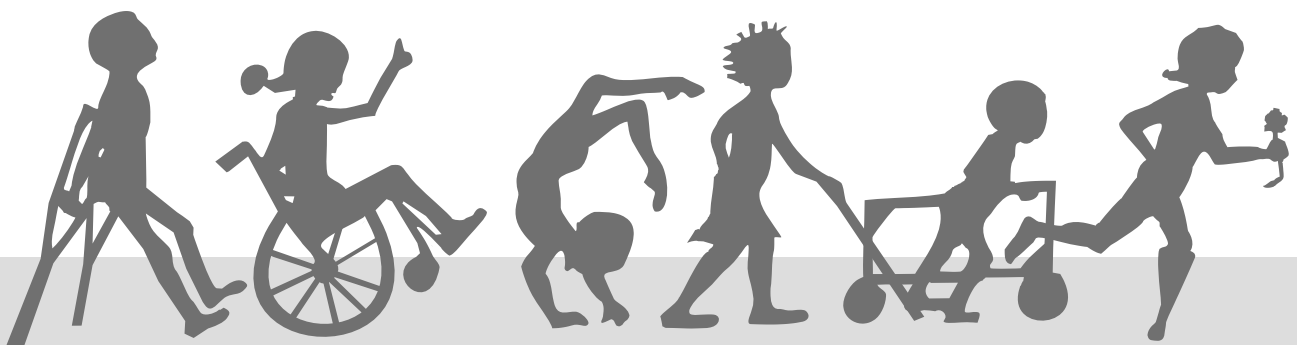


# Behinderung und internationale Entwicklung

## Disability and International Development



Frühkindliche Entwicklung und Inklusion  
Early Child Development and Inclusion





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## Editorial

Liebe Leserinnen und Leser,

die besonderen Risiken für die frühkindliche Entwicklung, die mit dem Aufwachsen im Globalen Süden verbunden sind, sind seit langem bekannt. Weltweit leben mehr als 200 Millionen Kinder unter Bedingungen von Armut, gesundheitlichen Risiken, Unter- und Fehlernährung. Die medizinische Versorgung und pädagogische Unterstützung, die sie für eine gesunde Entwicklung brauchen, bleiben ihnen vielfach vorenthalten. Dieses Schwerpunktheft bietet drei Beiträge zu diesem Themenbereich:

*Akhil S. Paul, Biju Mathew, Uttam Kumar, Sachin Rizal und Atul Jaiswal* stellen die Situation von Menschen in Indien vor, die von Taubblindheit betroffen sind, und zeigen die Chancen auf, die frühe Hilfen für Kinder und ihre Familien beinhalten. *Kozue Nagata* öffnet die Perspektive in Richtung des Diskurses um Intersektionalität. Basierend auf vorliegenden Forschungserkenntnissen und einer Befragung von Frauen mit Behinderungen in Pakistan werden Aspekte von Gender, Mutterschaft und Behinderung in ihren Wechselwirkungen als Faktoren sozialer Ausgrenzung diskutiert. Der dritte Beitrag von *Reshma Parvin Nuri* und *Heather Michelle Aldersey* widmet sich den Unterstützungsbedarfen von Familien, die Behinderungserfahrungen haben. Durch eine systematische Literaturanalyse wurden die zentralen Bedürfnisse dieser Familien herausgearbeitet. Sie beziehen sich auf Informationsbedarfe und die Gestaltung von Unterstützungsarrangements, zugleich aber auch auf Anforderungen an die alltägliche Lebensgestaltung als Familien mit Angehörigen mit Behinderungen. Die Beiträge unterstreichen die Bedeutung früher Unterstützung, um Familien zu stärken und zu befähigen, positive Zukunftsperspektiven zu entwickeln.

Wir wünschen eine anregende Lektüre.

Ihr Redaktionsteam

Dear Readers,

living in the Global South implicates special risks for a child's development. Worldwide, more than 200 million children under the age of 5 live in conditions of poverty, health risks, and malnutrition. The lack of equal access to health care and pedagogical support in many low income countries negatively influences early cognitive and socio-emotional development. Identifying special needs as early as possible and providing adequate support are crucial aspects for growing-up and healthy development.

*Akhil S. Paul, Biju Mathew, Uttam Kumar, Sachin Rizal, and Atul Jaiswal* focus on the situation of people living with deafblindness in India and describe barriers and enablers in providing early intervention programs for this special group. *Kozue Nagata* opens the view into the discussion on intersectionality by focusing on gender, motherhood and disability as closely interrelated factors of social exclusion. The presented research project analysed available statistics and studies, and assessed the voices of Pakistani women with disabilities, drawing attention to the connection of disability and development from a gender perspective. The third article reviews needs of families with disability experiences. *Reshma Parvin Nuri* and *Heather Michelle Aldersey* conducted a systematic analysis of literature to identify families' needs regarding information and service provision as well as everyday life challenges of the families.

These three articles demonstrate that early childhood intervention can contribute to individual development as well as to enabling families to envision a positive future with their children with disabilities.

We wish you a good reading.

Your editorial board



# Early Intervention (EI) for Children with Deafblindness in India: Barriers and Enablers

Akhil S. Paul/Biju Mathew/Uttam Kumar/Sachin Rizal/Atul Jaiswal

Research on early intervention programs meeting sensory disabilities is very limited in India and at a global level. Sense International India (SII) as a national level organisation developed a model of EI services specified for persons with deafblindness in 2012. This paper uses the SII-EI model as a case study to highlight the barriers and enablers in providing EI services for children with deafblindness in India.

## Introduction

Deafblindness is a disability involving a combination of varying degrees of hearing and visual impairment causing difficulties with communication, access to information, and mobility (Sense International India n.d.). It is a heterogeneous disorder also referred to as "dual sensory loss" (Dammeyer 2014) encompassing a spectrum from mild loss in hearing and vision to total deafness and blindness depending upon its varied combinations. It could be congenital or acquired and varies with regard to medical aetiology, age of onset, severity of vision and hearing loss, and presence of associated medical conditions. Aetiology includes pre-, peri- and postnatal causes, as well as genetic and chromosomal disorders. Prenatal causes include infections of the foetus with rubella or cytomegalovirus. Perinatal causes include low birth weight and postnatal causes include intoxication and infections, such as meningitis. This peculiar combination of hearing and vision loss under the ambit of dual sensory loss results in a unique condition that is more disabling than the sum of its impairments (Dammeyer 2014).

It is a low incidence disability, however, given the morbidity pattern in most low/middle income countries due to advancement in medical services, it is estimated that the incidence of deafblindness is significant and likely to increase. Earlier children born with complex medical conditions could not survive due to lack of advance medical services in less developed cities in India. However, medical services have improved and has resulted into their survival of these children with complex medical conditions, however, most often they have conditions with developmental delay and other sensory issues such as in deafblindness.

There is an estimation of 2.5 million people with deafblindness worldwide and the majority of them experience high levels of poverty and social exclusion with limited access to resources (Source n.d.). Estimates indicate that there

could be more than 500,000 persons with deafblindness in India (Sense International India 2015). Overall, India is home to 26.8 million persons with disabilities (PwDs) (Census 2011). Despite having progressive disability policies, people with disabilities in India are subject to multiple deprivations and limited opportunities in several dimensions of their lives and have limited awareness of entitlements and services available by law for people with disabilities (Menon/Parish/Rose 2014). World Bank report in 2009 reveals that persons with disabilities are excluded from exercising their human rights and achieving higher levels of human development (O'Keefe 2009). They often face barriers to information and services due to the ignorance and negative attitudes of society and individuals (Barnes/Mercer 2003). Among this population, children with disabilities are the most vulnerable groups who need proper and timely interventions to avert their disability and/or its impact on their lives. The United Nations Children's Emergency Fund (UNICEF) and the Institute for Statistics' (UIS) South and East Asian Regional Report highlighted that approximately 11.9 million children with disabilities are out of school in India (UNICEF-UIS 2014). Within this larger population of children with disabilities who are still underserved and excluded are also children with deafblindness.

India ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2007 and is trying to harmonise the laws and policies with the convention. One key step towards this harmonisation is revamping the older welfare-law The Persons with Disabilities Act 1995 into the newer rights-based The Rights of Persons with Disabilities Bill 2014 (EPW 2014). Deafblindness has not been recognised as a separate category of disability in the current disability law The Persons with Disabilities Act 1995 in India. Due to the non-recognition, they are deprived of government schemes and social security benefits. Once enacted by legislature of India, the newly drafted bill would



replace the current disability act, and cover 19 specific impairments including deafblindness (PRS 2015).

Because 95 % of what one learns about the world comes through sight and hearing, challenges in communication, mobility and accessing information makes deafblindness one of the most isolating impairments and affects the whole development of the child. Identification at an early age and access to need-based EI plays a vital role in the development of each child with deafblindness. EI services for young children (aged 0-6 years) through hearing screening, visual testing, multisensory stimulation, functional visual training, speech therapy and developmental therapeutic interventions enhances the chances of reaching maximum potential for children with deafblindness significantly (Sense International India n.d.).

Sense International India (SII) is the first and only national level organisation working with deafblind people across India since 1997. SII is working in 23 states of India through a network of 57 partner organisations, supporting over 71,500 persons with deafblindness in some of the poorest areas of the country for the last 18 years (Sense International India 2015). The SII theory of change imbibes two main principles – partnership with local grassroots organisations and capacity building to transfer skills and knowledge to partner organisations and professionals, so that they can work with the deafblind population. SII has been involved in early identification and intervention since 1998 and has worked on community based rehabilitation (CBR) approaches to EI, in order to ensure children with deafblindness get the best possible start towards achieving their potential. Based on the learning and experience, SII developed its model of EI service delivery in 2012. This was done in partnership with hospitals and partner organisations. Hospitals were involved to ensure early screening of *at-risk* new-born children with dual sensory loss and timely intervention to minimise the impact of dual sensory loss.

## Research Question

The paper is guided by the following research question: “What were the barriers and enablers in early intervention services for children with deafblindness in India?” This article will reflect upon EI services for children with deafblindness in India and highlight barriers and enablers identified, while implementing projects for EI services following the SII-EI model.

## Methods

This paper uses the SII-EI Model as a case study to highlight the barriers and enablers in providing EI services for children with deafblindness in India. The paper relies on a review of literature on EI for deafblindness, EI project reports and documents of Sense India to highlight barriers and enablers in EI services. Online database sources of CINAHL, MEDLINE, PubMed and Google Scholar were used for secondary literature review. The keywords used to retrieve the relevant articles included early intervention, deafblindness, deaf-blind, children, India, barriers, enablers or facilitators. Relevant reports of the World Health Organisation (WHO), the United Nations Development Fund (UNDP), the United Nations Children's Emergency Fund (UNICEF) and the UNESCO Institute for Statistics (UIS) are also used along with the SII publications.

The article is divided into three main sections. The first section gives a brief introduction on the development of EI services and their significance for children with deafblindness in the Indian context. In the second section, SII-EI model for children with deafblindness will be introduced and in the third section, barriers and enablers for deafblind specific EI services are described and suggestions on how EI programs can be planned and implemented effectively and efficiently are mentioned. It is acknowledged that there is a range of project management challenges as in any project, however, for the purposes of this article, the discussion will exclusively focus on the barriers and enablers in EI services specific to children with deafblindness.

## Early Intervention and its Significance for the Deafblind Population

Research in the field of deafblindness is limited (Dammeyer 2014, Danermark/Moller 2008) and is further limited in the context of EI for children with deafblindness (Murdoch 2004). Deafblindness can have many different causes including poor nutrition or trauma during pregnancy; as a result of the mother having rubella leading to Congenital Rubella Syndrome; Usher Syndrome; or due to an illness such as meningitis or following premature birth. Effective early identification & EI services directly influence the impact of underlying medical impairments turning into a disabling condition, and help to reduce the risks that children with sensory impairments would otherwise face. Early intervention also provides long-term benefits to families and society by reducing mental distress



of families and the risk of the child requiring more intensive care (services) later on. It helps in promoting parent-child bonding and enhances the caregiving process for the child (Chen/Haney 1995).

One of the major challenges in the field of developing deafblind interventions in India are ill-equipped public systems to identify and diagnose children at risk of deafblindness at an early age and to provide them EI services instantly to avert their level of disabilities. These gaps in the public health service delivery include a lack of neonatal screening and EI support for children with deafblindness in their crucial early years. The Government of India initiated a National Child Health Programme Rashtriya Bal Swasthya Karyakram (RBSK) aimed to reduce child mortality and early identification as well as intervention for children from birth to 18 years to cover defects at birth, deficiencies, diseases, and development delays including disability (Ministry of Health and Family Welfare 2013). The programme was notified in the year 2013, however, the country has not seen much progress in terms of establishing early identification and intervention systems for children with disabilities.

The developmental consequences of deafblindness indicate the need for EI involving families, coordinated with specialist intervention or services (Murdoch 2004). Early intervention services need to be set up in partnership with hospitals where infants from 0-6 years can be screened by doctors with follow-up through one-to-one training by professionals. However, most of the time, especially in rural or distant areas, services are practically non-existent or insufficient for young children with deafblindness. Access seems to depend on where the child lives. This results in precious time being lost as the first three years of life are the crucial period when maximum learning and development takes place.

### **The Sense International India Model of Early Intervention for Children with Deafblindness**

SII has been working with persons with deafblindness for over 18 years, and has adopted various models like home-based, centre-based, and community-based rehabilitation programs. Sense India will reach two decades of unique service with the children and adults with deafblindness across the states of India by the year 2017. A focussed EI service with the aim of establishing a system of specialist, multi-disciplinary support for deafblind babies & children and their families was initiated in the year

2011. SII identified that while there are hospital-based identification programmes for children with deafness and blindness separately, these programmes missed out on identifying children with deafblindness. This was also due to the reason that there was lack of reliable tools for identification of visual impairment and hearing loss, especially when children have multiple disabilities. In some cases, visual impairment was diagnosed but the child's hearing status remained unknown.

The pilot programme was set-up in Patna, Bihar in 2011 with the help of SII's partner organisation that was already working in the state. A collaboration was built with the local hospital that helped in the early identification of at-risk new-born children with dual sensory loss and timely intervention to minimise the impact of sensory loss. Main objectives of the EI programme are:

- i. To identify children at a high risk of deafblindness in the age group of 0-6 years;
- ii. To provide necessary support and intervention to overcome and/or reduce difficulties in accessing information, communication, mobility and orientation as early as possible;
- iii. To assist in providing comprehensive home-based and/or centre-based services including assessment, and clinical and therapeutic services to the children with deafblindness including necessary aids and appliances;
- iv. To provide support and counselling to the families, helping them reduce the feelings of isolation, stress and frustration that families may experience;
- v. To provide training in motor, communication, sensory, oro-motor, cognitive, social and activities of daily living (ADL) skills.

In order to achieve these objectives, the following main activities are undertaken:

- i. Orientation and advanced skill training to educators and field workers in EI for young infants with deafblindness;
- ii. Developing an individualised education plan (IEP) for each child;
- iii. Training and counselling of family members/caregivers;
- iv. Production of information materials in local languages;
- v. Awareness and sensitisation activities at regional and state level;
- vi. Sensitisation training of medical and para-medical professionals.

Based on the learning and experience, the program was tested and validated and has now been expanded in eight additional states (Andhra Pradesh, Goa, Gujarat, Karnataka, Kerala, Madhya Pradesh, Maharashtra, and Ta-



mil Nadu) in India. The program is being managed with the help of SII's partner organisations working in the states. The overall process involves field surveys with the help of special educators and CBR workers to identify children with deafblindness or children at risk of developing deafblindness in the community (see Figure 1).

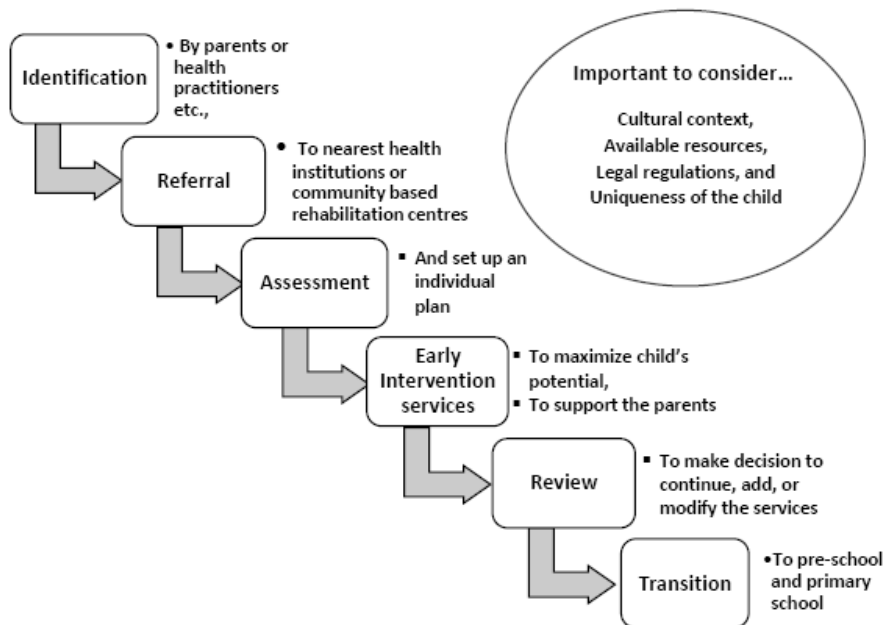


Figure 1: Process steps for the Early Intervention Model  
(Source: Sense International [India] Document on Early Intervention Model 2011)

This is followed by the referral of children identified as at risk of developing deafblindness to the partner hospital where assessment is carried out by medical doctors. After identification and referral, one-to-one training is provided by qualified deafblind educators or experts. An observational checklist on visual and hearing behaviour is given to all parents that help families to monitor any deviation from normal development pattern (refer to Annexure 1). The range of services includes family counselling, needs-based training support by trained educators, provision of necessary aids & appliances and continued medical support. In addition to this, services are provided to cater for the individualised need of each child identified with deafblindness. This includes audiology, family training, physiotherapy, occupational therapy, clinical psychologist services, nutrition services, counselling, home visits, assistive technology, speech language therapy, and special education training. Individualised plans and achievements are revisited periodically to ensure the individualised intervention plan is appropriate and working. Between 2012-2015 (December), 5433 new-born infants (2939 males and 2494

females) were screened using the Otoacoustic Emission (OAE) technique and 331 children (200 males and 131 females) were enrolled into the EI programme to receive services (Sense International India 2015).

The guidelines are prepared for reference of the partner organisations in undertaking the EI activities in their respective project areas (refer Annexure 2). This also helps the partner NGOs to follow a standardised procedure for undertaking the activity. Regular onsite trainings and mentoring support is being provided by SII experts. The programme is monitored regularly with the help of quantitative and qualitative indicators like number of babies assessed, number of appointments held with EI specialists, confidence level of parents to follow the individual development plan, confidence level of EI specialists to follow the progress of a child against developmental milestones in the individual development plan. Participatory review workshops are organised annually where all the stakeholders groups represent themselves. After an agreed period of time, usually 1.5 to 3 years, an independent evaluation of the effectiveness of the pilot EI service is undertaken, with learning shared amongst stakeholders and used to make improvements to the EI services.

### Barriers and Enablers

The most common challenge found in both research and practice when working with deafblind population is to communicate with them. Similarly, it becomes important to be aware of the consequences of dual sensory loss in providing treatment (Southern/Drescher 2005). The main goal of the SII-EI program is not merely development of a particular skill or shaping behaviour but to encourage an increased level of engagement with the world in general through exploring, imitating, turn taking, anticipation, mutual acceptance and role modelling. Through the programme it became apparent that working with children with deafblindness requires particular sets of skills, and many educators/professionals experience challenges in adapting their skills to best benefit these children. Many special educators work-



ing within the EI project reported facing problems in planning EI services, along with how to assess; which areas should be given importance; what goal to take; how to and how long to teach the particular skills to children with deafblindness. Keeping these factors in mind is crucial to the program and its success. The barriers and enablers have been classified and described at three levels – community level, partner organisation level, and hospital level.

#### *At Community Level*

Deafblindness is not yet recognised as a separate disability in India. Lack of recognition of deafblindness in current disability law deprives children with deafblindness in getting appropriate EI services for them in government hospitals. Moreover, government public health systems are not equipped with skills to identify and diagnose children at risk of deafblindness at an early age and to provide them EI services on time. There are hospital-based identification programmes for children with deafness and/or blindness, but these programmes miss out on identifying children with deafblindness. In addition to this, there is a lack of early reliable identification of visual and hearing loss in the same child, especially when children have multiple disabilities like deafblindness.

In India, there is a cultural practice that a pregnant woman moves to her parents' place for the delivery of the child, and goes back to her husbands' place after a few months. Due to this practice, babies identified *at risk* lose follow-up care and remain untraced after moving to a different place. In case of weak or low birth weight babies, parents happen to pay attention to their child's survival and other health issues for the first few years and hearing and vision issues become evident later. Sometimes, getting consent of the parents for visual/hearing testing on their new-born becomes difficult and requires counselling. In some places, the society and the family expect the EI services for the child only from the female trainers due to socio-cultural issues. In India, there is still a situation where women (mothers) mostly stay at home to take care of children and home, and men go out to work. In this condition, women prefer some women worker to come home when they are alone. Females are also preferred over males while working with the new-born in home based/CBR services because parents feel females can provide better care to the young baby.

Lack of adequate public transport facilities, especially in rural and difficult terrain areas, make it difficult for parents to reach the EI cen-

tre. This is also associated with the economic situation of the parents. Sometimes the parents of at risk babies from villages rely more on the *Tantriks* and *Gurus* (religious/spiritual healers) than the medical interventions, which leads to the loss of crucial time for EI. Delays in accepting their children with dual sensory loss or with development delay also add to barriers in providing EI to the children. In many parts of the country, many people still consider disability as medical issue, and during the early years, parents mostly focus on *medical treatment* rather than intervention. The lack of awareness and understanding among the parents of the interventions such as sensory stimulation, gross-motor/ fine-motor training, activities of daily living training and other therapeutic interventions hampers the process of EI. In addition, the ignorance by medical professionals about these interventions also compounds the overall scenario.

In contrast to the above mentioned barriers, the enablers are increasing deafblindness awareness in the community and among key stakeholders such as medical and para-medical professionals. Specific to the SII, the network of partner organisations working across 23 states of the country helps in the process of reaching out to the *at-risk* children through their community based rehabilitation programmes and enrolling the child into the nearest available EI programmes.

#### *At Partner Organisation Level*

The major barriers faced by partner organisations included difficulty in creating partnerships with hospitals for early screening of children, and getting referrals from them to EI centre. In addition, lack of man power trained in EI at partner organisation to provide need-specific EI services to the identified child is another major barrier. Specific teaching learning materials are required to be developed for the EI services and service providers need to be trained in development of teaching learning materials. Another barrier is the lack of time as it takes long to adapt the environment according to the needs of the child, and these children take long time to show results of the training. However, only limited time of services (might be ten hours a week or less) could be provided to the children with deafblindness due to constraints of resources in terms of man power and funding.

Enablers at partner organisations' level are the on-going transfer of EI technical skills to their staff and regular support through onsite mentoring and training on different skills and competencies of EI services. Rapport of the





partner organisations with the local hospitals and its visibility within the community through community based rehabilitation programs also act as enabling factor in EI service delivery.

#### *At Hospital Level*

Lack of availability of trained professionals in EI services directly affects the services. Only the trained professionals are eligible to do OAE screening, as neo-natal screening for deafblindness cannot be done like regular screening for deafness or blindness. Other associated health issues like epilepsy in young infants affect the screening of vision and hearing impairment. In addition, costs of OAE machines and equipment for testing and maintenance are high, which acts as a barrier in delivery of EI services. In some cases, where a child is recognised as having deafblindness and needs surgery such as a cochlear implant, the costs are high for the family or for the partner organisation and SII to support. Most of the time, medical professionals are focussed on their subject, and tend to ignore the issues which are not in their domain. For example, an otolaryngologist will not be much interested in visual behaviour or vision-related issues unless it is very evident. Similarly, the ophthalmologists are not concerned about hearing capacity. This impacts the identification at the early age and referral to the EI service or therapy centres.

Enabling factors are willingness of hospitals and healthcare professionals for the training on deafblindness and deafblind specific EI services. Their cooperation to develop EI services within their hospital infrastructure creates a win-win situation for all the stakeholders. In addition, advancement in and use of health care technology within hospitals to screen the children at an early age has facilitated the process of screening of children for any *at-risk* symptoms.

Sustainability of the EI programs for this unique population is a major challenge at all three levels. Providing EI services to *at-risk* infants or children with deafblindness and supporting their families requires substantial investment of efforts, time and resources.

The suggestions for developing effective and efficient deafblind specific EI services are:

1. Awareness programmes for parents, especially new parents, and community members on early identification of developmental delay or sensory impairment will enable the parents to identify problems at an earlier age.
2. Development of Information, Education and Communication (IEC) materials on early signs of *at-risk* of deafblindness and infor-

mation of nearest EI centres.

3. Sensitisation on the aspects of screening, assessment on the needs of persons with deafblindness, and their referral to the EI centres at the earliest.
4. Proper counselling sessions for the parents to make them understand the importance of neonatal screening and enhance the cooperation from parents for screening and later in receiving intervention for the child.
5. Regular training sessions for parents and other family members to equip them with skills and knowledge for providing services at home.
6. Ongoing knowledge upgradation of EI staff members on EI techniques to equip them with latest skills and knowledge to provide quality level of services to the child.
7. Proper data management information system at partner institution level for screened children, *at-risk* children, and children who have been diagnosed and referred to the nearest EI centre. Project implementers should take verified permanent address of the children screened. This will help to track the new-born and her/his overall development and rehabilitation outcomes from the date of identification till the level they are ready for the school education.

### **Limitations of the Study**

The inherent conflict of interest in this paper is that the article is written by the SII team based upon their own experiences of implementing EI projects in different parts of India. Worldwide research on deafblindness is sparse (Dammeyer 2014, Danermark/Moller 2008) and is further limited in the context of India. Hence, the paper is primarily based on the field-based observations and experiential learning of implementation of EI projects by SII in eight states of India.

### **Summary and Conclusions**

Providing EI services to infants who are deafblind and their families is complicated. Not only do the age, abilities, and needs of each child require an individualised approach, but family priorities, local culture and language, location, program resources, and state policies do also influence the nature of intervention services. These complexities emphasise the need for EI services and the requirement to work together to provide professional development activities for service providers and educational and networking opportunities for families of children who are deafblind. There is an ur-



gent need to initiate and reach out to the remote parts to ensure that every child with deafblindness gets the required intervention on time. Moreover, children with deafblindness take long time to show results of their training and education. Hence a continued and sustained program that would bring about transformation in the lives of children with deafblindness is a must. It is therefore vital for the rehabilitation professionals to be critically cognisant of the various interplaying factors which act as barriers and enablers in EI services received by children with deafblindness. There is a need for further research to explore the potential for improvement in EI programmes.

This paper concludes that comprehensive rehabilitation of children with deafblindness cannot be attained in isolation, but requires a multi-pronged approach and timely interventions to facilitate the optimal development of the child. It does require a planned approach with tested models of service delivery in place to ensure that no child *at-risk* is left out. There is a strong need for a conducive environment where every *at-risk* child in need for EI services gets access to quality services on time. The application of the SII-EI model and insights related to its implementation in India may serve as useful information for other organisations in developing EI models for children with deafblindness in other parts of the world.

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**Zusammenfassung:** Es gibt nur wenig Forschung zu Frühförderprogrammen (EI) bei sensorischen Beeinträchtigungen in Indien und global. Sense International India (SII) hat 2012 als nationale Organisation ein Model zur Frühförderung speziell für Menschen mit Taubblindheit entwickelt. Dieser Beitrag verwendet das SII-EI Model als Fallstudie, um Barrieren und Förderfaktoren in der Bereitstellung von Frühförderung für Kinder mit Taubblindheit in Indien aufzuzeigen.

**Résumé:** La recherche sur les programmes d'intervention précoce répondant aux déficiences sensorielle est très limitée en Inde et au niveau mondial. En tant qu'organisation nationale, Sense International India (SII) a élaboré, en 2012, un modèle de services IP spécifiquement prévues pour les personnes avec surdicécité. Ce document utilise le modèle SII-IP comme une étude de cas pour mettre en évidence les obstacles et les facilitateurs dans la fourniture de services IP pour les enfants avec surdicécité en Inde.

**Resumen:** La investigación sobre los programas de intervención temprana (IT) con respecto a la discapacidad sensorial es muy limitada en la India, como a nivel mundial. Sense Internacional India (SII), que es una organización a nivel nacional, desarrolló en 2012 un modelo de servicios de IT especificados para las personas con sordoceguera. Este artículo utiliza el modelo de SII-IT como un estudio de caso para poner en relieve las barreras y facilitadores en la prestación de servicios de intervención temprana para los niños con sordoceguera en la India.

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# Women, Motherhood, Children and Disabled Persons – Mainstreaming Disability in Development in Pakistan

Kozue Nagata

Women with disabilities in Pakistan do suffer from double or triple discrimination. Disability and gender is a closely interrelated developmental issue. This paper aims at analysing highlights covering gender, motherhood and disability in Pakistan, based on available statistics and studies, and the voices of disabled Pakistani women. The study gives insight into some causes and consequences of disability and development from the gender perspective.

## Introduction

Everywhere all over the world, women and girls are discriminated because they are women, and more so in some countries. Having a disability compounds this gender-based prejudice. Women with disabilities in Pakistan do suffer from this double discrimination. Disability and gender is a closely interrelated developmental issue, as both disability and gender inequality are a cause and a consequence of underdevelopment. Disabled women are often poor, thus, poverty adds a new dimension to this double discrimination. In Pakistan, the issue of disability has been neglected and ignored from all aspects of development, which includes administrative, financial and legal development. Women with disabilities are the most marginalised because they are not represented in the country. They are invisible, hidden, and their voices are not heard.

So far, there is no serious effort by the Government to conduct a comprehensive national survey to assess the socio-economic characteristics and problems of persons with disabilities. In the absence of national data, it is difficult to estimate accurately the scale and magnitude of problems being faced by women and girls with disabilities. Thus, this paper aims at analysing a couple of highlights covering gender and disability in Pakistan, based on available statistics and studies, the real voices of disabled women

in a series of focus groups and the author's informed observations during her three and a half year official function in Pakistan. It looks into some causes and consequences of disability and development (disability dynamics) from the gender perspective.

## Disability Statistics

In Pakistan, there are no updated statistics on women and girls with disabilities. Disability has been included in the National Census. According to the National Population Census of the year 1998, 2.49 percent (3,286,630) of the total population in Pakistan lived with some kind of disability. This is far less than the World Health Organisation's estimate of seven to ten percent for developing countries and the world average. It is most likely an underestimation.

According to the highly *medical model* classification system of disability statistics in Pakistan, the breakdown of disability was: 8.06 percent were blind, 7.43 percent deaf/mute, 18.93 percent physically disabled defined as 'crippled' in the National Population Census, 6.39 percent mentally ill defined as *insane*, 7.60 percent mentally challenged defined as *mentally retarded*, 8.23 percent having multiple disabilities and 43.37 percent others<sup>1</sup>.

The number of males (58%) with disabilities is significantly greater than females (42%). Sci-

Table 1: Population with disabilities by sex, nature of disability\*

Sex	Total	Blind	Deaf and mute	Crippled	Insane	Mentally retarded	Multiple	Others
Both sexes	3.286.630	264.762	244.254	622.025	210.129	249.823	270.381	1.425.256
Male	1.915.102	145.656	139.168	379.989	119.139	134.489	140.393	856.268
Female	1.371.528	119.106	105.086	242.036	90.990	115.334	129.988	568.988
Male	58,0 %	55,0 %	57,0 %	61,0 %	57,0 %	54,0 %	52,0 %	60,0 %
Female	42,0 %	45,0 %	43,0 %	39,0 %	43,0 %	46,0 %	48,0 %	40,0 %

Source: Population Census 1998, Government of Pakistan

\* Terminology used in the national statistics are considered "not appropriate"; however, for absolute accuracy purpose, the original terms are kept in this quoted table.



entifically and biologically speaking, similar to the pattern of general population distribution, the men-women ratio of disability incidences shall be close to one to one. This gender gap is possibly because of disabled women being non-visible and uncounted due to social shame, and also possibly a higher incidence of selected female infanticides (of disabled girls) caused by discrimination. This represents deep-rooted gender insensitivity within households. The above-mentioned gender imbalance of disability may be caused also by higher mortality among disabled girls, due to social discrimination, namely, preference for male children or non-disabled girls within the same households. Often, more resources are used in rearing a disabled boy than a disabled girl. A disabled girl child may receive less nutrition, less attention and mediocre health care, and thus die young<sup>2</sup>. In either way, the statistics indicate that disabled women are invisible and hidden sisters. It is a total denial of the very existence of women with disabilities.

From the total disabled population, 2,173,999 (66 percent) were in rural areas and 1,112,631 (34 percent) in urban areas. As general population distribution of Pakistan in 2014 indicates that 62 percent live in rural areas, this is more or less similar to the national trend, but with slightly higher incidence in rural areas. Concerning the provinces, the highest number of persons with disabilities was reported in Punjab (1,826,623), followed by Sindh (929,400), Khyber Pakhtunkhwa (375,448) and Baluchistan (146,421) (Government of Pakistan 1998)<sup>3</sup>, following the general population distribution pattern in the country.

## Institutional Framework

### International Human Rights Ratifications

On 12 March 1996, Pakistan ratified the Convention on the Elimination of all Forms of Discrimination against Women (CEDAW). On 25 October 1994, Pakistan ratified the ILO Vocational Rehabilitation and Employment (Disabled Persons) Convention of 1983 (No 159). However, there is little effort for enabling disabled persons to secure, retain and advance in decent employment. In August 2011, Pakistan ratified the UN Convention on the Rights of Persons with Disabilities (UN CRPD) which recognises priority concerns of disabled people, including particular problems and rights of women and children with disability in Articles six and seven respectively<sup>4</sup>. In 2012, prior to the Devolution, the Directorate General Special Education and Social Welfare (DGSE&SW) established a small

unit which is named UN Convention on the Rights of Persons with Disabilities (UNCRPD) Secretariat for the Implementation of the Convention. In addition, a Core Committee was formulated to monitor/coordinate with the Federal Ministries, Departments, and Provincial Government Departments as well as NGOs/DPOs for the implementation of the Convention<sup>5</sup>. But after the Devolution, these institutional mechanisms were naturally dissolved. Concerning childhood disability, Pakistan is also a signatory of the United Nations Convention on the Rights of the Child (CRC). Dating back to 12th of November 1990, Pakistan ratified CRC that recognises fully the rights of children with disabilities in its articles 2 and 23<sup>6</sup>. These articles shall apply to all children including girls.

A National Plan of Action (NPA) exists since 2006 to implement the country's National Policy for Persons with Disabilities of 2002. The NPA identified 17 key areas of intervention, based on a comprehensive assessment of the problems in service delivery systems. Out of the total 17 areas of key action, two goals were about children with disabilities. The first goal is to strengthen special education for children with severe or multiple disabilities, those who often face difficulties in integrated or inclusive educational system. However, only less than one to two percent of children with disabilities have access to the existing special education centres. Rural children have almost no access to them – it is just a dream for them and their mothers. Another goal is to promote *inclusive education*. However, as of today, most of the regular schools in Pakistan are not geared to accommodate children with special needs, except a dozen of so-called pilot schools located in urban areas such as Islamabad or Punjab Province.

### The Institutional Mechanisms

In result of the 18th Constitutional Amendment (Devolution) in 2010, the Federal Ministry of Social Welfare and Special Education was devolved, which had been responsible for coordination with the concerned bodies and departments in Pakistan for welfare, education, training and rehabilitation. After the 18th Amendment, the matters concerning disability have been devolved and transferred to local governments of the Federal State of Pakistan, namely four provincial governments<sup>7</sup>; therefore, now there is an urgent need to look into provincial projects, programmes and plans of action mainly by provincial entities, together with disabled people.

Concerning the implementation of the UN



CRPD (human rights issue), the responsibilities have been transferred on paper to the Federal Ministry of Human Rights, but its capacity and funding is rather limited. About the status of women in general, the National Commission on the Status of Women is fully responsible for monitoring the rights of Pakistani women, as well as mainstreaming the concerns and needs of women with disabilities. After the Devolution, there has been great confusion and chaos in the responsibilities and coordination between provincial governments and the Federal Government. Civil society is very active in Pakistan. There are a number of civil society organisations that have been working to promote the wellbeing of persons with disabilities (including disabled women) but their efforts are not well coordinated and scattered. Some of these NGOs are run by persons with disabilities; thus they are eligible as Disabled People's Organisations. As of today, however, there is no independent and third party national monitoring mechanism about the implementation of UN CRPD.

### **Causes of Impairment and Disability**

Disability prevention at the social, medical and policy levels have been identified as a priority in every meeting and encounter that the author has had with officials and PWDs in Pakistan between 2011 and 2014. Governments and civil society organisations in all provinces are dealing with the most direct causes of disability and have been devising comprehensive policies to tackle them. One of the main tools in prevention is public awareness raising and mass media public campaigns.

### **Poverty and Malnutrition**

In poor rural and urban communities, poverty, insufficient level of pre-, neo- and post-natal care, and the high illiteracy rate among mothers<sup>8</sup>, all contribute to the increase in impairment and exacerbate the conditions of disability among newborns/infants, children and young women. Harmful child marriage practice<sup>9</sup> in some conservative villages is another cause of impairment. Measures are being taken to increase the legal age for marriage and to provide mothers with health and nutrition knowledge and training, particularly in rural areas and poor urban slum communities. Having too many children without proper spacing is also a gender-specific social issue as pregnant mothers might be over a critical age by the time they give birth to their last child<sup>10</sup>. Malnutrition including the lack of micro-nutrients<sup>11</sup> is still an

issue in many communities and across the social classes of Pakistan. Iron tablets, Vitamin A supplement and iodised salt are to be outreached. Poverty alleviation must be managed as a part of overall national development strategy, and also to reduce disability incidences.

### **Insufficient Immunisation**

Some vaccination campaigns also face a serious challenge, particularly those related to polio. For instance, polio virus can cause complete or partial paralysis of infected children. The world-wide polio rate has declined but today the virus is active only in three countries of the World, Afghanistan, Nigeria and Pakistan. Pakistan counted about 85% of world polio infections in 2014<sup>12</sup>. Some religious and terrorists groups such as Pakistan Taliban (TTP) reject polio campaigns as a Western plot to sterilise, and a number of polio workers and mothers have been shot by them. In villages, many mothers refuse to have their children vaccinated because of fear and threats, in addition to their misunderstanding of religious grounds. Some UN agencies such as WHO and UNICEF, together with provincial governments, are working hard, utilising female health workers, to eradicate polio in high risk areas such as the North Waziristan area.

### **Violence against Women Including Acid Attacks**

Violence against women in general is a cause of mortality and morbidity, including various permanent physical damages, disfigurement and psychological traumas. Studies done by several organisations indicate that an increase in violence against women has been noted recently. Honor killing, domestic violence, rape and gang rape, and forced marriages are among some of the violence against and violations of human rights of women and girls in Pakistan. Among the victims, Malala Yousafzai is a famous Pakistani girl and Nobel Prize winner who stood up for education of girls and was shot by the Pakistan Taliban. She has recovered well from the bullet injury and inspired many people of the world by sharing her terrifying experiences and showing her courage. However, in the country, there are many more *Malala-girls*, some of whom just died, or became permanently disabled and continued to be oppressed. There is also common and socially accepted domestic violence (DV), in which husbands may beat, kick, permanently disfigure, or disable their wives whenever they feel upset.

Acid attack is worth being mentioned. Pakistani women are also afraid of acid attacks,



particularly in rural communities. According to the newspaper article<sup>13</sup> entitled, Acid Attacks on Rise in Pakistan as Women Left Disfigured and Blinded for Life in Horrific Assaults by Daily Record<sup>14</sup>, at least 160 women were attacked in the first four months of 2015. Victims normally suffer from multiple forms of disabilities including blindness and mental trauma.

### War, Civil Conflict and Terrorism

Pakistan has been paying high human costs of war, terrorism and civil conflicts including deaths, injuries and permanent disabilities. There have been so many civil conflicts, ethnic fighting, terrorist attacks, and civil unrests, in addition to the long lasting India-Pakistan war. According to one report, at least 100,000 families suffered direct human costs on account of the four wars between India and Pakistan. In addition, troop mobilisation in the Operation Prakaram (December 2001-October 2002), cost India and Pakistan a combined three billion dollar<sup>15</sup>. Though those conflicts affect all without discrimination, both men and women alike, there is an important gender dimension, in terms of war and disability, among which martyrdom and opportunity costs deserve particular attention.

Negative perceptions of physical disability may have changed during these conflicts, as the issue of disability became a political agenda. The conflicts caused a number of people with permanent physical disabilities. The group that suffered most was relatively young men with permanent disabilities. Though disability was a stigma in the past, it can be a heroic trophy now for the noble cause for which they are fighting. However, this politically high agenda and new profile of disability brings a totally different focus, the physical injuries of young combatants. Disability can be seen as *martyrdom* where young Pakistani men sacrificed their lives for the cause, to live in wheelchairs. This new focus can divert attention and resources from women with disability and those with congenital disabilities. The country's long lasting civil conflicts and social unrests also diverted the limited Government's resources (that could have been used otherwise for social services) to the national defense budget as the top priority. Indeed, Pakistan's ratio of defense budget vs. social services budget is among the worst in the world<sup>16</sup>.

### Cultural Practice and Life Style

Marriage preferences are largely determined by social norms in a given society. In Pakistan, consanguineous marriages have been always

preferred. Cousin marriages are highly common. Pakistani society is highly complex with different ethnic groups, religious sects, languages and still existing castes; thus, it is up to social values and culture to decide what sort of marriage is desirable for an individual. According to the Pakistan Demographic Survey, as quoted by Ali-Khan's study (Khan/Sultana/Siraj 2011)<sup>17</sup>, 66 percent of marriages in Pakistan are consanguineous. This phenomenon is also triangulated by the observations and interviews by the author during her three and a half years working life in Pakistan. This type of marriage is everywhere and preferred by many different ethnic and language groups, due to a highly complex fabric of socio-cultural, economic, religious and anthropological factors. Such consanguineous marriage practice is among the major causes of various kinds of congenital impairments including multiple disabilities.

One new trend is a growing number of traffic accidents as a cause of permanent impairments. In most places in Pakistan, road-related infrastructure and traffic safety measures do not meet the international standards. Young men with super high-speed automobiles, open roads, and careless driving often end up with a head or spinal cord injury. Disabilities caused by traffic accidents have been on the rapid increase as the standards of living have risen in many urban areas. Drivers may be men but the victims are men and women, boys and girls alike.

Athletic activities are not often encouraged for women and girls, particularly those of marriageable ages. Socially it is not easy for women and girls to walk freely and openly in public, and there are limited indoor sports clubs and facilities in the country. Thus, it is not easy for women to locate within their vicinities affordable, sustainable and open public spaces when rehabilitation or rehabilitative daily exercise is needed to maintain healthy and athletic life style. This may be a cause of early aging-related mobility impairments of some adult women, coupled with the growing obesity.

### Insufficient Education of Women in General and Childhood Disability

Many studies in Pakistan confirmed the positive relation between women's/mothers' literacy and child mortality and morbidity. Family illiteracy is also a major barrier to social integration. The education of women could significantly reduce the incidence of childhood disability, as rates are much higher among the children of illiterate women than among those of mothers who have received even just a basic education.



In a study in Egypt, female illiteracy was proven to be a significantly relevant variable<sup>18</sup>. An illiterate woman lacks an awareness of health issues, and she tends to prefer the traditional or unqualified practitioner when seeking health services. During the UNESCO co-hosted 2013 National Forum to observe the UN Disability Day, on third December, held in Islamabad, the importance of mothers' literacy was stressed as a prerequisite for the early intervention and management of disability in Pakistan.

## Consequences of Disability

From the perspective of consequences of disability, there is a long shopping list of challenges and constraints facing women and girls with disabilities as well as their families. The issues of women and girls with disabilities are not addressed separately from men with disabilities. However, there are particular socio-economic characteristics of women with disabilities in Pakistan, among which three domains, i.e. education, employment/productive activities and marriage, are selected in this paper. There are many other areas that require gender sensitive solutions to the socio-economic problems of women and girls with disabilities. Also, in the process of decision making, there is little ownership of the issues of persons (women) with disabilities and the commitment and political will of the Central Government and provincial governments are also weak, which has resulted in the gloomy situation of women and girls with disabilities.

### Education of Children with Disabilities

Research conducted by the office of the UNESCO Pakistan<sup>19</sup> has shown that children with disabilities are not integrated into the mainstream educational system in Pakistan, in all provinces. School buildings have not been made accessible nor are there educational materials in accessible formats such as Braille. Public transportation is not available in many villages and if available, not accessible. In rural areas, many schools have no toilets and no clean drinking water. Additionally, teacher training in special needs education is also relatively scarce. Although illiteracy rates vary considerably from one province to another, UNESCO has placed the illiteracy rate in the country as a whole at about 39.6% for women and 66.7 % for men<sup>20</sup>. There are some good indicators available about level of literacy among disabled people of ten years or above in Pakistan. According to the National Population Census in 1998, only 28% of disabled peo-

ple (men and women combined) are literate and the rest, 72%, are illiterate<sup>21</sup>. As disabled women's illiteracy is presumably much higher than that of male counterparts, one can conclude that the majority of Pakistani disabled women are illiterate. It would not be an overstatement to say that the lack of educational opportunities for women and girls with disabilities contributes to the sizable percentage of illiteracy in the country.

Sign language interpretation and interpreters constitute a major challenge for deaf women and men in Pakistan. Deaf children and adults are being deprived of their right to education and communication due to the lack of interpretation services in schools and higher education institutions, as well as in mass-media. The mass-media institutions have no concept about the necessity of subtitling or sign language interpretation. In a joint initiative with a local NGO in Punjab province, UNESCO Pakistan launched a pilot effort of mainstreaming a few deaf children into non-formal literacy classes and through mobile phone-based literacy projects in Punjab Province with training of teachers and volunteer interpreters.

### Employment

In Pakistan, the overall women's labor-force participation is increasing gradually. Indeed, nowadays, employment and productivity is the first step towards self-reliance and dignity of human beings in Pakistan like elsewhere. Working women are considered to be cool. However, women with disability, face a serious challenge in employment and productive activities. Vocational rehabilitation institutions are mainly located in large cities or urban areas which deprive a great number of disabled women and adolescents. The physical infrastructure of Pakistani society is made basically to accommodate the needs of people without any disability such as the working-age male population. The very fundamental concepts of barrier-free, accessibility and universal design are nonexistent in the society. Women with disabilities face multiple barriers to access public places such as work places, hotels, government offices, schools, shopping centers and restaurants. Most of the public buildings are not barrier-free. In order to commute to offices, the public transport sector does not accommodate the needs of working women with disabilities, and women in general, whether disabled or not disabled, are almost deprived of seats in over-crowded public transport with the staring eyes of men.

According to the above mentioned 1998 National Census quoted by Anzar Aziz (2012), the





gender-disparity in employment is unbelievably high, between disabled men and women of ten years or above. Only about two percent of disabled women (>10) are in employment in contrast with 62% of disabled men (>10) in employment. More disabled men than disabled women are actively looking for employment. Disabled women's school enrollment rate is less than a half of disabled men's.



Figure 1: Men and Women with Disabilities (>10 years) by Activity (Source: National Census 1998)

Ironically, women from poor communities, particularly rural areas, who are challenged by mild developmental or intellectual disabilities, are often forced into domestic work, where they are regularly subjected to non-remuneration and/or all kinds of abuses. Community Based Rehabilitation (CBR) can be a highly viable solution for this problem. Until recently, the project of Vocational Rehabilitation and Employment of Disabled Persons, that was established in 1993, had been working to promote CBR through skills training and micro-financing facilities, but this was phased-out and abolished due to financial constraints<sup>22</sup>.

### Marriage and Social Life

Pakistani women with disabilities face difficulty in marriage, family life and sexuality. A disabled man with means of income and resources may be able to find a wife who is willing to take care of him, but this is a challenge

for a disabled woman<sup>23</sup>. In conservative Pakistani communities where a woman's status is dependent on finding/maintaining a good marriage, being a good wife and a good mother, women and girls with disabilities are not valued by the society. Marriage is still considered to be the most important success indicator for women's life in Pakistan, across the social classes. However, disabled women are not considered *marriageable* and often their non-disabled siblings, particularly sisters, are also overlooked in the marriage market by reason of their association with impairment. As mentioned above, this is why they become hidden sisters and liabilities within the households.

Sexuality of women with disabilities is a taboo issue even in intellectual circles<sup>24</sup> as the society in general fails to recognise the sexuality of women with disabilities (and even of women generally) and discourage their expression of sexuality. Marriage is still the most important social institution that performs many vital functions including social life and entertainment for individual members. Often, it is a core for one's entire social life, and also marriage is a foundation that provides identity, succession, social life and inheritance. Without marriage, a human being is never considered to be complete. The society is family and community oriented, unlike the individualistic style of many other societies; thus, there is a strong belief that families, particularly female family members, shall take care of their own rather than share the responsibilities with the public. This can result in too much financial burden in poor households. Thus, this tightly knitted family structure, along with insufficient government support and an organisational and institutional foundation for public services, results in an awkward phenomenon of a forced, superficial family integration of female members with disabilities. Such family-based integration is not supported by an accessible physical environment (e.g. universal design) or public social services. In summary, unmarried Pakistani women with disabilities today may be stuck at home, often feeling total isolation within extended family and kinship-based social structures.

### Recommendations

In light of the afore-mentioned challenges and problems, the author recommends the Government of Pakistan and civil society institutions to review all administrative, legal and resource-allocation measures related to the implementation of the UN CRPD, to which Pakistan is a



State Party. The third party and independent national monitoring mechanism of the UN CRPD should be set up with a number of representatives of women and men with disabilities, who are recruited from all provinces. Furthermore, the existing national forum of DPOs shall be better coordinated and strengthened to produce a national shadow report on the implementation of the UN CRPD, fully reflecting the real views of disabled persons. It is also necessary to allocate appropriate resources, by increasing educational and vocational rehabilitation institutions for capacity development of women and girls with disabilities. Gender-specific separate facilities may be necessary for women and girls in conservative areas of the country. Always, inclusive settings are the best, but supplemented by alternative forms as appropriate for some disabled persons who require individualised and specialised support.

Governments and opinion leaders must strengthen the measures for eradicating the negative causes of impairments, including violence against women, through devising comprehensive policies (e.g. literacy, education, public awareness) to reach out to general populations. One of the effective tools in prevention is mass-media public campaigns, perhaps utilising TV, mobile phone systems and other electronic forms of media. Negative cultural practices should be eliminated for future generations. Culture is dynamic in many South Asian countries with similar GDP per capita.

Not many DPOs or self-help groups have been exposed to the concept of gender mainstreaming or gender training, and ironically, many women's human rights-based organisations do not recognise the concerns and needs of disabled women, though gender equality and disability are so interlinked in the Pakistan context. Women rights and disability rights aspects should be mainstreamed in development activities of DPOs and general women's organisations, as well as in international cooperation efforts.

Last but not least, there is a need for capacity development and training of disabled women leaders to represent their views at national and international levels, and to be agents for positive and progressive social reforms in the country. Better public resources allocation and official development assistance (ODA) channeled to capacity development of disabled women may be considered in the future.

## Notes

- 1 The category of others is not specified. It may include causes unknown to households.
- 2 Based on the paper presented by Anzar Aziz at the Expert Group Meeting on Effective Data Generation for Incheon Strategy Indicators, 6-7, November 2012. Available at <http://www.unescapsdd.org/files/documents/Pakistan.pdf#search='literay+rate+of+disabled+women+pakistan>. Visited on 1st November 2015.
- 3 Government of Pakistan, Population Census Organisation; Disabled Population by Nature of Disability; Available at <http://www.census.gov.pk/Disabled.htm>. Visited on 1st November 2015.
- 4 Article 6 - Women with disabilities: 1. States Parties recognise that women and girls with disabilities are subject to multiple discriminations, and in this regard shall take measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms. 2. States Parties shall take all appropriate measures to ensure the full development, advancement and empowerment of women, for the purpose of guaranteeing them the exercise and enjoyment of the human rights and fundamental freedoms set out in the present Convention. Article 7 - Children with disabilities: 1. States Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children. 2. In all actions concerning children with disabilities, the best interests of the child shall be a primary consideration. 3. States Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realise that right.
- 5 The Ministry of Capital Administration Development Division; Directorate General of Special Education and Social Welfare. Available at <http://www.mocad.gov.pk/gop/index.php?q=aHR0cDovLzE5Mi4xNjguNzAuMTM2L2NhZC8uL2ZyZURldGFpbHMuYXNweD9vcHQ9bWlzY2xpbmtzJmlkPTEz>. Visited on 1st November 2015.
- 6 Article 23 of the CRC stipulates "a disabled child has the rights to special care, education and training to help him or her enjoy a full and decent life in dignity and achieve the greatest degree of self-reliance and social integration possible".
- 7 The four provinces of Pakistan are Punjab, Sindh, Khyber Pakhtunkhwa and Baluchistan. In addition, there are a few directly administered federal areas/territories including the capital district of Islamabad.
- 8 As of 2010, the overall female literacy rate in Pakistan is only 39.6 % at the national level, in contrast with that of males at 67.7% (Government National



Statistics compiled by UNESCO Pakistan August 2014). According to more recent UNICEF Data (UNICEF Statistics/Pakistan retrieved in August 2014), the female education enrolment among 15-24 olds has increased significantly. However, UNESCO estimates that about seven million children are out of school, of which 2/3 are girls (UNESCO, Education for All Global Monitoring Report 2011). Female illiteracy and uneducated motherhood is a serious development issue and a cause of child impairment.

- 9 Child marriage is common in Pakistan. It sometimes includes transfer of money and settlement of debts sanctioned by Jirga (local council of seniors). It is estimated that 21% of all girls are married under age, before 18, the legal age set by some provinces. Some of them are married off at as early as 12-13.
- 10 Young age (<18) and old age (>35) women are classified as high risk of child bearing. Total fertility rate in Pakistan is 3.73 in 2008. Available at <http://www.indexmundi.com/g/g.aspx?c=pk&v=31>.
- 11 About 40% of edible salt in Pakistan is not yet properly iodised thus making iodine deficiency disorder still an issue. Available at <http://micronutrient.org/mi-in-the-world/asia/pakistan/>. Visited on 1st November 2015.
- 12 Global Polio Eradication Initiative as quoted by Al-Jazeera News. Available at <http://www.aljazeera.com/indepth/features/2015/03/pakistan-polio-problem-vaccination-danger-150328091807399.html>. Visited on 1st November 2015.
- 13 These newspaper articles are in journalistic nature and not supported by scientific date.
- 14 Dated 25 April 2015. Available at <http://www.dailyrecord.co.uk/news/uk-world-news/acid-attacks-rise-pakistan-women-5580535>.
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- 18 United Nations Children's Fund (UNICEF), The State of the World's Children 1994, New York, Oxford University Press, 1994.
- 19 Observed by the Author during her function as the Director UNESCP Pakistan (2011-2014) and based on the interviews with officials in Punjab Province and Islamabad as well as representatives of DPOs across the provinces of Pakistan.
- 20 See UNESCO publication, Education for All Global Monitoring Report 2011.
- 21 The National Census in 1998, as quoted by the paper presented by Anzar Aziz at the United Nations ESCAP Expert Group Meeting on Effective Data Generation

for Incheon Strategy Indicators, 6-7, November 2012, available from the Social Development Division, UN ESCAP Bangkok, upon request.

- 22 The Institute for Social Justice (ISJ). Study on Women, Minorities and Children in Pakistan. Available at <http://www.isj.org.pk/situation-of-women-children-and-minorities-with-disability-in-pakistan/>. Visited on 1st August 2015
- 23 Based on a series of interviews of women with disabilities, conducted by the Author, during 2011-2014.
- 24 The author's own observation through various contacts during her assignment with UNESCO Pakistan in 2011-2014.

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**Zusammenfassung:** Frauen mit Behinderung in Pakistan sind von doppelter oder mehrfacher Diskriminierung betroffen. Behinderung und Geschlecht sind ein eng miteinander verknüpfter Entwicklungsbereich. Dieser Artikel hat zum Ziel, den Geschlechter-, Mutterschafts- und Behinderungsdiskurs in Pakistan, basierend auf vorhandenen Statistiken und Studien, aber auch basierend auf den Stimmen pakistanischer Frauen, zu analysieren. Die Studie gibt Einblick in einige Ursachen und Auswirkungen von Behinderung und Entwicklung aus der Genderperspektive.

**Résumé:** Les femmes handicapées au Pakistan souffrent d'une discrimination double ou triple. Le handicap et le genre sont des questions de développement étroitement liés. Sur la base des statistiques et des études disponibles, ce document vise à analyser les faits saillants, en couvrant le genre, la maternité et le handicap au Pakistan, ainsi que les voix des femmes pakistanaises handicapées. L'étude donne un aperçu de certaines causes et conséquences du handicap et du développement de la perspective du genre.

**Resumen:** Las mujeres con discapacidad en Pakistán sufren de doble o triple discriminación. Discapacidad y género es un asunto de desarrollo que está estrechamente relacionado entre sí. Este documento quiere analizar aspectos importantes que cubren género, maternidad y discapacidad en este país, basados en estadísticas, estudios disponibles y las voces de las mujeres pakistaníes con discapacidad. El estudio da una idea de algunas causas y consecuencias de discapacidad y desarrollo desde la perspectiva del género.



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of the author and do not represent the views of UNESCO or the United Nations.

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## Needs of Families Impacted by Disability: A Scoping Review

Reshma Parvin Nuri/Heather Michelle Aldersey

Globally, family plays a major role in ensuring that a child with a disability gets adequate support. A systematic literature review offers knowledge about the needs of families impacted by disability. The most frequently discussed needs were related to information on disabilities and challenging behavior, and on service provision. The study allows identifying gaps and implications specific for families from low- and middle-income countries.

### Introduction

Around 150 million children worldwide have some kind of disability, with most of them living in developing countries (Maulik/Darmstadt 2007). It is estimated that childhood disability prevalence ranges from 0.4% to 12.7% (UNICEF 2005). Families can be incredible resources in the lives of children with disabilities. For example, they can provide important information about the child's disability and behavior to health service providers, which may help in setting up a holistic treatment plan for the child (Siebes/Wijnroks/Ketelaar et al. 2007). Additionally, with proper training and support, family members of a child with a disability can continue long term therapeutic treatment at home (Siebes/Wijnroks/Ketelaar et al. 2007). Family members can even provide training to other families of children with disabilities who are unable to benefit from traditional or state-sponsored services (Helander 1992).

Although families of children with disabilities

often have different and greater needs than families of children without disabilities, some researchers have found that family members, especially parents, often struggle to express their family needs, as they are more concerned about the specific needs of their child (Siebes/Wijnroks/Ketelaar et al. 2007). Rehabilitation researchers have noted that family outcomes can be improved by addressing the needs and strengths of families (Serio/Kreutzer/Witol 1996; McLinden 1990; McGrew/Gilman/Johnson 1992), yet service providers have often not explored families' issues (Rosenbaum/Gorter 2012). In order to best meet the needs of family, it is important to identify what, specifically, the needs of families are. Identifying and incorporating family needs may increase participation of family members in the rehabilitation process and improve treatment planning (Oddy/Humphrey/Uttley 1978), thus potentially improving family functioning and child well-being (Alsem/Siebes/Gorter et al. 2013).



To that end, we conducted a scoping review of the literature to better understand needs of families around the world, with a particular objective of understanding family needs in low- and middle-income countries. Specifically, the search was guided by the following research questions: (a) What are the needs of families impacted by disability? (b) What are the methods/tools commonly used to identify family needs? And (c) What are the factors that may influence the needs of families of children with disabilities? Having a child with a disability in the family can often have wide-reaching impacts on the family unit – in both positive and negative ways. For example, although families report greater sense of purpose, higher advocacy skills, increased networks and more decision-making power (Stainton/Besser 1998; Yousafzai/Farrukh/Khan 2011), family members of children with disabilities, especially parents, also experience higher risk of physical and mental health problems such as fatigue, stress, anxiety and depression (Zuurmond/Mahmud/Polack et al. 2015; Davis et al. 2010; Mobarak/Khan/Munir et al. 2000). Caring for a child with disabilities can also negatively impact parents' marital and social lives. For example, previous studies have found that parents of children with disabilities are more likely to get divorced (Corman/Kaestner 1992; Mauldon 1992) and less likely to participate in social events (Seltzer/Greenberg/Floyd et al. 2001). The high level of care often required by a child with a disability may also reduce the productivity of both fathers (Noonan/Reichman/Corman 2005) and mothers (Powers 2001) and increase dependability on public assistance (Reichman/Corman/Noonan 2006). Given that family is generally the first, most important, and often longest enduring unit in a young child's life, it follows that positive and negative impacts on the family can also directly impact the child with the disability. When provided with adequate support for their needs, families of children with disabilities can play a vital role in rehabilitation, inclusion, and overall wellbeing of the child with a disability.

## Methods

This scoping review followed methods outlined by Arksey and O'Malley (2005), which include: 1) identify research question(s) and operationalise the definition, 2) identify relevant studies through electronic databases, reference lists and hand searching of key journal, 3) establish inclusion and exclusion criteria, 4) chart and collate the data and, 5) summarise and report the results.

In September and October 2015, we systematically searched the following databases: PubMed, CINAHL, Summon (Queen's Library), and Google scholar. We conducted our search using the following search terms: "Family Needs OR Family Support OR parents' needs of children with disabilities OR disabled children". For this study, we considered children to be anyone under the age of 18, and we included articles with mention of "disability" in the broader sense, with no discrimination for specific type of disability (e.g., physical, intellectual, sensory). Our initial search identified 4663 articles. After reviewing titles, we excluded 4618 articles as those articles were not relevant to the study. Next, we reviewed the abstracts of the remaining 45 articles and conducted a manual search of the selected articles' references to check for additional relevant articles. Finally, we included 23 articles for full review based on following inclusion criteria: 1) Identified needs of families or parents of child/children with disabilities, and 2) Published in English in peer reviewed journals with no restriction of the publication date. We excluded 22 articles due to irrelevant content ( $n = 17$ ), duplicate articles ( $n = 3$ ), full article was not available ( $n = 1$ ), or published in different language ( $n = 1$ ). Figure 1 provides a visual depiction of our search process. We analysed the content of the 23 eligible articles and extracted the country of focus, data collection tools used to identify the family needs, type of expressed needs and factors influencing the needs of families.

## Results

This review uncovered articles that can be organised along the following themes: Article characteristics, methods/tools to assess family needs, type of family needs, and influencing factors.

### Article Characteristics

The 23 articles uncovered in this review revealed data from ten different countries (Australia, Canada, China, India, Japan, the Netherlands, Taiwan, Turkey, UK and USA). Eight articles were from USA, four articles were from China, and three articles from the Netherlands. Two articles tested the reliability and validity of Family Needs Survey scale in different population such as Turkish (Bilgin/Coban/Tanriverdi 2013) and Japanese (Ueda et al. 2013). One article tested the Family Needs Assessment Tool in Taiwan (Chiu et al. 2013). One article tested different models of determinants of family needs in the USA (Almasri et al. 2011). Across



the articles, there was representation of families impacted by many different types of disabilities (e.g., physical disability, intellectual disability, developmental disability, hearing impairment, visual impairment and multiple disabilities). All studies identified family needs from the perspective of the primary caregivers, and mainly parents. Only two articles involved parents as well as health service providers. The most frequently used method/tool to explore the needs of families was the Family Needs Survey ( $n = 9$ ) followed by Focus Group Discussions ( $n = 5$ ).

### Type of Family Needs

We identified 101 unique terms for needs of families of child with disabilities. Using the ICF as conceptual grounding, we organised these identified needs into two broad categories and nine sub-categories<sup>1</sup>. The needs most frequently described in the articles were related to information. Family members often noted that they would like to obtain information about services that are available and services that might be needed in future for their child with a disability ( $n = 13$ ). Families also noted needing information about the child's disability ( $n = 9$ ), the child's growth and development ( $n = 8$ ), how to handle challenging behavior ( $n = 8$ ), and how to teach the child ( $n = 9$ ). Families also identified a need to learn how to share information about their child's disability with other people ( $n = 6$ ).

In addition to informational needs, families identified a need for different supports to cope with changes in family situation. The supports identified include financial support ( $n = 9$ ), peer support from other parents of child with disabilities ( $n = 4$ ), emotional support ( $n = 4$ ), and support for child care, especially daycare ( $n = 5$ ). Further, families identified a need for recreational support, in particular, a need for extra time for themselves ( $n = 5$ ). Families also identified a desire for meaningful employment for their child with a disability ( $n = 3$ )<sup>2</sup>.

### Influencing Factors

This review extracted many factors that influenced the expressed family needs. Factors have been organised along the following themes: child's characteristics, parental characteristic, method of data collection, service related fac-

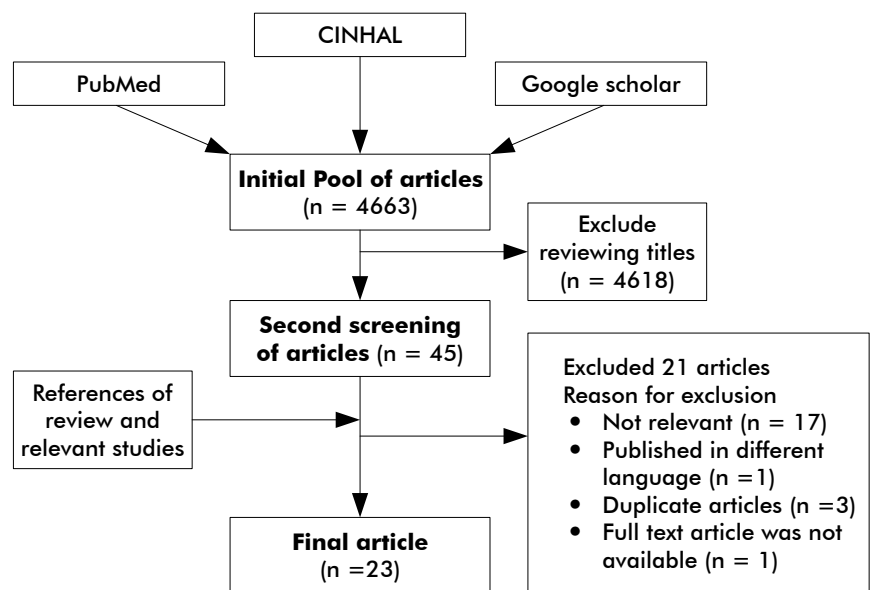


Figure 1 Flowchart of the studies included in the review.

tors and family related factors. We found that the most frequently reported factors related to the child were the age and the gross motor function of the child. Although age of the child was a primary influential factor, we found an inconsistency in the literature. For instance, Verma and Kishore (2009) found that parents expressed great need for information regarding sexuality, marriage, vocation, and future planning as a child ages. In contrast, Palisano et al. (2009) found an insignificant relationship between age of the child and type of family needs. Some of the identified articles also found that a child's motor function can influence the type of family needs expressed (Palisano et al. 2009; Almasri et al. 2011; Piškur et al. 2014). For instance, parents of children/youth who use a wheeled mobility device expressed a need for home modifications (Palisano et al. 2009). In addition to a child's age and disability type, one article highlighted differences across gender and noted that parents of girls expressed more needs than parents of boys (Verma/Kishore 2009) in several domains of the NIMH Family Needs Schedule such as information-condition, child management, service, marriage, sexuality, personal-emotional, personal-social, support-physical and government benefits and legislation.

Along similar lines, many studies have found that mothers and fathers of children with disabilities expressed different types of needs (Verma/Kishore 2009; Bailey/Skinner/Correa et al. 1999; Hu et al. 2015; Bailey/Blasco/Simeonsson 1992). For example, mothers expressed more needs related to emotionality, family, and



social area, whereas fathers expressed more needs related to social aids and future plans for the child (Verma/Kishore 2009). In contrast, one study indicated that the average number of needs generally do not differ for mothers and father across the subscale (Hendriks et al. 2000). One study found that the needs of families may also depend on the fathers' employment. Ellis et al. (2002) found that families expressed less needs when the father worked greater numbers of hours per week. Furthermore, family needs were impacted by whether parents lived in the rural or urban areas. For instance, Chen and Simeonsson (1994) found that rural families expressed more financial needs than their counterparts in the city. Further, they found that families in rural settings indicated significantly more concerns about the child's health, education, and marriage prospects, while urban families expressed greater concern about their child's future occupation (Chen/Simeonsson 1994).

In addition to family characteristics, the literature revealed that the method of data collection could also influence how family needs are expressed. Parents expressed more needs if they were given a structured question/checklist rather than asking an open-ended question. For example, Alsem et al. (2013) identified less family needs via open-ended questions in the individual interviews compared with asking parents to complete a 99-item initial inventory<sup>3</sup>.

## Discussion

The purpose of this scoping review was to identify the needs of families of children with disabilities, methods/tools commonly used to identify the needs and the factors that might influence family needs. We identified a total of 101 unique needs from 23 articles. These needs were categorised into nine sub-categories which further clustered under two board categories. Although the date was not limited in our search, the earliest articles we uncovered in this review were from 1990. It was also notable that most articles reviewed were focused on children with physical and intellectual disabilities, with little focus on psychosocial, hearing, or visual impairments. Only two out of 23 articles targeted families of children with hearing and/or visual impairments.

In spite of undertaking this review with a particular desire to learn about family needs globally, and specifically in low- and middle-income countries, the vast majority of articles uncovered in this review were from Western and higher-income nations. Specifically, out of the

23 studies uncovered in our search, 15 articles were from high-income countries, 8 articles were from middle-income countries, and no studies were from low-income countries. This is concerning, as disability prevalence is high in low-income countries (Mitra/Sambamoorthi 2014) and strong associations exist between disability and poverty (Braithwaite/Mont 2009). There are many possible explanations for why Low-Income Countries (LICs) were not well represented in the literature. First, research capacity is often weaker in LICs, due to limited national investment in research infrastructure, lack of skilled, local, and relevant research expertise, political instability, and intellectual isolation because of poor internet connectivity (Sitthi-amorn/Somrongthong 2000). Second, because many LICs experience stigma and misunderstanding related to disability at potentially higher levels than higher income countries (Groce 1999), research about children with disabilities and their families might be deemed unimportant, lower priority, or taboo. Finally, disability is often underrepresented in national census or surveys in developing countries (Palmer 2011). This might result in the needs of families and children with disabilities going unaccounted for in national health, social service, and research priority considerations. Future research should seek to understand family needs in these underrepresented contexts.

Among the wide range of family needs, the most prevalent were related to informational needs. In particular, articles noted that families need information about their child's disability, how to teach their child and how to manage challenging behavior. This indicates a need for increased efforts on behalf of service providers to help families understand the nature of the disability, how to interact with the child and how to solve problems and improve coping skills. Information about disability and how to manage challenging behavior of the child may be particularly important for the families in low-income countries in light of previous studies which have found have lack of understanding about the cause of disability and myths surrounding disability can contribute to increased marginalisation and stigma of people with disabilities and their families (Aldersey 2012; Zuurmond et al. 2015; Maloni et al. 2010). For instance, some parents of children with Cerebral Palsy (CP) in Bangladesh believe that their child became disabled due to the influence of evil spirits (Zuurmond et al. 2015). Further related to stigma and disability in many LICs (Aldersey 2012; Zuurmond et al. 2015; Gona et al. 2011), some believe that having a child with



disability is a kind of punishment for a mistake made by the parents and these beliefs can sometimes isolate the family members from mainstream society (Zuurmond et al. 2015).

The review uncovered that many families also do not have enough information about the existing services that were available for the child with disabilities. Again, this finding can be applicable for the families of low-income contexts. It has been reported that some families in Tanzania did not have access to government support because of lack of information about how to access it (Aldersey 2012). Therefore, health service providers can play a vital role in disseminating such information. Service providers might develop service directories and distribute it among families or connect the families with informational networking opportunities.

In addition to informational needs, this scoping review also revealed that families often need financial support for different purposes, even basic expenses. The costs associated with caring for children with disabilities can be both direct and indirect. Direct costs include disability-specific services such as therapy and assistive devices (Davis et al. 2010; Chen/Simeonsson 1994) and indirect costs include those for transportation to therapy services (McConachie et al. 2001) and parents reducing work commitments to meet the needs of child with disabilities (Pillay et al. 2012). Families with both low and high economic levels identified financial challenges associated with having a family member with a disability (Hu et al. 2015) within our scoping review. We anticipate that family needs in LICs might be more highly focused on financial needs, in addition to informational needs, as the cost associated with caring for a member with a disability in these contexts can have a more drastic impact on the living standard of the family, particularly where formal welfare systems, and medical, rehabilitation, and support services are limited (Palmer 2011). Indeed, even though family needs are often wide-ranging in contexts characterised by poverty, financial needs as they relate to basic, daily survival may rise above all other concerns (Aldersey/Turnbull/Turnbull, In Press). Moreover, financial needs may impact a family's ability to meet other disability-related needs. For instance, in one study, parents of children with disabilities in Bangladesh were unable to participate in early intervention due to financial needs related to transportation (McConachie et al. 2001).

This study also revealed some other needs that could be applicable for the families in developing countries such as positive attitudes to-

ward families, and who completes household tasks, or has access to leisure time. Families in LICs can often have very limited opportunities for leisure activities and may feel exhausted due to the care demand of the child combined with their household chores (Zuurmond et al. 2015). The occurrence of disability within a family can often result in significantly increased caregiving responsibility, often throughout the lifetime, for parents, siblings and/or other guardians. In LICs such as Bangladesh, inequality in distribution of caregiving can impact gender parity and the advancement of women. Women spend on average three times more on unpaid care work than men (Ferrant/Pesando/Nowacka 2014). The OECD Development Centre research on unpaid care work shows correlations between unequal levels of unpaid care work and levels of female vulnerable employment and gender wage gaps. For instance, in countries where women spend twice as much time on unpaid care activities as men, they earn 63% of male wages. This decreases to 40% of male wages, however, when women spend five times more time on unpaid care work than men. Thus, caregiving of children with disabilities can often be gendered, in particular in low- and middle-income countries (LMICs), and this can result in increased disadvantage for women.

In addition to considerations related to a gendered burden of care, this scoping review uncovered that family needs can be influenced in other ways by the gender of the parents and the age of the child. One reviewed article also noted that parents of girls expressed more needs than parents of boys in several domains of NIMH Family Needs Schedule such as information-condition, child management, service, marriage, sexuality, personal-emotional, personal-social, support-physical and government benefits and legislation (Verma/Kishore 2009). Gender differences in family needs could be an interesting area particularly in LMICs, where roles and family expectation from a men and women are often greatly influenced by social norms (Sultana/Zulkefli 2012). Further, gender inequalities in health, education, economic and political participation is high in LMICs (UNICEF 2007). Future research on family needs in LMICs should pay particular attention to understanding the impact that gender (of both caregivers and children) can play in the system of a family impacted by disability.

This review also demonstrated that families need moral support from other family members and other parents of children with disabilities. Previous studies have found that informal sup-





port from family members was important for parents of children with disabilities (Trivette/Dunst 1992) especially support from the spouse (Grant/Whittell 2000). In LMICs, social networks can be an important resource for support, particularly where formal systems of support are limited (Aldersey/Turnbull/Turnbull, In Press). As one Senegalese man states, "the most important asset is an extended family and well-placed social network from which one can derive jobs, credit and financial assistance" (Narayan 2000, p. 55). Family members of children with disabilities might seek informal support from other parents with similar experiences. Indeed, previous studies have found that where family members were able to share experiences with other parents who struggled with similar issues, this helped them to view their children with disabilities as a human beings who have potential to contribute in life (WHO/SHIA 2002; cited in Fuzikawa 2008).

In addition to insight related to specific needs, this review also provided further information about the specific tools used in the field to collect data on family needs. A large number of articles reviewed employed the Family Needs Survey, developed by Bailey and Simeonsson in 1988, to identify the needs of families involved in early intervention. This tool was developed based upon experiences of families in the United States, and thus there may be gaps for researchers and service providers attempting to use this tool in other contexts. Indeed, other articles in our review that reported data from contexts outside of the United States identified family needs that are not reflected in the Family Needs Survey. For instance, families noted needing home based training, inclusive education (Hu et al. 2015), accessible environments (Piškur et al. 2014; Sloper/Turner 1991), and disability specific services (Buran et al. 2009; Sloper/Turner 1991). Thus, although it may be useful to adopt standardised family needs measurement tools due to their comparability and transferability, researchers attempting to adapt standardised tools developed in higher income countries to assess family needs in LMICs would be wise to first evaluate and test these tools for usefulness and relevance in a different context.

## Limitations

This review is not without its limitations. For example, we did not specify type of disability in our search terms, rather we included all types of disability in an attempt to gain a widest possible sense of the scope of the field of family

needs literature. A potential limitation of this article is that by using an all-inclusive perspective of disability, we have missed identifying patterns and trends of family needs according to specific disability category (e.g., physical, sensory, intellectual), or even by our wide age range for "children" (0-18). Future studies that target specific disability categories or age groups (e.g., early childhood, pre-teen) may uncover age and disability specific insight related to family needs. Additionally, due to limitations in time and resources, we searched a limited number of databases for this review (e.g. PubMed, CINAHL, Summon (Queen's Library), and Google scholar). Scoping reviews of different databases may uncover different or additional insight on family needs.

## Conclusion

Disability services could be more effective if they are delivered in a family-centered manner and address the specific needs identified by the family (King/King/Rosenbaum et al. 1999). When families have a clear understanding about, and are involved in setting short term and long term goals, they may be motivated and engaged in efforts to achieve these goals (Caro/Derevensky 1991). Parents can also experience improved psychological wellbeing demonstrated as reduced stress, anxiety, and depression when disability services are provided in a family-centered way (King et al. 1999; Van Riper 1999). As such, it is crucial to understand existing research on how to best identify and meet the needs of families impacted by disability. This scoping review was an initial step in understanding existing global literature related to the needs of families of children with disabilities. Articles uncovered informational needs as the most pervasive within the suite of family needs. A major gap in the identified literature is the limited focus on family experience in low- and middle-income countries. Future studies focused in these contexts could provide great contributions to the global body of literature on family and disability. Given the potentially radically different aspects of family experiences related to disability for families living in poverty and in lesser-studied cultural contexts, future research targeted at family experience in low-income countries or low- and middle-income countries would be highly beneficial for identifying and appropriately and effectively meeting the needs of families worldwide.



## Acknowledgments

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## Notes

- 1 The overview of all categories of family needs is summarised in a table, which can be requested from the author via E-Mail.
- 2 A table providing further details about specific terms used by the researchers for each broader theme can be requested from the author via E-Mail.
- 3 A table providing further details about specific terms used by the researchers for each broader theme can be requested from the author via E-Mail.

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**Zusammenfassung:** Der Familie kommt allgemein eine wesentliche Rolle in der Sicherstellung einer ausreichenden Unterstützung eines Kindes mit Behinderung zu. Eine systematische Literaturanalyse bietet Wissen über die Bedürfnisse von Familien, die von Behinderung betroffen sind. Die

am häufigsten diskutierten Bedürfnisse bezogen sich dabei auf Informationen zu Behinderung und herausforderndem Verhalten und der professionellen Leistungserbringung. Die Studie ermöglicht es, die Unterschiede und Auswirkungen speziell für Familien aus Ländern mit niedrigem und mittlerem Einkommen zu identifizieren.

**Résumé:** À l'échelle mondiale, la famille joue un rôle majeur pour assurer que l'enfant handicapé reçoit un soutien adéquat. Une revue systématique de la littérature offre des connaissances sur les besoins des familles touchées par le handicap. Les besoins les plus fréquemment abordés sont liés à l'information sur les handicaps et le comportement exigeant, ainsi que sur la prestation de services. L'étude permet d'identifier les lacunes et les implications spécifiques pour les familles dans les pays à revenu faible ou intermédiaire.

**Resumen:** A nivel mundial, la familia juega un papel importante en asegurar que un niño con discapacidad obtenga un apoyo adecuado. Una revisión sistemática de la literatura ofrece un conocimiento sobre las necesidades de las familias afectadas por la discapacidad. Las necesidades discutidas con mayor frecuencia se relacionan con la información sobre la discapacidad y el comportamiento desafiante, así como también en la prestación de servicios. El estudio permite identificar los desafíos y las implicaciones específicas para las familias de los países con bajos y medianos ingresos.

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## Kurzmeldungen/Announcements

### Human Rights Watch Submission to the CRPD on Draft General Comment No. 4 on Article 24 - The Right to Inclusive Education

The CRPD Committee works on a General Comment on Article 24 of the Convention on the Rights of Persons with Disabilities in January 2016. Human Rights Watch provided their observations and suggestions to strengthen the draft. A reasonable accommodation and accessibility to education, especially in rural areas was one of the central topics. Human Rights Watch has found that many schools exclude children with disabilities on the basis of their dependence on staff to help them access toilets or sanitary facilities. Similarly, the lack of accessible housing is a key barrier affecting access for many children who often have to travel long distances to enroll in an adequate school. The Training of staff is also important to promote inclusive education. Human Rights Watch research in South Africa and China found that many teachers often do not have the relevant training in sign language or braille, and often may not have adequate knowledge of sign language or braille script to teach children with sensory impairments. Health staff and doctors need to be trained to, because they often play a role in deciding which type of school children with disabilities attend. Human Rights Watch also found that students with sensory disabilities are often limited in the subjects they can access in secondary education, particularly where governments fail to provide accessible materials or specialised teachers. This limits their academic or career choices later on in life. School fees are a financial barrier so that it is recommended to provide free and compulsory primary education, and progressively introduce free secondary education. Furthermore, special support and accommodation should be provided free of charge, taking into account the financial resources of the parents or others caring for the child. Another key topic is a quality education that ensures equivalent standards of public education. A focus should be on the quality of the learning environment, of teaching and learning processes and materials, and of learning outputs. Human Rights Watch has found that systemic marginalisation of children with disabilities also takes place within ministries of education, particularly where responsibility for persons with disabilities lies solely with often small and under-resourced inclusive education or special education units. Paragraph 61 of the General Comment could include an explicit recommendation for governments to ensure all relevant departments within ministries of education have a shared responsibility and accountability for children with disabilities. Women and girls with disabilities are particularly affected by discrimination. Many girls with disabilities drop out of education before they complete compulsory education, and many may be limited in their educational choices due to their gender and their disability. Adolescent

girls with disabilities are subjected to distinct barriers in secondary education, for example during menstruation and puberty. The high risk of women and girls with disabilities in schools and education institutions to be exposed to physical or sexual violence, abuse and neglect, due to the lack of adequate sanitation facilities and menstruation management in schools, compounded by the lack of adequate redress or child protection mechanisms for girls should be taken into account. Human Rights Watch has found that protective or sheltered workshops are used to engage people with intellectual disabilities after basic education, though they are often a means to ensure people with intellectual disabilities have access to protective spaces and activities, rather than to strengthen life skills and other skills for meaningful, inclusive employment. Furthermore, Human Rights Watch welcomes that the General Comment 4 draws attention to the link between the right to education (Article 24) and the right to live in the community (Article 19). To address the needs of children who are currently living in institutions, in addition to community services and support to families, the General Comment could be strengthened with references to adoption and foster parents. Another important point is access to information, especially for poor families and in an accessible format.

**Information:** <https://www.hrw.org/news/2016/01/15/submission-crp-draft-general-comment-no-4-article-24>.

### People with Disabilities at Added Risk in War

People with disabilities face added risks of abandonment, neglect, and lack of equal access to food and healthcare during conflict and displacement, Human Rights Watch emphasised on 3<sup>rd</sup> December 2015, the International Day of Persons with Disabilities. While governments, donors, and aid agencies are overwhelmed with many competing priorities during emergencies, they should ensure that the needs and concerns of people with disabilities are addressed in humanitarian efforts. Between January and November 2015, Human Rights Watch has interviewed more than 100 people with disabilities, along with their families, and assessed their needs during the current conflicts in Yemen and the Central African Republic, as well as the European refugee crisis. People with disabilities, as women and children, face special challenges in situations of war. While anyone affected by a crisis needs help, people with disabilities are especially at risk. Challenges created by war, natural disasters, and other situations of risk are compounded for people with disabilities by physical, communication, and other barriers. For example, people with disabilities often have difficulties getting aid because facilities are not designed to allow independent



navigation by people who are blind or use wheelchairs, and information is not provided in accessible, easy-to-understand formats. According to the Women's Refugee Commission, 6.7 million people with disabilities are forcibly displaced as a result of persecution and other human rights violations, conflict, and generalised violence. Children with disabilities in particular are at-risk of abandonment and violence during emergency situations, and yet their particular needs are often not taken into account in aid efforts. Governments, donors, and humanitarian agencies should ensure that the needs of people with disabilities are addressed as a priority in conflict and displacement situations, Human Rights Watch said. Those providing aid should consult with and engage people with disabilities and organisations representing them to develop a more effective and inclusive response.

The World Humanitarian Summit in Istanbul in May 2016 will be an opportunity to ensure that the voices of people with disabilities are heard in this debate. Governments and United Nations agencies should develop and endorse global standards and guidelines on disability inclusion in humanitarian action, Human Rights Watch said, together with CBM, Handicap International, International Disability Alliance, Women's Refugee Commission, and other partners. The standards and guidelines should address coordination, implementation, monitoring and financing, and further support of inclusive practices in all aid programs and efforts.

**Information:** <https://www.hrw.org/news/2015/12/03/people-disabilities-added-risk-war-displacement>.

### Disability-Inclusive Humanitarian Action

Persons with disabilities, when compared to the general population, face higher risks in conflict situations and natural disasters. Research shows that the mortality rate among persons with disabilities tends to be two to four times higher than among the general population, as demonstrated in cases such as the 2011 Japan earthquake and tsunami and hurricane Katarina in the USA. Moreover, for every person who dies during a disaster, it is estimated that three people sustain an injury, many causing long-term disabilities. To compound matters, persons with disabilities are disproportionately more likely to be left behind in emergency responses and to fail to benefit from humanitarian services due to a range of environmental, physical and social barriers. A recent UNHRC study (2015) has confirmed that three-quarters of persons with disabilities do not have adequate access to basic assistance, such as water, shelter or food in a crisis situation. Half of the persons with disabilities being surveyed also reported no access to disability-specific services, such as rehabilitation or assistive devices. Persons with disabilities are a unique resource of knowledge and experience, which is often overlooked, to help build resilient societies and communities. A barrier-free environment enables full and equal participation in society by all, regardless of age, gender or

disability status. The newly adopted international agreement, the Sendai Framework for Disaster Risk Reduction 2015-2030, set the stage to call for actions to meaningfully engage persons with disabilities in all stages of disaster risk reduction and responses, as well as for investment in accessibility, in both the physical environment and information and communication sectors, and ensuring that disability disaggregated data are in place for implementation, monitoring and evaluation of the Sendai Framework. The first-ever World Humanitarian Summit (WHS), set to take place in Istanbul, Turkey on 23-24 May 2016, provides a timely opportunity to build on the progress made in Sendai and ensure that the Sendai Framework, together with other important international agreements such as the 2030 Agenda, are effectively and efficiently implemented on the ground.

**Information:** <https://www.un.org/development/desa/disabilities/news/news/disability-inclusive-humanitarian-action.html#more-5990>, <http://www.un.org/disabilities/documents/WHS/HRCart11SGR.docx>.

### Inclusive Disaster Risk Reduction in Ecuador

Design for All awarded the Inclusive Disaster Risk Reduction Strategy of Ecuador as example for good practice in 2015. As in case of a disaster, the death rate is at least two times higher among persons with disabilities, the Ecuadorian Government has set up a Technical Secretariat for the Inclusive Management on Disabilities (SETEDIS) coordinating the cross-sector implementation of public policies to incorporate inclusive strategies for the promotion of equal rights and opportunities for all in the case of an emergency or risk. The SETEDIS is part of the Inclusive Disaster Risk Reduction Strategy under the national program Ecuador Lives the Inclusion (Programa Ecuador Vive la Inclusion). In Ecuador, a country exposed to a wide range of natural hazards, the first governmental inclusive intervention was deployed in the year 2011 during the eruptive activity of the Tungurahua Volcano. This first experience set the base line for the design of a National Strategy lead by SETEDIS, which, since 2013, has been implementing inclusive projects to guarantee the rights of persons with disabilities and their families. As a result, the inclusive approach to disaster risk reduction of SETEDIS has been expanded to the National Risk Management Strategy and crosscutted into the Emergency Operation Committees (EOC). In August 2015, during the reactivation of Cotopaxi Volcano, a phenomenon that could affect 325.000 people, SETEDIS has been consulted for guidelines for the Inclusive Development Plan and also for the accessible infrastructure needed in case of evacuation. The Technical Form for Validation, Selection, Calculation and Basic Equipment of universal Accessibility for shelters makes a prompt evaluation of each space and selects the best option to be considered as a shelter for validation, selection and calculation of accessibility and basic equip-



ment for temporary shelters. The tool supports the decision making process during the phase of Reduction of Disasters because it allows to identify in short time the shelters that fulfil the basic accessibility requirements. Additionally, it calculates the specific number of elements from a Kit that mandatorily have to be implemented in the selected infrastructure. It is divided into four Phases: (1) Phase of Alert; (2) Phase of Evacuation; (3) Pre Hospital Attention and (4) Attention on reception homes and of temporary shelters.

**Information:** <http://designforall.org/morecandidate.php?id=341>; [http://www.setedis.gob.ec/descargas/publicaciones/sendai\\_folleto-eng.pdf](http://www.setedis.gob.ec/descargas/publicaciones/sendai_folleto-eng.pdf).

### **Global Network on Monitoring and Evaluation for Disability-Inclusive 2030 Sustainable Development Framework**

The first meeting of the Global Network on Monitoring and Evaluation for Disability-inclusive Development, organised by UN DESA, took place from 6 to 7 October 2015. More than twenty international agencies, disabled persons' organisations, national agencies and research experts participated in this meeting. The meeting (i) identified existing initiatives which could provide relevant information and data for a UN flagship report to be released in 2018 assessing progress, for persons with disabilities, towards internationally agreed development goals and the provisions of the CRPD; (ii) in support of the Inter-agency and Expert Group on Sustainable Development Goal Indicators (IAEG-SDGs) work, reviewed disability indicators relevant for the SDGs; and (iii) discussed next steps for the Network till 2018. The discussions also led to new collaborations and better coordination among different initiatives.

**Information:** <https://www.un.org/development/desa/disabilities/resources/monitoring-and-evaluation-of-inclusive-development-data-and-statistics/global-network-on-monitoring-and-evaluation-for-disability-inclusive-development.html>.

### **Accessibility as a Central Part of Good Urban Policy**

The DESA/DSPD Forum on Disability Inclusion and Accessible Urban Development took place in Nairobi, Kenya, from 28 to 30 October 2015. The Forum brought together more than 70 urban planning and disability experts from governments, UN agencies, civil society, academia and the private sector to discuss policies and solutions to make urban development inclusive of and accessible to the world's one billion persons with disabilities, many of whom live in cities. The Forum presented a set of key findings, conclusions and recommendations to further advance accessible and inclusive urban development as its outcome and contribution to the on-going processes to-

wards HABITAT III and the New Urban Agenda. The Forum proposed (1) Accessibility and universal design in all built environments, both physical and virtual, should be seen as a public good that benefits all, rather than a defined benefit for a specific group of people, and shall be a central part of good urban policy to achieve inclusive and sustainable urban development; (2) The New Urban Agenda should be inclusive of persons with disabilities and advance accessibility in all aspects of urban development designs, policies, programmes and construction; (3) Accessible urban development, which includes inclusive and disability responsive urban policy frameworks, appropriate regulatory structures and standards, *design for all* approaches in planning and design, and predictable reliable resource allocations, can be realised everywhere if there is strong political commitment; (4) Inclusive urban development requires full consultation and engagement of persons with disabilities as agents and beneficiaries of development.

**Information:** <http://www.un.org/disabilities/default.asp?navid=15&pid=1641>.

### **Accessible India Campaign for an Accessible Environment for All**

The Accessible India Campaign is a nation-wide awareness campaign toward achieving universal accessibility by creating an enabling and barrier-free environment for all citizens, including persons with disabilities. The campaign aims to enable persons with disabilities to gain access to equal opportunities and live independently, participating fully in all aspects of life in an inclusive society. The campaign targets the accessibility of built environment, transport systems and the information and communications eco-system. A multi-pronged strategy will be adopted for the campaign with key components as (a) leadership endorsements of the campaign, (b) mass awareness, (c) capacity building through workshops, (d) interventions (legal framework, technology solutions, resource generation, etc. and (e) leverage corporate sector efforts in a Public-Private Partnership.

**Information:** [http://disabilityaffairs.gov.in/content/accessible\\_india.php](http://disabilityaffairs.gov.in/content/accessible_india.php).

### **Strengthening the Capacity of Networks of Women with Disabilities on Humanitarian Action**

Women leaders with disabilities from the Network of African Women with Disabilities (NAWWD) representing ten African countries, and refugee women with disabilities met in Nairobi, Kenya from 11-12 February to participate in the workshop Enhancing the Network's Humanitarian Advocacy at Regional and Global Events. During the two-day workshop, approximately 30 participants identified gaps and opportunities, mapped capacity-building needs



on humanitarian issues, learned about humanitarian issues, systems and processes, shared experiences, and developed regional advocacy plans on key humanitarian issues. The importance of increasing the number of members and mentorship of young women leaders with disabilities were also addressed. The workshop was held as part of UN Women's one year project on strengthening the capacity of networks of women with disabilities in humanitarian action. UN agencies including UN Women and UNHCR and other humanitarian actors such as the International Rescue Committee presented about their role in humanitarian crises and opportunities to collaborate with the regional network. Women with disabilities should be empowered through gender needs assessments; capacity building on mainstreaming gender and women's empowerment in the humanitarian response for government institutions, UN agencies and non-governmental organisations (NGOs); and strengthening the capacity of women to participate in peacebuilding and enhance their leadership skills. In this regard, civil society organisations, including those of, or working with women with disabilities, need to use this space for participating in gender assessments to include their needs across sectors, and advocate for their concerns to be articulated at the highest level. To support this, participants of the workshop developed regional advocacy plans on key humanitarian issues with a view to the formation of community-based structures of women and girls with disabilities in humanitarian settings to ensure self-representation. These advocacy plans also aim to promote the inclusion of women and girls with disabilities in humanitarian action, including the World Humanitarian Summit, as well as the inclusion of humanitarian issues of women and girls with disabilities in disability rights forum, including in the Conference of State Parties to the Convention on the Rights of Persons with Disabilities.

2016 marks the tenth anniversary of the Convention on the Rights of Persons with Disabilities. The Convention mainstreams gender perspectives and has a standalone article, Article 6, on women with disabilities. Article 11 focuses on situations of risk and humanitarian emergencies. This year also marks the 25th anniversary of the Committee on the Elimination of Discrimination against Women (CEDAW) general recommendation 18 on disabled women. It will also be the year in which the Committee on the Rights of Persons with Disabilities will adopt a general comment on women with disabilities. To effectively address gender equality concerns across the humanitarian-development continuum, as we move to implement the Sustainable Development Goals and prepare for the World Humanitarian Summit, it is more important than ever to ensure the participation of women and girls with disabilities. Of significance for women and girls with disabilities is that both gender equality perspectives and disability are mainstreamed in the goals and targets of the 2030 Agenda. Goal 5 to achieve gender equality and empower all women and girls and its six related targets, as well as the systematic mainstreaming of gender equality throughout the framework, provide the opportunity to ad-

dress the needs and priorities of women and girls with disabilities. Furthermore, most of the targets with specific reference to disabilities or persons with disabilities also include references to gender or women.

**Information:** <http://www.unwomen.org/en/news/stories/2016/2/strengthening-the-capacity-of-networks-of-women-with-disabilities-on-humanitarian-action>.

### **African Disability Forum (ADF) First General Assembly**

Delegates from 30 organisations of persons with disabilities (DPOs) in Africa, members of the African Disability Forum (ADF), held their first General Assembly from 31 October to 1 November in Nairobi, Kenya. The ADF is a democratic, representative, pan-African membership organisation of DPOs at continental, sub-regional and national levels, created to unify and amplify the voice of persons with disabilities in Africa and strengthen the technical capacity of their organisations. Until this meeting, Africa was the only region of the world without a democratic, representative, regional disability forum of member DPOs. During the meeting, the ADF draft constitution and bylaws were formally adopted. 46 African DPOs submitted their applications to become members of the ADF. With the support of the UN Partnership to Promote the Rights of Persons with Disabilities (UNPRPD) toward its establishment and operationalisation, the ADF plans to work closely with the African Union, the UN and its system organisations, key international and regional disability organisations, including the International Disability Alliance (IDA), the International Disability and Development Consortium (IDDC) and the European Disability Forum (EDF), as well as with African development organisations and academic institutions.

**Information:** <http://inclusion-international.org/wp-content/uploads/2015/11/ADF-First-General-Assembly-31-Oct.-1-Nov.pdf>.

### **Commission for Social Development to Discuss Disability Issues**

The 54th Session of the Commission for Social Development (CSocD54) took place from 3 to 12 February 2016 at UN Headquarters in New York under the priority theme: Rethinking and Strengthening Social Development in the Contemporary World. Three draft resolutions were approved for adoption by the Economic and Social Council with one on Africa's development, traditionally endorsed by consensus, requiring a rare vote to address the United States' concerns over language around trade issues, and more generally, the right to development. In closing remarks, Commission Chair Ion Jinga (Romania) said the Commission had taken stock of achievements and challenges in countries, regions and around the world in reducing poverty and inequality and creating jobs. Millions





of workers continued to fall behind and too many people lacked access to education, gender equality and climate change mitigation services. The session had called for integrated economic and social policies, devised with the engagement of a broad range of stakeholders to give life to a shared vision. The programme included a multi-stakeholder panel discussion entitled: Implementation of the 2030 Development Agenda in Light of the CRPD. The panel discussion highlighted existing mechanisms within the UN system that could contribute to mainstreaming disability and cooperation at all levels on the implementation of the 2030 Agenda for Sustainable Development. The Commission also considered the possibility and modalities of another international monitoring mechanism on disability. A side-event on Addressing the Structural Issues Concerning Inequalities Faced by Persons with Disabilities was organised to address the inequalities faced by persons with disabilities and promote the implementation of the 2030 Agenda for the full and effective participation of persons with disabilities in society and development.

**Information:** <https://www.un.org/development/desa/disabilities/issues/csocd54.html>; <http://www.un.org/press/en/2016/soc4837.doc.htm>; <http://www.un.org/development/desa/dspd/united-nations-commission-for-social-development-csocd-social-policy-and-development-division/54th-session-of-the-commission-for-social-development-csocd54/csocd54-draft-resolutions.html>.

### Transforming Mental Health Services in Jamaica

The World Health Organisation's (WHO) Quality Rights Project is transforming mental health services in Jamaica. Poor quality treatment and wide-ranging human rights violations of people with psychosocial disabilities are all too common across the world. With support from WHO, the Jamaican Ministry of Health plans to tackle this situation by assessing current conditions in mental health services in the country and then improving them. The stakeholders will receive training on the WHO Quality Rights toolkit and methodology for assessing and reporting on conditions in mental health services.

**Information:** [http://www.who.int/mental\\_health/policy/qrs\\_jamaica/en/](http://www.who.int/mental_health/policy/qrs_jamaica/en/).

### Disability Indicators Proposed for the SDGs

The Inter-agency and Expert Group on Sustainable Development Goal Indicators (IAEG-SDGs) is the focal point on developing a global indicator framework for the 17 Sustainable Development Goals (SDGs) and the corresponding targets. The IAEG-SDGs Member States and observers increasingly recognised the need to integrate disability in the SDGs indicator framework, which is reflected in the recently released IAEG-SDG Report to the 47<sup>th</sup> session of the UN Statistical Commission, which will be held in March 2016. This report proposes a list of indicators for the monitoring of the goals and targets of the 2030 Agenda for Sustainable Development at the global level. At that session, the Commission will decide on the adoption of the proposed list of SDG indicators. Disability is reflected in the IAEG-SDG Report in two ways. First, the report calls for data disaggregation where relevant by disability. Secondly, nine indicators explicitly refer to persons with disabilities, an improvement in integrating disability from the three indicators included in the outcome document of the 2nd IAEG-SDG meeting in October 2015. These nine indicators are under six SDGs focusing on poverty eradication (Goal 1), education (Goal 4), employment (Goal 8), reducing inequalities (Goal 10), inclusive cities (Goal 11), and promoting peaceful and inclusive societies (Goal 16). To monitor these global indicators, international guidelines for collecting reliable and comparable data on disability will have to be further expanded, quality standards will have to be defined and good practices should be identified and followed. Furthermore, efforts should be made in enhancing the national and international capacity to transforming disability statistics into real policy impacts through establishing strong data reporting mechanisms and formal processes to inform policy through high-quality data.

**Information:** <https://www.un.org/development/desa/disabilities/news.html>; [http://www.un.org/disabilities/documents/sdgs/iaeg\\_report.pdf](http://www.un.org/disabilities/documents/sdgs/iaeg_report.pdf).

### Together 2013- New Initiative on Sustainable Development Goals

Together 2030 is a civil society initiative that will promote national implementation and track progress of the 2030 Agenda for Sustainable Development. The initiative aims to generate knowledge and project voices from different civil society stakeholders around the world on the challenges and opportunities for the 2030 Agenda. They want to bring together actors to discuss the way to formulate and implement roadmaps at national level and hold governments to account at all levels.

**Information:** <http://www.together2030.org/en/>.



## Literatur/Reviews

The Governance and Social Development Resource Centre (GSDRC)

### **Disability Inclusion - Topic Guide**

The Governance and Social Development Resource Centre (GSDRC), has published a topical guide that summarises evidence on the key debates and challenges of disability inclusion in development and humanitarian response. While disability does not necessarily imply limited well-being and poverty, there is growing evidence that the estimated one billion people with disabilities face attitudinal, physical and institutional barriers that result in multi-dimensional poverty, exclusion and marginalisation. Disability inclusion could increase earnings, tax revenues, and individual and societal well-being, and it does not need to be costly or complicated. Inclusive approaches are more cost-effective than piecemeal disability interventions. The tool has three central features; self-reported impairment based on a person's activity limitation; additional simple clinical screening for impairment, where activity limitation is reported as present but not significant to identify the population with moderate impairments; and measure of barriers to participation in society, to identify and overcome disabling factors external to the individual.

**Bezug:** <http://www.gsdr.org/wp-content/uploads/2015/11/DisabilityInclusion.pdf>; <http://www.gsdr.org/topic-guides/disability-inclusion/disability-inclusive-approaches/>; <http://blogs.lshtm.ac.uk/news/2014/12/16/new-global-measure-disability-guide-better-inclusion-society-impaired-people/>.

UN Development Programme (UNDP) Bangkok Regional Hub and World Blind Union

### **Our Right to Knowledge: Legal Reviews for the Ratification of the Marrakesh Treaty for Persons with Print Disabilities in Asia and the Pacific**

The report is intended to facilitate policy dialogue, legal reforms and community engagement in the Asia-Pacific region with respect to efforts to ratify the Marrakesh Treaty to Facilitate Access to Published Works for Persons Who Are Blind, Visually Impaired, or Otherwise Print Disabled and ensure that those with disabilities can realise their rights guaranteed by international law.

**Bezug:** [http://www.asia-pacific.undp.org/content/rbap/en/home/library/democratic\\_governance/hiv\\_aids/our-right-to-knowledge--legal-reviews-for-the-ratification-of-th/](http://www.asia-pacific.undp.org/content/rbap/en/home/library/democratic_governance/hiv_aids/our-right-to-knowledge--legal-reviews-for-the-ratification-of-th/).

ILO

### **Decent Work for Persons with Disabilities: Promoting Rights in the Global Development Agenda**

Based on two previous editions, the latest publication from the International Labour Organization (ILO): Decent Work

for Persons with Disabilities: Promoting Rights in the Global Development Agenda presents the main approaches which have been taken in countries across the globe to ensure that persons with disabilities can access employment and work to advance professionally, and on an equal basis with others. These approaches include legislation, vocational training, employment services as well as financial, technical and personal support mechanisms. The latest publication provides an overview of the principal international legal instruments, policies and initiatives that aim to promote the rights of persons with disabilities, particularly in terms of work and employment. It also proposes an agenda for future action for promoting the rights of persons with disabilities within the 2030 Development Agenda.

**Bezug:** <http://labordoc.ilo.org/record/462523?ln=en>.

Marcia H. Rioux/Paula C. Pinto/Gillian Parekh (Eds.)

### **Disability, Rights Monitoring, and Social Change**

Disability, Rights Monitoring, and Social Change is a collection that explores and challenges the ways in which disability rights are monitored. The contributors to this edited volume range from grassroots activists to international scholars and UN advisors. The chapters address the current theoretical, methodological, and practical issues surrounding disability rights monitoring and offer a detailed look at law and policy reforms, best practices, and holistic methods. This unique compilation crosses the divide between the global South and North and explores the complex issues of intersectionality that arise for women with disabilities, indigenous peoples with disabilities, and people with diverse disabilities.

**Bezug:** <http://bit.ly/1P9Uc2i>.

UN Economic and Social Commission for Asia and the Pacific (ESCAP)

### **Disability at a Glance 2015: Strengthening Employment Prospects for Persons with Disabilities in Asia and the Pacific**

The report focuses on barriers to the employment of persons with disabilities in the Asia-Pacific region, and offers solutions to strengthen their employment prospects. The publication offers a regional overview of disability legislation, policies and practices, as well as relevant country-specific information with a particular emphasis on the employment of persons with disabilities. The information is drawn from a targeted disability survey carried out in 2015 by the ESCAP secretariat, and research undertaken by other organisations and scholars.

**Bezug:** <http://www.unescap.org/resources/disability-glance-2015-strengthening-employment-prospects-persons-disabilities-asia-and>; [http://www.unescap.org/sites/default/files/SDD%20Disability%20Glance%202015\\_Final.pdf](http://www.unescap.org/sites/default/files/SDD%20Disability%20Glance%202015_Final.pdf).



## UN Habitat

### **The Right to Adequate Housing for Persons with Disabilities Living in Cities**

This study reviews the literature on the meaning and impact of the right to adequate housing for persons with disabilities in cities. It uses the foundational framework of the International Covenant on Economic, Social and Cultural Rights (ICESCR), and demonstrates how the Convention on the Rights of Persons with Disabilities (CRPD) provides a new understanding of this complex right. The authors link the right to adequate housing not only to other international treaties, but also to the diverse groups of individuals who are persons with disabilities and the complexity of the identities involved. They outline major types of barriers that persons with disabilities encounter (physical inaccessibility, lack of access to transportation services, insecurity of tenure, among others), and identify trends in relation to policy and legal framework and national and sub-national solutions to the realisation of the rights of persons with disabilities.

**Bezug:** <http://unhabitat.org/books/the-right-to-adequate-housing-for-persons-with-disabilities-living-in-cities/>.

## S. Ronoh/J.C. Gaillard/J. Marlowe

### **Children with Disabilities and Disaster Preparedness: A Case Study of Christchurch - New Zealand**

The study presents key issues and highlights challenges in disaster preparedness for children with disabilities drawing from a wide range of sources, including interviews with children with disabilities.

**Bezug:** Kōtuitui: New Zealand Journal of Social Sciences Online

Vol. 10, Iss. 2, 2015; <http://www.tandfonline.com/doi/full/10.1080/1177083X.2015.1068185>.

## Human Rights Council

### **Thematic Study on the Rights of Persons with Disabilities under Article 11 of the Convention on the Rights of Persons with Disabilities, on Situations of Risk and Humanitarian Emergencies**

In the present study, the Office of the United Nations High Commissioner for Human Rights sets out the standards on the human rights of persons with disabilities in situations of risk and humanitarian emergencies, and presents a harmonised understanding of existing international humanitarian law under article 11 of the Convention on the Rights of Persons with Disabilities. The aim of the study is to clarify the scope of the Convention in the context of ongoing global discussion relating to disasters and humanitarian emergencies, to identify good practices, and to make recommendations thereon.

**Bezug:** <http://reliefweb.int/report/world/thematic-study-rights-persons-disabilities-under-article-11-convention-rights-persons>; <http://www.un.org/disabilities/documents/WHS/HRCart11SGR.docx>.

## HelpAge

### **Minimum Standards for Age and Disability Inclusion in Humanitarian Action**

The Minimum Standards for Age and Disability Inclusion in Humanitarian Action inform the design, implementation, monitoring and evaluation of humanitarian programmes across all sectors and phases of response, and in all emergency contexts, ensuring older people and people with disabilities are not excluded. Targeting practitioners involved in humanitarian response at local, national, and international level, this document includes a set of key standards as well as sector-specific standards, accompanied by suggested actions for humanitarian agencies to take.

**Bezug:** <http://www.helpage.org/download/56421daeb4eff>; <http://www.helpage.org/download/55cdbcca06aab>.

## Valentina Lemmi et al.

### **Community Based Rehabilitation for People with Disabilities in Low and Middle Income Countries: A Systematic Review**

This Campbell Collaboration systematic review assesses the effectiveness and cost-effectiveness of community-based rehabilitation (CBR) for people with physical and mental disabilities in low- and middle-income countries, and/or their family, their carers, and their community. This review identified 15 studies that assessed the impact of community-based rehabilitation on the lives of people with disabilities and their carers in low- and middle-income countries.

**Bezug:** Campbell Systematic Reviews 2015:15; <http://www.asksourc.info/node/71069>; <http://www.campbellcollaboration.org/lib/project/244/>.

## Handicap International

### **Disability in Humanitarian Context: Views from Affected People and Field Organisations**

This report is based on the results of a global consultation carried out in 2015 as a contribution to the World Humanitarian Summit and is intended to better identify the changes needed for a disability inclusive humanitarian response. A total of 769 responses were collected through three online surveys targeting persons with disabilities, disabled people's organisations (DPOs) and humanitarian actors. The results demonstrate that while most humanitarian actors pledge to target vulnerable persons in crisis time, few of them are putting in place specific mechanisms and procedures to effectively reach to, and taking into account, persons with disabilities in their programmes.

**Bezug:** <http://www.asksourc.info/node/71175>; <https://www.worldhumanitariansummit.org/node/504293>.



Tanvi Bhatkal/Emma Samman/Elizabeth Stuart  
**Leave No One Behind:  
The Real Bottom Billion**

This paper sets out why the leave no one behind agenda should be a key priority (i) in implementing the SDGs in all countries and (ii) in assessing whether or not governments have met them. It underlines how deeply entrenched marginalisation is, how vulnerabilities often overlap to amplify multiple disadvantages, and just how little we know about some groups that are likely to be deprived.

**Bezug:** <http://www.asksource.info/node/71209>; <http://www.odi.org/sites/odi.org.uk/files/odi-assets/publications-opinion-files/9846.pdf>.

Lars Bosselmann  
**Dialogues on Sustainable Development:  
A Disability-Inclusive Perspective**

This publication highlights the many commonalities between disability-inclusive development and a range of overarching development themes. It is structured around the three basic elements of sustainable development – economic, social and environmental sustainability – and discusses a range of sub topics relevant to these areas.

**Bezug:** <http://www.asksource.info/node/71161>; [http://www.cbm.org/article/downloads/54741/CBM\\_Inclusive\\_Development\\_Dialogues\\_2015.pdf](http://www.cbm.org/article/downloads/54741/CBM_Inclusive_Development_Dialogues_2015.pdf).

Susan Nicolai et al.  
**Projecting Progress:  
Reaching the SDGs by 2030**

The report presents an analysis that begins to systematically quantify the scale of the challenge that the world has set itself with the Sustainable Development Goals for the first time. The authors select one target per goal – a total of 17 – and project forward to 2030, grading them from A-F according to how near they will be to completion in 2030. This is based on available projections of current trends sourced from leading institutions, alongside the Overseas Development Institute where there were gaps. The resulting scorecard shows that unless significant changes are made, none of the SDGs will be met.

**Bezug:** <http://www.asksource.info/node/71166>; <http://www.odi.org/sites/odi.org.uk/files/odi-assets/publications-opinion-files/9839.pdf>.

James Smith  
**A Systematic Literature Review of the Quality of Evidence for Injury and Rehabilitation Interventions in Humanitarian Crises**

This review assesses the quality of evidence that informs injury and physical rehabilitation interventions in humanitarian crises. Peer-reviewed and grey literature sources are assessed in a systematic manner. The article concludes that while there is now a greater emphasis on research in this sector, the volume of evidence remains inadequate given the growing number of humanitarian programmes worldwide. Further research is needed to ensure a greater

breadth and depth of understanding of the most appropriate interventions in different settings.

**Bezug:** International Journal of Public Health, Vol 60; <http://www.asksource.info/node/71177>; <http://link.springer.com/article/10.1007/s00038-015-0723-6>.

Handicap International  
**Making it Work: Initiative on Gender and Disability Inclusion. Make Disability and Gender Equity Work**

The Making it Work report is documenting the results of the last two years of the Making it Work initiative on gender and disability inclusion. This global initiative was started by Handicap International and implemented with a global Technical Advisory Committee of experts on disability, gender and development. The initiative identified good practices across the globe which showed sustainable and CRPD compliant results in ending violence, abuse and exploitation of women and girls with disabilities. The initiative visited and documented ten good practices and one emerging practice across the three major areas of a) Awareness raising, b) Access to justice and legal advocacy c) Empowerment of women with disabilities. The recommendations of the report are formulated around those three key areas, and made by the global and local expert women with and without disabilities to change global policy dialogues and programming around gender and disability. They are based on their analysis and exchanges around the good practices taking place during the Disability and Gender Forum in New York in June 2015.

**Bezug:** [http://www.makingitwork-crpd.org/fileadmin/user/News/update\\_may\\_2015/MIW\\_GenderAndDisability-Inclusion\\_LL08\\_low.pdf](http://www.makingitwork-crpd.org/fileadmin/user/News/update_may_2015/MIW_GenderAndDisability-Inclusion_LL08_low.pdf).

International Disability Alliance (IDA) & International Disability and Development Consortium (IDDC)

**The 2030 Agenda: The Inclusion of People with Disabilities: Introductory Toolkit**

This toolkit provides a general overview of the 2030 Agenda and focuses on practical examples on how to participate in the national implementation of the SDGs.

**Bezug:** <http://asksource.info/node/71446>; <http://www.internationaldisabilityalliance.org/en/article/2030-agenda-toolkit-and-guide-persons-disabilities>.

United Nations Department of Economic and Social Affairs (UNDESA)

**Operationalizing the 2030 Agenda: Ways Forward to Improve Monitoring and Evaluation of Disability Inclusion**

This note concerns monitoring and evaluation of disability and inclusion in light of the sustainable development goals. The note identifies steps which can be taken by individual countries and the international community as a whole to address the gaps in data disaggregation and collection concerning people with disabilities. The note con-



cludes with a discussion of possible ways forward for better monitoring and evaluation for disability inclusion in the 2030 Agenda for Sustainable Development.

**Bezug:** <http://asksource.info/node/71398>; [http://www.un.org/disabilities/documents/desa/operationalizing\\_2030\\_agenda.pdf](http://www.un.org/disabilities/documents/desa/operationalizing_2030_agenda.pdf).

Charles Ngwena

### **African Disability Rights Yearbook**

This volume of the African Disability Rights Yearbook is divided into three sections presenting articles, country reports and commentaries on regional developments, and has added a new feature in the form of a book review section. The first section of the journal presents a number of articles on issues affecting people with disabilities in Africa, ranging from sexual and reproductive rights to socio-economic issues. The second section presents a number of country reports on Eritrea, Lesotho, Morocco, Sierra Leone, Swaziland, Tunisia. The third section presents two articles focussing on regional development; one on disability rights and emergency legislation, and another one on the right to political participation for people with disabilities in Africa. Finally the journal presents a review of A.S. Kanter's 2014 book "The development of disability rights under international law: From charity to human rights".

**Bezug:** <http://asksource.info/node/71387>;  
<http://www.adry.up.ac.za/index.php/table-of-contents>.

Janice Tipney

### **Interventions to Improve the Labour Market Situation of Adults with Physical and/or Sensory Disabilities in Low and Middle-Income Countries: A Systematic Review**

This systematic review analyses the methodology, collection, and results of fourteen individual studies that examined the effectiveness of fifteen different intervention methods to assist students with disabilities in low and middle income countries to improve the labour market situation.

**Bezug:** Campbell Systematic Reviews 2015:20;  
<http://asksource.info/node/71388>;  
[http://scholar.google.com/scholar\\_url?url=http://campbellcollaboration.org/lib/download/3893/Tripney\\_Labour\\_Market\\_Review.pdf&hl=en&sa=X&scisig=AAGBfm36pl108Dtw\\_PTznHgY2Qy\\_t7jisw&noss=1&oi=scholaralrt](http://scholar.google.com/scholar_url?url=http://campbellcollaboration.org/lib/download/3893/Tripney_Labour_Market_Review.pdf&hl=en&sa=X&scisig=AAGBfm36pl108Dtw_PTznHgY2Qy_t7jisw&noss=1&oi=scholaralrt).

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## VERANSTALTUNGEN/EVENTS

- 11.04. - 13.04.2016 9th World Assembly of Disabled People's International (DPI), New Delhi India.  
**Information:** <http://www.dpiworldassembly2016.com>.  
Kontakt: NCPEDP (DPI INDIA): C - 43; South Extension Part II; New Delhi - 110 049; India; Tel.: 91-11-26265647 / 26265648; Fax: 91-11-26265649; E-Mail: [secretariat.dpi@gmail.com](mailto:secretariat.dpi@gmail.com).
- 25.04. - 26.04.2016 Pacific Rim International Conference on Disability and Diversity, Hawaii.  
**Information:** [www.pacrim.hawaii.edu/](http://www.pacrim.hawaii.edu/).  
Kontakt: Charmaine Crockett; 1410 Lower Campus Rd., #171F  
Tel: 808 956 7539; Fax: 808 956-4437, E-Mail: [cccrocke@hawaii.edu](mailto:cccrocke@hawaii.edu).
- 25.04. - 27.04.2016 VIII Latin-American Congress of the Blind, Montevideo, Uruguay.  
**Information:** [www.ulacdigital.org/montevideo2016](http://www.ulacdigital.org/montevideo2016).  
Kontakt: Unión Latinoamericana de Ciegos - Organización Internacional no Gubernamental, Mercedes 1327 C.P. 11100, Montevideo, Uruguay; Tel: +598 2901 9797 22; Fax: +598 2901 9797 21; E-Mail: [ulac@ulacdigital.org](mailto:ulac@ulacdigital.org).
- 23.05. - 24.05.2016 World Humanitarian Summit, Istanbul, Turkey.  
**Information:** <https://www.worldhumanitariansummit.org>.  
Kontakt: [info@whsummit.org](mailto:info@whsummit.org).
- 27.09. - 29.09.2016 2nd Community Based Rehabilitation (CBR) World Congress, Kuala Lumpur, Malaysia.  
**Information:** <http://www.2ndcbrworldcongress.com/>.
- 03.10. - 05.10.2016 The Social Forum of the Human Rights Council, Geneva Switzerland.  
**Information:** <http://www.ohchr.org/EN/Issues/Poverty/SForum/Pages/SForum2016.aspx>.  
Kontakt: E-Mail: [socialforum@ohchr.org](mailto:socialforum@ohchr.org);
- 17.10. - 20.10.2016 Habitat III: UN Conference on Housing and Sustainable Urban Development, Quito, Ecuador.  
**Information:** <https://www.habitat3.org/the-new-urban-agenda/about>.
- 07.09. - 18.09.2016 2016 Paralympic Games, Rio de Janeiro, Brazil.  
**Information:** <http://www.paralympic.org/rio-2016>.



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

- 2/2016: 2030 - Agenda und Inklusion/2030 Agenda and Inclusion (verantwortlich/responsible: Gabriele Weigt)
- 3/2016: 10 Jahre UN-BRK: Chancen, Grenzen, Perspektiven/10 Years of the CRPD: Chances, Limits, Perspectives (verantwortlich/responsible: Christine Bruker/Isabella Bertmann)
- 1/2017: 10 Jahre UN-BRK: Chancen, Grenzen, Perspektiven/10 Years of the CRPD: Chances, Limits, Perspectives (verantwortlich/responsible: Christine Bruker/Isabella Bertmann)

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

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### Deadlines for the upcoming issues:

	2/2016	3/2016	1/2017
<b>Hauptbeiträge/Focal articles</b>	15.03.2016	15.07.2016	15.10.2016
<b>Kurzbeiträge/Other contributions</b>	15.03.2016	15.07.2016	15.10.2016

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

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Handicap International



Behinderung und  
Entwicklungszusammenarbeit e.V.

bezev wird gefördert aus Mitteln des Kirchlichen Entwicklungsdienstes *Brot für die Welt - Evangelischer Entwicklungsdienst*