, political or social status of people who have a disability in developing countries. To understand why people with disabilities continue to be among the most disadvantaged people in the world we must consider how people with disabilities are perceived by policy makers and how development policy addresses disability. If real progress is to be made in achieving better lives for people with disabilities both the perception of people with disabilities and our policy objectives must change. This paper outlines the need for a shift from disability policy to inclusive development policy and proposes that civil society organizations require expanded strategies to contribute to this shift. The global strategy developed by *Inclusion International* to promote the inclusion of people with intellectual disabilities and their families in the UN *Millennium Development Goals* illustrates what this shift means for an international disability organization and demonstrates how we can “link local voices to global change”.

Disability has traditionally been characterized and diagnosed primarily as a condition requiring medical attention and rehabilitation – an assumption that has led to care and treatment based on treating individual deficits. The widespread creation of specialized and separate services for persons with a disability including special education and vocational training are the legacy of this approach.

A 1997 study commissioned by the *Inter-American Development Bank* indicated service coverage in Central America was less than 3%, between 1.5% and 15% depending on the country. Strategies to create more traditional services cannot achieve significant coverage of people who have a disability particularly in countries where the projected population of people who have a disability is expected to make up the majority of the population (as in some African countries).

Moreover, these services and investments have not proven effective in improving the well being of people who have a disability. Over and over investments in disability initiatives have focused on the provision of therapies or services which are intended to ameliorate the impact of a disability either by preventing the disability; providing rehabilitation, aids or services. There has been less investment in the supports needed for people to participate in the social, economic, political and cultural life of their societies. Even where such supports have been provided, there has been inadequate investment in schools, health care, and child development schemes to ensure they are *designed* to be inclusive.

Few initiatives which have as their objective the inclusion of people who have a disability have focused on changing the systems in which a person with a disability is attempting to participate in – classrooms; work environments; communities, etc. Investments continue to focus almost exclusively on

the disability with little or no effort being made to build inclusive systems.

While the disability movement has evolved over time to reflect a human rights approach to disability issues (rejecting the medical model of disability), the international human rights community has become increasingly frustrated by the limited mechanisms available for promoting social change. Many human rights monitoring mechanisms, while useful in raising awareness about human rights abuses, have done little to put in place the institutional and cultural building blocks for societies that are inclusive of all groups. In response to the call for recognition of the human rights of people with disabilities development agencies, governments and international institutions have developed models and approaches to redressing exclusion of persons with disabilities focused on the provision of direct support. The disability human rights agenda has largely been interpreted by policy makers and development agencies as a service provision agenda; developed as a segregated system of disability specific measures that inadvertently contribute to segregation and exclusion. As a result social exclusion of people with disabilities remains the predominate challenge facing advocacy organizations at the domestic and international level.

Much has been made of the *new economy* emerging as information and knowledge capacities that are increasingly becoming a driving force of economic value. Economic globalization is advancing, but with it there is a growing polarization between regions of the world. Societies may be more knowledge-driven, but often it is economic goals driving knowledge and information development rather than social goals. The result is uneven social and economic progress globally. Many civil society groups have pointed to the negative impact of contemporary economic globalization on people who are already

vulnerable, and on regions already struggling with lack of infrastructure, poverty, and economic degradation. This is certainly the case for people who have a disability, for whom the changing structure of economies has the potential to further marginalize and disadvantage.

Given the emerging challenges of a new economy, the limitations of our human rights instruments, and the limitations of current disability related investments in enabling inclusion, what strategies can be used globally to advance the human rights and inclusion of people who have a disability in our societies?

As one of the seven international disability organizations recognized by the United Nations, *Inclusion International* (II) has set out a plan to respond to these challenges and has developed strategies for making a contribution to the global agenda for poverty reduction and the inclusion of people with disabilities and their families. The following outlines *Inclusion International's* efforts to respond to these issues of social exclusion by drawing from the knowledge of our membership in over 200 countries around the world and by mobilizing that knowledge to impact on governments and donor agencies.

Achieving Human Rights Means Addressing Social, Economic and Political Exclusion

While significant poverty reduction strategies are being developed by governments, multi-lateral agencies and international financial institutions, issues of equity, participation and inclusion are left to human rights and legal judicial disconnect between human rights systems and the systems that generate and control wealth. Current initiatives to combat poverty through international financial institutions and governments are not effectively, if at all, evaluating the exclusion of people who have a disability from economic and social participation in the construction of policies.

Civil society organizations active in international cooperation and development have become in many instances the delivery agents for these supports supplying a parallel and substandard social infrastructure. This model of social and economic development has proven unsustainable and ineffective because the real barriers to inclusion lie in the structure and implementation of social and economic policy. While services and supports are important elements in the lives of people who have a disability; and disability specific rights raise awareness of the issues affecting people

who have a disability, it is mainstream policies and investments in education, poverty reduction, health care, strengthening civil society, child protection and others that have the greatest impact on the inclusion or exclusion of people who have a disability.

An Expanding Role for Disability and Family Organizations

In analyzing the slow progress toward inclusion, it is increasingly evident that while significant knowledge exists about how to make inclusion happen in discrete communities, schools or other settings this knowledge is not being translated into resources which can be used in decision making about policy development or investments by governments and multilateral agencies. What is needed are strategies to translate *what we know about inclusion, how it works in communities and why* into structural, economic and social policies that governments, donor agencies and international institutions can adopt and implement as a part of mainstream sustainable development plans.

This means that traditional strategies of advocacy organizations to act as watch dogs and service deliv-

Some Strategies and Tactics Employed by CSOs

Strategies	Tactics	Skills
Education	Meetings, media, workshops, conferences, commissions	Research, information, analysis, dissemination, communication and articulation
Collaboration	Building relationships, links, cooperate with governments and other CSOs	Communication, organization, mobilization, networking technical capabilities, transparency openness and effectiveness
Persuasion	Meetings, workshops, coalition, lobbying, media, demonstration	Organizing, communication, motivation, negotiation, commitment and vision
Litigation	Use of courts	Legislation, communication
Confrontation	Demonstration, public gatherings, speeches	Mobilizing, communication, motivation, leadership

Chart 1: Role of Civil Society Organizations in Governance, Dr. Aisha Ghaus-Pasha, December 2004, United Nations

ery agents must be expanded to include other roles such as knowledge brokers and advocates for policy change. This shift is not unique to the disability sector, the increasing global trend toward democratization has opened up the political space for civil society organizations to play a more active policy influencing role.

Traditionally we have used strategies such as awareness raising; litigation and protest to place demands on the state. We believed that the establishment of human rights for people with disabilities would lead directly to the achievement of those rights. International cooperation between disability organizations continue to emphasize the need to establish a framework of rights in developing countries and countries that are in the processes of democratization. We know now that rights are not

enough. We need strategies to help governments and donor agencies develop inclusive policy approaches.

Persuasion/Awareness Raising

The first challenge we face is in establishing disability as an issue that donors, international agencies and *International Financial Institutions* (IFIs) recognize within their priorities. A recent study done by II of selected donor agencies showed that few had policies on the inclusion of people with disabilities in their development priorities and none had successfully incorporated disability across development priorities.

One reason for this has been that the current emphasis on the United Nations MDGs has left out any reference or consideration of people with disabilities. For this reason II developed a strategy to demonstrate how each of the MDGs is relevant to people with intellectual disabilities. The II MDGs provide both targets for the achievement of each MDG for people with disabilities along with evidence of the particular vulnerability of people with disabilities – especially people with intellectual disabilities (see chart 2).

To be effective we need evidence that these issues are substantial and will impact on the achievement of the MDGs. For example in the area of education it is not sufficient to point out that less than 2% of children with disabilities receive an education; rather we must show that 40 million of the 120 million children who are out of school have a disability. This means that achieving the MDG on Education requires strategies to develop inclusive education systems. It puts the issue in the mainstream development agenda.

Education/Knowledge Development

If we are successful in establishing the importance of our issues in relation to the larger policy agenda (MDGs) it will likely generate investments in research and knowledge development by governments and donor agencies. As the World Bank for example, begins to consider the relationship between poverty and disability, it has begun to invest in data collection and to encourage governments to determine what portion of national populations are impacted by disability. However the information produced by these processes (census data for example) provides only a static and one dimensional picture of the issues affecting people with disabilities. The knowledge that people who have a disability and their families have is of the relationship between people with disabilities and their families, their com-

munities and the social, economic and political structures with which they interact. It is this knowledge that provides a real understanding of the barriers to participation and inclusion. Civil society organizations are a key source for this knowledge and must be supported to share and contribute this knowledge with governments and donor agencies.

Collaboration/ Policy Engagement

Even where there is evidence that the issues affecting people with disabilities are important in achieving development objectives and where data and information is supplemented by real knowledge about the issues of exclusion, disability and family based organizations need to play the role of translating these issues into policy. We now know that people with disabilities are at increased risk of HIV/AIDS infection; we understand that this is due to their vulnerability in society and the lack of access to public education programming as well as cultural myths about disability that exist in many countries. What policy issues does this raise for governments and for donor agencies? A simple response would be prevention education targeted at this population. But if these prevention programmes are delivered through schools: are young people with disabilities in school, how will deaf people hear public awareness campaigns on the radio etc.?

Being part of defining the policy issues is critical if we are to achieve inclusion but grassroots organizations need the capacity and skills to know what to ask for. Much has been made of the fact that people with disabilities and the organizations that represent them have been left out of the Poverty Reduction Strategy Paper consultations and the fact that disability where mentioned in PRSPs is seen as a social protection issue. Little has been said about the fact that DPOs in many countries do not have the resources or skills to contribute to this process beyond the identification of issues. Family based organizations may identify needs (services and disability aids for example) but few would have the capacity to introduce tax reform measures to support families who have a member with a disability or teacher training and curriculum adaptation strategies for inclusive education. Building this capacity requires investment in civil society organizations and knowledge networking strategies. II's MDGs have proven to be a valuable communication tool that helps to raise awareness about the link between poverty and disability but they are also an important framework for advancing a policy agenda for inclusion.

To be effective beyond awareness raising, civil society organizations like II must become sources of

Inclusion International MDG's	Data Shows	What We Know From People
1. Eradicate Extreme Poverty For People with Disabilities and their Families	<i>The World Bank estimates that people with disabilities account for as many as one in five of the world's poorest people, suggesting that 260 million (43%) of the estimated 1.3 billion people world wide living on less than \$1 per day have a disability.</i>	Due to lack of inclusive education, basic services and health care, people with disabilities are prevented from integrating into society. It is very difficult to gain employment with a lack of training and facing employer discrimination. Without a job or an education people with disabilities cannot break the cycle of poverty.
2. Achieve Inclusive Education	<i>Recent UNESCO studies suggest the highest incidence and prevalence of disabilities occur in the poorest areas, where less than 2% of children with disabilities attend school.</i>	The systematic discrimination and segregation of children with disabilities extends to the classroom where teachers have not been properly trained, and inadequate resources are in place to develop inclusive education for all children.
3. Promote Gender Equality for Women with Disabilities	<i>UNICEF estimates that only around 1% of girls with disabilities are literate.</i>	Responsibility of care giving falls disproportionately on mothers or female siblings resulting in even fewer opportunities for female family members to gain employment or complete schooling.
4. Reduce the Mortality of Children with Disability	<i>Mortality for children with disabilities may be high as 80% in countries where under five mortality as a whole has decreased to below 20%.</i>	The lives of infants with disabilities are often so undervalued that they are not cared for or fed as families struggle with meager resources.
5. Achieve the Rights of Children and Families	<i>It is estimated that only 2% of people with disabilities in developing countries have access to rehabilitation and appropriate basic services.</i>	Families report that time to build social networks and support circles, friendships, get involved in their community are consumed with the need to just <i>get by</i> resulting in fewer mechanisms for support and limited social capital
6. Combat HIV/AIDS	<i>The World Bank performed an international survey which concluded that HIV/AIDS is a significant and almost wholly unrecognized problem among disabled populations worldwide.</i> <i>While all individuals with disability are at risk for HIV infection, subgroups within the disabled population – most notably women with disability, disabled members of ethnic and minority communities, disabled adolescents and disabled individuals who live in institutions – are at especially increased risk.</i>	Extreme poverty and social sanctions against marrying a disabled person mean that they are likely to become involved in a series of unstable relationships. Disabled woman are often a target for rape, which puts them at risk. There are almost no sexual education programs targeted towards people with disabilities. The global literacy rate for people with disabilities is estimated to be only 3%, thus making sexual education and HIV/AIDS information difficult to disseminate, especially for those who are deaf and/or blind.
7. Ensure Environmental Sustainability	<i>UN statistics state that about 20% of all disabilities are caused by malnutrition and over 10% are caused by infectious diseases.</i>	Poor nutrition, dangerous working and living conditions, limited access to vaccination programmes, and to health & maternity care, poor hygiene, bad sanitation, inadequate information about the causes of impairments, war and conflict, and natural disasters all cause disability.
8. Develop a Global Partnership for Development	<i>Recent estimates indicate that there are approximately 450 million people with disabilities living in the developing world. Approximately 30-40% of households care for a member with a disability.</i>	The exclusion and systemic undervaluing of people with disabilities perpetuates a cycle of poverty and isolation. Unless disabled people are brought into the development mainstream by creating global partnerships for advocacy and development it will be impossible to achieve full human and economic rights.

Chart 2: Inclusion International's MDGs

knowledge. Using the II MDGs as a framework for our agenda II has developed a three part strategy:

- Drawing from the knowledge of our members (local families, and people who themselves have a disability) to more fully understand and articulate the profound costs of exclusion to communities and societies;
- Strengthening the capacity of member organizations to meaningfully participate in policy dialogue and governance processes by engaging them in strategic dialogue about the structures and processes that impact on their well-being;
- Effecting the development of inclusive policies and practices at the national, regional and international level by contributing our collective knowledge about why people are excluded; what works; what doesn't and why.

Strategies to advance inclusion must include the establishment of processes and forums which take advantage of the knowledge that exists in communi-

ties by building on and scaling up from existing local, grassroots and civil society development activities, experiences and knowledge. The processes must link the knowledge of communities to policy development, implementation and monitoring by governments and international institutions. Shifting from *disability policy* to *inclusive policy* is a critical step in realizing the human rights of people who have a disability. In order for societies to value and respect the contributions of people who have a disability, political, economic and social policies must be designed to be inclusive. *Inclusion International*, its members and networks can play an important role in strengthening the capacity of institutions to adopt inclusive approaches at the global (World Bank, UNESCO, OECD, The G8 etc.); regional (European Union, Organization of American States, African Union etc.) and national (governments and donor agencies) levels.

A Plan of Action

Increasingly governments and international financial institutions are recognizing that real knowledge about how to address the sources and underlying causes of poverty lies with people and communities at the local level who live in poverty. The World Bank's Voices of the Poor research is based on an understanding that the real experts on poverty are people who live in poverty. Likewise people who have a disability and their families are the experts on disability and the factors affecting their inclusion or exclusion. In order to ensure that people who have a disability are considered in strategies and investments to meet the MDG's, *Inclusion International* has designed a global initiative to *Link local knowledge to global change*, bringing the voices of people who have a disability and their families who are also poor to the tables and processes where decisions are made.

Inclusion International is entering the second year of a three-year initiative to draw global attention to the conditions of poverty and their impact on the lives of people who have a disability and their families. The initiative will support people with disabilities, their families, associations and networks to come together in each of the four participating regions (the Americas, Africa and the Indian Ocean, Europe and the Middle East) to develop strategies to identify the causes of poverty and address those conditions. With the financial support of the *Norwegian Association for Persons with Developmental Disabilities* (NFU), member of *Inclusion International*, *Inclusion International* is working with each of its regional associations to host a regional forum at which the initial research findings will be used as a basis for developing strategies and implications for policy in different sectors.

The initiative will use the process leading up to and following each of the regional conferences to build a base of knowledge about poverty and disability. Over the three years of the project II will develop a baseline global report on poverty and disability using the II MDGs as a framework to be released at II's World Congress in Mexico in 2006.

To date reports from the Americas and Africa have been completed and strategies for advancing agendas of poverty reduction in those regions have begun to take shape.

Drawing from the voices of people who have a disability and their families, *Voices from the Americas* (www.inclusion-international.org) provides an analysis of the implications of each of the Millennium Development Goals for people with disabilities and their families: "Listening to families

helps us to understand that poverty does not affect only individuals but poverty is systemic human issue affecting families, communities and nations." (Dr. Roberto Leal, Executive Director Inclusion Inter-Americana). By examining the experiences of people who have a disability in the Americas, the report demonstrates that the way in which a person's disability is experienced is significantly impacted by conditions of poverty (personal and community). The findings of this report reflect the need for a shift in the focus of development assistance from addressing disability as unique programming issue to begin to integrate disability issues into government, donor agency and NGO strategies across sectors at the national, regional and global level. It also points to the need for approaches to poverty that acknowledge poverty as an issue of exclusion.

The *Interim Report on Poverty and Disability in Africa* identifies structural reform issues such as good governance and the need for effective processes for civil society participation in policy development along with sectoral issues such as the increased vulnerability of people with disabilities to HIV/AIDS and the need for inclusive education reform.

Parallel processes for collecting knowledge and analysis from families and individuals are underway in Europe (with a particular focus on Eastern Europe) and in the Middle East North Africa for 2005.

Making a Difference in People's Lives

Ultimately, the effectiveness of *Inclusion International's* strategies can only be measured by whether we are making a difference in the lives of people who have an intellectual disability and their families. Yet measuring progress in this regard is difficult. As an international organization our job is not to deliver projects that help ten, twenty or a hundred individuals at a time, this is the job of our member organizations. Rather II's job is to support our members in their efforts and to scale up that work internationally so as to create change at a systemic level. Making sure that the voices of people with intellectual disabilities are heard and respected in the negotiation of a new UN Convention on Disability; playing a leadership role in having the people with disabilities included in the Millennium Development Goals; providing our members with a platform from which they can take advantage of opportunities such as the Commission for Africa's work. There is some evidence that governments and international agencies are taking seriously the call to include people who have an intellectual disability in their programming and investments. Some results to date that are directly or indirectly linked to our efforts include:

- In Honduras, the national Federation embarked upon an intense lobbying effort and managed to have the state include persons with disabilities as a sector into its national programme against poverty and extreme poverty;
- In Panama, the First Lady will convene a regional meeting of first ladies on poverty and disability drawing from *Inclusion International's* report;
- In Nicaragua, the Ministry of Health with our member organization has a pilot programme to distribute folic acid, covering 16,000 women residing in four of the areas most affected by poverty;
- In Africa, a network of family organizations across west and south Africa have agreed to collaborate on poverty and disability research;
- The Commission For Africa included children with disabilities in their recommendations on education in Africa.

Inclusion International has committed itself to addressing the systemic issues of social, economic and political exclusion faced by people who have an intellectual disability and their families. To achieve these objectives we will need to have an impact on development agencies, international financial institutions and governments. Our job is to strengthen the capacity of these institutions to develop inclusive strategies for development. It is no longer enough to say we want to be included, now we must show them how.

Zusammenfassung: Trotz internationaler Unterstützung von Initiativen zu Gunsten von behinderten Menschen in Entwicklungsländern hat sich deren wirtschaftlicher, politischer und sozialer Status bislang kaum bis gar nicht verbessert. Um zu verstehen, warum Menschen mit Behinderung noch immer zu den am meisten benachteiligten Bevölkerungsgruppen auf der Welt gehören, müssen wir einen Blick darauf werfen, wie sie von politischen Entscheidungsträgern wahrgenommen werden und wie Entwicklungspolitik mit dem Thema Behinderung umgeht. Wenn ein wirklicher Fortschritt im Hinblick auf die Lebensverhältnisse behinderter Menschen erzielt werden soll, müssen sich sowohl die Wahrnehmung von Menschen mit Behinderungen als auch unsere politischen Ziele ändern. Die Autorin unterstreicht die Notwendigkeit eines Wandels von einer Behindertenpolitik zu einer inklusiven Entwicklungspolitik und stellt fest, dass zivilgesellschaftliche Organisationen erweiterte Strategien benötigen, um zu diesem Wandel beizutragen. Die globale Strategie, die *Inclusion International* entwickelt hat, um die Einbeziehung von Menschen mit geistigen Beeinträchtigungen und ihren Familien in die Millennium Development Goals der Vereinten Nationen voranzutreiben, zeigt, was dieser Wandel für eine internationale Behindertenorganisation bedeutet, und verdeutlicht, wie aus lokalen Initiativen ein globaler Wandel entstehen kann.

Résumé: En dépit d'investissements internationaux pour développer les initiatives visant les personnes handicapées, les investissements par les gouvernements locaux supportant les personnes handicapées et les implications par les gouvernements vis-à-vis des engagements internationaux et locaux des droits de l'homme, pratiquement peu a été accompli pour améliorer la condition économique, politique ou sociale des personnes qui souffrent d'une infirmité dans les pays en voie de développement. Pour comprendre pourquoi les personnes handicapées continuent à être parmi les plus désavantagées au monde, il faut que nous considérions comment ces handicapés sont perçus par les faiseurs de politique et comment la politique de développement aborde l'infirmité. Si un réel progrès doit être réalisé en améliorant la qualité de vie des personnes handicapées, la perception des handicapés et nos buts politiques doivent tous les deux changer. L'étude souligne la nécessité pour un changement de la politique pour handicapés à une politique globale de développement et propose que les organisations de société civile réclament des stratégies élargies pour contribuer à ce changement. La stratégie globale engendrée par *Inclusion International* afin de promouvoir l'inclusion des personnes handicapées intellectuellement et de leurs familles dans le Millennium Development Goals des Nations Unies, illustre ce que ce changement signifie pour une organisation internationale d'handicapés et démontre comment nous pouvons relier les voix locales au changement global.

Resumen: La autora subraya la necesidad del cambio de la política de la discapacidad a la política del desarrollo inclusivo, y constata que las organizaciones de la sociedad civil requieren estrategias mas amplias para fortalecer este cambio. *Inclusion International* desarrolló una estrategia global para integrar Personas con Discapacidad Mental y sus familias en las Millennium Development Goals de las Naciones Unidas. La estrategia enseña el significado que tiene este cambio para una organización internacional en el área de la discapacidad, y muestra además como un cambio global puede surgir de iniciativas locales.

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Perspectives on Disability, Poverty and Technology

David Seddon, Bill Albert, Rob McBride

The *Knowledge and Research* (KAR) Programme of British *Department for International Development* (DFID) has linked *disability* with *healthcare technology* and for this reason DFID has been interested in the potential role that technology plays – and can play – in reducing (or possibly in increasing) disability. It is axiomatic that technology plays an important role in affecting the physical environment and the immediate physical circumstances in which disabled people live and work. It can produce built environments that constrain or offer facilities to disabled people, it can produce equipment and machinery, which also has the potential to provide opportunities or create restrictions for disabled people. Technology is rarely *disability-neutral*. It is often argued that improvements in specific *disability related* technology can play a major role in improving the lives of disabled people. These improvements do not always imply more *advanced* technology, but often technology that is *3A* – appropriate, accessible, and amenable – to the needs of disabled people across the world. For most poor and disabled people, however, appropriate technology is not accessible and what technology is available is not amenable to their needs. This paper is concerned with the relationship between disability, poverty and technology in the developing world.

A conceptual approach

It is suggested, firstly, that the concepts of disability, poverty and technology are all best understood in terms of dynamic social processes and this paper sets out an approach to disability, poverty, technology and development based on the social model of disability. It argues that *disability* is both different from and more comprehensive than *impairment*, and defines disability as the consequence of various forms of social discrimination and exclusion for people with impairments. For this reason, national and international statistics on the prevalence or incidence of physical and/or mental impairment are inadequate as a guide to the prevalence and incidence of disability. Furthermore, such data offer a partial and often misleading notion of social reality of disability in developing countries. It cannot, therefore, be used to gauge the specific needs of disabled people or as a basis for estimating the costs and benefits of any particular programme. This paper argues the need to formulate an integrated strategy towards disability and development. It recognises the value of programmes like the *Knowledge and Research* (KAR) programme supported by DFID and recommends the funding of such initiatives in applied or action-research to examine further the relationship in different contexts of disability, poverty and technology.

Disability, poverty and technology

Although poverty and disability are often conceived as static and specific *states of being* – a sort of *negative endowment* – and technology as infrastructure or equipment, they are all better understood

as the manifest and specific outcomes of dynamic social processes. Disability is not the same as impairment, and the problems and methods of dealing with impairment prevention and with disability are, therefore, often, although not always, significantly different. Disabled people have increasingly challenged the view that disability should be equated with impairment (the medical model of disability), arguing that what disables people are the various social and physical barriers and negative attitudes, which prevent equal participation in community life. Within this social model, disability is seen as the result of social exclusion and discrimination – as a dependent variable.

The social model offers a powerful framework for understanding the complex issues of disability, poverty and technology. It reveals disability as a crosscutting social issue, and the primary policy focus then becomes changing the conditions and circumstances in which disabled people are constrained or prevented from full participation as equal citizens – that is, reducing social exclusion. DFID's statement on Disability, Poverty and Development tends to confuse the two approaches (medical and social), but leans towards the medical model, seeing disability as "long term impairment, leading to social and economic disadvantages, denial of rights and limited opportunities..." thereby equating impairment and disability and characterising them as independent variables.

Poverty used also to be characterised very much as a state of being requiring intervention and *rehabilitation*; increasingly, however, it is being defined as the consequence of social discrimination and social exclusion. Poverty in this sense needs to be understood as an outcome of social processes, which produce and reproduce it – oppression, subordination, exploitation and discrimination. Poverty is not only a dependent variable, and the consequence of social processes, it also is the root cause of many forms of impairment. But being poor is, even more

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significantly, a major factor in transforming impairment into disability. Poverty may generate impairment, through malnutrition, disease and inability to gain access to adequate health services; it also excludes those with impairments from many normal everyday activities and thereby increases disability. Disability exacerbates poverty, while having impairment makes being poor more gruelling and inexorable. Poverty, disability and impairment are clearly linked in a deadly mutual embrace.

Technology is best seen as the process of the *application of knowledge* to find effective solutions to social problems. Technology and its outcomes (which may include buildings, transport systems, assistive equipment, etc.) can dramatically affect the environment within which people live and work and may itself significantly increase or decrease the barriers which prevent disabled people from participating fully in social life. Technology can be immensely liberating and empowering for disabled people if developed within a framework which prioritises their real needs as well as their genuine participation at all levels. The provision of appropriate technological solutions in a manner which empowers the users, should not be seen as outside or opposed to a social-model approach, but as a critically important element in this approach. For example, for millions of poor disabled people, the lack of low-cost, appropriate mobility aids and assistive equipment is a major barrier to social integration.

The social model in practice

The social model has been the foundation for the disability movement, because it offers a true representation of disabled people's experience and has proved a powerful lever for antidiscrimination legislation and other policy changes. It provides a protean challenge to the disablist paradigm so often associated with the medical model. The needs of disabled people (like disabled people themselves) have all too often been equated with *special* – outside the *normal* – and disability has all too often been equated with *abnormality* and with *illness*.

There is a tendency for those concerned about *disability* to speak and act *on behalf of* disabled people. Charities and NGOs tend to be run by members of social and political elite groups, who may capture or divert programmes and projects. The need for disabled people and their organisations to be actively involved in defining their own needs and designing their own solutions is central for the social model approach.

Self-reliance does not necessarily mean *standing alone*; it does mean being in control of what kind of support is wanted and required, by whom or what,

and when. This implies a *demandled* support system in which disabled people, together with specialists and others serving as facilitators can begin to work together to make judgements about what might prove to be appropriate and sustainable technologies with respect to disability in specific social contexts.

The extent of disability in developing countries

Very little is known in detail about the nature, extent and severity of disability in developing countries; not much more is known about the prevalence and incidence of impairment. Social discrimination based on gender is widespread; so too is discrimination based on other sociocultural definitions of identity – caste and ethnicity in particular – and on socio-economic status, or class. These forms of discrimination affect the nature and severity of disability among people with impairments, according to their gender, caste or ethnic group, social class – or indeed age. But relatively little is known in detail about how precisely disability and social discrimination relate to other forms of social division – it may be that poor, low caste women are more severely disabled than wealthy, high caste men with the same physical or mental impairment, but this is not necessarily the case.

The nature of impairment is also poorly understood. Usually taken as a given, even in the social model of disability, impairment – like disability – is in fact socially defined and constructed. What is regarded as an *impairment* in one social context, may not be in another. The registered prevalence of *learning difficulties*, for example, is rapidly rising as hitherto socially unrecognised *conditions* (e.g., dyslexia) are diagnosed, or as new conditions arise (as in the case of HIV/AIDS, which now falls within the remit of *disability legislation* in several countries).

Global statistics on impairment (often confused with disability) – because definitions vary, investigations are incomplete and people with impairments are often not recorded or identified as such – are unreliable and based on guesstimates. The figure of 600 million people or 10 per cent of the total population is often cited – but this too is a guess. Across countries, estimates vary from as high as 12-15 per cent (in some developed countries) to as low as 1-2 per cent (in many developing countries). This suggests that data are unreliable and misleading. Furthermore, although some of the reasons for this are, as indicated above, the result of deficiencies in definition or counting, there may be other, more important reasons which remain unclear. The apparently low incidence of impairment in many developing countries may simply indicate that mortality

rates are very high among poor people with impairments, and they disappear from the recorded population. It may also indicate generally lower rates of *recognition* (where physical or mental impairment is more common, the *threshold* for its definition as *serious* may be higher). All too little is known.

The new *International Classification of Functioning, Disability and Health* (ICF) attempts to measure impairment and disability from a perspective that is somewhat closer to the social model (although it still emphasises the capacities and capabilities of the individual rather than the barriers and constraints of his or her social and physical environment) and was adopted by the WHO in May 2001. It will take some time, in any case, to implement. Attempts have been made to address the problem in a more systematic *objective* fashion. The WHO has compiled figures on *Disability Adjusted Life Years* (DALYs) by region, to reveal some significant differences in the impact of impairment (and disability) on life expectancy and life expectations, but the measurement itself is based on essentially arbitrary, negative assumptions about the quality of disabled people's lives.

The available global and regional data indicate that malnutrition, resulting from material poverty, is one of the most common causes of impairment and that many kinds of impairment are the result of specific diseases or conditions for which there exist relatively straightforward and inexpensive preventive measures. Poverty and poor access to simple remedies are thus key factors in the prevalence and incidence of impairment.

The identification and classification of impairment in a population is not the same as the analysis of the nature, extent and severity of disability in a society. Both are of major importance, but it is the latter that is crucial for the reduction of *disability*, but is even more difficult to identify and deal with. Such a task is best undertaken at the national, sub-national and local level where there is a greater opportunity for the specifics of *disability* and *impairment* to be recognised and understood and the appropriate forms of intervention (whether involving technology or not) devised.

The value of interventions

The use of conventional benefit-cost analysis, with its emphasis on direct economic value within a specified (usually limited) time-frame is not really appropriate, as usually applied, in assessing the benefits of interventions designed to address disability issues. Nonetheless, broad social costeffectiveness must be a consideration in the selection of poli-

cies, programmes and projects. If interventions (technological or other) are both appropriate and sustainable then they will tend to be costeffective in the sense that they are likely to be widely adopted by relatively large numbers of disabled people and used over a relatively long period of time.

Ideally, the more disabled people are involved in debates on assessment and evaluation, in their local or national context, the more any debate about costs and benefits can be grounded in the social and political realities. This has already been recognised as effective in various forms of participatory evaluation, whether it is participatory action-research or participatory learning and action, of so-called poverty alleviation policies, programmes and projects. There is a growing recognition that it is effective as well as appropriate to involve people at all stages in the formulation, design, implementation, monitoring and evaluation of policies, programmes and projects. Effective, interactive participatory techniques for *needs assessment*, project appraisal, implementation, monitoring and evaluation, which include and involve disabled people must become part of the repertoire of all those working in the development field, particularly at the local level. A review of experience with disability projects and examination of specific case studies suggests that all projects should be firmly rooted in the expressed needs and demands of disabled people in a specific local social and physical context.

In most developing countries, the national level is involved where government and international (bilateral and multilateral) agencies are most likely to develop policies, programmes and even projects with respect to disability reduction. But it may be at the sub-national (regional, district and local community) level that such *higher-level* agencies will need to work together systematically with local NGOs, organisations of disabled people, researchers and others with relevant skills and expertise, to develop appropriate projects, programmes, policies and legislation to reduce disability.

Disability and development: towards a global strategy

Despite the undoubtedly vast number – hundreds of millions at least – of poor disabled people in the developing world, disability as an issue does not figure in either of the British Government's *White Papers on International Development*, and is barely mentioned in any of the key documents of the international development agencies over the last decade. There has been growing interest in, and concern about, disability – notably in specific agencies. The World Bank, for example, and USAID; JICA and the

Asian Development Bank; NORAD and the other Scandinavian government aid agencies, and some of the international NGOs (like Save the Children) have turned their attention increasingly towards disability issues. Some have even begun to talk about policy to mainstream disability, just as *gender* has been mainstreamed in recent years. Mainstreaming disability in a major development agency means that all policies, programmes and projects should include disability as a key issue, and that monitoring and evaluation should track both the involvement and empowerment of disabled people in the design and implementation of policies, programmes and projects and the impact of these policies, programmes and projects on disability reduction.

The authors believe that development agencies should increasingly integrate disability within the mainstream of their development policy and practice by adopting a social-model approach and by identifying disability as a major crosscutting issue. This would imply, in effect, adopting a twin-track strategy – already advocated by DFID in its paper on *Disability, Poverty and Development* – and adopted with respect to gender issues. Several other development agencies have already moved quite a way in this direction. In order to implement such a strategy and policy for *disability and development*, it is essential that all development agency staff recognise the links between reducing disability and other development priorities, such as alleviating poverty. But for this to happen, they have to *see* disability as a crosscutting development issue. One important way in which this can be facilitated is to introduce appropriate, social-model based disability equality training. Just as *gender-blindness* has been identified even at the highest levels in international development agencies and NGOs, so too the risk is strong that *disability blindness* may affect these agencies, unless strong preventive measures are taken.

There is a growing interest in, and concern for, disability issues in development among the major international agencies. Several international NGOs and some organisations specifically concerned with disability and development have already charted the broad direction in which theoretical and practical work should be moving. Greater effort needs to be put into disseminating new information and best practice with regard to disability and development between institutions and agencies. Publications such as *Asia Pacific Disability Rehabilitation Journal* produced by *Action for Disability* should be able to play a significant role by publishing ideas, experience and case material, examples of best practice and of innovations which can feed into what needs to be a fuller and more comprehensive international

discussion and dissemination process. At the same time, those working in the field of disability and development should be aiming to write for publications in development studies so as to reach a wider and different audience, of development policy-makers, practitioners and professionals. On the other hand, those with experience and expertise in disability and rehabilitation should be equipping themselves with an appreciation and understanding of the latest thinking in development, bringing development and disability studies and practice closer together.

Proposals for the development of DFID's disability strategy

In 2001, DFID produced a paper on *Disability, Poverty and Development* in which an attempt was made, for the first time, to focus on disability as a significant development issue linked to poverty, and to develop a framework for addressing disability as a policy issue. The establishment and continuation of DFID's *Knowledge and Research (KAR) Disability and Healthcare Technology Programme* is another sign that DFID is beginning to address disability as an issue for action-research as well as for policy and practice. But while the establishment of the KAR Programme and the production of the strategy paper mentioned above indicate an emerging awareness within the agency of the need to address disability within the context of development policy and practice, there is as yet little evidence of an integrated and coherent approach to the issue. Disability remains institutionally as well as conceptually and practically marginalised, with responsibilities within DFID itself fragmented.

Recent re-structuring of DFID has meant that a certain amount of impetus has been lost as old departments and divisions have been replaced by new teams and focal areas. It is not at all clear where responsibility for disability issues and development sit in the new DFID that is now beginning to emerge from its re-organisation. Perhaps it is a good time to define a new strategy. Such a strategy should be developed in collaboration with other like-minded international agencies seeking to integrate disability work with development priorities, whether these are essentially disability – or development – focused, and with the existing international organisations of disabled people.

The authors suggest that DFID establish a cross-sectoral, cross-thematic Disability and Development task force or team with a clear mandate to mainstream disability and to focus more attention on it as a specific development issue. In the new KAR Programme for 2006 there is a specific *project* to

assist DFID in developing such a focus on disability and development. In terms of defining strategy for DFID, one possibility would be to commission the redrafting of the short paper on *Disability, Poverty and Development*, to provide a more substantial and substantive document on which to base policy and practice throughout the organisation. Another would be to produce more focused papers showing how disability would be integrated into the work of specific teams and focus groups.

The need for research on disability and development

One urgent priority is to increase knowledge about existing approaches to disability and development, both in theory and in practice, and to identify best practice as regards disability and development, both in government agencies and in non-government organisations. This should be undertaken through an initial review of research and publications on *disability and development*, which could complement existing reviews of CBR and related programmes.

At the same time, a register or compilation of statements and policies on disability and development by international, bilateral and non-government agencies and organisations would be valuable, as would an international register of organisations and institutions with a proven capacity to design and implement innovative disability projects (including research institutions, NGOs, DPOs and private sector enterprises). *Healthlink Worldwide* under the previous *KAR Disability and Healthcare Technology Programme* has made a start on this. Thirdly, in the context of a stated concern with respect to technology for disability reduction, an international network of technology providers for disability reduction needs to be compiled.

The authors also argue that it would be useful to undertake a comprehensive study, which would involve a review of literature (and other sources) relating to disability and development, a review and analysis of significant programme or project initiatives (involving research and/ or implementation), and a listing and discussion of country-by-country experience with respect to disability and development. This would constitute a fairly substantial project, but could be undertaken on a collaborative basis.

There are several areas in which new research should be carried out. The issue of disability and older people is becoming a matter of major concern in many developing countries as the demographic structure changes. Projects related to this issue, would be a priority. There is evidence to suggest that in developing countries many children with impair-

ments die young or are ignored. We need to know much more about such children and their early lives. Finally, the relationship between disability and poverty requires more systematic investigation on a comparative basis across countries.

Conclusion

This paper emphasises the need to recognise the importance of disability as a development issue, as a social issue, and as an issue closely linked to the stated priorities of the major international and bilateral development agencies and NGOs.

Technology generates outcomes and products which could be liberating and empowering for disabled people, but, like both *disability* and *poverty*, it needs to be seen as essentially a social process, capable of generating negative as well as positive outcomes as far as disabled people are concerned.

More research is needed to identify examples of *best practice* as regards developing appropriate technology for disabled people. Access to technologies, which reduce barriers to inclusion and participation (not only assistive or specifically healthcare technologies) should be seen as a basic human right.

Disability should be mainstreamed in the policies, programmes, projects and daily practice of development agencies and consideration given to the development of appropriate technologies as one component of a strategy for disability and development.

Development agencies, like DFID, need to recognise the importance of disability at all levels, and develop an appropriate institutional response, including the introduction of disability equality training and a greater degree of decentralisation in terms of policy and practice, given the importance of the specific social context of disability.

Each country development strategy should include a section on disability and development, as an integral part of their overall vision for the development of the country concerned; and country level staff should also receive disability equality training.

DFID and other development agencies should promote a twin-track approach to disability, as has been done with gender. All development initiatives or projects should be able to demonstrate that they are truly inclusive of disabled people. Significant additional funds should be made available to support disability-specific initiatives.

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Zusammenfassung: Das Knowledge and Research (KAR) Programme des britischen Department for International Development (DFID) beschäftigt sich mit der Rolle, die Technologie beim Abbau (möglicherweise auch beim Anstieg) von Behinderung spielt – und spielen kann. Es ist davon auszugehen, dass Technologie für Menschen mit Behinderung eine hohe Bedeutung hat, da sie die physische Umgebung und die unmittelbaren physischen Umstände beeinflusst, in denen behinderte Menschen leben und arbeiten. Durch die Herstellung von Geräten und Maschinen kann sie eine Umgebung schaffen, die Menschen mit Behinderung einschränkt, oder die ihnen Möglichkeiten bietet. Technologie ist selten behinderungsneutral. Häufig wird argumentiert, dass Verbesserungen in bestimmten behinderungsrelevanten Technologien eine wichtige Rolle bei der Verbesserung der Lebensumstände von behinderten Menschen spielen können. Diese Verbesserungen bedeuten nicht immer eine fortschrittlichere Technologie, sondern eine, die angepasst an die Bedürfnisse behinderter Menschen auf der ganzen Welt ist. Die meisten armen und behinderten Menschen haben jedoch keinen Zugang zu angepasster Technologie, und die verfügbare Technologie ist nicht angepasst an ihre Bedürfnisse. Der Artikel untersucht die Beziehung zwischen Behinderung, Armut und Technologie in Entwicklungsländern.

Résumé: Le programme Knowledge and Research (KAR) du Department International Development (DFID) britannique s'intéresse au rôle potentiel joué par la technologie - ou peut jouer en réduisant (ou éventuellement en augmentant) l'infirmité : On peut présumer que la technologie pour handicapés joue un rôle de première importance en influençant l'environnement physique et les circonstances physiques immédiates dans lesquelles les personnes handicapées vivent et travaillent. Grâce à la fabrication d'appareils et de machines elle peut créer un environnement constructif qui limite ou qui leur offre des possibilités. La technologie est rarement neutre à l'infirmité. On prétend fréquemment que des améliorations dans certaines technologies appliquées à l'infirmité peuvent jouer un rôle important en améliorant la qualité de vie des personnes handicapées. Ces améliorations ne sont pas toujours synonymes d'une technologie de pointe, mais d'une qui est adaptée aux besoins des personnes handicapées dans le monde entier. La plupart des personnes pauvres et handicapées n'ont cependant pas accès à une technologie adaptée et la technologie disponible n'est pas adaptée à leurs besoins. L'article étudie le rapport entre infirmité, pauvreté et technologie dans les pays en voie de développement.

Resumen: Este artículo examina la relación entre discapacidad, pobreza y tecnología en los países en vías de desarrollo. El programa Conocimiento e Investigación (KAR) del Departamento para el Desarrollo Internacional (DFID) de Gran Bretaña trabaja sobre este tema. En pocos casos, la tecnología es neutral para la discapacidad, ella siempre influye al medio ambiente físico de la persona y la producción de medios técnicos puede disminuir o aumentar las posibilidades para la participación de la Persona Discapacitada. Lo importante en todo el mundo no es la tecnología más avanzada o moderna, sino la tecnología apropiada a las necesidades de la Persona con Discapacidad. Lamentablemente, la gran mayoría de los pobres y discapacitados no tienen acceso a esta tecnología, pues la tecnología accesible no es apropiada.

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STIFTUNG

Applying the Minority Perspective to Disability in Afghanistan

Majid Turmusani

As a minority group, disabled people throughout the world continue to be excluded from mainstream society and this is often exaggerated for those belonging to ethnic minority groups. This paper argues that this exclusion is also pertinent in the context of Afghanistan, especially where ethnic conflict applies. Although the ethnic relations and their dynamics have changed and notably improved since the fall of Taliban in late 2001, disabled Afghans who belong to these groups continue to be severely excluded from various spheres of social, economic and political life. Generally speaking, there are three groups of disabled people in Afghanistan which experience higher levels of discrimination and exclusion than others. These groups at risk include: children with disabilities, disabled women, and elderly disabled people, to be further discussed below. The new National Constitution guarantees the rights of all citizens including those with disabilities and so does the recently completed Comprehensive National Disability Policy. However, both of these instruments lack the necessary mechanisms and strategies for their proper implementation concerning disability issues. Therefore, a collective and coordinated action is needed for better highlighting and integrating the concerns of disabled people, especially those at risk groups on the public agenda. This may include researching, disseminating and further debating various issues of disability and ethnic relations both nationally and internationally – with the lead given to disabled Afghans in this process.

Ethnic background

Historically and until recently, many societies have been designed to meet the needs of the majority population. The needs of minority groups including those with disabilities as a result have been excluded or poorly addressed. This institutional exclusion is not only in terms of services, but can also be seen in policy and program planning. This is especially true for disabled people who belong to minority ethnic groups (Asch 2001).

In Afghanistan, racial and ethnic difference is an issue which has contributed to the escalation of conflict in the country and widened the difference between various sections of society. There are at least 6 major ethnic groups in the country with a majority being Pushton. These groups have their own language, and culture. This makes differences obvious even under the same religion of Islam – there are variations of Islam such as Sunni and Shiite and recent years had seen conflict between them. This is particularly the case between the largely Pushton followers of Sunni Islam and the mainly Hazara Shiite. While the geographic variation between rural and urban living contribute to this difference, language and religion remain two determinants of group identity in Afghanistan.

Difference, naturally, generates an opportunity for learning and for growth. In a democratic environment where the human rights of all people are respected, difference always is a healthy sign for potential development. For some individuals and groups however, difference may generate fear and fear may generate more difference unfortunately. Unless these differences are resolved in a healthy

manner – through communication – they will escalate and cause rifts and gaps between groups such as in Afghanistan. Difference however, is not only confined to expressed values and beliefs but also manifest in the way people look, physical materialist appearance and physical status, and which group people belong to, etc. The core issue of difference is the exclusion of those perceived as different from the norm.

Disability and exclusion

The difference of disability is often perceived as a ground for exclusion from society, especially the economy, and this is also evident in Afghan society. Oliver and Barnes (1998) argue that much of the exclusion of disabled people has been supported by institutional practices. The fact that disability was considered a charity issue, few provisions were made for disabled people. Available provisions therefore did not give disabled people the rights to accessing education, employment etc., but instead were left to the good will of society to provide disability services voluntarily and not according to the law.

There are certain sectors which experience a higher level of exclusion among disabled people, intensifying or multiplying the level of exclusion based on ethnic minority origin. This is evident in Afghanistan and includes people with severe intellectual – mental and psychiatric – or multiple disabilities, elderly people, rural disabled, those displaced by violence, the war disabled and disabled refugees. Children with disabilities have traditionally been seen as less worthy of social investment – access to education for example – than other children. Women with disabilities often suffer double discrimination. Minority groups, including racial

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and ethnic minorities, are similarly disadvantaged.

The invisibility of disabled Afghans means exclusion from all spheres of socioeconomic and cultural life as well as exclusion from the democratic process in its various levels. A lack of participation in the political process can result in policy being formed without the active involvement of groups likely to be affected by its outcome. It can also lead to passivity and dependence which serve to perpetuate the invisibility of disabled people. Invisibility often means that the universal right of equal opportunity is simply not applied equally to disabled people, contrary to what is outlined as recommended by the UN Standard Rules and the current UN draft disability convention.

While disabled people have been largely excluded from the mainstream in Afghanistan, progress has been made in understanding disability issues and providing specialized services including CBR programs mainly for physically disabled people. Notably, there has been greater advocacy for disabled peoples' rights and gradual development of skilled professionals working in this sector. For example, the recently completed Comprehensive National Disability Policy has been developed in close collaboration with the disabled community.

There are three groups of disabled people in Afghanistan which experience higher levels of discrimination and exclusion than others: children with disabilities, disabled women, and elderly disabled people, to be further discussed below.

Children with Disabilities

There are no reliable national data available on the incidence of disability among children or among the population in general in Afghanistan. However, the U.S. *Centre for Disease Control* (CDC) and UNICEF conducted a disability survey in 2003 and they found that 1% of Afghan children are disabled (CDC/UNICEF 2003). It is believed however that there are more children with disabilities than 1% in Afghanistan. Landmines alone have disabled thousands of children who often fetch water, collect wood, tend the flocks, or play in the fields unaware of the danger buried under their feet. The weak preventative health services have led to a high incidence of disabling conditions such as polio and tuberculosis. The high level of birth complications and under-nourishment amongst girls and women, and inadequate medical care, also gives rise to impairments such as cerebral palsy in newborns. According to WHO, the infant mortality rate is 165 per 1000 live births (WHO 2002). Malnutrition, poverty, and road accidents contribute to a higher rate of disability among children.

Exclusion of disabled children from services is evident in Afghanistan regardless of their ethnic minority backgrounds. For example, The *Civic Voluntary Group* (GVC), an Italian NGO, conducted a study on disabled children in education in the city of Kabul in 2003 and found that only 1.11% of total students were with disabilities. In rural areas where ethnic groups are more evident due to the tribal nature of Afghan society, exclusion of disabled children is clear due to total absence of services in such places. Until recently, exclusion of girls from education was a common practice, but this is slowly changing. However, the lack of female professionals continues to exclude many girls from receiving services due to cultural restriction on female/male relations. This is especially true for rehabilitation and medical services where women's bodies may only rarely be examined or treated by male professionals. The *International Convention on the Elimination of All Forms of Racial Discrimination* recognizes that racial discrimination can itself cause disability. For example, racial groups may be restricted or denied access to services and this may escalate impairments into disability. Given the gravity of the situation of disadvantaged minority groups in Afghanistan such as Hazarah for example, there are a number of NGOs who focus their work on serving these groups.

Nowadays, there are little opportunities for children to play and practice normal childhood life activities. There is a rather dangerous phenomenon in Afghanistan concerning street children. In big cities, especially in the capital Kabul, there are hundreds of kids who took to the street as home and as a place for earning a living, mainly from begging – many of these children are disabled. The fact that war has left many children without fathers or without family altogether, meant that these children have to survive on the street especially in the absence of an effective education and welfare support system. Moreover, the war has brought the risk of displacement of countless number of families and individuals. Many families of disabled children have moved to urban centers in search of security and job opportunities especially after the ban of poppy (illegal drugs) production in their rural areas or when losing the breadwinner. While, urban living helped many children get an education, it exposes them to other forms of city dangers such as road accidents and increased pollution, homelessness and gang habits, and street children life.

The majority of Afghan children lost members of their family in the war and all of them had been through the war and the resulting aftermath. It is believed that children have been traumatized by the war, especially if this involves the loss of family

members. While this is the situation, there are still nearly no psychological and counseling services for these children at all. It is believed by both the international community and the government that the traditional family unit has mechanisms to cope with such mental health problems. However, this has not been properly debated, researched or documented.

Based on the above analysis, growing up as a disabled child in Afghanistan is a challenging process that is full of dangers and exploitations as cited above. Although Afghanistan has ratified the CRC, there are no special laws to promote and protect the rights of disabled children which are prescribed by Article 23 of the international *Convention on the Rights of the Child* (CRC) unfortunately.

Disabled women

Although the situation of women in Afghanistan is improving, there is still much to be done regarding women's rights and the status of women in society. The traditional gender role that confines women to the role of housewives and deprives them of education and employment is still common, especially in rural areas. The lack of sufficient female rehab workers has also affected the use of rehab services by girls and women as indicated earlier. Female early marriage, the lack of mother and child health care and the high fertility rate for women are all factors that work against the progress of women in Afghanistan.

When women are disabled they are more vulnerable to marginalisation and exclusion. Disabled women are often deprived of education altogether as well as other life opportunities including work, participation in political debate and denied the right to establish their own families. There is lack of awareness regarding women with disabilities and reproductive health needs – more often disabled women are regarded as sexless (Nagata 2003).

To raise the profile of women in the country, the Transitional Government of Afghanistan has established a separate ministry for women issues. Despite this ministry, gender and women issues have not been mainstreamed into other government programs until now. Moreover, disability issues among women have not been taken into account in the programs of this ministry either. There is an obvious lack of a gender and disability strategy for this ministry as well as throughout the country.

As far as we can ascertain, there are no studies on the situation of disabled women in Afghanistan. The working group on disabled women which was set up for drafting recommendations for the national disability policy has debated the issues of disabled women in terms of needs and priorities. The needs of

disabled women have been identified to include: education including higher education, health and medical care, participation in all spheres of life including public events with media coverage, involvement in policy making process and employment of disabled women in all key ministries. These were guided by the international framework of CEDAW, the *Biwako Millennium Framework* (BMF) and the new draft disability convention.

This working group comprised representatives of all stakeholders working with women including disabled women themselves. They recommended a number of strategies for meeting the above needs including mainstreaming disability and gender, setting up an office responsible for the employment and advocacy of disabled women's rights, setting up modern training programs as well as reviving old techniques of home based training, promoting accessibility standards including accessible housing system, policy monitoring should be carried out with participation of disabled women, and supporting disabled women against violence including psychological support and counseling services. The latter is interesting to note as both the government and the international community regularly question the value of psychological services. Yet, we find disabled women calling for psychological support among their priorities for independent living.

Elderly disabled people

There are indicators showing the aging population in Afghanistan and the urgency for special programs to cater for their needs. The fact that many men were killed in the war meant that widows were left to age and die naturally. Moreover, as the war ended, it is expected that the mortality rate for both women and men will rise above the low life expectancy of 45 years (UNICEF 2003). This means more people will live to old age and experience old age impairments such as hearing and vision problems as well as other mobility problems. Indeed, aging and disability will develop a closer association.

Traditionally, disability services reached primarily those disabled by war, usually young or adult males. Although, these war disabled persons have grown up now, until this moment, disability programs have not considered services for the elderly population apart from limited orthopedic services. This is especially true for older women who require interventions different from the population of younger women who need an emphasis on maternity care. Recently, however, disability programs have paid attention to children's issues as a priority in terms of education and physical rehabilitation. Overall, the

elderly disabled population remains very under-researched and underserved, deserving the attention of planners, service providers and policy makers.

Cross cutting issues

Trauma and psychological support: The long years of war resulted in not only an increased death toll, but also bereaved, stressed, and traumatized society who requires much psychological support. The Taliban practices of punishments in public including amputation and stoning, has also been another source of trauma and distress, especially among children and women. Psychosomatic illness is quite common among women due to stress and depression. The social and economic capacity of many families has been significantly reduced due to the loss of breadwinners or other family members. State welfare support to families of martyrs and disabled people are nearly nonexistent. Many families are being left with war or landmine disabled members who need rehabilitation services including counseling. The mental health situation of women, children, and refugees, are particularly poor within this war-torn country. Although there is a substantial proportion of drug users and dealers who also have mental health problems, there is hardly any service for this group either.

The low profile of mental health issues in Afghanistan is mainly due to negative public perception and stigma of those who are mentally ill. There is stigma towards mental illness, often perceived as being punishment of sin. Many families conceal the presence of mentally ill members to protect the family reputation and marriage prospects for other siblings. Mentally ill people are therefore often kept away from sight and remain an invisible group among the already excluded disabled population. They are as a result prevented from education, vocational training and other community services.

The national health plan adopted by the Ministry of Health had no specific reference to the problems of people with mental health impairments. The Interim Health Strategy 2002-2003 and the *Basic Package for Health Services for Afghanistan 2003* have both identified mental health issues as a challenge for post conflict development of health sector in the country. However, neither identified mental health issues as a priority and, therefore, no plans for specific programs were proposed. It is therefore, perhaps, no surprise to find a lack of mental health facilities and mental health professionals in the country.

Accessibility: An effective inclusion strategy for the largely excluded disabled people in Afghanistan requires comprehensive rehabilitation program

including psychological support system. This will be possible only within a barrier-free environment that keeps universal design ideals in mind. It is not enough to make buildings accessible if there is no accessible transport system to get people to such places. Equally, it is important for disabled people to have accessible housing where they can live independently. Accessible environment can be useful not only to disabled people but to everybody including elderly population, pregnant women, children, and other groups.

Central to accessibility standards is an information and communication system that covers all types of disability, gender, geographic areas, and all age groups. This system may include training programs and provision of specialist devices when necessary.

Self help groups: Disabled people know best about their priorities and their organizations have a strategic advantage to advocate their rights and influence public decisions concerning their issues (Kasnitz 2001). Currently there are a number of informal self-help groups of disabled people in Afghanistan including one group for disabled women – the *National Association of Disabled Women in Afghanistan* (NADWA). These groups are independent from the government and have the potential to foster disability movement in the future. However, training, awareness raising, financial support, and collaboration with other stakeholders, especially the government, is all necessary for the development of this sector. DPI Asia and Pacific have conducted leadership training for these groups in Afghanistan last year and communication continues between DPI and some of these groups.

There is an obvious need for grass roots action to support the future disability movement in Afghanistan. The working group on self-help groups for planning the national disability policy has identified the needs of disabled people to include different self help groups according to types of disability, financial support for such groups, friendly and cooperative government relations, and supporting the development of self-help groups into recognized organizations including umbrella organizations.

Conclusion

The fact that disabled Afghans were a hidden group meant that society knew very little about their situation: their needs and aspiration, and more importantly about their abilities and their rights. It can be argued that empowering minority disabled groups, therefore, necessitate not only giving power to disabled people over their lives, but also making knowledge about disability available to the public including policy makers and the disabled communi-

ty themselves, hence making disability a visible issue. This will create opportunity for debate over disability issues and present a chance for change. The participation of disabled people and their organization in this debate is fundamental and goes in line with the *Afghan Comprehensive National Disability Policy 2003* as well as in line with UN Standard Rules, BMF and the recently drafted disability convention.

Despite the fact that the recently endorsed National Constitution of Afghanistan made all citizens equal before the law in terms of their rights and responsibilities, disabled people continue to be deprived of services on many grounds and this is often justified by lack of resources. Until now national plans took little notice to integrate disability concerns into their respective programs. The *Comprehensive National Disability Policy* has emphasized the value of coordinated and collaborative effort between all stakeholders in dealing with disability issues including those pertaining to minority invisible groups.

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Zusammenfassung: *Als Minderheit werden Menschen mit Behinderung auf der ganzen Welt immer noch ausgeschlossen von der Mehrheitsgesellschaft. Dies gilt umso mehr für solche, die einer ethnischen Minderheit angehören. Der Artikel zeigt, dass dies auch für den Kontext Afghanistans zutrifft, besonders dort, wo ethnische Konflikte vorherrschen. Obwohl sich die Beziehungen zwischen den Volksgruppen seit dem Fall des Taliban-Regimes 2001 deutlich verbessert haben, werden behinderte Afghanen, die diesen Gruppen angehören, immer noch von allen Bereichen des sozialen, wirtschaftlichen und politischen Lebens ausgeschlossen. Es gibt drei Gruppen von behinderten Menschen, die ein höheres Maß an Diskriminierung und Ausgrenzung erfahren als andere. Diese Gruppen sind: Kinder, Frauen und alte Menschen. Die neue Verfassung wie auch die nationale Behindertenpolitik garantieren allen Bürgern die gleichen Rechte – auch denen mit einer Behinderung. Jedoch fehlen beiden Instrumenten die nötigen Mechanismen und Strategien zu ihrer Umsetzung. Daher ist eine koordinierte und konzentrierte Aktion notwendig, um die Belange behinderter Menschen ins Rampenlicht zu stellen, besonders diejenigen der Risikogruppen. Dies schließt die Erforschung, Verbreitung und Diskussion von Behindertenthemen und ethnischen Beziehungen auf nationaler und internationaler Ebene ein – wobei die Leitung dieses Prozesses den behinderten Afghanen obliegen sollte.*

Résumé: *En tant que groupe minoritaire les personnes handicapées du monde entier continuent à être exclues de la société majoritaire. Ceci est d'autant plus valable pour ceux qui appartiennent à une minorité ethnique. L'article souligne que cette exclusion est également exacte dans le contexte de l'Afghanistan, spécialement où il y a les conflits ethniques. Bien que les relations entre les ethnies se soient considérablement améliorées depuis la chute du régime taliban en 2001, les Afghans handicapés faisant partie de ces groupes, continuent à être exclus de tous les secteurs de la vie sociale, économique et politique. Il existe trois groupes de personnes handicapées qui dans une grande mesure expérimentent plus que d'autres la discrimination et l'exclusion. Ces groupes sont les enfants, les femmes et les personnes âgées. La nouvelle constitution ainsi que la politique nationale des handicapés garantissent à tous les citoyens les mêmes droits - également pour ceux souffrant d'une infirmité. Cependant, à chacun de ces deux instruments font défaut les mécanismes et les stratégies nécessaires pour leur réalisation. Il est donc nécessaire qu'il y ait une action coordonnée et concertée pour mettre en avant les intérêts des personnes handicapées, surtout pour ceux des groupes à risque. Cela englobe la recherche, l'élargissement, les débats sur*

les sujets concernant l'infirmité. Est aussi englobé sont les rapports ethniques au niveau national et international où la conduite de ce procès devant incombée aux handicapés afghans.

Resumen: Este artículo tematiza la discriminación que conviven las Personas Discapacitadas como miembros de una minoría étnica en Afganistán. Aunque se ha mejorado la situación después de la caída del régimen de los Talibán en el año 2001, las Personas con Discapacidad de estos grupos están todavía marginadas en todas las áreas de la vida social, económica y política. Entre ellos hay tres grupos donde la discriminación es más alta: niños, mujeres y personas de mayor edad. Lo más necesario son actividades coordinadas y concertadas de concientización, incluyendo investigaciones y discusiones sobre los temas de la discapacidad y relaciones étnicas.

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Challenging International Development's Response to Disability

Tamsin Bradley

This article argues that developing countries are often portrayed as being backward in appreciating the importance of inclusion. In addition the stigma attached to disability is thought to be greater in the Developing World. This article acknowledges the implications scarce resources have on inclusivity but argues that this does not necessarily reflect deeper prejudice in regard to disability. The development discourse has constructed a category of *underdeveloped Other* which is used to depict all marginalised people. This label fails to acknowledge and appreciate the different experiences and needs of people living with impairments. This article then goes on to highlight the support networks that are indigenous to many societies and suggests that development interventions should build on these rather than transplant a western model of inclusion. The article will develop these arguments through a case study documenting the life experiences of a rural poor, low caste Indian family of four. The wife and two daughters are blind. The sighted husband is the primary carer and cannot work because of the level of support required by his wife and two daughters. In the absence of a state welfare system this family is supported by families within the community who belong to the same social caste. The UK NGO working in the area uses images of this family to highlight extreme suffering and discrimination; it does not seek to appreciate how they cope with everyday life. The argument stressed throughout this article states that outside agencies must be motivated by a desire to *know* and understand the experiences of those living with impairments if their interventions are to be effective.

Introduction

This article argues that the voices of disabled people have been systematically excluded from international development agendas because a homogenous image of an underdeveloped Other continues to influence development practice and policy. When depicted the disabled body is presented as an example of extreme and desperate human suffering. Whilst the link between poverty and disability is affirmed by this article the oppressive impact of using broad labels and images to describe the experiences of others is critiqued. If the complexities of exclusion and social marginalisation experienced by disabled people in the Developing World are to be fully appreciated and responded to then the voices of people living with impairments must be listened to.

This article supports a right-based social model of disability. This defines disability as the loss or

limitation of opportunities to take part in everyday life of the community on an equal level with others due to physical and social barriers. The term *impairment* is used as defined by Barnes (1991) as a functional limitation within the individual caused by physical, mental or sensory impairment. My view expressed throughout this article (and shared by many) is that impairment need not lead to exclusion and inequality if inclusive policies are implemented. This article argues that at present this view is not shaping development policy on disability. The relatively few interventions directed at disabled people stress the need for medical solutions rather than societal.

A common critique directed at development interventions claims that insufficient attention is given to understanding local knowledge and little attempt is made to understand the life experiences of those aid is targeted towards (Chambers 1996, Pottier 1993, Gardener and Lewis 1996, Hobart

1993, Mosse 2005). Furthermore an assumption is made that the West has got it right. Western models of social inclusion enshrined in legislation are propounded as the *way forward* in the quest for greater social equality for disabled people. This article begins by critiquing the work of development agencies on disability through an analysis of the approach taken by many agencies. Focus will be placed on how these goals translate into development practice. The primary argument states that such approaches fail to acknowledge the agency of disabled people and do not seek to acquire deeper knowledge and insight into the experiences of disabled people across the Developing World. This article emphasises the importance of dialogue between agents of change (disabled people) and agents of development (NGOs). This dialogue involves a disruption of the usual power relation between recipient and givers of aid. In a development relationship it is usual for the recipient to be in the weaker or subordinate position. The giver (of aid) holds power over the Other (recipient of aid) and can bypass the experiences of others in deciding what is best for them. This process marginalises disabled people further and fails to acknowledge and respect the agency of each individual person whose desires and needs may be very different from others.

The starting point for any intervention must be the acknowledgment that disabled people as individuals have voices. As individuals they should be listened to as they articulate their experiences of marginalisation. Development interventions must be designed through a dialogue between all parties and must be open and constant. This dialogue must build upon existing support networks rather than implant western constructed models of *ideal social inclusion*. Policy and practice must influence each other in a constant and ongoing manner (Mosse 2005). This process should be mediated by the experiences of those it is intended to help.

This article uses ethnographic research techniques in presenting a case study of one family's experiences of living with impairments. The case study focuses on a family of four, three of whom are visually impaired. The family are from a low caste and live in rural Rajasthan. I visited this family in January 2002 with a Gandhian NGO and their western donor agency. The experience of visiting this family provoked many feelings and reactions in me which I feel should also be documented in this article. These experiences have allowed me to think about disability and international development with a certain openness and reflexivity which should be an integral part of the development process. I am an outsider and in my attempt to understand the experi-

ences of others I must be open in exposing my own prejudices and the impact of my western culture on my perceptions of social exclusion in rural Rajasthan. I spent six months living in the same area of Rajasthan as this family. I visited them on a few occasions and learnt of their progress through the local Gandhian NGO. It was clear that although there are limits in terms of life opportunities open to this mother and her young daughters they are supported by a caring community who firmly believe they have a right to a secure subsistence. As with all ethnography the account of this family represents a story, my story which I very much hope is also theirs.

Critique of Development Practice in Regard to Disability

The image of a physically disabled person living in extreme poverty is often used by NGOs. The use of such an image assumes that to be disabled in the Developing World means you are acutely poor. This link between disability and poverty then conjures up many more assumptions of extreme hopelessness and desperation. In using this image the notion of disability and poverty as the worse case of human suffering is asserted. Beresford (1996) points out that an analysis of disability based solely on poverty is both inaccurate and misleading. Clearly disabled people are presented as specimens of truly oppressed victims of backward societies in need of salvation.¹ Although it is true that disabled people are among the poorest in the Developing World (Kauppinen 1995) the constant use of extreme images of impairment and poverty homogenises disabled people into a single category of *underdeveloped*. The result of this homogenisation is highly oppressive. Berresford states: "There has been a tendency to isolate and lump people together indiscriminately as poor, without examining the different causes of their social and economic exclusion, and to stereotype them as dangerous or dependent. The effect has been to obscure both people's differences and their shared oppressions." (1996:554-5)

The labels of *poor* and *disabled* are highly stigmatising and an unhelpful basis for action. To be poor and disabled is not just about a low standard of material comfort and subsistence but is also about a denial of rights. In addition such labels fail to allow individual disabled people to articulate their different experiences of both poverty and living with impairment. These experiences are often excluded and systematically ignored by development policy. Instead a larger image of an *underdeveloped* Other is used by the international community towards which policy and aid is directed. This overarching image of an underdeveloped person cannot respond to the

huge variants of marginalisation and is the reason disability has been consistently ignored by international development agendas.

The term *underdeveloped*² is used to denote those whom the West sees as in need of enlightenment (Esteva 1993). According to Hobart (1996), development practice is in reality a strategy for the maintenance of western sovereignty through transforming the underdeveloped in order for them to fit into a vision that reflects the way the dominant powers (West) would like the world to be (Sachs 1992, Escobar 1988, Chambers 1996). Gramsci (1971) anticipates this argument when he describes how modernisation theory sees society or culture as the obstacle and the element that must be changed if hegemonic values are to be imposed and western power assert its control. Through this process of transformation the underdeveloped Other is encouraged to strive for the status of a developed person: "the knowledges of the peoples being developed are ignored or treated as mere obstacles to rational progress." (Hobart 1993:2) In fact, the individuals who are supposed to be the recipients of improved lives are rendered passive. Agency is identified only with changes in the economic or political structures of a country, and western knowledge, through the process of development, consequently embeds itself in the political culture of underdeveloped countries.

Those that are placed in the category of underdeveloped are considered ignorant and in need of the continued presence of western NGOs. If a project fails development practitioners will often blame the lack of appropriate knowledge of the local community (Mamdani 1972). Local knowledge is thereby impoverished by the development discourse (Richards 1993). Those targeted to receive aid are not involved in the decisionmaking (Black 1991); instead western constructions of knowledge determine who is qualified to know and act and who is not. The discourse creates the development expert (typically white, middle/upper-class and educated), the only one who possesses the wisdom to effect positive and lasting change (Parpart 1999). This *expert* designs the development policies which through their micro focus hide a macro level political agenda which is detached from the daily realities of the poor.

An Other has been created to symbolically represent the supposed needs of the Developing World, but because this Other has been constructed by the development discourse it blocks access to real people and real needs. The huge budgets that development agencies command contrasted with the limited success their interventions achieve clearly suggests that something is going wrong. De Sousa Santos (1999) states: "Suffice it to recall how the great promises of modernity remain

unfulfilled or how their fulfilment has turned out to have perverse effects." (1999:30) De Sousa Santos lists statistics that reveal an ever-widening gap between the rich and the poor. Further evidence to support the claim that development is failing to deliver on its promise of global equality can be found in the numerous analyses of failed development projects (Gardener and Lewis 1996, Crewe and Harrison 2000, Marchand and Parpart 1999, Mosse 1994, Hobart 1993). A main reason for a project's lack of success is often identified by the authors of case studies as being inadequate consultation with members of the target community. NGOs' actions suggest that they believe that consultation between NGO workers and the recipients of aid is not needed because NGOs believe they already *know* the focus of their compassion. However, if they really knew what their recipients needed than surely the success rate would be higher? The effects of NGOs will continue to be limiting for as long as they are focused on this symbolic Other rather than the lived realities of others. Hobart (1993), Escobar (1988), Esteva (1993:90), Mosely (1987:21), Hayter (1971) and Sobhan (1989) all describe how the overarching discourse of development functions to prevent reality from emerging through its repressive homogenisation of whole populations into this image of a poverty stricken Subject (or Other).

Yeo and Moore (2003) and Masset and White (2004) state that disability has been systematically ignored by development agencies, this is clear by the fact that it rarely appears as a separate issue on international development agendas. Until this overarching notion of an underdeveloped Other is eradicated there exists little chance of a space opening up for meaningful dialogue based on a respect for individual rights. Such a space requires, not just an appreciation of difference, but a consensus over the rights that have been so far denied to disabled people. Attitude change alone cannot achieve inclusion of disability in the development discourse. A dramatic shift must occur that depassifies the disabled body by acknowledging the voices of people living with impairments. The current impulse dominating the development industry in which the diversity of voices are ignored must be replaced with a desire to know and understand the needs of others.

At present the development discourse believes that there is only one path for human progression, which involves the transformation from *underdeveloped to developed*. In relation to disability this process utilises medical intervention to rectify the perceived damage of the disabled body (Coleridge 1993). Although disabled people living in the Developing World do need money, this money must be channelled through a dialogue that wishes to hear

and respond to their specific experiences of marginalisation. In other words, if the social model of disability is to work effectively in the Developing World it must be founded on a shift in how disabled people are viewed by development agencies.

The biggest barrier to the implementation of a rights-based social model of disability is that at present power is exercised through money, and those who want donor aid must conform to the dominant rationality of the *giving* institution (Hulme and Edwards 1997). According to Hulme and Edwards (1997) and Edwards and Hulme (1992) NGO workers insist on certain conditionalities (which have often been set by larger donor agencies) that determine the specific nature of the projects implemented. These conditions remove the possibility of dialogue through which projects can be constructed in partnership with local communities. Individuals within target communities are therefore treated as passive subjects and are denied the agency to shape their own futures. This imposed subjectivity contradicts the stated objectives of development practice as it serves to limit human freedom rather than increase it. Escobar (2002) and Sachs (1992) go as far as to describe this process as violent. This oppression is hidden within development because of the objective of alleviating suffering. It is not the stated desire to rid the Developing World of poverty that is the problem but rather the way in which this suffering is symbolised within the boundary of a subject projected as the *underdeveloped Other*. This symbol acts as a camouflage, and as long as this suffering subject exists it requires a second subject who presents itself as possessing the potential to liberate. However, rather than liberate, the second subject dominates and dictates how the Other should live. Until this relationship of dominance at the heart of the aid industry is challenged the experiences of disabled people will continue to be ignored. Furthermore the increased levels of poverty and global inequality will continue. A shift in power must therefore occur that allows for both parties in the aid relationship to be regarded equally. In such a relationship Fagan (1999) argues that local people should be perceived as agents of development rather than as passive recipients. The giver of aid merely facilitates and supports the actions and desires of the person living with impairment.

Deconstructing the Passive Subject

The answer to overcoming this hegemony is not the withdrawal of western assistance from the Developing World. It is not acceptable for NGOs just to disappear from the lives of others for fear of being accused of dominating and suppressing them

(as Hobart 1993, Bloch 1983, Hayter 1971, Escobar 1995 and Sobhan 1989 seem to suggest). Di Leonard rejects such an outcome, arguing that “post-modern cultural relativism falls into politicised irresponsibility.” (1991:24) Theory falling in the category of “post development” (Parfitt 2002) can certainly be accused of this. Fagan similarly argues: “adopting the privilege of being antidevelopment is not in my view politically or morally viable when sitting in an ‘overdeveloped’ social and individual location.” (1999: 180) Instead the challenge to the macro level power structure must come from the grass roots; the lived experiences and agency of those this symbolic order wishes to maintain as passive subjects. Images of disabled people living in acute poverty must be replaced by a plurality of voices talking about their life experiences and dreams.

Listening and responding to others

The relationship between others or specifically between NGO workers and agents of development must be founded in respect between others and a desire to understand their differences. The work of Luce Irigaray is useful in understanding the qualities that must be present in a relationship that is free from power. Irigaray (2000) states that the space between subjects must be transformed from one in which power is contested to one shaped by peace and tranquillity. In such a space listening to the other does not involve the destruction of the other. Irigaray claims that an equal and harmonious relationship with an other is worth striving for since it offers the possible of reciprocity from which both parties can benefit. She states that it is through a relationship with an other that you should come to know yourself. There is a reflexive dimension in the dialogue with the other. “As I know you I let you see what I know of you; in return you allow me insight into what you know of me.” (Irigaray 2000:32) This dialogue relies upon the determination of each party to know the other and in doing so facilitate the other in their own personal development.

Irigaray describes a relationship based on a perfectly reciprocal dialogue in which both beings reflect what they have learnt of each other. *Silence* is a vital component in this discourse; without it reflection is not possible. Without *silence* the voice of the other cannot be heard. According to Irigaray, if such relationships comprised society, then the arms of the state would operate to preserve and respect individuality rather than to master it and acquire supremacy. If such a dialogue founded development practice then the present tendency in development practice to dominate the Developing World through replicating western values and models would cease.

NGO workers must acknowledge their positioning within the binary opposition Developed/Underdeveloped and move towards a reciprocal relationship as outlined above. However, if reciprocity is to be achieved then the NGO worker has to allow her/himself the possibility to change as a result of interacting with agents of development. If change is acknowledged as a benefit of such a relationship the power imbalance caused by the presence of donor money can be reduced. Although the agent of development will not give money back to the NGO worker they can at least give them the chance to see themselves in a new way. If aid were to be conceived of in terms of a reciprocal gift which all parties benefit from the power embedded in the term *aid* could be replaced with a sense of equality. Stirrat and Henkel (1997) state that as it currently stands, there is nothing reciprocal about the act of giving in development. "Here, the act of receiving is hedged with conditionality at best, while at worst the gift may become a form of patronage and a means of control." (1997:72) Aid is a vehicle through which the giver can attain dominance over an Other. The concept of *gift* could be reciprocal if the giver could let go of the desire to transform the Other and realise the potential for their own growth through dialogue with others. To be open to what the other can give you driven by a concern to express love and respect holds powerful potential to restructure the relationship between NGO workers and agents of development.

The case study presented below represents my attempt to gain an understanding of how others live and experience their specific impairments. My informants have raised provocative questions that challenged assumptions that the Developing World possesses the most *backward* and prejudicial of attitudes towards disabled people. Whilst Yeo and Moore's (2003) article can leave us in no doubt that disabled people in the Developing World are marginalised by societal factors these case studies suggest that more ethnographic research is needed documenting how different communities respond and react to living with people who have impairments.

Case Study: Blind family in Rajasthan North India

Neela is a blind forty-three year old mother of two daughters. Both daughters – Prem who is twenty, and Shobila who is twenty-four – are also blind. The father's name is Krishnam, he is fifty-five and is the only sighted member of the family. This family is from a low caste known as Kumhar which translates as potters. It is traditional for Kumhar families to make their living making and selling clay pots.

These pots are used to fetch and carry, and store water. Krishnam is unable to work because he must remain at home to look after his wife and daughters. Because this family is so poor they do not have access to technology and life is hard. Cooking is done over a fire which requires wood to be collected. The process of collecting, laying and lighting a fire is complex and virtually impossible without sight. The process of collecting and carrying water from the village well is also complicated when you have no sight. Neela, Prem and Shobila cannot go out unguided.

I first visited this family in January 2001, it was a fleeting trip and I was with a group of representatives from a UK donor agency. It was a strange and uncomfortable experience. We visited this family in the pitch black. The family's home has no light mostly because of the cost of electricity. Suddenly flashes started going off from cameras. I caught glimpses of Neela, Prem and Shobila, in the split seconds as the flashes went, obviously they could not see me. Others in my group were keen to capture this family on camera, keen to expose, reveal what could not be seen in the darkest of the night. I later saw the photos of that night and felt uneasy. The camera had been pointed straight at their eyes. The eyes captured in this shot clearly belonged to someone who had a severe visual impairment. The pictures were then used on a display board to promote the work of the NGO. This family was used as an example of disadvantage and extreme poverty much in need of western help. Whilst Krishnam, Neela, Prem and Shobila did need help, what was not told in that picture or elsewhere was the extent to which they were being supported. I asked them on another visit how they coped with everyday life. Krishnam described how family friends came each day with food and helped with household chores.

In Krishnam's own family it was only his younger brother and his wife who came to help. Krishnam's family was poor and not seen as a good match. Neela's family were keen to marry her to someone who would look after her. The only family willing to take her was Krishnam's. The financial drain Neela was thought to bring was too great for other more wealthy families. The difficulties Neela found in getting married highlights her social exclusion. Harris-White (1999) documents the difficulties disabled people in Tamil Nadu face in getting married and argues these experiences point to an unequal access to rights of passage. Despite this level of exclusion Neela and her daughters have been supported by families belonging to the same caste. This support was maintained throughout long spells of heavy drought. This sense of responsibility towards them expressed by their community is perhaps linked to notions of caste identity. Both Zene (2004) and

Leslie (2004) explore notions of collective caste identity, which they argue unites families and individuals regardless of levels of poverty, gender and disability.

The experiences Neela and her daughters have of living with an impairment were not appreciated by the donor NGO. The photographer ceased a photo opportunity. The image provided him with evidence of extreme poverty and suffering. This NGO did not attempt to access the specific needs of this family but used their image to further create a category of an underdeveloped Other. If effective strategies to ease the marginalisation of this family are to be implemented they must be founded on an understanding of what support already exists and appreciation of what kind of life Neela and her daughters would like to lead. This information can only be gathered through open and empathetic dialogue.

Conclusion

Although a rights-based approach is needed in terms of addressing the lack of resources given to disabled people in many developing societies the mechanism through which these rights are to be delivered also needs to be examined more closely. At present the aid industry has not adopted a methodology that is reflexive enough to allow for the experiences and voices of others to be heard. Until a more effective model is formulated and adopted it is unlikely a social model of disability will ever be successfully implemented in the Developing World.

Anmerkungen

- 1 De Groot makes a similar argument in relation to women. She describes how women in this discourse are understood to be "exotic specimens, as oppressed victims, as sex objects or as the most ignorant and backward members of 'backward' societies." (1991:115) Women are portrayed as a weak Other contrasted against the strong liberated women of the West.
- 2 Bloch and Bloch (1980:127) discuss the binary opposition inherent in the development discourse, which separates the North (civilised) from the South (uncivilised).
- 3 "The advanced capitalist countries, amounting to 21 per cent of the world's population, control 78 per cent of the world production of goods and services and consume 75 per cent of all the energy produced. Textile or electronics workers in the Third World earn twenty times less than workers in Europe and North America doing the same jobs with the same productivity. Since the debt crisis emerged in the early eighties, Third World countries in debt have been contributing to the

wealth of developed countries in liquid terms, by paying each year an average of \$30 billion more than what they get in new loans. During the same period, available food in Third World countries decreased by about 30 per cent." (de Sousa Santos 1999:30)

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Zusammenfassung: Entwicklungsländer werden häufig als rückständig in Bezug auf die Wertschätzung von Inklusion dargestellt. Das Stigma, das der Behinderung anhaftet, scheint dort größer als in den Industrieländern zu sein. Die Autorin gesteht ein, dass knappe Ressourcen die Inklusion beeinträchtigen, betont jedoch, dass dies nicht unbedingt tiefere Vorurteile gegenüber Behinderten widerspiegelt. Der Entwicklungsdiskurs hat die Kategorie des unterentwickelten Anderen geschaffen, in der alle marginalisierten Menschen zusammenfasst werden. Diese Bezeichnung ist jedoch ungeeignet, die verschiedenen Erfahrungen und Bedürfnisse von Menschen mit Beeinträchtigungen abzubilden. Die Autorin stellt traditionelle Unterstützungsnetzwerke vor, die in vielen Gesellschaften existieren, und schlägt vor, dass Entwicklungsprojekte auf diesen aufbauen sollten, anstatt westliche Modelle von Inklusion zu exportieren.

Résumé: Cet article montre que les pays en voie de développement sont fréquemment décrits comme étant arriérés en ce qui concerne l'appréciation de l'inclusion. De plus, le stigmate, inhérent à l'infirmité, semble y être plus important que dans les pays industrialisés. L'auteur admet que des ressources rares entravent l'inclusion, mais cependant souligne que cela ne reflète pas forcément les préjugés profonds concernant l'infirmité. Le discours du développement a créé une catégorie des autres sous développés dans laquelle sont groupées toutes les personnes marginalisées. Cette étiquette est cependant inappropriée pour reproduire les divers besoins et expériences de personnes ayant des entraves. L'auteur présente des réseaux de soutien traditionnels qui existent dans beaucoup de sociétés et propose que les projets de développement devraient être construits sur ces réseaux au lieu d'exporter des modèles occidentaux d'inclusion.

Resumen: Los países en vías de desarrollo muchas veces son vistos como países subdesarrollados con respecto a la inclusión. El discurso del desarrollo ha creado la categoría del Otro Subdesarrollado, la cual contiene todos los seres humanos marginados. Pero esta categoría es inadecuada para dar un imagen de los diferentes experiencias y necesidades de las Personas con Discapacidad. El autor constata, que principalmente los pocos recursos en estos países frenan a la inclusión, mucho más que los prejuicios existentes, y él presenta redes de apoyo tradicionales y propone, que los proyectos de desarrollo se orienten más en ellos, en vez de exportar modelos de inclusión occidentales.

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Disabling Infant Hearing Loss in a Developing South African Community: the Risks

D. Swanepoell/S.R. Hugo/B. Louw

Late identification of infant hearing loss leads to serious negative consequences for the individual, family and society. In contrast, the early identification of hearing loss yields dramatic benefits, since infants whose hearing loss is identified before 6 months of age have significantly better language abilities compared to those whose hearing loss was identified later. In developed countries early identification is becoming the de facto medical legal standard of care whilst in developing countries it is not a healthcare priority at all. An intermediate solution for developing countries was suggested in the form of targeted screening of infants at risk for hearing loss. Unfortunately very little epidemiological data is available regarding the incidence of risks in developing communities. The current study therefore describes risks for disabling hearing loss amongst a group of 510 infants younger than 12 months and their caregivers attending immunisation clinics in a developing South African community. Results indicate that infants demonstrate an increased risk for congenital and acquired disabling hearing loss in the developing community investigated. Poverty, low levels of education, and a high percentage of teenage pregnancies are all contributing environmental risks toward a higher risk for disabling infant hearing loss. In addition to these environmental risks the incidence of risk indicators specifically identified for hearing loss were also considerably higher in the investigated community compared to developed countries. The increased risk emphasises the need for further research and comprehensive screening programmes to address the silent epidemic of disabling infant hearing loss in developing countries.

Introduction

Undetected hearing loss leads to irreversible language, speech and cognitive delays, with far-reaching social and economic ramifications (Yoshinaga-Itano & Gravel 2001, JCIH 2000, Yoshinaga-Itano et al. 1998, Mohr et al. 2000). Significant delays in language development and academic achievement have been reported widely for the majority of children with sensori-neural hearing losses (Carney & Moeller 1998). These delays are documented for numerous aspects such as vocabulary development, grammatical skills, concept attainment, social conversational skills and development of literary skills. Children with congenital bilateral severe-to-profound hearing loss who leave the educational system at the age of 18 years demonstrate an average middle-third to middle-fourth grade reading level and language abilities that are 50% to 90% of their chronological age, equivalent to a 9 and 10-year-old (Yoshinaga-Itano & Gravel 2001). On average, children with a hearing loss who are identified late (after 12 months) exhibit a discrepancy of 40 to 50 points between nonverbal performance test scores and language ability. Even for the children who score in the top 10% of this distribution, the nonverbal/language discrepancy average is 20 points (Yoshinaga-Itano 2003). These reports and others have provided conclusive evidence of the serious negative effect of late identification of a hearing loss.

Fortunately early identification of hearing loss is a form of secondary prevention that yields dramatic benefits, since infants whose hearing loss is identified before 6 months of age have significantly better language abilities compared to those whose hearing loss was identified later (Yoshinaga-Itano et al. 1998, Moeller 2000, Calderon & Naidu 2000). The reason for this is

that intervention (hearing aid fitting and supportive services) before the age of 6 months, enables infants to develop and maintain normal language skills on par with their cognitive development (Yoshinaga-Itano et al. 1998). This is in stark contrast with the persistent language delay of two to four years for infants identified after 6 months of age (Yoshinaga-Itano et al. 1998).

In developed countries, like the USA and UK, where *Universal Newborn Hearing Screening* (UNHS) programmes are being implemented, early identification of hearing loss has become the de facto medical legal standard of care. In contrast screening for hearing loss in developing countries has remained a low priority. It is not uncommon to find that healthcare needs in most of these countries are ranked into high and low priorities with emphasis on life-threatening conditions and diseases such as diphtheria, tetanus, meningitis and HIV/Aids, whilst conditions perceived as non-life-threatening such as hearing loss are neglected (Olusanya 2000). Although hearing loss is indeed not a life-threatening condition, it becomes a severe threat to essential quality of life indicators unless intervention occurs early in infant development. It is therefore unfortunate that the benefits of early identification have not been pursued successfully in developing countries of the world.

In an attempt to address the lack of hearing screening programmes in developing countries the *Joint Committee for Infant Hearing* (JCIH) recommended a more affordable intermediate option in the form of targeted *Newborn Hearing Screening* (NHS) (JCIH 2002). Targeted NHS is based on the principle that screening a small number of infants with high risk indicators will yield a large number of infants with hearing loss. The JCIH 2000 position statement has compiled a

list of risk indicators for hearing loss (JCIH 2000). A number of different studies conducted in developed nations have reported that the at-risk population constitutes approximately 10% of all births and accounts for approximately 50% of infants with congenital hearing loss (Chu et al. 2003, Davis & Wood 1992, Watkin et al. 1991; Mauk et al. 1991). This may therefore be viewed as an effective way to keep screening costs low whilst attaining a relatively high return of identified infants with hearing loss.

In developing countries however no systematic studies are available that have investigated the prevalence of risk factors for hearing loss amongst the newborn population. Such data is essential before large-scale targeted NHS programmes are launched to ensure planning is based on research evidence. This fact is further emphasized by the compounding effect of additional environmental risk factors that may well make developing populations more prone to having a hearing loss. The prevalence of congenital hearing loss has recently been demonstrated to be associated with deprivation, which is characteristic of developing countries (Kubba et al. 2004).

The fact that the majority of children with hearing loss live in developing countries emphasises the necessity for effective and accountable screening programmes built on accurate data for these communities (WHO 1997). This is particularly true of South Africa, a country characterised by pockets of developed areas but where the majority of the population live in poverty in urban, peri-urban and rural areas (Fair & Louw 1999). Although epidemiological data for developmental risk conditions in South Africa is incomplete and difficult to obtain, it is clear that there is an increased prevalence of risk conditions for infants and young children (McPherson & Swart 1997).

The *Professional Board for Speech Language and Hearing Professions of the Health Professions Council of South Africa* (HPCSA) has recently produced a position statement in which it recommends targeted NHS as an intermediate step towards Universal NHS in South Africa (HPCSA, 2002). One of the major screening contexts proposed were in line with the primary healthcare philosophy of the country in the form of immunisation clinics distributed throughout South African communities. Before such widespread targeted screening is implemented, however, it is essential that research be conducted to address the dearth of information regarding the incidence of risk factors for hearing loss amongst communities in South Africa. This data will ensure that informed and accountable decisions are made toward better hearing healthcare in South Africa and other developing countries. The current study therefore aimed to describe the risk factors, including environmental risks, for hearing loss identified in a group of caregivers and infants attending immunisation clinics in a developing South African community.

Method

The institutional review board at the University of Pretoria approved this project before any data was collected.

Subjects

Neonates/infants younger than 12 months and their caregivers served as paired research subjects. Caregivers were considered to be the person responsible for bringing the neonate/infant to the immunisation clinic. Subjects had to be registered patients of the Refentse and Eersterus immunisation clinic in the Hammanskraal district and a file had to be available for each participant. These two clinics were selected because both centers provide services to significant numbers of infants representing typical developing contexts in South Africa. 510 infants between the age of 0-12 months and with an even gender distribution (51/49%) were enrolled in the study. The mean age of the group was 14 weeks with 68% of infants younger than 16 weeks (4 months). The majority of infants were younger than or equal to 10 weeks of age with a large proportion (26%) of infants screened being younger than one month of age. The subject race was almost exclusively black (n=508) with the exception of two coloured infants. This is in agreement with the demographical indicators specified for this community, which is predominantly representative of black South Africans (Tshwane 2020 Plan 2002). The mere fact that these infants are born as black South Africans places them in the least developed group of South African citizens with 66% of black South Africans living in poverty compared to less than 2% of white households, 8% of Asian households and 25% of coloured households (Woolard & Barberton 1998). In addition to this the fact that the infants are from the Hammanskraal district also places them at an increased risk since it is a developing context characterised by socio-economic strains (Tshwane 2020 Plan 2002).

Data collection material

A structured interview schedule was compiled to obtain a profile of biographical characteristics and risk indicators for hearing loss from the sample of subjects. The schedule constituted two sections which formed part of the recording sheet and was completed by interviewing the caregiver supplemented by information from the immunisation clinic file. The first section consisted of biographical type questions. The second section of the interview schedule was a risk indicator checklist for hearing loss. The list of risk indicators was compiled from the JCIH 1994 and 2000 position statements (JCIH 2000). Widespread in-utero infections that are characteristic of South Africa were also added to the list and included HIV and malaria

(Department of Health 2000, Department of Health 2001). HIV has become a pandemic in South Africa with 1 in every 9 South Africans being infected (Department of Health 2002). The children born of HIV/AIDS infected mothers are at increased risk for hearing loss due to significantly lower birth weights, increased vulnerability for acquiring infections such as meningitis and cytomegalovirus (Spiegel & Bonwit 2002). Malaria was included as a risk indicator because it is particularly dangerous for pregnant women, the medications for treatment are ototoxic, and many regions of South Africa are malaria prone (Claesen et al. 1998). The risk indicator questions were in the format of a checklist requiring a *yes, no, or information unavailable* choice.

Procedure

All data was collected in Hammanskraal at the two MCH clinics. The research was conducted over a five-month period from mid January to mid June 2003. The Refentse MCH clinic was visited on Mondays, Tuesdays, and Wednesdays whilst the Eersterus MCH clinic was visited on Thursdays and Fridays. Data collection was not done every day over the five-month period due to practical schedule considerations. The following procedure was used to obtain information. The interview was conducted as part of a routine hearing screening protocol conducted at these clinics for research purposes. Two of the fieldworkers were able to speak one or more African languages and these individuals assisted if the caregiver could not understand English or Afrikaans. In some instances information could not be obtained for all questions. The number of acquired responses is therefore specified for each result.

Results

Primary caregiver and marital status of mother

Single mothers were the primary caregivers in 82% of cases with both parents involved for only three cases. The second largest numbers of primary caregivers were the grandparents, who comprised 14% of the sample. The remainder stayed with extended family (2%) or with the father (1%). In addition to this only 18% of the mothers of the neonates and infants were married.

Age of mothers and number of children

The age of mothers of infants in this study varied between 15 to 43 years. Figure 1 provides the distribution (in percentage) of mothers for different age categories. It is clear that the majority of mothers are in their late teens and early twenties. 58% of the mothers were 25 years of age and younger with almost two-thirds (29%) of mothers 20 years of age and younger.

A majority (72%) of the mothers had 1 or 2 children. This corresponds to the high percentage of young

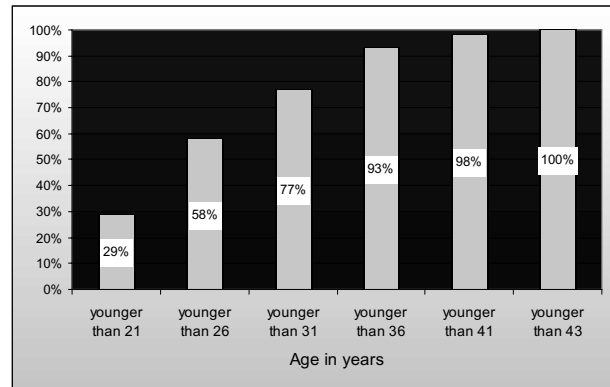


FIGURE 1. Frequency distribution of mothers according to age (n=510)

mothers in the sample who had their first or second child. 21% of mothers were 19 years of age and younger meaning that they were still school-going age and 29% were 20 years of age and younger.

Educational qualifications of parents

The highest educational qualifications attained by the group of mothers and fathers are presented in Figure 2.

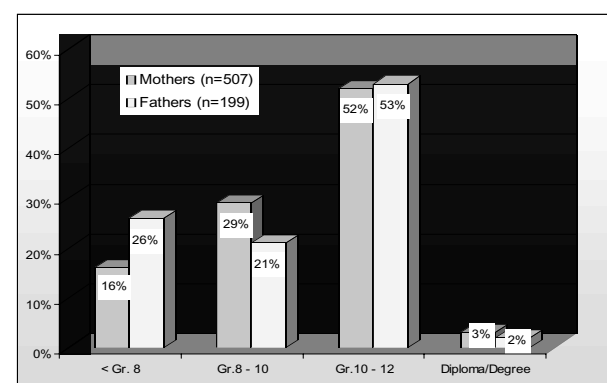


FIGURE 2. Educational qualifications of mothers (n=507) and fathers (n=199)

The majority (52%) of mothers had a grade 10 to 12 educational qualification. A significant percentage (26%) of the fathers had obtained less than a grade 8 school qualification and this figure rises to 47% if all fathers with a less than a grade 11 school qualification are considered. In general, the fact that the number of responses for paternal educational qualifications is much less than for the mothers and that caregivers, who were mostly mothers, reported the fathers' qualifications must be considered as possible factors which may have affected the results.

Average household income

The distribution of average household incomes recorded for this study is presented in Figure 3.

A significant majority of respondents (77%) reported an average monthly household income less than

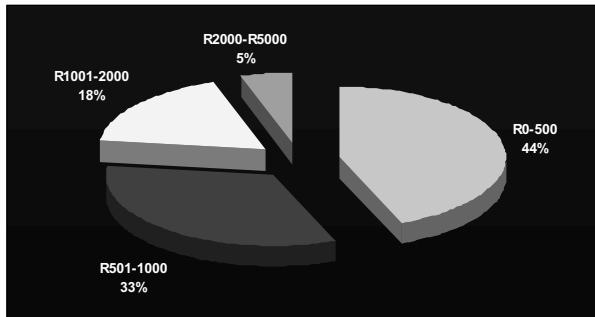


FIGURE 3. Average monthly household income (n=184)

R1000 (±US\$ 154) (US\$ 1.00 = ± R 6.50). Only a small minority (5%) reported an average monthly household income of more than R2000 (±US\$ 308). According to the 1996 Census, African women earned the least with 47,5% earning less than R500 per month and a further 21,4% earning between R500 and R1000 (Census 1996). This is comparable to the results in the current study with 44% of households earning less than R500 per month and a further 33% earning between R500 and R1000. The only difference is that this data comes from seven years after the census date. Also, the fact that inflation has taken its toll over these years, exacerbates the picture of poverty in Hammanskraal.

Risk indicators for hearing loss

A summary of the incidence of risk factors is presented in table 1.

Risk indicators were reported for all categories except meningitis. The cases where no information regarding risk factors was available either in the clinic file or from the caregiver varied between 0,3 and 1,8% across the different risk categories. In the majority of these cases a relative brought the infant and the mother was not present to provide all the required information. The high response rate for reporting risk indicators indicates promise for the effective use of a high risk register for this population in an immunisation clinic.

In the current study 21% of infants (106/510) presented with at least one risk factor for hearing loss. 11,3% of these at-risk infants had more than one risk factor meaning that 2,4% of infants tested had more than one risk factor for hearing loss. The risk factor with the highest incidence was family history of congenital hearing loss (13%) followed by congenital infections (5%), NICU admittance (2,4%), ototoxic medication (1,2%), low birth weight (1%), craniofacial defects (1%), asphyxia (0,8%), persistent pulmonary hypertension (0,4%), presence of a syndrome (0,2%) and hyperbilirubinaemia (0,2%). The risk factors present in the group of NICU infants (n=12), from most prevalent to least, included low birth weight (n=5), asphyxia (n=4), ototoxic medication (n=4), family history (n=2), and craniofacial defects (n=1).

The sub-sample of infants who had been admitted to

the NICU (n=12) presented with 17% of the documented risk factors (apart from the NICU as risk factor), despite only comprising 2,4% of the entire sample (n=510). This means that risk factors in this study were 10 times (1/1,5) more prevalent in the NICU population than in non-NICU exposed infants (1/0,15). Since NICU admittance was considered as a risk factor by itself in the current study the incidence of risk factors for this sample, in actual fact, was 16 times (1/2,5) more prevalent in the NICU population than for the rest of the sample (1/0,15). Five of the NICU infants (42%) exhibited at least two additional risk factors in addition to NICU admittance. This is compared to only one infant (1%) from the non-NICU exposed at-risk group (n=94), presenting with more than one risk factor. This makes NICU infants in this study 42 times more likely to have more than one risk indicator apart from NICU admittance.

Discussion

Environmental risks

The description of infants and caregivers sampled for this study indicates that this developing Hammanskraal population is a predisposed high-risk group. South Africa has seen an increase in female-headed households with a staggering 42% of South African children younger than seven years of age reported in 1995 to be living only with their mother (Nyman 1999). The figure is almost twice as high in the current study. Possible reasons for the high percentage of single mothers in the current study left to care

RISK INDICATOR	RESULT	DESCRIPTION
a) Family History of childhood hearing loss (n=501)	YES	13 %
	NO	87 %
	No info	0.4 %
b) Hyperbilirubinaemia (n=500)	YES	0.2 %
	NO	98.6 %
	No info	1.2 %
c) Congenital infections (n=495)	YES	5 %
	NO	95 %
		Syphilis – 17 Rubella – 1 HIV – 5
d) Craniofacial defects (n=506)	YES	1 %
	NO	99 %
		7 subjects – atresia and ear tags
e) Birth weight less than 1500 grams (n=503)	YES	1 %
	NO	99 %
	No info	0.2 %
f) Bacterial meningitis (n=500)	YES	0 %
	NO	99.4 %
	No info	0.6 %
g) Asphyxia (n=500)	YES	0.8 %
	NO	97.8 %
	No info	1.4 %
h) Ototoxic medication (n=504)	YES	1.2 %
	NO	97 %
	No info	1.8 %
i) Persistent pulmonary hypertension. Prolonged mechanical ventilation ≥ 5 days (n=504)	YES	0.4 %
	NO	98.6 %
	No info	1 %
j) Syndrome present (n=504)	YES	0.2 %
	NO	99.8 %
		1 subject had a syndrome – Albinism
k) Admitted to the NICU for more than 48 hours (n=505)	YES	2.4 %
	NO	97.6 %
		12 subjects were admitted to the NICU for between 3 and 30 days

TABLE 1. Summary of the risk indicators for the sample

for the children are probably due to the following reasons: (1) it is a peri-urban developing community representing the most underprivileged sections of the South African population; (2) high numbers of children are born out of formal partnerships; (3) high numbers of pregnancies among teenagers in temporary relationships; (4) a number of South African men establish dual households (Tshwane 2020 Plan 2002, Children in 2001). It is therefore not uncommon for grandparents to be the primary caregivers of children in South Africa (Children in 2001). This may often also be due to the mother and/or father working far away from home or due to death, which is increasingly becoming the case with the spreading HIV/Aids pandemic (Children in 2001). In this light it is not surprising that grandparents are playing an increasing important part in caring for the children of South Africa.

These factors are risk factors that have important implications for screening and intervention programmes since effective early intervention is heavily reliant on parental or caregiver involvement (JCIH, 2000). Single mothers and grandparents are under increasing strain due to economic pressure and the breakdown of the family structure and single parenthood places a child at an increased risk for developmental delays (Children in 2001). In addition to this, the breakdown of family structures create stressors, which could seriously impede the nurturing of family-centred intervention programmes for infants identified with hearing loss.

Another stressor is the high incidence of teenage pregnancies. The obtained percentage closely approximates the estimated South African average of 19% of female learners (18 years of age) and 30% of females 19 years of age who have been pregnant at least once (Bhana 2004, Department of Health 1999). The high incidence is not surprising considering a 41% sexually active teenage population in South Africa exacerbated by limited use of contraceptives (Bhana 2004). It is a common fact in maternal and child health programmes that the youngest mothers are at the highest risk for adverse reproductive and parenting outcomes (Ventura et al. 1998). The high rate of teenage pregnancies in this study therefore increases the risk of developmental disabilities in this community. This is even more so due to an increased low-birth weight incidence present in adolescent mothers, which already predisposes the infant to developmental disorders such as hearing loss (Northern & Downs 2002). Another factor that must be considered is the increase in school dropout rates among adolescent mothers, which adds to the economic burden of the household and limits future prospects due to poor education (Children in 2001).

Another important environment risk factor is evident in the poor educational levels of parents in the current study. Previous reports have indicated that one in

five African females have had no education at all (Central Statistics 1998). There has, however, been a steady improvement in educational qualifications among South Africans with a reported 28% of Africans between 20-24 years of age having obtained at least a grade 12 qualification (Central Statistics 1998). Very few post grade 12 educational qualifications were reported for both fathers and mothers. According to a large study with a cohort of 17,091 infants and caregivers in Hawaii the mothers who had not completed high school were less likely to have their infant complete the hearing screening/follow-up process than were more educated women (Prince et al. 2003). Educational level is therefore significantly correlated to the completion of a screening/follow-up process.

The poor level of education and subsequent high vulnerability to unemployment are factors that place the population of infants in this study at an increased risk for developmental delays and disabilities as well as for poor involvement of parents in the early hearing loss detection and intervention process (Prince et al. 2003). A related environmental risk indicator for the current sample is the extreme poverty evident in households. Poor households have less access to essential services such as water and sanitation, communications, roads and energy sources, particularly in rural and peri-urban regions such as Hammanskraal (Children in 2001). These factors create enormous time burdens on poor households and promise to be serious barriers to the implementation of family-centred early intervention services for infants with hearing loss. On the other hand, poverty related stressors also place this population of infants at an increased risk for developmental delays and disabilities such as hearing loss (Kubba et al. 2004), which emphasises the need for early detection and intervention programmes.

Risk indicators for hearing loss

The percentage of high risk factors for hearing loss (21%) recorded in this study is considerably higher than previous reports in developed countries. Kennedy et al. (1998) reported that 11,6% of a sample of 21,279 infants in England had risk factors for congenital hearing loss. A larger study (n=283,298) from the USA reported a 9% incidence of risk factors and a more recent report indicated a 13.1% incidence of one or more risk indicators in a sample (n=2701) of infants from well-baby nurseries (Mahoney & Eichwald 1987, Vohr et al. 2000). Reasons for the high incidence of infants with risk factors in the current study were discussed in previous paragraphs and relate to the high incidence of a family history of hearing loss in the study sample.

Except for family history of congenital hearing loss, the incidence distribution of existing risk indica-

tors in the current study was similar to previous reports. Kennedy et al. (1998) in a sample of 21,279 infants reported incidences of 6,6% for family history of hearing loss; 4,2% for congenital infections; 1% for asphyxia; 0,2% for chromosomal abnormalities; and 0,3% for exchange transfusion due to high bilirubinaemia levels. The fact that family history was the most prominent risk factor in this study is similar to previous studies investigating large samples of infants differing only by the incidence margin (Mahoney & Eichwald 1987, Kennedy et al. 1998, Vohr et al. 2000). Previous studies have reported a 6 to 7% incidence of family history of congenital hearing loss compared to the 13% reported in the current study (Mahoney & Eichwald 1987, Kennedy et al. 1998, Vohr et al. 2000).

The high incidence of family history of congenital hearing loss in the current study may be explained by two possible factors. Firstly, depravity is known to correspond with increased incidence rates of congenital hearing loss (Kubba et al. 2004) and therefore the existing depravity in this community as evidence in discussion of subaim #1 can contribute to this high incidence of family history with congenital hearing loss. The second reason relates to the difficulty in obtaining an accurate history of family hearing loss and the importance of correctly phrasing the question to avoid misunderstandings or erroneous responses (Cone-Wesson et al. 2000, Kountakis et al. 2002, Northern & Downs 2002). It is possible that caregivers misunderstood or misinterpreted the posed question and gave an incorrect answer, which may have inflated the incidence slightly. This risk factor, however, is very important since it is commonly reported as the most prevalent (22 – 42%) risk factor in at-risk children identified with hearing loss and therefore accurate documentation of its presence is essential (Vohr et al. 1998, Mahoney & Eichwald 1987). This emphasises the importance of parent or caregiver education and counselling about the increased risk for hearing loss when there is a family history.

Another important aspect requiring consideration is the incidence of congenital infections reported by mothers in this study. Due to the HIV/Aids pandemic in South Africa, with an estimated 11,4% of the general population infected, HIV was included as one of the congenital infection risk factors for infants in this study (Department of Health, 2002). Children born of HIV/Aids infected mothers are at increased risk for hearing loss due to significantly lower birth weights, increased vulnerability for acquiring infections such as meningitis and cytomegalovirus (Spiegel & Bonwit 2002). These children are also at a much greater risk of developing otitis media, which results in conductive hearing loss that may lead to sensori-neural hearing loss in certain cases (Bam, Kritzinger & Louw 2003,

Matkin et al. 1998, Singh et al. 2003).

The fact that only five mothers, comprising only 1% of the sample, indicated that they were HIV infected compared to a reported 26,5% of women attending immunisation clinics in South Africa being infected, indicates gross underreporting in the current study (Mngadi 2003). According to the estimated average rate of HIV infection in this population of mothers approximately 135 should have reported being infected. This under reporting can be ascribed to a number of reasons including unawareness among mothers regarding their status or reluctance to disclose such information due to a fear of isolation or social stigma.

Conclusion

Neonates and infants demonstrate an increased risk for congenital and acquired disabling hearing loss in the developing community investigated. Poverty, low levels of education, and a high percentage of teenage pregnancies all contribute toward a higher risk for disabling infant hearing loss. In addition to these environmental risks the risk indicators specifically identified for hearing loss are also considerably higher than in developed countries. Infectious diseases such as HIV/Aids further increase the risks for disabling infant hearing loss especially in light of the reluctance to disclose HIV status by mothers. These higher risks emphasises the need for comprehensive screening programmes that are contextually and culturally suited to address the silent epidemic of disabling infant hearing loss in developing countries.

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Zusammenfassung: Die späte Diagnose von kindlichen Gehörschädigungen hat ernste Folgen für das Individuum, die Familie und die Gesellschaft. Im Gegensatz dazu hat die Früherkennung großen Nutzen, da Kinder, deren Hörschaden vor dem Ende des sechsten Lebensmonats entdeckt wird, deutlich bessere Sprachfähigkeiten haben, als solche, bei denen die Gehörschädigung erst später festgestellt wird. Während in Industrieländern die Früherkennung medizinischer Standard ist, hat sie in Entwicklungsländern keine Priorität. Daher wurde hier ein Mittelweg vorgeschlagen, in Form eines Früherkennungsprogramms für besonders gefährdete Kinder. Leider liegen jedoch nur sehr wenige Daten über das Auftreten von Risiken in *developing communities* vor. Die vorliegende Studie beschreibt anhand einer Gruppe von 510 Kindern unter einem Jahr und ihren Erziehungsberechtigten die Risiken für Gehörschädigungen bei Kindern. Armut, geringe Bildung und Teenager-Schwangerschaften erhöhen demnach die Risiken für einen Hörschaden beträchtlich. Der Befund verdeutlicht die Notwendigkeit weiterer Forschung sowie umfassender Früherkennungsprogramme, um der stillen Epidemie kindlicher Gehörschädigungen in Entwicklungsländern Einhalt zu gebieten.

Résumé: Le diagnostic tardif des dommages de l'ouïe chez les enfants a des conséquences sérieuses pour l'individu, la famille et la société. En revanche, le dépistage précoce présente un grand avantage, car les enfants, dont les problèmes auditifs sont découverts avant la fin de leur sixième mois, présentent des compétences linguistiques

*beaucoup plus marquées que ceux chez qui des dommages de l'ouïe ont été constatés plus tard. Alors que dans les pays industriels le dépistage précoce est chose normale, celui-ci n'a aucune priorité dans les pays en voie de développement. C'est la raison pour laquelle un compromis a été proposé sous la forme d'un programme de dépistage précoce pour les enfants spécialement en danger. Malheureusement, il n'existe, cependant, que très peu de données sur l'apparition des risques dans les *developing communities*. L'étude en cours décrit, en s'appuyant sur un groupe de 510 enfants ayant moins d'un an et les personnes chargées de leur éducation, le risque de dommages de l'ouïe chez les enfants. Pauvreté, manque de formation, grossesses d'adolescentes augmentent considérablement les risques de dommage de l'ouïe. Le résultat indique la nécessité d'une recherche continue ainsi que des programmes de dépistage précoce pour mettre fin à cette épidémie rampante de dommage de l'ouïe infantile dans les pays en voie de développement.*

Resumen: El diagnóstico temprano de la Deficiencia Auditiva es muy importante porque mejora significativamente la posibilidad de elaborar la capacidad para el lenguaje del niño con deficiencia auditiva. Mientras que en los países industrializados el diagnóstico temprano es *standard médico*, en los países en vías de desarrollo no tiene prioridad. Por eso se propone aquí un camino medio de forma de un programa de diagnóstico temprano para niños con alto riesgo. El estudio presentado describe a través de un grupo analizado de 510 niños con menos de un año y sus padres los riesgos para las deficiencias auditivas de niños. Pobreza, falta de educación y embarazos de adolescentes aumentan la deficiencia auditiva notablemente. Este resultado enseña la necesidad de otros estudios y de la implementación de programas de diagnósticos tempranos para frenar a la epidemia silenciosa de la deficiencia auditiva de los niños en los países en vías de desarrollo.

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Empowerment and Disability

Reporting from the International DCDD Symposium *Disability, Self-organisation and Aid*

On November 15th, 2004, 150 people from seventeen countries got together in The Hague/Netherlands to discuss empowerment for people with disabilities. The central question was how donor organisations could best support self-organisations of disabled people in developing countries and throughout Eastern Europe. The symposium participants agreed that there is an urgent need for donors to address the issue of mobilization and emancipation of people with disabilities more effectively.

DCDD – Dutch Coalition on Disability and Development – was the organiser of this symposium and invited speakers from the World Bank, PSO (the Netherlands), Handicap International and SHIA (Sweden) to give plenary contributions in the morning. In the afternoon, six workshops were given by leaders of grassroots disability organisations from Uganda, Swaziland, Kenya, India, Bosnia-Herzegovina and Bulgaria. This article highlights some of the issues discussed and specifically reports on how donor organisations can work on capacity building of disabled people organisations. The full report of the symposium can be downloaded on DCDD's website (www.dcdd.nl).

Disability: an unrecognised problem

Disabled people are highly discriminated against when it comes to access to education, employment, health etc. The groups most affected are disabled women and children and especially intellectually disabled people. To fight poverty and exclusion, a complex chain of different components is needed. Besides direct poverty alleviation measures, advocating the rights of people with disabilities is a key strategy. In many developing countries the belief and practice that disability is an NGO matter is dominant and therefore usually does not get financed through government. Poverty alleviation strategies of most foreign donor organisations, however, are rarely directed towards people with disabilities. Though some donors promote the mainstreaming of disability, their actual knowledge about disability is limited and there is little sharing of experience.

Empowerment, what is needed?

The symposium did not attempt to answer the question: "What is Empowerment?" but tried to identify the most important elements needed when empowering people with disabilities. It is obvious that the core value – "nothing about us without us" – should not be neglected. Disabled people and their grassroots organisations are stakeholders in the development process, and should be empowered and, perhaps, even educated to see development from a longer-term perspective.

Often disability is still seen as a medical issue instead of a human rights issue. But, the emphasis should be on inclusion rather than on disability. It's about equal participation in society, not about rehabilitation alone.

What kind of approach?

At the symposium there was much debate on the best approach to empowerment, a needs driven or a policy driven approach. Needs are assessed by asking the target group different variations of the general question "what do you need/want?" The policy driven approach makes use of preset priorities in grant making decisions. The main problem with utilising a needs driven approach is that a more global perspective and a longerterm view prioritizing development-orientated items (such as access to education or to independent living) is usually not taken. Instead the focus is on immediate needs such as food or (higher) income, and if possible, on demanding free transport (instead of accessible). For a practical example see the box *Dangers of a needs driven approach*. A lot of mistakes can be avoided if development interventions use a combination of the two approaches.

Disabled people organisations (DPOs)

There is a need to make more resources available for the capacity building of organisations of disabled people in developing countries. But, there is currently a tendency in donor organisations to allocate resources to organisations that are already empowered and forget about those that still need capacity building. By supporting DPOs, donor organisations could help them to identify their needs and priorities.

Donors however, need to take into account that the

Dangers of a needs driven approach

There is a widespread "fashionable" practice of setting up day care centres for children with disabilities in many countries, which is frequently justified by the needs of the parents. Time and again the needs assessments among parents show that what they need most is qualified medical and psychological care for their disabled children. Also fundraising for this purpose is much easier for donor organisations in their countries of origin. However, in practice, the day care centres actually become specialised institutions and, as a result, disabled children are being isolated from their peers, their education is usually of a poor quality and the time spent at the day care centre does not prepare children for adulthood. The day care centres example shows us how international donors can give money that meets the identified needs of the target group but that this money does not necessarily contribute to the equalisation of opportunities nor to entitlement to human rights.

current education system in many countries is grounded in a system that segregates disabled people. Special schools that exist have very limited capacity. Mainstream schools are almost never accessible for children with disabilities. This results in the exclusion of a vast majority of learners with disabilities from accessing education, thus very few disabled people gain access to higher education. Leadership and management of DPOs is therefore an issue that requires specific attention. In Eastern Europe the situation differs from that in developing countries. Most of the DPO leaders in Eastern Europe still have a centralist system mindset, trying to keep or recover what they had, instead of looking for a new system that is more inclusive than protective.

Disability on the PRSP agenda

PRSPs (Poverty Reduction Strategy Papers) are a key government policy instrument for poverty reduction and are seen as the operational framework for implementing the Millennium Development Goals (MDGs). PRSPs have put poverty reduction at the centre of development planning. There is an increase in the number of PRSPs in which disability is mentioned, but this is only partial progress. Disabled persons still remain largely invisible in PRSPs. The result is an incomplete policy agenda: in 67% of the PRSPs, disability is only mentioned as a social protection measure. PRSP measures to economically integrate disabled people are rare.

It is at the level of disability policies that PRSPs face their greatest challenge: PRSP programs need to be translated into annual government budgets but there is a strong risk that the initial policy commitment will evaporate. Data show that in only approximately one third of the planned interventions in social protection, education and health, are targets and budgets allocated. There are three key constraints hindering the participation of disabled people in poverty alleviation: they are economically excluded from pro-poor growth, there is social exclusion from education and health and they have a weak political voice. The weak political voice of disabled people (organisations) is a concern. Associations representing disabled people are consulted in only a few cases, in 29% of PRSPs, and in the follow-ups, like the policy discussions of PRSPs, they are rarely involved at all.

Evidence from the PRSPs studied shows that when DPOs participate in PRSP consultation, the social focus of disability policy on social protection measures decreases and the economic focus increases, and the problem is analysed more in terms of a list of human potential. DPOs should be involved not only in the preparation of PRSPs, but also during the policy discussions. Capacity building may be required: training in advocacy (for example, how to formulate economic argument for disability policy), and financial support.

Central values for donor organisations when working with DPOs

When it comes to development in the disability arena, donor agencies should both adopt and encourage a policy driven approach that utilises the vision of an accessible social and physical environment, equal opportunities and independent living. Donor organisations should promote advocacy activities that represent

social justice, so that the questions related to disability are taken into account at each stage of the decision making process. More attention, coordination and exchange are essential because the disability movement is still weak; this is exacerbated by the competition and the struggles which exist amongst DPOs. Donors should ensure more consistent and longer-term support for programmes. They should ensure better followup of implemented projects for special groups of beneficiaries, instead of frequently changing the focus onto groups they want to support. Donors are also dependent on DPOs for their own improvement, for example, donors need information from DPOs to be in a position to manage the programmes better. Donors should avoid over-funding, they should not always draw on the same faces. Many DPOs are new organisations and lack professional expertise. It is necessary, for example, to avoid *jargon* as this can be an obstacle to getting grants. Grant application formats should be accessible. The keyword is collaboration, use strengths from both sides.

A unified voice: common issues to work on

How can DPOs motivate mainstream NGOs to work with disabled people? Go and meet the NGOs! In this case people with disabilities can really contribute instead of (being seen as) only draining family resources. A big challenge for DPOs is that their voice should include all categories of disabled persons at all levels. And, only a unified voice on key issues among people with disabilities can achieve significant change. Therefore DPOs should work on key issues together. For example getting disability on the PRSP agenda (see box *Disability on the PRSP agenda*), or joining efforts in raising awareness about the international (UN) convention on the protection and promotion of the rights and dignity of persons with disabilities. Learn from developments in other areas, for example from HIV/Aids, which is now understood more accurately as a human rights issue. Northern and Southern DPOs could work together on certain issues. The base for common understanding between them is very strong and could stimulate joint action.

More attention on empowerment

The symposium demonstrated that there is an urgent need for donor organisations to work more on the empowerment of people with disabilities. Disability is a human rights issue and donor organisations should help DPOs to build capacity and to better advocate access to human rights for disabled people throughout their region or country. In this way, disabled people can make a real difference and contribute equally to the development of their society.

Mark Rajmakers

VERANSTALTUNGEN

- 18.09.-13.10.2005 International Course in CBR Management, Alphen aan den Rijn, Niederlande
Information: Enablement, Huib Cornielje, Langenhorst 36, 2402 PX Alphen aan den Rijn, Niederlande, Tel: ++31-172-436953, Fax: ++31-172-244976, E-Mail: h.cornielje@enablement.nl, www.enablement.nl
- 26.09.-29.09.2005 International Symposium "Inclusion and the Removal of Barriers to Learning, Participation and Development", Bakittingi, West Sumatra, Indonesia
Information: Braillo Norway, P.O.Box 1365 JKS, 12013 Jakarta, Indonesia, symposium2005id@idp-europe.org, www.idp-europe.org
- 30.09.-01.10.2005 "Our Rights - Our Future" - International Conference of World Federation of the Deaf, Helsinki, Finnland
Information: Tel.: +358-9-4542190, Fax: +358-9-45421930, www.wfdhelsinki2005.org
- 17.10.-18.10.2005 Disability: A global perspective on rights to education and livelihoods, Bangkok/Thailand
Information: Leonard Cheshire International, Fiona McConnon, 30 Millbank, London SW1P 4QD, Großbritannien, Tel: +44-20-7802 8217, Fax: +44-20-7802 8275, Email: Fiona.McConnon@lc-uk.org, http://lcint.org.uk
- 17.10.-19.10.2005 International Conference on Accessible Tourism, Nairobi/Kenia
Information: Kenya Disabled Development Society, P.O.Box 40500-00100 GPO, Nairobi/Kenia, Tel.: +254-20-826185, Fax : +254-20-821375, Email: bodo@avu.org, http://rdi.pl/kdds
- 21.10.2005 7. RC-Forum: Zwischen Ideologie und Realität: Enthospitalisierung in Europa
Information: REHA CONSULT e.V., Lenther Steig 8, 13629 Berlin, Tel.: +49-30-38305467, Fax: +49-30-38305358, E-Mail: ina.riek@rehaconsult.org, www.rehaconsult.org
- 04.11.-06.11.2005 Entwicklungszusammenarbeit als soziale Aufgabe und praktische Erfahrung - Teil II. AufbauSeminar zur Vorbereitung von Arbeits-, Praktikums- und Studienaufenthalten in Afrika, Asien und Lateinamerika in Kooperation mit der Akademie Frankenwarte in Würzburg
Information: Behinderung und Entwicklungszusammenarbeit e.V.
- 09.12.-11.12.2005 Seminar für RückkehrerInnen: Entwicklungszusammenarbeit als soziale Aufgabe und praktische Erfahrung - Teil III in Kooperation mit der Akademie Frankenwarte in Würzburg
Information: Behinderung und Entwicklungszusammenarbeit e.V.
- 06.01.-07.01.2006 EU-India Conference: Circles of Support (CoS) in India and the EU - towards person-centred community inclusion networks in Bhubaneswar, Indien
Information: Prof. Dr. Evamarie Knust-Potter, Fachhochschule Dortmund, Emil-Figge-Str. 44, 44227 Dortmund, Tel.: +49 231 755 5192, Sekr.: +49 231 755 6832, Fax: +49 231 755 6833, E-mail: knust-potter@fh-dortmund.de, Internet: www.cos-transnational.net

Für weitere Veranstaltungen auf dem Gebiet der Entwicklungszusammenarbeit weisen wir auf den Rundbrief Bildungsauftrag Nord-Süd des World University Service hin. Bezug: World University Service, Koordinationsstelle Nord-Süd im Bildungsbereich, Goebenstraße 35, 65195 Wiesbaden, <http://www.tu-darmstadt.de/wusgermany>.

NEWS

Demolition of poor people's homes and market stalls in Zimbabwe

The *Southern Africa Federation of the Disabled* (SAFOD) is "appalled and disgusted" by the destruction of people's homes and businesses by the Zimbabwean Government in the so-called clean-up campaign "Operation Murambatsvina" (translated as "drive out the rubbish"). The campaign, that started in May, has seen thousands of people living in the urban areas of the country being evicted from their homes and market stalls. During the forced evictions which are being carried out without notice and without court orders, police and other members of the security forces have been using excessive force to either burn or pull down homes and informal market stalls, destroying property, and beating up individuals. In Harare alone, the capital city of Zimbabwe, an estimated 300 000 families have so far been displaced by the clean-up campaign, and there are police threats that this campaign will spread to other areas beyond the urban centres.

SAFOD are particularly concerned with the situation of disabled men and women, and their families, who have been affected by this diabolic operation. Being the poorest of the poor, a majority of disabled urban dwellers were living in the type of housing units that were destroyed. For those who were running small businesses such as fruit and vegetable stalls, hair salons, flea markets, etc., also had their businesses destroyed. The forced destruction and/or closure of informal businesses and settlements has obviously worsened the situation of disabled people and their families in the country.

Quelle: SAFOD

bezev-Preis für wissenschaftliche Arbeiten zum Thema Behinderung und Entwicklungszusammenarbeit

Der bezev-Preis für hervorragende wissenschaftliche Arbeiten zum Thema Behinderung und Entwicklungszusammenarbeit wird jährlich verliehen. Eingereicht werden können Diplom-, Zulassungs- und Magisterarbeiten, die an deutschen Universitäten oder Fachhochschulen vorgelegt und nicht älter als zwei Jahre sind. Genauere Informationen erhalten Sie im bezev-Regionalbüro Süd.

Kontakt: Behinderung und Entwicklungszusammenarbeit, Regionalbüro Süd, Heike Fischer, Kidlerstr. 24, 81371 München, E-Mail: fischer@bezev.de

Wanderausstellung zu MDGs und Behinderung

Im September 2005 werden die Staats- und Regierungschefs auf einer UN-Konferenz eine Zwischenbilanz der im Jahre 2000 vereinbarten Millennium Development

Goals (MDGs), der internationalen Entwicklungsziele ziehen. Diese sehen unter anderem vor, die Zahl der in absoluter Armut lebenden Menschen bis zum Jahre 2015 zu halbieren oder allen Kindern eine Primarschulbildung zukommen zu lassen. Obwohl die internationalen Entwicklungsziele für Menschen mit Behinderung von besonderer Relevanz sind, finden sie darin keine Erwähnung.

Welche Bedeutung die MDGs für Menschen mit Behinderung haben, zeigt die Wanderausstellung „Es ist an der Zeit...“ auf, die von *Behinderung und Entwicklungszusammenarbeit* (bezev) im Rahmen des Projektes *Armut - Behinderung - Entwicklung* erarbeitet worden ist. Die Ausstellung hat im Vorfeld der UN-Zwischenkonferenz bereits wichtige Stationen durchlaufen, um darauf hinzuweisen, dass Menschen mit Behinderung bei der Umsetzung internationaler Vereinbarungen nicht vergessen werden dürfen. So ist sie bereits im *Bundesministerium für wirtschaftliche Zusammenarbeit und Entwicklung* (BMZ) in Bonn, der *Kreditanstalt für Wiederaufbau* (KfW) in Frankfurt, bei *InWEnt* in Bonn, dem *Ministerium für Umwelt und Naturschutz, Landwirtschaft und Verbraucherschutz* des Landes Nordrhein-Westfalen oder dem Tag der Begegnung in Xanten zu sehen gewesen. Im September wird die Ausstellung im Eine Welt Haus in München sowie bei InWEnt in Bad Honnef gezeigt.

Wenn Sie die Ausstellung gerne in Ihre Stadt holen möchten, nehmen Sie bitte Kontakt mit bezev auf. Der Verleih der Ausstellung (inkl. einer umfangreichen Begleitbroschüre) ist kostenlos. Weitere Informationen zur Ausstellung sowie die aktuellen Ausstellungstermine finden Sie auf der bezev-Homepage (www.bezev.de), wo Sie sich die Ausstellung auch vorab online ansehen können.

Kontakt: Behinderung und Entwicklungszusammenarbeit (bezev), Wintgenstr. 63, 45239 Essen, Tel.: 0201/40 87 745, Fax: 0201/40 87 748, E-Mail: info@bezev.de

Belgischer Senat verbietet Streubomben

Der belgische Senat hat im Juli einem Gesetzentwurf zum Verbot der Herstellung, Lagerung und Verbreitung von Streubomben zugestimmt. Nach dem Abwurf verteilen diese Bomben Hunderte von Sprengkörpern über Flächen in der Größe von mehreren Fußballfeldern. Viele der Bomben explodieren beim Aufprall nicht und werden damit de facto zu Anti-Personen-Minen, die unterschiedslos Leid über Soldaten und Zivilisten bringen. Die Streitkräfte der USA und Großbritanniens haben 2003 bis zu zwei Millionen Streubomben über dem Irak abgeworfen, von denen nach Schätzungen zwischen 100.000 und 600 000 heute noch immer herumliegen. Ohne massive Räumungsprogramme werden sie früher oder später von Zivilisten ausgelöst. Während in vielen Ländern inzwischen parlamentarische Initiativen zum Verbot von

Streubomben ergriffen wurden, stellen 34 Staaten weiterhin Streubomben her, darunter auch die Deutschland.

Quelle: Handicap International

"Treffpunkt Eine Welt"

Jugendliche und junge Erwachsene, die mittels Begegnungen, Praktika oder längerfristigen Freiwilligendiensten fremde Länder kennen lernen möchten, finden Tipps, Termine, Informationen und Adressen in der Broschüre "Treffpunkt Eine Welt 2005/2006". Die Broschüre kostet bei Einzelbestellungen 2,80 Euro. Bei größeren Bestellungen gibt es Preisnachlass.

Weitere Informationen: www.dieeinewelt.de,

E-Mail: info@dieeinewelt.de, Tel.: 030 - 61074815.

Quelle: LHÜ-Info, Mai 2005

Stellenmarkt Global

Die Stellendatenbank des Arbeitskreises Lernen und Helfen in Übersee (AK LHÜ) unter www.oneworld-jobs.org enthält zurzeit mehr als 1 800 Angebote. Dabei handelt es sich zum einen um Stellen in der Entwicklungszusammenarbeit, im Entwicklungsdienst und im Zivilen Friedensdienst. Zum anderen werden internationale Freiwilligendienste, Workcamps und Praktika angeboten. Etwa 130 Anbieter sind aktuell in der Datenbank registriert. Die Angebote sind überwiegend soziale und entwicklungspolitische Tätigkeiten in Afrika, Asien, Lateinamerika und Osteuropa.

Quelle: LHÜ-Info, Juli 2005

Neue Datenbank vereinfacht Recherche zu entwicklungspolitischen Themen

Entwicklungspolitische Zeitschriften sind der aktuelle Pulsmesser entwicklungspolitischer Diskussion. Doch sie sind auch mehr: ein lebendiges Gedächtnis der Arbeit. In der Kooperation mit Hochschulen, Schulen u.a. werden NROs und Initiativen immer wieder nach inhaltlich fundierten Beiträgen gefragt. Im Herbst 1998 haben sich daher elf Archive und Dokumentationszentren zur Kooperation Dritte Welt Archive zusammengeschlossen. Ergebnis dieser Vernetzung ist das Archiv³, eine neu gestaltete Datenbank, mit deren Hilfe eine einfache Recherche zu entwicklungspolitischen Themen möglich ist. Die gesammelten Materialien und Informationen sind in anderen Dokumentationszentren und Bibliotheken kaum erhältlich. Auch deswegen ist die Datenbank für eine globalisierungskritische und entwicklungspolitische Bildungs- und Öffentlichkeitsarbeit äußerst wertvoll. Mit komfortablen Bestellmöglichkeiten bietet sie einen schnellen Zugriff auf einen Informationsschatz, der im Internet sonst nur über umständliche Recherchen oder Zufallstreffer zu finden ist. Der Datenbestand umfasst zurzeit gut 150.000 Zeitschriftenartikel und "graue Literatur". Weitere Infos: www.archiv3.org.

LITERATUR & MEDIEN

Frist, Tom

Don't treat me like I have leprosy

2003

ISBN: 094754325 2

In recent years, medical science has won a series of great victories over leprosy. Since the introduction of Multi-Drug Therapy (MDT) in the early 1980s, millions of people have been cured; and we know much more about the epidemiology of the disease, and about how to prevent the disabilities associated with it.

Yet such medical advances have not been accompanied by progress in tackling the psycho-social problems caused by leprosy. These include disability, social stigma, segregation - and the poverty that is the inevitable consequence. Millions of people who have been medically cured remain affected by these problems.

This highly readable book looks at the progress that has been made in the battle against leprosy, and outlines both the challenges and the way ahead in the fight for social and economic integration. It will be of value not only to those wishing to look at leprosy from a non-medical viewpoint, but to those working with other stigmatising conditions who would like to share the experience of others in fighting social isolation.

Bezug: ILEP, 234 Blythe Road, London, W 14 0HJ, Großbritannien

SINTEF

Living Conditions among People with Activity Limitations in Zimbabwe. A representative regional survey

2003

ISBN 82-14-03242-3

This research report provides results from a study on living conditions among people with and without activity limitations in Matabeleland, Manicaland and Midlands, Zimbabwe. The study began in 2001 and was completed in 2003.

Bezug: SINTEF Unimed, P.O.Box 124, Blindern, 0314 Oslo, Norwegen, Tel.: ++47 22 06 73 00, Fax: ++47 22 06 79 09, www.sintef.no

Hoogeveen, J.H.

Measuring Welfare for Small but Vulnerable Groups, Poverty and Disability in Uganda

World Bank, 2004

When vulnerable population groups are numerically small - as is often the case, obtaining representative welfare estimates from non-purposive sample surveys becomes an issue. Building on a method developed by Elbers, Lanjouw and Lanjouw (2003) it is shown how, for census years, estimates of income poverty for small vulnerable populations can be derived by combining sample survey and population census information. The approach is illustrated for Uganda, for which poverty amongst households with disabled heads is determined. This is possibly the first time that, for a developing country, statistically representative information on income poverty amongst disabled people is generated.

Bezug: http://www-wds.worldbank.org/servlet/WDSContentServer/WDSP/IB/2004/10/14/000090341_20041014091219/Rendered/PDF/301680SP004190.pdf

Jones, Hazel & Reed, Bob

Water and Sanitation for disabled people and other vulnerable groups

2005

Over 500 million people in the world are disabled, the majority of whom live in poverty in low-income communities. A major contributing factor to the poverty of disabled people is their lack of access to sanitation and safe water. The Millennium Development Goals of poverty reduction, health and access to safe water and sanitation will be difficult to achieve equitably without addressing the access needs of disabled people. Many other vulnerable groups also experience difficulties using water and sanitation facilities, such as frail, elderly people, pregnant women, parents with small children, and people who are injured or sick - including people with AIDS. Despite the size of the problem, almost nothing has been published on this subject to date, and disabled people continue to be ignored by providers of water and sanitation services. Based on three years of international research with WATSAN and disability sector organizations, this book fills a significant gap in knowledge.

Bezug: WEDC Publications, Loughborough University, Leicestershire, LE11 3TU, Großbritannien, Tel.: ++44 (0) 1509 222618, Fax: ++44 (0) 1509 211079, E-Mail: K.J.Betts@lboro.ac.uk, Internet: <http://www.lboro.ac.uk/wedc/publications>

Koordinator/in für den Bereich Gesundheit – Behindertenarbeit in Vietnam

Der Deutsche Entwicklungsdienst (DED) ist einer der führenden Personal- und Fachdienste in der Entwicklungszusammenarbeit. Mittelpunkt unserer Arbeit ist die Entsendung von berufserfahrenen, sozial engagierten Entwicklungshelferinnen und -helfern als Fachkräfte auf Zeit in über 90 Länder weltweit. In Vietnam hat sich der DED im Bereich Gesundheit auf die Unterstützung von Menschen mit Behinderung spezialisiert.

In Kooperation mit staatlichen, nichtstaatlichen und internationalen Organisationen unterstützt der DED durch den Einsatz von Fachkräften Projekte und Programme im Bereich Community Based Rehabilitation (CBR), Sonder- und Integrationspädagogik sowie Ausbildung von vietnamesischen Fachkräften für Rehabilitation und Pädagogik. Ziel des Einsatzes ist die Weiterentwicklung, fachliche Steuerung und Koordination des DED Beitrags zur Behindertenarbeit im Landesprogramm Vietnam.

<p>Ihre Aufgaben</p> <ul style="list-style-type: none"> • Koordinierung und Weiterentwicklung des Sektors Gesundheit/ Behindertenarbeit einschließlich P. M&E-Verfahren und Fortschreibung der landesspezifischen Fachleitlinien • Beratung der DED-Fachkräfte und Projektpartner • fachliche und inhaltliche Unterstützung der Fachgruppenarbeit • Fortführung und Ausbau der Zusammenarbeit mit anderen vietnamesischen und internationalen Organisationen • Sondierung, Prüfung und Etablierung neuer Kooperationen • Zusammenarbeit mit den anderen deutschen EZ-Organisationen bei der Programmbildung im Sektorschwerpunkt Gesundheit (Sektorstrategiepapier) • Zusammenarbeit mit dem Landesdirektor und den beiden anderen Koordinatoren bei der Programmentwicklung und Koordinierung des Tagesgeschäfts • Mitarbeit in der Kerngruppe Qualitätsmanagement des DED Vietnam 	<p>Ihre Voraussetzungen:</p> <ul style="list-style-type: none"> • 5-jährige Berufserfahrung • sehr gute Englischkenntnisse • Berufsprofil: Sozialwissenschaften, (Sonder-) Pädagogik, Rehabilitation oder Medizin • Kenntnisse und Erfahrungen im Bereich „Rechte von Menschen mit Behinderung“ und Bereitschaft, sich in das Problemfeld Behindertenarbeit in Entwicklungsländern einzuarbeiten • fundierte Auslandserfahrung in der EZ • Beratungskompetenz und gute Kommunikationsfähigkeit sowie gute interkulturelle Kompetenz <p>Wünschenswert:</p> <ul style="list-style-type: none"> • Kenntnisse der Region und der internationalen Organisationen im Bereich Behindertenarbeit • Masters in Public Health oder andere relevanter Richtung • Erfahrung in der Organisationsentwicklung • Erfahrung im Bereich Zivilgesellschaft • Managementerfahrungen, Planung, Monitoring und Evaluierung
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Ihr Engagement ist auf 2 Jahre befristet mit der Möglichkeit der Verlängerung. Auf Ihre Aufgaben werden Sie intensiv vorbereitet. Die Leistungen richten sich nach einem DED-eigenen Vergütungssystem, inkl. Sozialversicherungen. Wenn Sie an einer dieser Aufgabe interessiert sind, freuen wir uns auf Ihre Bewerbung mit den üblichen Unterlagen unter Angabe der Kennziffer 9050.



Deutscher Entwicklungsdienst gGmbH, Bewerberreferat, Kzf. So50,
Tulpenfeld 7, 53113 Bonn; Weitere Informationen unter: www.ded.de

Netzwerk Menschen mit Behinderung in der Einen Welt

Menschen mit Behinderung in der Einen Welt ist ein Netzwerk von Organisationen und Einzelpersonen, die sich wissenschaftlich und/oder praktisch mit dem Thema Behinderung in der so genannten Dritten Welt auseinandersetzen. Mitglieder des Netzwerks können sein: Organisationen der Entwicklungszusammenarbeit, Institutionen, Arbeitsstellen an Studienstätten, Arbeitskreise und Arbeitsgruppen, Fachkräfte aus dem entwicklungspolitischen sowie behinderungsspezifischen Kontext sowie an der Thematik interessierte Einzelpersonen. Das Netzwerk ist ein Kommunikationsforum, das die wissenschaftliche und praxisorientierte Auseinandersetzung zur Thematik fördern und unterstützen will. Dies wird umgesetzt durch die ihm angehörenden Mitglieder.

Das Netzwerk übernimmt die folgenden Aufgaben:

- Herausgabe der Zeitschrift Behinderung und Dritte Welt
- Durchführung gemeinsamer Veranstaltungen (z.B. Symposia)
- Koordinationsstelle für an der Thematik Interessierte
- Vermittlung von Kontakten
- Diskussionsforum zu relevanten Fragestellungen
- Zweimal im Jahr Netzwerktreffen in unterschiedlichen Regionen Deutschlands
- Vernetzung

Anschrift Netzwerk Menschen mit Behinderung in der Einen Welt
c/o Behinderung und Entwicklungszusammenarbeit e.V.
Wintgenstr. 63, 45239 Essen
Tel.: 0201/40 87 745, Fax: 0201/40 87 748, Email: bezev@t-online.de
Internet: www.bezev.de

Schwerpunkthemen kommender Ausgaben der Zeitschrift Behinderung und Dritte Welt

- 3/2005** Regionale Perspektiven der Behindertenarbeit (Asien) - (verantwortlich: Mirella Schwinge/Susanne Arbeiter)
- 1/2006** Menschen mit Behinderung in der humanitären Hilfe (verantwortlich: Gabriele Weigt)
- 2/2006** Wege zur Einkommensförderung für Menschen mit Behinderung in Entwicklungsländern

Interessierte Autorinnen und Autoren werden aufgefordert, nach vorheriger Rücksprache mit der Redaktion hierzu Beiträge einzureichen. Darüber hinaus sind Vorschläge für weitere Schwerpunkthemen willkommen.

Einsendeschluss für Beiträge

	Ausgabe 3/2005	Ausgabe 1/2006	Ausgabe 2/2006
Hauptbeiträge	15. Juli 2005	15. November 2005	15. Februar 2006
Kurzbeiträge	15. August 2005	15. Dezember 2005	15. März 2006

Liebe Leserinnen und Leser,
bitte informieren Sie uns über eine eventuelle Adressenänderung oder wenn Sie die Zeitschrift nicht mehr beziehen möchten. Geben Sie uns bitte ebenso Bescheid, falls Ihnen die Zeitschrift nicht zugestellt worden ist.

Zeitschrift Behinderung und Dritte Welt

Behinderung und Dritte Welt ist die Zeitschrift des Netzwerks Menschen mit Behinderung in der Einen Welt. Sie erscheint seit 1990 dreimal jährlich in einer Auflage von 850 Exemplaren und wendet sich v.a. an deutschsprachige Interessierte im In- und Ausland.

Vor allem dank der Unterstützung der Bundesvereinigung Lebenshilfe e.V., Kindernothilfe e.V. und Behinderung und Entwicklungszusammenarbeit e.V. erreicht sie viele WissenschaftlerInnen, Fachleute und sonstige Interessierte in allen Kontinenten.

Ihr Anspruch ist einerseits, ein Medium für einen grenzüberschreitenden Informationsaustausch zur Thematik darzustellen und andererseits, die fachliche Diskussion zu pädagogischen, sozial- und entwicklungspolitischen sowie interkulturellen Fragen im Zusammenhang mit Behinderung und Dritter Welt weiterzuentwickeln.

Die Redaktion und der sie unterstützende Fachbeirat sind insbesondere darum bemüht, Fachleute aus allen Teilen dieser Erde hierfür zu gewinnen und einzubinden. Publikationssprachen sind Deutsch und Englisch; Beiträge in Französisch, Spanisch oder Portugiesisch werden nach Möglichkeit übersetzt. Das Profil der Zeitschrift zeichnet sich durch jeweils ein Schwerpunktthema pro Ausgabe, eine über mehrere Hefte hinweglaufende Schwerpunktserie sowie einen Informationsteil aus.

Die Ausgaben der Zeitschrift Behinderung und Dritte Welt sind auch im Internet abrufbar unter:
<http://www.uni-kassel.de/ZBeh3Welt>

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