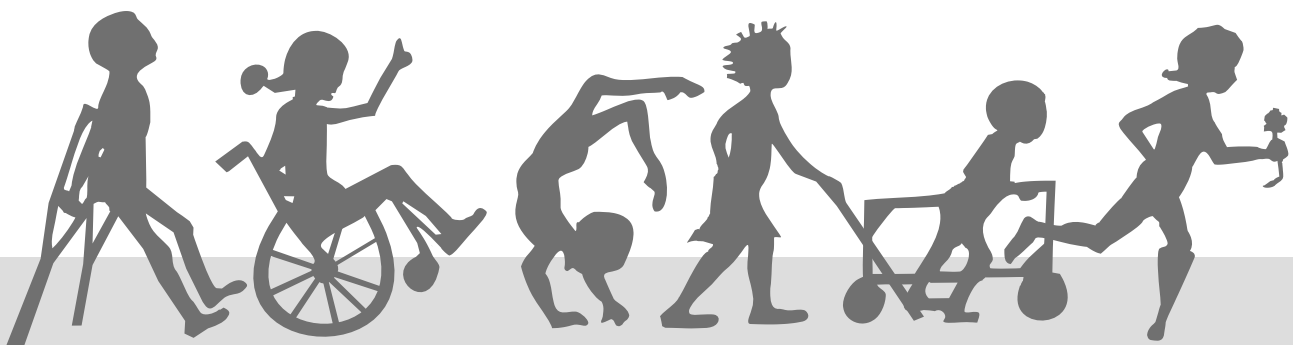


Behinderung und internationale Entwicklung

Disability and International Development



Kinder mit Behinderung im Licht der UN-Konvention über
die Rechte von Menschen mit Behinderung
Children with Disabilities and the UN Convention on the
Rights of Persons with Disabilities





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Editorial

“Children with disabilities and their families constantly experience barriers to the enjoyment of their basic human rights and inclusion in society. Their abilities are overlooked, their capacities are underestimated and their needs are given low priority.” (UNICEF 2007)

Liebe LeserInnen,

Die Rechte von Kindern sind seit mehr als 20 Jahren in der UN Kinderrechtskonvention (CRC) verankert und jene von Kindern mit Behinderungen werden durch die UN Behindertenrechtskonvention (CRPD, 2008) nachdrücklich bestärkt. Dies eröffnet neue Einflussmöglichkeiten, um für die Rechte von Kindern mit Behinderungen einzutreten und diese zu schützen.

Die Behindertenrechtskonvention fordert die Rechte von behinderten Kindern explizit in dem allgemeinen Grundsatz der „Achtung vor den sich entwickelnden Fähigkeiten von Kindern mit Behinderungen und die Achtung ihres Rechts auf Wahrung ihrer Identität“ sowie in den Artikeln 7 zu Kindern mit Behinderungen und Artikel 24 zu Bildung.

Neueste Zahlen des Weltbehindertenberichtes (WDR 2011) zeigen, dass weltweit zwischen 93 und 150 Millionen Kinder mit Behinderungen leben. Diese Variationen lassen sich u.a. auf Uneinheitlichkeiten bei der Identifizierung und Charakterisierung von Behinderung zurückführen, die wiederum auf unterschiedlichen kulturellen Auffassungen, Diskursen und Methoden zur Erfassung von Behinderung, besonders von Behinderungen bei Kindern beruhen.

Der Weltbehindertenbericht behauptet, dass dies zu den Unstimmigkeiten bei den Prävalenzdaten beiträgt und damit Kinder mit Behinderungen nicht identifiziert werden und keine notwendigen Dienstleistungen erhalten (WDR 2011:36).

Offensichtlich besteht eine große Lücke bei der Forschung und evidenz-basierter Praxis für Kinder mit Behinderungen, zum Beispiel hinsichtlich der Identifizierung, des Zugangs zu Dienstleistungen sowie allgemeiner sozialer Inklusion.

Die vorliegende Zeitschriftenausgabe untersucht die Lebenswirklichkeiten von Kindern mit Behinderungen sowie ihren Familien und Gemeinden in ressourcenarmen und ‚einschränkenden‘ Lebensbedingungen und wie ihre Rechte (auf Gesundheit, Bildung, Schutz, etc.) geschützt und umgesetzt werden können. Hierbei werden sowohl der Einfluss von Gesetzgebung und Politikpapieren wie auch die alltäglichen Praktiken zur Gestaltung einer befähigenden Umgebung für und mit behinderten Kindern beleuchtet, um zu zeigen, wie sie ihre Rechte ausleben und ihre Potenziale entwickeln können.

Ein großer Dank an alle AutorInnen dafür, ihr wertvolles Wissen an dieser Stelle zu teilen!

Wir wünschen Ihnen allen ein interessantes Lesevergnügen.

Ihre Redaktionsgruppe

Dear Reader,

The rights of children are enshrined in the UN Convention on the Rights of the Child (CRC) for more than 20 years, and those of children with disabilities are since 2008 reiterated in the UN Convention on the Rights of Persons with Disabilities (CRPD) opening a new leverage in promoting and protecting the rights of children with disabilities. The CRPD reinforces the rights of children with disabilities in the guiding principle of “Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities”, in Article 7 on “Children with Disabilities” and in Article 24 on “Education”.

Recent figures from the World Disability Report (WDR 2011) estimate that the number of children living with disabilities globally range between 93 million and 150 million. The differing figures are due to inconsistencies in identifying and characterizing disability due to varying cultural notions, discourses and tools for assessing disability, especially in children. The WDR states that “this may account in part for the variation in prevalence figures and suggests that children with disabilities are not being identified or receiving needed services” (WDR 2011:36).

It seems there is a wide gap in research and evidence-based practice advice for children with disabilities, e.g. with regard to identification, access to services, and overall social inclusion.

This journal issue aims at exploring the realities of children with disabilities and their families and communities in low resource and ‘disabling’ environments, and how their rights (to health, education, protection, etc.) can be protected and realised. It is to be focused both on the legislation and policy influence, but also on the day to day practices in creating an enabling environment for and with children with disabilities to live up to their rights and potentials.

Thanks to all the contributors for sharing their valuable knowledge!

We wish you an inspiring reading.

Your editorial board



Sexual Violence against Children with Disabilities

Corinna Csaky

Sexual violence against children with disabilities is a global issue affecting every country of the world. New research suggests that the severity and impact of abuse is extremely high with lasting consequences both for children and for the development and well-being of the societies in which they live. This article outlines why children with disabilities are especially vulnerable and what needs to change to ensure these children are better protected.

Sexual Violence Against Children is a Gross Violation of their Rights

Save the Children together with Handicap International recently conducted a multi-country study to shed more light on an issue we come across time and time again in our programmes around the world¹. First-hand qualitative research in four African countries – Burundi, Madagascar, Mozambique and Tanzania (Zanzibar) – as well as a global literature review confirmed that children with disabilities are suffering from all kinds of sexual violence. This includes sexual slavery, indecent sexual assault, prostitution, verbal sexual abuse, child pornography, child trafficking linked with commercial sexual exploitation, forced sterilisation and forced sex². Both boys and girls are vulnerable to abuse. The violence takes place at all levels of society and in all settings: in the home, in institutions, in schools, in the juvenile justice system, in the workplace and within the community.

"I was alone at home when my uncle gave me bread and took me to his bed to rape me. Another family member used to give me money to persuade me to have sex with him." (Girl from Burundi, aged five at the time of abuse)

Sexual violence against children with disabilities is a gross violation of their rights – as stated in both *The UN Convention on the Rights of the Child*³ and *The UN Convention on the Rights of Persons with Disabilities*⁴. Both Conventions recognise that whilst these rights apply to all people, additional measures are needed to ensure that those rights are realised for certain groups, including children and children with disabilities. This point was also elaborated upon by *The Committee on the Rights of the Child* in its *General Comment on Children with Disabilities*⁵.

This is a Global Problem

It is estimated that 200 million children have a disability worldwide, 80 % of whom live in the developing world⁶. Although there is very little

concrete data on sexual violence against them, evidence suggests high levels of abuse are present in every country of the world. For example:

- In the US, a study of 40,000 children found that children with disabilities were over three to four times more likely to be neglected, or physically, emotionally or sexually abused⁷.
- A national survey of deaf adults in Norway found 80% of all deaf individuals had experienced sexual abuse at some point in their childhood⁸.
- In Kenya, 15-20 % of children with disabilities have experienced severe levels of physical and sexual violence, with girls with intellectual impairments particularly vulnerable⁹.
- In Orissa, India, 25 % of women with intellectual disabilities had been raped and 6 % of disabled women had been forcibly sterilized¹⁰.
- In South Africa, children with physical disabilities are three to four times more likely to be abused than able-bodied children¹¹. And a comparative analysis showed that intellectual disabilities are three to eight times more common in abused than in non-abused children¹².

Discrimination is a Key Cause of Vulnerability

The UN Study on Violence against Children recognises the particular vulnerability of children with disabilities to all forms of violence, including sexual violence¹³. This is due, in large part, to the discrimination against children with disabilities found across all countries and cultures. Children with disabilities are among the most marginalised and stigmatised children in the world. This can take several forms. For example:

"In our country the disabled are treated differently by their families who do not treat them as normal people. Often they live hidden inside houses." (Lawyer from Mozambique)

Children with disabilities face widespread so-



cial exclusion stemming from complex cultural prejudices surrounding disability itself. For example, in some cultures children with disabilities are considered evil or disobedient. They are often socially isolated, hidden away from view and denied access to other children, the wider family and to public or social events. Their invisibility means that there are no witnesses to the harm caused, it is hidden from public view, offering relative impunity for those who do perpetrate abuses. Children with disabilities are, therefore, an easy target.

"When I was born, my father separated from my mother saying that in his family there was no one born with a disability. I lived with my mother until one day she remarried and took me to my stepfather's house. When he was drunk and my mother was asleep he would come to the house where I slept with the other children and force me to have sex with him so he would continue to support me." (Girl, from Mozambique, aged 15 at the time of the abuse)

Linked to this is the chronic *lack of access to services*. For example, at least 90 % of children with disabilities in the developing world are denied the right to education¹⁴; they are disproportionately likely to live in poverty¹⁵; and mortality for children may be as high as 80 %¹⁶. As a result, children with disabilities are often more dependent on others for their survival and well-being and, therefore, more vulnerable to sexual exploitation. They are also far less informed of their rights or how to protect themselves. Where services do exist to prevent and respond to harm, they are rarely suitable to the particular needs of children with disabilities. For example, information campaigns on preventing sexual violence may be delivered through schools, from which many children with disabilities are excluded. In addition, for families in difficult socio-economic circumstances, or where limited or no social protection or service provision is available, the birth of a child with a disability can be very challenging, placing them under considerable pressure and stress. The child can become the focus of the consequent frustration, leading to anger and rejection, and sometimes violence.

"I lived with my parents, an uncle and my two brothers. I was the oldest. When my parents left for work and because I was not going to school anymore because they did not enrol me, my uncle would call me to his room and tell me to take my skirt off and he would tell me he would buy me a dress and he would

touch my vagina." (Girl, from Mozambique, aged 15 at the time of the abuse)

Impunity is Creating a Cycle of Violence

Children with disabilities often experience a series of sequential and often insurmountable barriers which limit their capacity to challenge violence. As already noted, they may not know what sexual violence is, how to protect themselves, or how to seek support if it does occur. For example, they will often lack awareness that what is being done to them is wrong, the availability of people and medical, law enforcement and legal services who can support them and protect them. Even where they have information about possible sources of help, children, for example, who are deaf or blind, or have restricted mobility, may find it impossible to reach that help. They may not be able to move from their home independently, have or use a telephone, or access the Internet. Their dependency on the people they are closest to (family members, carers, neighbours), who are also commonly the perpetrators, means they are often trapped into situations of violence and abuse. They are also likely to place themselves at risk of retribution if they do seek help.

"We have no concrete data concerning the number of disabled victims of sexual violence because the cases are not reported." (Police officer, Mozambique)

Even if all those hurdles are overcome, and they succeed in reporting abuse, it is all too common for the police and courts to refuse to believe, investigate or prioritise a report from a child with a disability, assuming that they lack the competence to make a reliable report or to serve as a credible witness in court. Furthermore, a chronic lack of awareness of sexual violence and the particular needs and rights of children with disabilities, means that doctors, lawyers, police and other professionals involved in handling cases of abuse, fail to act or mismanage the process leading to weak or no convictions and inappropriate care and rehabilitation of the survivor.

"I was coming from the bush where I'd been to find coconut leaves to make brooms. A man grasped my hand and told me, 'Come, I want to give you a nice meal.' I said 'No, I want to go home.' He pulled me into a small bush and laid me down and had unnatural sex with me. I told my mother and she reported it to the police. Also I was sent to hospital. The man was sentenced to 19 years in jail, but



after eight months he was out." (Young woman from Tanzania, aged 18 at the time of the abuse)

These multiple barriers can result in a cyclical pattern of inadequate protection on the part of the state¹⁷. With the few cases of violence and abuse that tend to be reported and a lack of systematic data collection on children with disabilities results in very limited awareness of the scale of problem. This in turn leads to poor levels of investment in prevention or protection. In the rare cases which come to light, it is the child, rather than the perpetrator who tends to be further victimised, discriminated against and / or removed. All too often there is a lack of appropriately designed and equipped accommodation or adequately trained staff. Children are therefore likely to be placed in orphanages without adequate facilities, remand homes alongside other children who are in conflict with the law or sent to live on the streets¹⁸. In these environments, they are at significant risk of facing further abuse, which then leads to a reluctance to report in the first instance.

"There is no seriousness in the system for such cases. If the child is between 16 and 17 years, she or he is considered to have enjoyed and accepted it" and "infrastructures are not designed for such children and also no adequate translator for mute persons and deaf." (Male judge from Zanzibar)

Recommendations

Save the Children and Handicap International have developed the following recommendations in consultation with children, young people and professionals working on this issue around the world. We hope they will be taken forward by governments, donors and civil society organisations, communities and children and young people.

1. Tackle the social and structural discrimination that prevent children and young people accessing services, by, for example, guaranteeing equal access to education, reporting mechanisms, and other opportunities that decrease the isolation of children and young people with disabilities.
2. Invest in high-quality, free services that prevent and respond to sexual violence against children and young people with disabilities and prioritise the best interests of the individual child at all times.
3. Support children and young people with disabilities to play an active part in society and in the services that affect them.

4. Make children and young people with disabilities more visible both in society and in development programming by, for example, conducting more research on issues that affect them and including impairment-specific disaggregated information in data collection.
5. Ensure that national laws and policies prevent and respond to sexual violence against children and young people with disabilities in line with international and regional human rights instruments by, for example, making explicit and specific mention of their particular rights and needs in national child protection and sexual violence legislation and policies.

Opportunities in 2011 and Beyond

2011 holds some key opportunities for promoting these recommendations in order to improve the protection of children with disabilities from sexual violence. These include:

- The UN Omnibus Resolution on the Rights of the Child, which has a thematic section on children with disabilities.
- The Conference of States Parties to the Convention on the Rights of Persons with Disabilities to be held at the UN in New York.

There are also several longer-term opportunities in which this agenda could be promoted. In particular:

- International human rights mechanisms continue to review contexts in which this violation occurs including the Human Rights Council, the Universal Periodic Review Process, the Special Representative on Violence against Children, the UN Committee on the Rights of Persons with Disabilities and the UN Committee on the Rights of the Child.
- The Council of Europe has recently produced guidelines on protecting children and adults with disabilities from violence which it could promote internationally.
- Finally, the donors may choose to fund programming, research or advocacy on this issue at the national, regional and international level.

Notes

- 1 Ibid.
- 2 Where an adult physically forces a child to have penetrative sex. For an adult this would be termed rape.
- 3 For example, Article 19 emphasizes the right of every child to protection from all forms of violence and imposes explicit obligations on governments to take the appropriate measures necessary to ensure that protection; in addition, Article 34 requires governments



to protect children from sexual exploitation and abuse; Article 37 prohibits torture or other cruel, inhuman or degrading treatment of children; and Article 39 requires the introduction of programmes of recovery and reintegration. Article 3 demands that the best interests of the child is a primary consideration in all actions affecting the child, and that all institutions, services and facilities provided for children are of an adequate standard. And all these provisions must be informed by the obligation, embodied in Article 12, to ensure that children are enabled to express their views on these matters and have their views taken seriously in accordance with age and maturity.

- 4 For example, Article 16, which addresses the right to protection from violence, requires that all prevention, protection, recovery and rehabilitation, as well as investigative services are age, disability and gender sensitive. Article 23 introduces obligations on governments to provide information, support and services to families to prevent the neglect and abandonment of children with disabilities. And measures are also introduced in Article 12 to strengthen access to justice, by ensuring that all stages of legal proceedings are sensitive and accessible to people, including children, with disabilities.
- 5 CRC General Comment No.9, The Rights of Children with Disabilities, CRC/C/GC/9, Feb 2007
- 6 UNICEF (2007): Promoting the Rights of Children with Disabilities, Florence
- 7 SULLIVAN, P. M./KNUTSON, J. F. (2000): Maltreatment and disabilities: A population-based epidemiological study. *Child Abuse & Neglect*, 24, pp. 1257–1274
- 8 KVAM, M. (2000): Is Sexual Abuse of Children with Disabilities Disclosed? A retrospective analysis of child disability and the likelihood of sexual abuse among those attending Norwegian hospitals. *Child Abuse & Neglect*, 24:8, pp. 1073-1084
- 9 STÖPLER, L. (2007): Hidden Shame: Violence against children with disabilities in East Africa. Terre des Hommes, The Hague
- 10 www.un.org/disabilities/convention/facts.shtml
- 11 LAMPRECHT, L. (2003): Sexuality in children with intellectual disabilities. Presented at a workshop of the South African Association for Scientific Study of Mental Handicap, Johannesburg General Hospital
- 12 DHAI, A. (2003): Ethical & societal issues in the care and management of the intellectually disabled child as they grow up. Presented at a workshop of the South African Association for Scientific Study of Mental Handicap, Johannesburg General Hospital
- 13 Summary Report: Violence against Children with Disabilities, Findings and recommendations of a consultation convened by UNICEF, New York, July 28, 2005, UN Secretary General's Study on Violence

against Children, Thematic Group on Violence against Children with Disabilities

- 14 UK DEPARTMENT FOR INTERNATIONAL DEVELOPMENT (2000): *Disability, Poverty and Development*. DFID, London
- 15 Ibid.
- 16 THOMAS, P. (2005): *Disability, Poverty and the Millennium Goals*. DfID
- 17 See, for example, STÖPLER, L. (2007): *Hidden Shame: Violence against children with disabilities in East Africa*, Terre des Hommes, The Hague
- 18 SHISHU POLLI PLUS and SAVE THE CHILDREN (2008): *Safe Custody of Children in Bangladesh: Thinking for a Better Alternative*

Zusammenfassung: Sexuelle Gewalt gegen Kinder mit Behinderungen ist ein weltweites Problem, das alle Länder betrifft. Neue Nachforschungen weisen darauf hin, dass der Schweregrad und die Auswirkungen von Missbrauch extrem hoch sind mit bleibenden Folgen für die Kinder und die Entwicklung und Gesundheit von Gesellschaften, in denen sie leben. Dieser Artikel fasst zusammen, warum Kinder mit Behinderungen besonders verletzlich sind und was sich ändern muss, damit diese Kinder besser geschützt sind.

Résumé: Les violences sexuelles envers les enfants handicapés est un problème mondial qui concerne tous les pays. De nouvelles recherches attirent l'attention sur le fait que le degré d'importance et les répercussions des abus sont extrêmement hauts et entraînent des conséquences pour les enfants, le développement et la santé des sociétés dans lesquelles ils vivent. Cette informations résume en quoi les enfants handicapés sont particulièrement sensibles et ce qui doit être changé pour que ces enfants soient mieux protégés.

Resumen: La violencia sexual contra niños discapacitados es un problema global. Nuevos estudios indican que las consecuencias del abuso son extremadamente altas. Los niños sufren toda su vida en su desarrollo y su salud, así como también en las sociedades en que viven. El artículo resume, porqué niños con discapacidad son particularmente vulnerables, y lo que hay que cambiar para protegerlos de mejor manera.

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How Operational¹ Research can Inform the Planning of Programmes for Children with Disabilities in Low Income Countries

Sue Mackey, Christiane Noe, Mohammad Muhit,
Johurul Islam Jewel, Gudlavalleti Venkata Murthy

This article describes the rationale, progress and preliminary findings of an innovative and low cost method of using Key Informants (KIs) to identify children with a range of disabilities in a poor resource setting in Bangladesh. This four year project funded by CBM, an international disability and development organization, has shown to be effective in case identification for hearing, visual, physical impairments, and epilepsy in children and young adolescents aged 0-18 years. Evidence was gained regarding numbers of children, type of impairments and their causes, together with important demographic data such as gender, age band, parental literacy, school attendance and health seeking behaviour.

This information is important in showing the need for future disability-related services as well as for inclusion of children with disabilities in society. With some adaptation, KIM (Key Informant Method) can be implemented in other country settings and is currently being tested in Pakistan.

Introduction

In low income countries, the majority of children with disabilities have limited access to health care, rehabilitation, and education and they are often socially excluded. Most of the children with disabilities and their families live in poverty and their needs and rights are often overlooked (UNICEF 2007). A first challenge to address the needs of children with disabilities is finding the most effective way of identifying these children without incurring the high costs of a household survey, or raising expectations that cannot be met.

Maulik and Darmstadt confirm that "despite the large burden on child development, family life, and economics, research in the area of childhood disability is woefully inadequate, especially from low- and middle-income countries" (2007:1). In addition, there is a need for more robust studies on epidemiology as such (Maulik and Darmstadt 2007). Trani also notes that there are few data available for the "complex topic of children with disabilities" (2009:1086). In classical research projects on children where base line studies have been conducted, e.g. by UNICEF on child protection in the Pacific, there have been lost opportunities to include the concerns and interests of children with disabilities and to collect valuable information (UNICEF 2007).

Rationale and Project Design

There is an obvious need for more evidence-based information on the number of children affected, the causes of impairment and disability, health seeking behaviour and barriers to ac-

cessing services in order to plan district wide services. Furthermore, it is important to assess the real impact disability has on the children and their families within their community, especially in terms of social inclusion.

Previously, a collaboration between the International Centre for Eye Health (ICEH) of the London School of Hygiene and Tropical Medicine (LSHTM) and a Bangladesh NGO, Child Sight Foundation (CSF), funded by CBM developed a novel, low cost method of identifying childhood blindness using Key Informant Methodology (KIM), which proved to be successful in Bangladesh (Muhit et al. 2007) and was routinely followed by surgery, assistive devices or CBR interventions. KIM has also been used for identifying blind children in other countries such as Malawi (Kalua et al 2007), Iran (Razavi H et al.) and for epilepsy in India (Pal et al 1998).

The current project involves the same collaborative partners and was designed to test and validate whether KIM could be equally successful for identifying other types of childhood disabilities such as hearing and physical impairments and epilepsy (generalized tonic-clonic seizures) as a health condition. The preliminary pilot study outcomes indicate that KIs can identify children with other impairments and that the data so gained can contribute to district level planning for appropriate health and educational services (unpublished data). The study is on-going and will collect information on the outcome of health and rehabilitation interventions arising as a result of the project at one year follow up.



Members from a local self help group working alongside our community mobilisers to register the families at the KIM camp.

The Bangladesh Context

Bangladesh, with 164 million inhabitants has a high child and maternal mortality rate, with under 5 mortality ranked 57/193 (UNICEF 2009). It is one of the poorest countries in Asia, with a Human Development Index of 0.547 ranking 129 out of 169 countries. Poverty is widespread with about 50 % of the population estimated to be living below the poverty line (UNDP 2010). Due to its geography, with most parts of the country at sea level severe flooding is common.

These socio-economic and environmental conditions pose additional challenges to identifying children with disabilities and establishing the network of services required to meet their needs.

Evidence for Practice

CBM is committed to improving the quality of life of people with disabilities and hence, also of children with disabilities. Given the knowledge gap needed for programme planning, CBM decided to fund this operational research project on *Using Key Informants to Identify Children with Disabilities in Bangladesh and Pakistan* in order to, a) validate if KIM is effective in finding children with disabilities and b) learn more about the type of services required to support children with disabilities in low income settings.

The information arising from this project will help CBM supported programmes to plan more effectively and improve the quality of work. In addition, the identification of gaps and potential support services with regard to children with disabilities can be a powerful advocacy tool to hold all relevant stakeholders, including governments, responsible for providing and ensu-

ring access to them.

In addition, local partner organisations involved in this research project developed high commitment and engagement, consequently building their capacity in a range of aspects such as research methodology, more comprehensive knowledge and awareness of child disability and community engagement. This will be of great value for future activities, increasing the evidence for programme planning and the integration of data collection tools during programme implementation, thus providing continuous learning and quality assurance opportunities.

The results and recommendations of the project will be made accessible and available to the various stakeholders involved and also to the wider public adding to the national, regional and global knowledge base. If the KIM is found to be valid for childhood disabilities in other countries, it will find immense use in countries constrained by the lack of adequate human resources as it is a low cost method for finding those *hard to reach* children, compared to the standard household surveys. It also has the advantage of community participation which increases public awareness and knowledge about disability as well as conveying more positive messages concerning the abilities of children with impairments.

Key Informant Method for Identifying Children with Disabilities

This methodology involves holding training workshops in local sub districts for volunteer key informants (KIs) from the community (such as teachers, disabled people groups, NGO or health workers, imams, local government or business people etc.). A standard training of presentations, discussion, and role play with the use of illustrated flip charts and information leaflets was given, training approximately 100 key informants in each sub district (50,000 population sample).

KIs spread the messages within their normal working environment and had 4-6 weeks to prepare a list of children found, with their contact details. The project community mobilisers then coordinate the activities for the families to attend a medical assessment camp, where a team of specialists (paediatrician, ophthalmologist, ENT (Ear, Nose and Throat), physiotherapist, counsellor) examine, diagnose, advise, give information, counsel or make referrals.

Apart from clinical findings, the main child data form also included demographic data as



well as sections on e.g. school attendance, access to rehabilitation, activity limitations, together with specific referral details. With this information, stakeholders and providers have important and useful data for planning child disability services in the district.

Referral System

According to need, referrals were made for further investigations, medication, surgery, plaster, assistive devices or therapy. Prior to the KIM camps, a focussed service mapping was carried out in the districts. Where possible, service provision was made through established local systems, or when necessary to further more specialised treatment centres. Some referrals were to routine health facilities but a large number of other children required specialised services such as surgery for cleft lip, cataract, or club foot, or more complex services such as assistive devices - hearing aids or wheelchairs. From the results estimates can be made for planning purposes for larger populations.



Bringing their children to the KIM assessment camp from further away using local transportation

Summary Findings

- KIM proved effective in case identification for the target conditions of hearing, visual, physical impairments and epilepsy.
- Cerebral palsy, epilepsy and hearing impairment were the most common conditions found.
- The case finding process could be carried out at relatively low cost as the KIs are volunteers. However, resources are needed to cover the costs of four community mobilisers and bringing a medical team from the capital, Dhaka.
- Training the KIs enhanced disability awareness in the community and spread positive messages about the potential of children with disability to attend school and participate with their peers.
- Access to health services was improved, through activating local referral systems and establishing a network of NGO, private or Government providers for more specialised services.

- A national Task Force was established in Dhaka to include key stakeholders from the disability sector in order to guide the study and provide a means of sustainable action and advocacy after the project withdraws. The available study data has been shared with the group since the beginning through task force meetings and bulletins.

Discussion

Lessons Learnt

Establishing a Task Force of local key stakeholders in-country was important in ensuring effective referral mechanisms and sustainability of service delivery – it is the anchor for local ownership of the project. The complexity of the project meant that it could only succeed in

the long term if a wide range of local actors and service providers in the field could be mobilised to support the needs of the children and families identified through the project.

In preparing the training materials for KIs to identify children with disabilities, it was crucial to clearly define the target impairments and include appropriate screening questions into the tools for identification. The necessity of pre-testing the study instruments in-country was highlighted and they were further refined accordingly. It was also important to make a detailed manual to complement the child clinical data forms and draw up referral guides and flow charts for each of the districts to inform the medical and project teams. To supplement this, periodic refresher training was held with the teams prior to each new district. Briefing the medical team together before each assessment camp was also a helpful way of discussing any common data entry errors and highlighting the integrated sections of the clinical data form where different clinicians needed to coordinate their entries.

In the beginning stages of KI recruitment, there was poor representation from females and persons with disabilities. Through encouragement and continual reinforcement of the need for inclusiveness, the numbers improved so that by the final phase, 88 % of KIs were female as compared to around 20 % in the pilot stage, with a 5 % representation of persons



with disabilities in the final phase. Self-help groups of disabled persons and DPOs were approached before commencing the KIM study in a new district, in order to seek their guidance on available services and whether they knew of families who had children with disability. They also supported the KIM camp process, assisting on the day, as well as being active key informants.

The referral process proved to be one of the most complex aspects of the study, requiring intensive organisation and input throughout. In the pilot stage a variety of provisions for service referral had been made, offering financial support but requesting a parental contribution to those families who could afford to pay something. Most were expected to make their own way to Dhaka where they were offered support on contacting the CSF office.

However, this approach was not entirely satisfactory as some families did not take up services. Consequently, in subsequent phases, additional financial and logistical support was offered. It was found that a designated staff was needed to coordinate the process as a whole, between the community field staff, service providers, families and CSF central office staff responsible for finance and assisting the families. It was also important to record the cost of each type of intervention, both to keep within budget limits and to provide useful information for future district planning.

Limitations of the Study

It was observed that a number of families listed by KIs did not actually attend the KIM camps. Therefore remedial actions were employed i.e. fixing the camp dates earlier and not changing them, improved communication between community mobilisers and KIs, staggering registration times to decrease waiting time and increased guidance for KIs in the training workshops on types of children to list.

Similarly, as described in the previous section, there were issues in the uptake of referrals for service. To some extent this was alleviated by the financial and logistical steps taken in the study but there remained barriers for some families. (To investigate this further, a three month study was undertaken using a medical anthropological approach as well as a quantitative analysis of predictors to uptake and a systematic literature review – these are currently being written up.)

The children were examined in a medical camp setting for approximately 100 children per day, which together with their accompanying family members, is a large crowd. Stagge-



Children attending camps undergo field audiometry

red registration times helped but a large number of project staff and assistants were required to maintain an orderly process. Despite this, it is still not an ideal setting for examining children with disabilities, and time constraints particularly affect the level of advice, exercises and quality counselling that can be given. Children need to be followed up by the referral centres, as the research study moves onto different districts and is designed for making referrals, not service provision.

A significant limitation of this study is that it was not possible to include children with intellectual difficulties. An important consideration was to identify those children that could be referred for medical/physical interventions. No services were available for referral and on-going support of children with intellectual impairment in this rural setting.

Application of the Research to Practice

It was possible to demonstrate that key informant methodology can be used to identify children with hearing, visual and physical impairments as well as epilepsy, using volunteers from the community. This has huge benefits for case finding in disability and development programmes across Bangladesh, as the tools and methodology could be replicated.

Increased evidence was gained regarding numbers of children, type of impairments and their causes, information which is required for programme planning and service provision. The results have application for educational programmes, as questions on school attendance, type of schooling and reasons for non-attendance were elicited. Educational service providers will have more information on what proportion of disabled children are not going to school, which type of impairment they have and



Community Mobiliser using the flip chart for KI training

demographics such as age, gender, parental literacy and geographical location. Thus, the data collected may inform both health and education planners.

A quality of life measure for children called the PedsQL (Varni et al. 2002) was administered at the KIM camps by a counsellor and this contained data on physical, emotional, social and school functioning. Making comparisons not only with non-disabled peers, but also according to type of impairment enables practitioners to tailor their interventions for particular needs.

With some adaptation, KIM can be implemented in other country settings and is currently being tested in Pakistan. There is potential to reach adults, too, if the tools were revised to include additional impairments such as arthritis, diabetes or heart disease etc. It could be of particular value in an emergency context where development workers need to identify the most vulnerable groups quickly.

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Notes

- 1 Operational research is research directed to improve the operations of an organisation and/or specific field or work. It encompasses a wide range of problem-solving techniques and methods applied in the pursuit of improved decision-making and efficiency.

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Zusammenfassung: Dieser Artikel beschreibt die Hintergründe, den Fortschritt und vorläufige Ergebnisse einer innovativen und günstigen Methode zur Nutzung von Key Informants (KIs, Schlüsselinformanten) bei der Identifizierung von Kindern mit einer Vielfalt von Behinderungen in einer ressourcenarmen Umgebung von Bangladesch. Das 4-Jahres Projekt, finanziert von CBM, einer internationalen Organisation für Behinderung und Entwicklung, war effektiv dabei, Fälle von Hör-, Seh- und physischer Beeinträchtigung sowie Epilepsie bei Kindern und Jugendlichen im Alter von 0-18 Jahren zu identifizieren. Belege wurden hinsichtlich der Anzahl von Kindern, Typen von Beeinträchtigungen und ihrer Ursachen, zusammen mit wichtigen demografischen Daten wie Geschlecht, Altersgruppen, Alphabetisierung der Eltern, Schulbesuche, gesundheitsorientiertes Verhalten gewonnen.



Diese Informationen sind wichtig, um zu zeigen, wie der Bedarf an zukünftigen relevanten Leistungen in Bezug auf Behinderung sowie für die Inklusion von Kindern mit Behinderungen in der Gesellschaft ist. Mit einigen Anpassungen kann KIM (Key Informant Method, Schlüsselinformantenmethode) in anderen Ländern implementiert werden. Derzeit wird die Methode in Pakistan getestet.

Résumé: Cet article décrit la création, les progrès et les premiers résultats d'une méthode innovante et avantageuse de l'utilisation des Key Informants (KIs, informateurs clés) lors de l'identification d'enfants ayant divers handicaps dans une région à faibles ressources du Bangladesh. Un projet de 4 ans, financé par CBM, une organisation internationale pour le handicap et le développement, fut nécessaire pour identifier les cas de déficiences auditives, visuelles et physiques ainsi que d'épilepsie chez les enfants et adolescents entre 0 et 18 ans. Des références furent acquises en ce qui concerne le nombre d'enfants, les types de déficiences et leurs raisons, ainsi que les données démographiques telles que le sexe, l'âge, l'alphabétisme des parents, la scolarisation, le comportement sanitaire.

Ces informations sont importantes afin de montrer quels sont les besoins de services pour le handicap ainsi que pour l'insertion des enfants handicapés dans la société. Avec quelques adaptations le KIM (Key Informant Method) pourrait être implanté dans d'autres pays. Pour l'instant, la méthode est testée au Pakistan.

Resumen: Este artículo describe el concepto, el progreso y los resultados preliminares de un método para identificar niños con discapacidades múltiples a través de "Informantes Claves" (Key Informants Method, KIM) en zonas de poco recursos en Bangladesh. El proyecto de cuatro años, financiado por CBM, una organización internacional para discapacidad y desarrollo, tuvo efecto en identificar casos de

discapacidad auditiva, visual, física y epiléptica de niños y jóvenes entre 0 y 18 años. Se ganó datos en referencia a: cantidad, tipos de discapacidad, causas de la discapacidad, sexo, grupos de edad, alfabetización de los padres, escolarización y comportamiento en salud. Estas informaciones son importantes para tomar en cuenta la necesidad de futuros servicios. Con pocas modificaciones KIM puede ser implementado en otros países. Actualmente se ensaya el método en Pakistán.

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Emancipatory Research on Impact of CBR: Voices of Children with Disabilities

Sunil Deepak, Jayanth Kumar, Parthipan Ramasamy, Giampiero Griffo

An emancipatory research, controlled and managed by persons with disability from local communities, looked at different barriers faced by persons with different kinds of disabilities and at the impact of a ten year old community-based rehabilitation (CBR) programme in overcoming those barriers in nine sub-districts in south Karnataka (India). This research also involved 21 children below 15 years. This article discusses the issues emerging from their life-stories, about the barriers they face and the different ways in which CBR programme activities promote access to existing services. The article also raises issues regarding classification of disabilities in the CBR programme.

Introduction

Children with disabilities: Persons with disabilities of all age groups face different barriers to enjoy their basic human rights. For the 200 million children with disabilities in the world, enjoying effective and equitable access to basic social services and meaningful participation in society is yet a distant goal (UNICEF 2007).

Generally speaking, there is limited systematic research related to community-based rehabilitation implementation. Even in that limited research, voices of children with disabilities are rarely heard.

CBR Programmes in Mandya and Ramnagara districts in South Karnataka (India) covering nine sub-districts with a total population of about two million persons, managed by two non-governmental organisations, Maria Olivia Bonaldo (MOB) rural health centre and Sri Raman Maharishi Academy for Blind (SRMAB), were initiated more than ten years ago. This emancipatory research was conducted in these nine sub-districts in Mandya and Ramnagara districts between April 2010 to March 2011.

The CBR activities in the research area are organised in all the five areas of the CBR Matrix (WHO 2010) – health, education, livelihood, social and empowerment. At field level, the two CBR programmes are managed by taluk (sub-district) level *Taluk coordinators* and village level CBR workers. Every CBR worker looks after 25 - 40 villages. At village level, CBR activities are supported by volunteers, usually persons with disabilities themselves or their family members.

Along with home visits, self-help groups (SHGs) of persons with disabilities and their family members are key structures for implementation of different CBR activities. In 2010, the two programmes had 379 SHGs with a total of 5,846 members. Apart from other activities, SHGs are involved in savings and credits as

well as in advocacy activities at the village level.

The SHGs are federated at block level and send representatives to sub-district level to create taluk level Organisations of Disabled Persons (DPOs). The different taluk DPOs are federated into two district level DPOs.

In 2010, the two programmes together reached 23,486 persons with disabilities including 4,815 children (20.5 %) below 15 years in the nine sub-districts.

18 % of the 4,815 children with disabilities participating in these two CBR programmes are below five years of age, including 52.8 % boys and 47.2 % girls. Remaining 82 % are between six to 15 years, including 55.6 % boys and 44.4 % girls. Thus, more male children benefit from CBR programme activities compared to female children.

The 4,815 children are classified by the CBR programme in different groups of disabilities according to the classification used in WHO CBR Manual (WHO 1989) including 7.9 % children with visual disabilities, 18.8 % children with hearing and speech related disabilities, 45.7 % with physical disabilities, 0.3 % with disabilities due to leprosy, 1.5 % with convulsions, 0.2 % with mental illness, 17.4 % with intellectual disability and 9.7 % with multiple or other disabilities.

Emancipatory Research: The term *Emancipatory Disability Research* was first used in 1992 (Oliver 1992) to refer to a radical new approach to researching disability. Emancipatory disability research is based on social and human rights models of disability and includes the following core principles (Barnes 2003):

Accountability to the persons with disabilities and their communities – making sure that persons with disabilities themselves play decision-making role in the research.

Based on the social and human rights models of disability – focusing on the different bar-



riers that create disability as well as on the rights as enshrined in the UN Convention on Rights of Persons with Disabilities.

Should have meaningful practical outcomes for persons with disabilities including empowerment by making sure that the information produced by the research is accessible to persons with disabilities involved in the research.

Emancipatory Research in S-PARK/ CBR initiative (S-PARK/ CBR - ER)

S-PARK/ CBR (Samagama Participatory Action Research and Knowledge in Community-based Rehabilitation) is a comprehensive research initiative using different and inter-disciplinary approaches to look at impact of ten years of two CBR programmes in 9 sub-districts of Mandya and Ramnagara districts in south Karnataka, India. Emancipatory research in S-PARK/ CBR initiative (S-PARK/ CBR - ER) is one component of the research, looking at impact of CBR from the point of persons with disabilities living in the communities.

S-PARK/ CBR - ER was carried out from April 2010 to March 2011. A total of 28 persons with disabilities representing different kinds of disabilities, including both men and women, were identified and trained to be part of a Research Core Group and facilitators, that planned and implemented this research with support from a Scientific Advisory Group. Research Core Group and facilitators identified a number of priority research themes. On each priority theme a research protocol was prepared that discussed the main key issues and the criteria for identifying the participants. Each research theme meeting was organised by involving 18 - 24 persons with disabilities from the nine sub-districts, ensuring a balance between different factors including gender, age groups, severity of disabilities, education level, socio-economic level, etc. Thus, a total of 17 theme meetings were organised with a total of 369 participants representing persons with different disabilities, including children.

Each research theme meeting was organised around sharing of life-stories by the participants, identification of barriers and facilitating factors in the life stories, impact of CBR programmes, and discussions on what can be done to overcome the barriers by disabled individuals themselves, their families, SHGs, DPOs, CBR and other programmes and by the government. At the end of each research theme meeting a community-video was prepared by the meeting participants, including their messages to other disabled persons and to the communi-

ties regarding the research theme.

Thus, Emancipatory Research in S-PARK/ CBR has produced 18 theme reports and videos on different areas of interest to persons with disabilities, that look at barriers and enabling factors for their participation, inclusion, empowerment and effective access to services.

Involvement of Children in the Emancipatory Research of S-PARK/ CBR Initiative

A total of 21 children along with their care-givers participated in the research theme meetings of the emancipatory research (5.7 % of all the participants), including 47.6 % male and 52.4 % female. None of these children were below five years of age. The age of participating children ranged from six to 15 years and the average age was 11.6 years. Among them, seven children (33 %) had never been to a school.

Children participated in the following theme research meetings: technical aids and appliances (4), disability and health sector (1), intellectual disabilities (3), physical disabilities (3), multiple and other disabilities (5), speech and hearing disabilities (3), and disability and sports, recreation and leisure (2). There was no theme meeting specifically on children with disabilities and no children participated in the research theme meeting on education.

Disabilities among Child Participants in Emancipatory Research of S-PARK/ CBR

According to the CBR programme data about the 21 children participating in the Emancipatory Research, five children were reported to have multiple disabilities (23.9 %), while the remaining children were classified under one of the following disability groups - two children with seeing disability (9.5 %), three children with hearing and speech disability (14.3 %), eight children with physical disability (38 %) and three children with intellectual disability (14.3 %).

All 21 children or their care givers were asked specific questions, if the children had any difficulty in seeing, hearing, speaking, moving any part of the body, loss of sensation, convulsions, learning, strange behaviour and any other problems. An analysis of their answers showed that five children experienced some degree of difficulty in seeing (23.9 %), six children experienced some degree of difficulty in hearing (28.9 %), 12 children experienced some degree of difficulty in speaking (57.1 %), 11



children experienced some degree of difficulty in moving a body part (52.4 %), two children said they had loss of sensation (9.5 %), three children were reported to have episodes of strange behaviour (14.3 %) and 8 of them experienced some degree of learning difficulties (38 %).

Thus, children with disabilities and/or their care givers reported a much wider and variegated *areas of difficulties* compared to the disability classification done by the CBR programme.

Voices of Children and the Impact of CBR

All persons participating in the research theme meetings were explained about the emancipatory research process including the process of making the final video and asked to sign a consent form. They were also asked to select any another name that could be used in the research reports. Both children and their care givers had the possibility to not participate in the video reports. Thus, the names of children used in this article may not be their real names.

Research theme meetings were organised around sharing of life-stories. For some of the children and parents, it was the first time they had come out of their villages or had been together with other children with disabilities. Thus, they were not very articulate in sharing their life stories and explaining the different barriers they faced in their daily lives. Research Core Group members and Facilitators, coming from the same communities, helped the participants to overcome inhibitions by sharing their own life stories as well as by showing videos made by participants in other theme meetings.

For each research theme meeting a report in local language (Kannada) and in English was prepared. The report in Kannada was approved by the participants before the closure of the research meeting.

Issues Emerging from Analysis of Life Stories

An analysis of the life-stories told by the children and their care-givers in the research theme meetings brings out the following issues regarding impact of CBR:

Facing different barriers, lack of information and isolation are recurring themes in most life stories. The following story helps in understanding some of the difficulties faced by disabled children in the school:

Kuvana: "I am the first child to my parents and I have a younger brother. I am 10 ye-

ars old and I am studying in 5th class. I was born with low vision that was detected by my parents when I was three years old and they took me to a specialist centre in Bangalore for check-up. Soon after, I had a brain tumour so I was operated upon. However, this has affected my body and my hands and legs do not function well.

My parents had to struggle a lot to take me to different specialists so that I could regain the functional abilities of my body, but it was not very successful. When I started going to school, initially teachers were reluctant to admit me, but my parents insisted and finally I got admission in the school.

My class mates tease me, sometimes they call me blind or crippled, and sometimes I quarrel with them and complain to teacher. Sometimes I just try to ignore them because I feel confrontation is of no use.

I can see only things that are close and not things that are away. In the class, I generally sit in the fourth row but teachers make me to sit on the first row as they think that from first row I can see the black board. It is not true."

Her mother added, "She writes on her slate and not in the notebook even though she is in 5th class. She is still asked to do first standard lessons, which is my major concern."

Kavana continued, "I am in the CBR programme for almost a year but it has not helped me so much. I started getting monthly pension from the Government, even before coming in the CBR programme."

Two other children who had joined CBR programme only a few months earlier, shared their experiences:

Sushma: "I am 13 years old. I was student of 8th standard but I have stopped going to the school because my class mates used to tease me and to call me names."

Her mother added, "We joined the CBR programme only three months ago, and I have already joined a self-help group. At least, now I can talk to other persons about our difficulties. However, I didn't know that my daughter can also get pension from Government. Her problem is that she gets too angry when people call her names. She starts banging her head against the wall and even the school teachers get afraid."

Rajitha's mother said, "I am very poor.



She is 12 years old but she can't do anything by herself. I have no fixed job, I have to look for some work every day and if I don't find work, how will we eat? My husband left me when Rajitha was born and he found that she is disabled. My son goes to school, so who can take of her all the day? During the break in my work, I have to come home to give her some food because alone she can't even eat. I want to learn about self-help group and also about how to get pension for Rajitha."

In comparison, other children who have been associated with the CBR programme for longer periods, share more positive stories. Most of them receive government pension and are members of self-help groups. Many of them have received technical appliances including hearing aid, modified chair, walker, tricycle, etc. Some of them who need to take regular medicines such as the medicines for convulsions, now know how to receive them free of cost. Their life stories are more confident about the barriers they have overcome and about their rights, as can be seen from the following examples:

Arun said, "I am 15 year old and I didn't hear properly. Now I have the hearing aid and it has improved my communication in the class and with other people. I also receive pension and I am very good at studies."

Sujay said, "I am 11 years old and I am studying in 6th standard. I have low vision like my father and my grandfather. I need to change spectacles frequently. Earlier, we had to buy it in Bangalore and it was difficult for our family. Now I can get my spectacles locally and one pair free of cost every year. I think that government should give more help to poor disabled persons."

Darshan's mother explained, "We took him to so many hospitals but it didn't help him. However, with the modified chair and home based exercises, he is better. We also get small pension for him and I joined a self-help group. CBR programme gave us a sewing machine, and I am working from home as a tailor, so life has improved a little bit."

Zaid said, "I am 14 and my right side of the body is weak. My speech is not very clear and I cannot go to the school. So a volunteer comes home to teach me reading, writing, counting." His mother added, "Because of the volunteer coming regularly, his speech has improved. He is

also a member of taluk level DPO and gets government pension."

Shivananda shared his story, "I am 14 years old. I am short, but I also have fragile bones that break very easily. I frequently hurt myself. I can't walk properly because my knees knock with each other. I am in the CBR programme for six years. I joined school but other children used to make fun of me, so I used to become angry and throw stones at them. Many times, I was punished by the teachers. But slowly my class mates have become used to me, now I have many friends in the school. I also receive pension. There is no self-help group in our village but I am thinking of starting one. I have wheelchair, but someone has to push it and it is difficult. I hope to get a power wheelchair, that will be helpful."

Discussion

Emancipatory research component of S-PARK/CBR initiative has brought out different issues related to impact of CBR programme on children with disabilities.

Accessibility of CBR programme seems to be better for male children compared to female children, and seems to increase with age. This means that comparatively more male children benefit from CBR programme compared to the female children. As no general population survey was done to find out the actual numbers of children with disabilities in the community, the research does not tell us if there are less female disabled children in the community. The research also did not look at specific barriers faced by female children with disabilities in accessing CBR programme activities.

The classification and categorization of children into different groups of disabilities under the CBR programme does not match with the actual difficulties faced by these children in their daily lives. For example, out of total 21 children, only three children were put under "hearing and speech disabilities", while six children experienced some difficulties in hearing and 12 children reported having some difficulties in speaking.

This issue was discussed with CBR workers, who proposed different explanations about why this happens, including issues of stigma in the community, so that persons may prefer to be put under another category that carries less stigma. Another explanation was that certain groups such as persons who have convulsions, are not considered disabled according to the



Indian disability law and thus, these children are often put under a category like intellectual disability that is recognized by Indian law.

The group of persons with mental illness, intellectual disabilities and convulsions seems to be a very mixed up group, where categorization into different groups is difficult for the CBR workers.

Participation of children in this emancipatory research seems to be very limited. Though children below 15 years are more than 20 % of all persons benefiting from two CBR programmes, they constitute only 5.7 % of participants in the emancipatory research. This could have also been due to lack of understanding among the Research Core Group of persons made up of adult with disabilities.

The way this research was organised, it meant that participants have to come to a meeting place for four days. CBR workers were supposed to identify suitable disabled persons in the villages for each research theme meeting, according to the research proposal and selection criteria for participants defined by the Research Core Group.

Discussions with CBR workers showed that it was often difficult to convince disabled persons and their families to participate in the meetings. Many disabled persons had never left their villages and for them going out was difficult. Disabled persons and families could not understand about usefulness of coming to a meeting for four days and be away from home.

For children with disabilities, it raised issues of care-givers to accompany them. Thus, it was even more difficult to convince children with disabilities to join a research theme meeting. For girls, convincing the family to let them go away from home and sleeping outside, was difficult and thus, CBR workers had to spend long time to discuss and convince the families.

Life stories provide vivid examples of the difficulties faced by children with disabilities in the rural areas involved in the research programme, as well as the positive impact of CBR programme in ensuring access to pension, self-help groups and technical appliances. Self-help groups are also platforms for sharing ideas and experiences with other persons facing similar problems and for breaking out of isolation.

Theme research meetings of emancipatory research, also conducted analysis of barriers encountered and strategies for overcoming them. This analysis is not available specifically for children with disabilities.

The emancipatory research, including life stories, is a new important tool to permit to children with disabilities (and their families), in

a research contest, to "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 realize that right" art. 7 of CRPD (UN 2006).

The emancipatory research, in an area where the participation of persons with disabilities and their organization are strong, as in the Mandya and Ramnagara districts in South Karnataka, represent an empowerment tool, supporting the awareness of the condition of discrimination and lack of equal opportunities and promoting recognition of the rights in the community.

Difficulties in involving children in the emancipatory research: Disabled children were usually accompanied by their mothers and sometimes, by other family members, who usually feel that the children cannot express themselves. Therefore accompanying persons tended to speak more and usually it required some effort by facilitators to convince them to allow children to share their own ideas.

Issues of stigma and fear, were associated with the idea of going out of the villages and staying out for the night for 3-4 days meetings, as already mentioned earlier, and thus often families refused to allow their children from participation.

It was also difficult to explain the families the usefulness of participating in a meeting for the research, as the research did not offer them any immediate material benefits. However, once persons did participate in a meeting, they appreciated the opportunity to meet others in similar situations, to learn about different laws and schemes that could benefit from, to share experiences and ideas with others.

Conclusions

Emancipatory research, where persons with disabilities play decisive roles in planning and organising research, can have very strong impact on the way disability-related programmes are conducted. CBR personnel involved in the emancipatory research process has reported wide-ranging changes in the way programme activities are implemented.

Similarly, persons with disabilities and their families involved in the programme, have reported wide-ranging changes in their communities, especially in terms of advocacy activities for access to services and schemes, and for participation in self-help groups and DPOs.

However, this research could get only a limi-



ted involvement of children with disabilities and their families. Even this limited involvement, gives some ideas of the diverse issues that create barriers for the children with disabilities, even more for girls with disabilities. More specific emancipatory research experiences focusing on children with disabilities are needed.

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Zusammenfassung: Eine emanzipatorische Untersuchung, kontrolliert und geleitet von Menschen mit Behinderungen aus lokalen Gemeinden, betrachtete verschiedene Barrieren für Menschen mit unterschiedlichen Behinderungen und die Auswirkungen eines zehn Jahre alten gemeindebasierten Rehabilitationsprogramms (CBR), welches diese Barrieren in neun Unterbezirken von Süd Karnataka (Indien) zu überwinden versuchte. Die Untersuchung umfasste

auch 21 Kinder unter 15 Jahren. Dieser Artikel erörtert die Problematiken, die sich aus ihren Lebensgeschichten ergeben, die Barrieren, denen sie begegnen und die verschiedenen Wege, in denen CBR Programmaktivitäten Zugang zu existierenden Diensten fördern. Der Artikel spricht auch die Klassifikation von Behinderungen in CBR Programmen an.

Résumé: Une analyse émancipatrice, contrôlée et dirigée par des personnes handicapées de communautés locales, considéra plusieurs barrières pour les personnes avec différents handicaps ainsi que les répercussions d'un programme de réhabilitation à base communautaire (CBR) vieux de 10 ans et essaya de surmonter certaines de ces barrières dans 9 sous-régions du sud Karnataka (Inde). L'analyse comprend également 21 enfants âgés de moins de 15 ans. Cet article débat de problématiques qui résultent de leur projets de vie, des barrières qu'ils rencontrent et des différents chemins par lesquels le programme d'activités du CBR favorise l'accès aux services existants. L'article aborde aussi la classification des handicaps au sein des programmes du CBR.

Resumen: Este investigación emancipatoria, controlada y dirigida por personas con discapacidad de diferentes comunidades locales, enfoca las barreras que trató de superar un proyecto de Rehabilitación en Base a la Comunidad (RBC) en los últimos diez años en nueve distritos de Karnataka del Sur (India). El artículo cuestiona las problemáticas que se encuentra en las biografías de 21 niños menores de 15 años y los diferentes caminos en los cuales RBC ayudó a abrir acceso a servicios existentes.

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Changed *Vision* for Liana with Access to Education

Armenuhi Sahakyan

There are some 9,000 children in Armenia with different forms of disabilities. Because of stigma and discrimination and unfavourable environment some 90 children out of 200 blind children of school age stayed out of schooling. World Vision Armenia implements different projects to promote and support inclusive education throughout the country. Liana is one of those children who is back to school giving hope to others.

Liana Igityan, 14, was born with congenital retinal detachment – a common cause of visual impairment and blindness. She has undergone two operations, both of which were unsuccessful. Sadly, the missing conditions at school to guarantee proper education for a child with sight impairment have kept her out of schooling. Through World Vision's *Building Disabled Peoples Organisation (DPO) Outreach for Greater Disability Inclusiveness* project, Liana started to attend Pyunik DPO in Gyumri, Armenia since fall 2009. She has been identified through a local polyclinic where Liana was registered as a disabled child who was not attending school. In Pyunik DPO she is learning to use the computer with special software and also studying the Braille alphabet to eventually read and write using Braille. Recently, Liana was enrolled in a mainstream school.

First Step to Education – Hard but Hopeful

When Liana Igityan, 14, first entered Pyunik Disabled Peoples Organisation (DPO) it was unclear whether she had only sight impairments or whether she also had some serious speech problems.

“She was not talking to any of us, was always quiet and very isolated. She would sometimes rudely reject all our attempts to involve her in any activity”, remembers Armine Nikoghosyan, Head of Gyumri branch of Pyunik DPO.

“Liana’s behaviour was understandable: being a smart girl she was totally out of schooling and was unable to read and write. She was feeling uncomfortable understanding that she lacks basic knowledge and life skills”, continues Armine.

Liana has a Hard Access to Braille Alphabet

Liana’s life is very different today. She attends Pyunik Center in Gyumri on a regular basis and

has improved her skills in communicating and interacting with those around her. Liana has also grasped the opportunity to learn to read and write with the Braille alphabet.

“We write from right to left and read as usual from left to right. It is not easy. I started learning the alphabet only recently. My teacher Mrs. Gayane says I would have been able to learn this more easily if I had started classes at an early age”, shares Liana with regret.

And learning to read and write this way is costly. Each set of the special device that helps Liana to read and write with the Braille alphabet with a metal sheet and nail, costs US\$700. Another US\$14 is needed to acquire a copy book adapted for this alphabet.

“None of the parents of the students who attend our center can afford to buy such a device for their child. There are thousands of books translated according to the Braille alphabet and it is a pity that out of 339 children with sight impairments who live in Gyumri area only a few can read and write”, explains Liana’s Braille teacher, Gayane Nalbandyan, who has been blind from birth.

Computer Knowledge Makes Liana Full Member of the Society

Liana is also enrolled in a special computer class designed to help people with sight impairments to learn using a computer. Here, students use a computer software called Arev (Sun), developed by Armenian engineers.

“I enjoy mastering the computer. My teacher Hakob cannot see either and he is a real support to me. I wish one day I could be as proficient as he is while using the computer. And I will keep dreaming of having my own computer at home”, shares Liana.

The interaction with people who live with similar limitations has helped Liana to fight her fears and inhibitions. This is a unique method



used by the DPO to harness the capacities of people with disabilities to teach or train others.

"I have been blind from birth. I got used to perceiving the environment with my four senses and improved them to the extent that they fill the gap of having no sight", says Hakob Melikyan, Liana's computer class trainer. "As a beneficiary of Pyunik Center I know how essential it is to be involved in different initiatives. I have already trained four children to use the computer and I am proud to be able to contribute to their development", he continues.

Hakob himself has been trained by Armine. When she heard that some engineers visited Gyumri to introduce new software for people with sight impairments to learn using the computer, she approached them suggesting the space and computers to conduct the training. Then she asked to participate in the training and have one free copy of the software.

Armine invested a great deal of effort to study the software. "I was blindfolded to be able to use the programme as all other blind people do. It was not easy but the only way to learn. Then I passed my knowledge over to some 25 people. Now many of them are able to use their skills in a variety of ways", she explains.

Liana's Inborn Impairment Drastically Added to Family's Vulnerability

Liana's involvement in Pyunik DPO projects has also been a dream come true for her family who would never have afforded the costs themselves.

Liana is the firstborn to Susan and Fayem. Susan is completely blind in one eye and has partial sight in the other. Fayem is also registered as disabled, having limited sight.

Liana was born with congenital retinal detachment. In early childhood she was able to differentiate objects until she underwent surgery in the regional hospital.

"We were encouraged to hear that Liana was able to see things more clearly after the surgery. Sadly, it lasted only a week, then she stayed in darkness", remembers Susan who blames herself for not being able to treat her child in a more reliable and specialised hospital in the capital Yerevan.

Later on Liana underwent another surgical procedure in Yerevan but it was once again unsuccessful because her condition had become even more complicated. The doctor said that a continuous treatment might improve her sight

but because of the family's unstable financial condition her parents were not able to continue the therapy.

"We are six people in the family. We also have one more child, Arthur, who is eight years old. None of us work now and we survive on the disability allowances and pension my parents receive. This comprises less than US\$30 a month per person", says Susan.

To Get Education Liana was Forced to be Separated from her Family

Liana's real hardships began when she first attended a mainstream school. She only went for a year. Facing several difficulties she was transferred to Yerevan, a two-hour drive from Gyumri, to continue her studies in a special institution for blind children. But living away from her parents for two weeks at a time resulted in isolation and depression.

"I made the decision that Liana would never go back to Yerevan", says Susan who began to seek out solutions in Gyumri by knocking on the doors of different schools.

"My mother used to come home disappointed. Hearing bits and pieces of conversation between my mother and father I understood that none of the schools wanted to accept me", shares Liana.

New Prospects from Liana through Pyunik DPO

Pyunik DPO opened new prospects for Liana. World Vision's *Building DPO Outreach for Greater Disability Inclusiveness* project funded by the United States Agency for International Development, partners with six DPOs in Armenia to promote the inclusion of children with disabilities into mainstream education and society.

By increasing the outreach of DPOs, World Vision is advocating for inclusive education in mainstream schools and more effective ways of realising inclusion across the country. Special training courses and learning events conducted in schools and kindergartens help to change the attitudes and behaviour of teachers, parents and students towards the rights of children and their access to education.

World Vision also empowers local NGOs to promote child rights for elementary education. Simultaneously, awareness-raising programmes are being implemented through public events and special publications that focus on urgent issues faced by children with special educational needs.



"World Vision provides some funds to adapt school facilities to make them more accessible, especially for children in wheelchairs", says Voskan Ghazaryan, Coordinator for the Building DPO Outreach for Greater Disability Inclusiveness project.

"However, most importantly we facilitate the process of identifying children who have been out of school or who have a very high rate of absenteeism because of their disability. Children with disabilities who are out of schooling are registered in local polyclinics. DPO takes the names of children and works with them and their parents through social workers to prepare children for inclusion to mainstream education", he says.

New Generation will be the Owner of Their Rights for Basic Education

Liana is among many children who has since been enrolled back into mainstream education. She attends #40 school, one of the three schools in Gyumri that will receive additional state funding for providing inclusive education to all children starting from May 2011.

"Our school is located in the district where many people with disabilities live - injured during the devastating Spitak earthquake of 1988. Even psychologically our students and teachers are ready to accept children with different needs, but we still need more knowledge and tools to be able to meet all the needs of these children", shares school principle Anahit Papoyan.

"Sometimes children stay out of schooling just because their parents lack good will and are afraid of obstacles. We need to continuously work with those parents, bring them to school, and let them interact with parents of children already attending school", she suggests.

Still, stigma and discrimination exists among students and only continuous education will change this culture. "Recently, a TV programme was broadcast to introduce to the public that we will soon have a status of an inclusive school. While in the general footage people could see our students, one of the boys afterwards complained that he was shown in the footage with a disability topic", says Liana's teacher Gohar Vardanyan.

Education Gives Independence to Liana which Matures Day-by-Day

While NGOs and the government are working together to promote inclusion of children with special educational needs in Gyumri, Liana is already enjoying her studies and gaining new knowledge.

"I feel more independent now", explains Liana. "I was afraid I would never be literate.... Now I am even asked to approach the blackboard to answer the lesson. It brings me real joy", she continues.

"I take pleasure in history, literature, and geography classes very much", says Liana. "I have advanced in mathematics and geometry as well. My father helps me a lot", she says with a broad smile.

Liana Feels Life in All its Fullness through Gaining Friends

She also shares that her classmates have become good friends to her.

"They help me to mark the homework; they write a note for my mother so that she later knows how to help me do my classes. My teachers and friends involve me in different activities. I will recite a poem by Hovhannes Shiraz (famous Armenian poet of 20th century). I am a bit worried but also very glad I will stand on the stage next to other children", says Liana proudly.

Liana herself writes poems. Her family and specialists at Pyunik DPO encourage her to develop skills of writing sensitive poems about Armenia, her parents, and brother. Now she has a new topic to write about—her school.

"I process all the information in my head, polish the rhyming and then ask my mother to write it down. I really hope I can write it down on my own as soon as I am good at using Braille alphabet", says Liana with optimism.

World Vision Projects Directed to Improving the Life of Children with Special Needs:

Through Children in Especially Difficult Circumstances project World Vision established 15 Child Development Centres throughout Armenia and a unique National Multidisciplinary Assessment Center for the assessment of children with special needs. World Vision advocated for children's rights both redesigning dozens of kindergartens and schools, as well as establi-



shing a NGO Network.

Quality Education for ALL Children project promotes inclusive education in Syunik Region, through developing local capacities. World Vision not only built the capacity of the schools to insert inclusive education, but also supported policy change in terms of revision of the National Plan of Action on Child Protection as well as Law on Mainstream Education. Two branches of Yerevan Multidisciplinary Child Assessment Center made the assessment of children's educational needs available in northern and southern regions of Armenia.

Disabled People's Organization Outreach for Greater Inclusiveness supported six partner DPOs and strengthened the community social safety net to promote inclusion of children and adults with disabilities in society. The DPO's organizational and networking skills enhanced collaborative decision-making processes with local authorities and donor organizations. The website for Disability National Commission (www.disabilityarmenia.am) was established to bring together all active NGOs/DPOs. Thirty eight children with disabilities have already joined mainstream education since the start of the project.

Zusammenfassung: Es gibt um die 9.000 Kinder mit unterschiedlichen Formen von Behinderungen in Armenien.

Wegen Stigmatisierung, Diskriminierung und nachteiliger Umgebung bleiben etwa 90 von 200 blinden Kindern im Schulalter der Schule fern. World Vision Armenia setzt verschiedene Projekte um, die Inklusive Bildung im ganzen Land fördern und unterstützen. Liana ist eines der Kinder, welches wieder zur Schule geht und anderen Hoffnung gibt.

Résumé: Il y a 9.000 enfants avec différents handicaps en Arménie. À cause de la stigmatisation, de la discrimination et d'un environnement défavorable, environ 90 des 200 enfants aveugles en âge d'aller à l'école restent en dehors de la scolarisation. World Vision Armenia intègre différents projets afin de promouvoir et de favoriser l'éducation inclusive dans tout le pays. Liana est l'une de ces enfants qui retourne à l'école et qui redonne espoir aux autres.

Resumen: Armenia tiene aproximadamente 9.000 niños con diferentes tipos de discapacidad. Por razones de estigmatización, discriminación y un medio ambiente desventajado, un 45 por ciento de los niños ciegos quedan ausente de la escuela. World Vision Armenia realiza diferentes proyectos en todo el país para apoyar a la educación inclusiva. Liana es una de los niños, que nuevamente va a la escuela y da esperanza a otros.

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Affirmation of the Rights of Children with Disabilities in China – Perspectives and Experiences

Marta Prota

In China, child disability is a double-faced reality, since disabled children are either extremely cherished and cared for or abandoned in orphanages because of their disability. The possible main factors which may affect this situation and, consequently, their link to disabled children's rights are discussed in this article by reflecting on an one-year experience in the field.

In 2010, for the whole year, I worked in Beijing (People's Republic of China) for an Italian Non Governmental Organisation (NGO) called *OVCI la Nostra Famiglia*¹. The Organisation takes pride in years of experience in the field of care and rehabilitation of disabled children, implementing international cooperation projects in several foreign countries. I was in charge of the coordination of the local staff, which were composed of physiotherapists, occupational therapists and speech therapists, as well as the assistant of the responsible of rehabilitation technical area. The project mainly aims at: firstly, opening a Professional Service for the Evaluation of Residual Abilities and Guidance in Rehabilitation² for disabled children and their families; secondly, technical training for OVCI local personnel; finally, offering guidance and professional support to the local network of orphanages in Hebei Province.

Child Disability in China

From the very moment I had decided to leave and spend a whole year in China, I tried to picture the reality I could face once there, however, almost nothing figured out to be as I had imagined before. Now, whenever somebody asks me how I would depict the topic of child disability in China, my answer remains the same: *dichotomy* is the best word to describe it. Broadly speaking, I reckon this word able to portrait any aspect of life in China, even though it turns out to be particularly suitable when dealing with child disability: the conditions of disabled children not only vary from urban to rural areas, but also within large metropolises. The city of Beijing itself is emblematic. Here, it is likely to find excellent hospitals specialized in children care, where parents may spend months following their children in rehabilitation courses while providing them with a considerable amount of family, financial and human resources with the hope for a better future. On

the other hand, plenty of other children are left behind by their parents and abandoned in orphanages because of their disability and often regardless of the seriousness of their impairment. Despite the required and officially acknowledged university degree necessary to execute the profession of physiotherapist³, in the orphanages I had been, nobody of the rehabilitative personnel boasted a proper study background, having achieved only basic education in most of the cases.

When I achieved my degree in International Studies, I carried out a research on Chinese one-child policy by analysing its effects and social costs. In particular, the outcomes reveal that one-child policy is to be numbered between the main causes, although not the only one, that lead a disabled child's parents to abandon him/her in an orphanage. According to my personal experience in the field, I confirm in Chinese orphanages lives a high percentage of children who show some sort of disability and were abandoned because they had physical malformation or suffer from cerebral palsy, spina bifida, cleft palate, arthrogryposis and mental delay. Consequently, this makes me assume that physical or mental imperfection is probably considered not 'normal' and, then, rejected. Why do parents take the decision to separate themselves from their child in a country where offspring is considered extremely precious? Could we suppose that this choice is not painful for them? Surely, it is not possible. The reason behind this choice is due to a complex combination of factors, such as the cultural factor that leads parents to take for granted the help in their old age, the legal framework that do not allow them to have more than one child and also the lack of a sufficient economic support for the families with disabled children. As Holroyd (Holroyd 2003)⁴ states, according to Confucius's lesson a disabled child represents the interruption of the natural course of events between generations within the Chinese culture. If



parents take care of their children throughout childhood in exchange of help when elderly, thus disabled children will never be able to "pay off such a debt", especially those with serious disability. On the contrary, they will always be needing high intensity care and show deep special needs and consequently they are not worthy to be part of the family. I would like to lay emphasis on a linguistic curiosity: until the 1980s the term used to refer to people with disability was *can fei*, which means *one who is disabled and useless*⁵, while now it has been substituted with *can ji ren*, whose meaning is *person with disability*.

From a legal and social point of view, this opinion is endorsed by the laws related to the so-called *one-child policy*: in most of the Municipalities, if the first new-born is a disabled and parents can prove it by means of official documents, they are allowed to give birth to a second one. At first glance, this exception to the rule could be seen as a concrete help to families to lay foundations for their future by relying on a healthier new-born: this evidence enforces the belief that the value of an individual is related to only what one can perform and a healthy second-born offers a second chance to the parents to repair their 'mistake'. With reference to this assertion, I happened to meet a nuclear family composed of the two parents, a girl of nine years of age and a boy of three. In particular, the girl had a mild spastic right hemiplegia, which turned out to be the result of prolonged anoxia during delivery. At that time, she was attending a regular school and was a brilliant student. She was fully left-handed. We met her when her mother took the girl to our team of experts because she refused to use her impaired hand, even if she could (she had some fine-manipulation problems), because she was worried her daughter's hand could become thinner and weaker. The girl was very jealous of her younger brother and this is the reason why when I asked her if he was a good brother, she answered he was not nice to her. She added he wanted everything for him and her parents always blamed only her when they had arguments. She also said he should be grateful to her: he was born because she was the disabled one.

Speaking about factors and conditions that influence the families' choice about their disabled child destiny, definitely the economic factor is to be considered between the main reasons for child abandonment.

The Chinese health system is insurance-based and as a consequence all those treatments provided without insurance are quite expensive

(for instance, a foot-ankle orthotics costs around 700 Yuan, nearly 65 Euros at least) if compared to pro-capita salary which is less than 200 Euros⁶ per month. Moreover, it is to be noticed that insurances themselves are not so cheap to stipulate, especially as a grant for disabled children who are highly prone to be needing long-life treatments and health assistance. Therefore, especially in the North of China, one of the more common reasons that lead families with a disabled child to precarious conditions is the economic effort they make for his or her care. Nonetheless, it is extremely important to highlight here that it is not the only factor to be considered.

National Data on Chinese Orphanages

Official data about Chinese children hosted in orphanages, reported by the Chinese Ministry of Civil Affairs (2010)⁷, estimated that in the country there were nearly 712,000 orphans under 18 years of age; among them only 78,000 were living in hosting institutes, such as orphanages. Orphans are formally divided into two groups: *actual orphans* that means children whose parents are dead or missing for a period longer than four years and *formal orphans*, children that are orphans in fact even if one parent is still living but that for some reason is not taking care of the child (abandon, economic problems...). Data unbundled for disability are not available. Anyway, the Ministry of Civil Affairs reported in 2006 that the major part of abandoned children were female or disabled babies.

Examples of Institutional Care Giving for Children with Disabilities

In the OVCI project I took part, one of the pivotal points was the training of local personnel in orphanages in Hebei Province, an area surrounding Beijing. I worked in some private orphanages hosting children of any age, all of them affected by some sort of disability or health problems. Apart from the shared problems reported by the managers in charge of the three aforementioned orphanages (such as significant economic support from official institutions), the lack of resources for the children (namely milk, nappies, orthotics, wheelchairs), the high personnel turn-over, I would like to lay emphasis on the extremely low level of competence of care-givers for children with special needs. Neither specific competence nor previous experience and academic knowledge are



actually required to be hired in this field. Therefore, the only qualifications that matter are *heart* and *willingness of working*, unfortunately often at a low salary. Apart from primary causes of disability, most of the children I treated presented a secondary psycho-motor delay in their development, probably due to under-stimulation during first years of life, as well as lack of common experience and instruction. For instance, I remember an orphanage hosting about 40 children. Its structure included three different buildings, each of them hosting groups of children of different age (from 10 months to 14 years old), all of who show different causes of disability and are not able to speak. When my colleague asked the orphanage's manager about any potential reason of this particular situation, she was astonished and answered "I never noticed it, we just communicate with signs, it's easier and rapid". I would like to stress that children were clean, well-nourished and, first of all, loved in the aforementioned structure. The manager of the orphanage asked for our professional support since she had realised that the offered service was not sufficient, without thoroughly understanding the missing pieces. As far as I am concerned, on the grounds of a three-month intensive collaboration, I could posit the lack of an individualized, focused and long-term project of life for those children, since there is no clear idea about the quality of their future living conditions and chance to be integrated in society. Everyone was undergoing the same physical therapy exercise, following the same day schedule, playing the same games. No one was attending school, except of a small a group of children who were reckoned the smartest and could take part in non-structured classes twice a week. Why will it be necessary to guarantee them any education if they will spend their whole life in an orphanage? For us it wasn't easy to explain why it was so important for these children, as for every child, to receive education. Maybe we can suppose that in many people's mind education is considered a fundamental right for children, but not for the disabled ones, or at least not for every disabled child. The key concept of *utility* always recurs, often associated to *useful for the community*. Switching the focus of perspective from a community-centred to an individual-centred one is not effortless in China. However, as affirmed in the UN Convention on Rights of Persons with disability, it is essential that a disabled person's oneness, dignity, equity of opportunities and his peculiar needs are to represent not only a fundamental pillar for rehabilitation but for a

broader human approach too.

Disabled Children Adoption

I also treated children hosted by an orphanage situated in the midst of Beijing business area. In particular it hosted 40 children less than three years of age, who had either health problems or physical impairments. Lots of them had been transferred from other orphanages because the main goal of the founder organization of the facility is to raise funds for necessary children's surgical treatments. For instance, most of the common problems were arthrogryposis, cleft palate, spina bifida and some mild focomelia cases. The responsible of the structure told us that most of the children hosted had been adopted in the past years, both from Chinese and foreign families. She explained too that if the child's problem could be solved through surgery, after the operation the child would have a high possibility to be adopted by a Chinese family; instead if the child has a chronic impairment and a resulting disability, for him or her the only possibility of adoption would be an international one.

Analysis – Living Realities of Children with Disabilities in China

After the reported examples based on my everyday work experience, I reckon it is useful to attempt defining the factors that can make clear the precarious living and social conditions of disabled children in the People's Republic of China.

Firstly, as already mentioned before, from a family point of view, a disabled child is seen as an interruption on the *natural* chain of reciprocal support between generations⁸. Elderly and ancestors are extremely respected in China, they are considered as heritage of the community thanks to their wisdom and the contribution they made to the whole society during their work life. Honour and respect for ancient is expected to be shown by all family members, especially from the younger ones.

During moments of exchange of opinions with my Chinese colleagues about Chinese culture's attitude toward disability, they reported that the commonest assumption was that a disabled child will require special attentions for all his life and will never be able to work, get married, continue the line, take care of his elders and so on; therefore, in other words, he/she will never be able to face his culturally and socially assigned duty and pay off his debts with his parents throughout his/her life. Moreover,



raising a disabled child is often thought to require energy and resources, being aware that nothing will return in exchange. He/she might even prematurely die and delete even the residual hope for some utility.

Secondly, within a nuclear family, the main responsibilities for the birth of a 'defected' child are attributed to the mothers. As Huang et al. (Huang, Y./P. Kellet, U./M. ST John, W. 2010) assert, a mother who gives birth to a disabled child puts shame on the entire family and has not respected her duty to guarantee a safe future for the family. The author reported cases of mothers receiving less care in the family after delivery of a disabled child (care toward women after delivery is very deep in Chinese culture, for a month after delivery they rest at home, in bed, and only close relatives are admitted to visit them or the child); in many mothers sense of guilt is huge, loneliness is not only a feeling (many husbands decide to divorce after having a disabled child or after the mother refused to split up from the child) and the struggle with her family can overwhelm her until the point break to leave her child to an orphanage. One day I met the young mother of a twelve-year-old child, affected by serious mental delay and showing behavioural problems. She told us that she and her husband had noticed their child's difficulties since the age of four, by comparison with other children. In the local hospital, a doctor made his diagnosis and confirmed their fears, subsequently the father suggested that leaving the child in an orphanage very far from the city they lived in and try to have a 'normal' child as soon as possible was the best solution. When the mother refused to accept it, firstly she was abandoned by her husband and, consequently, also repudiated by his family and, secondly, obliged to go back and live with her family of origin (since she could not care for herself and her child due to financial difficulties). She wonders how her and her child's lives would have been if she had decided to abandon him, but always reaching the conclusion that she was very proud of her choice.

Thirdly, the low level of knowledge of ordinary people towards disability, especially for children, is particularly influential. Broadly speaking, mental and intellectual disability seems to be more socially accepted than the physical one principally because the former is less visible as a consequence, it enables to hide this condition from people's eyes thus, avoiding the judgement and shame. Incomprehension about the diagnosis of disability and prognosis of their own child often leads a couple of parents to rapidly take the decision to abandon him. Some-

times they do not realise problems could be overcome and solved by means of surgery, for instance as for a cleft palate. In addition, they may not thoroughly understand the real importance and positive effects of early rehabilitation and recognise the considerable potentialities that a child can have. Even if they are totally conscious of their child's disability and health conditions, there is lack of a proper support and guidance for them in following the hard route that any parents with a disabled child has worldwide have to face.

Fourthly, frequently only disabled children who are autonomous from a self-care point of view are admitted both in regular and special schools, giving that the personnel is composed of teachers and not care givers. Therefore, accordingly these standards, a physically impaired but clever child can usually not receive an appropriate education that is generally provided to the child by the parents themselves or private home teachers paid by the family

Fifthly, some families cannot afford the considerably expensive and continuous treatments, included the surgical ones, medicines and high rate health insurance for their child. Therefore, the family take the painful decision to leave the disabled child in an orphanage hoping for a better perspective of future life in case of being adopted or receiving the care he/she could not have access to if living within the family of origin.

Mistrust and discrimination always stem from ignorance. Fighting ignorance means providing these parents with tools and information that enable them to fully understand what is happening to their child and find the best way to help their kids express their complete potential, as well as communicate not only need but also feelings, ideas and dreams, which are vital components of human beings. During my work experience in China, I heard the following sentence plenty times: "Why should I speak to this child if he never answers? I just know when he needs something and I provide him with it".

Conclusion

In conclusion, I cannot deny (and I would not) acknowledging that in China several steps have been done towards increased public awareness on disabled people's rights. First of all, I met a lot of families who had decided not to abandon their disabled children, despite all the difficulties, because they truly considered them as an essential part of the family. Secondly, every member of the staff of orphanages decide to take care of disabled children that somebody



else has rejected, in the belief that those children were worthy of their attention. Thirdly, from an institutional point of view, the Chinese Government seems to have shown its commitment on both an international and national level in improving the living conditions of its citizens with disability. On one hand, the People's Republic of China ratified the UN Convention on persons with disability in 2008 (without the Optional Protocol) and on the other one law about the care of the disabled has been promulgated since the 1990s.

"In accordance with the aforementioned laws, people with disabilities are referred as those who suffer from abnormalities of loss of a certain organ or function, psychologically or physiologically, or in anatomical structure and has lost wholly or in part the ability to perform an activity in the way considered 'normal'. The term disabled persons is used in reference to people with, visual, hearing, speech or physical disabilities, intellectual disabilities, psychiatric disabilities, multiple disabilities and/or other disabilities. The criteria for classification of disabilities in China are established by the State Council, the cabinet of China's central government. China's definition of disability, as well as their policies and standards related to people with disabilities, were strongly influenced by the medical-social models of disability that became popular during the 1980's. The models included the World Health Organization's International Classification of Impairment, Disability and Handicap (IC-IDH)."⁹

Besides, before my return to Italy, a national law regarding economic support for families with a disabled child for the purchase of aids has recently been promulgated. Fourthly, more and more Chinese people have shown a true interest towards disabled persons' rights; for instance, I mention the group of Chinese citizen that, along with OVCI's help and consultancy, are attempting to establish an association for the protection of the rights of the disabled. Finally, I cite some members of the *China Disabled Persons' Federation*, a government office, who affirmed during an official dinner *Ren bu shi niu*, which means that *Human beings are not like cows whose value is measured through what they are able to produce*. Metaphorically speaking, I do think these words are seeds for the possible future assertion *the reason why we need to recognize disabled people's rights is because they are human beings*.

The purpose of this article is far away from

expressing judgements or criticism, and my analysis is definitely not complete and exhaustive. I just wanted to report my experience because I believe that the best way to implement children rights is to understand the local reality, the cultural background and the socio-economic conditions in which a person lives. Human rights are universal, fundamental and absolutely independent from the context. Instead, as far as I am concerned, the actions required to implement these rights and spread them worldwide are not universal but context-related. In any international cooperation project, the analysis of local reality is crucial for its final success and the promotion of the respect for child rights imperatively passes through a deep understanding of the socio-economical factors that lead to their violation or neglect. According to me, identifying the deeper causes of the phenomenon is the best way to address the worldwide problem of human rights violation. Whereas, with specific reference to the complex and delicate rights of children, a fruitful action is to involve their families in the first place, because they are seen as an irreplaceable network of social relations based on unconditioned love that any child has the right to enjoy.

Notes

- 1 The Volunteer Organisation for International Co-operation la Nostra Famiglia (OVCI la Nostra Famiglia) is an Italian Non Governmental Organisation, registered by the Italian Ministry of Foreign Affairs. Our motto is *per tutti i bambini del mondo*, which means *for all the children of the world*: since OVCI is mainly dedicated to the improvement of the life conditions of children in vulnerable social circumstances and/or disability.
- 2 It is currently operating in several developing countries, such as the Federal Republic of Sudan (in the cities of Khartoum and Juba), Morocco (in the capital city of Rabat), Ecuador (in Esmeraldas Province) and the People's Republic of China (in Beijing District).
- 3 OVCI achieves its humanitarian goals through: physical, mental and social rehabilitation, training of local people in developing countries, social assistance, primary health, education, awareness campaigns in Italy.
- 4 OVCI implements and supports activities such as Primary Health Care Centres and other medical services, Rehabilitation Units and Centres, Nutritional Units, Orthopaedic Workshops, Community Based Rehabilitation Programmes, Ordinary and Special Education Activities and, finally, Academic Courses on disability-



related subjects.

- 5 The project started in July 2010 and it is implemented in collaboration with the National Federation of Disabled People in Xicheng district.
- 6 The course of Physiotherapy counts two different levels, a three-year course (Graduate Degree) plus a two-year one (Post Graduate Degree).
- 7 HOLROYD, E. (2003): Chinese cultural influence on parental care-giving obligations toward children with disability. Hong Kong
- 8 WEISS, DA T. C. (2010): Overview of Disability In China in www.disabled-world.com/news/asia/china/disability-china.php
- 9 International Average Salary Income Database (2011), www.worldsalaries.org/china.shtml
- 10 From CHINA'S MINISTRY OF CIVIL AFFAIR (2011): China Children Welfare Policy Report, & HUANG, Y./P. KELLET, U./M. ST JOHN, W. (2010): Cerebral palsy: experiences of mothers after learning their child's diagnosis. Taiwan
- 11 WEISS, DA T.C. (2010): Overview of Disability in China in www.disabled-world.com/news/asia/china/disability-china.php

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Zusammenfassung: In China ist die Behinderung von Kindern eine zweischneidige Realität, da diese Kinder entweder besonders wertgeschätzt und umsorgt oder aufgrund ihrer Behinderung in Waisenhäuser abgeschoben werden. Die möglichen Hauptfaktoren, die diese Situation beeinflussen und folglich ihre Verbindung zu den Rechten von Kindern mit Behinderungen, werden in diesem Artikel auf Grundlage einer einjährigen Felderfahrung diskutiert.

Résumé: En Chine, le handicap chez les enfants est une réalité à deux visages, dès lors que les enfants handicapés sont soit extrêmement chéris et pris en charge, soit abandonnés dans des orphelinats à cause de leur handicap. Les principaux facteurs pouvant influencer cette situation ainsi que leurs liens avec les droits des enfants handicapés sont discutés dans cet article suite à une expérience d'un an sur le terrain.

Resumen: En China, la discapacidad de los niños es una realidad de dos caras. Se encuentra por un lado niños con discapacidad muy custodiados y protegidos, y otros abandonados en orfanatos. La autora discute, reflexionando una experiencia de campo de un año, los factores principales que afectan esta situación.

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Paths through Child Disability Analysis of NGO Intervention in Contemporary Morocco Against the Background of the UNCRPD*

Sara Cesari

According to the UN Convention on the Rights of Persons with Disabilities, "disability is an evolving concept and results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full effective participation in society on an equal basis with the others". In the disability studies, therefore, it becomes of fundamental importance to ask oneself how the *cultural map* of interpretation of the phenomenon gets its shape. The goal is to let emerge the experience of *suffering* or discrimination that people with disability live with their everyday life while interacting with the social order of reference. This inevitably implies matters of political, social and cultural nature.

Background

This article is based on the outcomes of a research carried out in Morocco in order to collect the necessary material for a degree thesis. The research lingered over some of the aspects regarding the social issues related to child disability in Morocco, precisely in the area of Rabat, in the attempt to bring out the difficulties that disabled children go through in their everyday life. From a methodological viewpoint, three different levels of knowledge were deepened by designing a concentric-circled path. The first to be detected was the *international level* with special reference to the documents and the political strategies concerning the issue of disability, then the *national level* connected to the social and health policies in Morocco and, finally, the *local level* in order to let emerge the everyday experiences of people with disabilities. In particular, it was interesting to find that in the country political strategies, blended with categories of cultural interpretations of disability, interact with each other and produce meanings that influence the perception of disease.

Hereinafter, the general lines brought out in the research by means of a focus on the spiral of suffering experienced by the children with disability and their families, who have to fight against political and social invisibility every day are being introduced. In the analysis, the role played by the Non Governmental Organizations (NGOs) as promoters of civil society became apparent. NGOs are at the interface of the complex realities of the developing countries and, consequently, their role cannot be neglected.

Approaching this reality, I tried to trace out theoretical perspectives with reference to *disability studies* based on the works of Davis,

Ingstad and Reynolds-White (1995). The attempt is to create a political anthropology of the experience of suffering, which is interdisciplinary and applicable in different contexts. In order to achieve this objective I also deepened the conceptualisation about the embodiment paradigm, as well the social suffering theories, which were carried out by authors such as Sheper-Hughes, Kleinman, Das and Lock (2001). Finally, regarding the anthropology of development and the criticism towards the humanitarian discourse, I based my research on the works of De Sardan and Saillant (2008).

Setting

From February to April 2009, I was hosted and supported by OVCI *la Nostra Famiglia*¹, a Non Governmental Organisation (NGO) which deals with providing access to basic services for disabled children and their families in the area of Rabat in Morocco. Once in the field, I tried to get access to a new reality by means of the acquisition of rules, the essential condition to be accepted by a community. My identity in that setting, as well as the goal of my research, was defined little by little, intertwining my experience with that of my interlocutors. After my first visits to the Social-Educational Centre in Temara, a facility aimed at the care of children with severe disabilities set-up by OVCI along with the local educational institutions, I realised that the Centre does represent their first way of contact with the external world.

This condition can be looked at by focussing on the political and social aspects of the problem, in other words, putting into consideration the individual ambit along with the social, cultural and political ones. Indeed, to *socialise* a



problem means interpreting the passage from nature to culture and, at the same time, nurturing the process of cultural transmission that makes it possible (Ferrucci 2004). To analyse this process, I tried to find an answer to some questions I reckon to be fundamental to comprehend the complexities implied in the interpretation of the phenomenon of child disability in the Moroccan area.

Main research questions were:

- When did disability become an issue of social interest in Morocco and which were the instruments activated in order to cope with it?
- Which are meanings that the political and social institutions convey about disability in Morocco, in the light of the local cultural representations?
- Who are the social actors dealing with the disabled children's path of socialisation in contemporary Morocco?

I will try to answer the aforementioned questions on the grounds of my research, by attempting to outline the spiral of suffering that, stemming from both the international and national macro-levels, affects the lives of specific individuals; being aware of the limitations to realise an in-depth analysis of the political, economic and social dynamics that the theme of children with disabilities would require.

Recent Socio-Political Developments in Morocco

In Morocco, a deep commitment in social politics has been recently manifested by King Mohamed VI, who decided to promote reforms to improve the living condition of his people. The most concrete strategy that has been put into practice so far, is the INDH (*Initiative Nationale de Développement Humain*), a fund aimed at unfolding the capacities of the local associations as well as the diverse expressions of the local community. Launched in 2005 and currently on-going, the initiative is strategically relevant on an international political level because, on the one hand, Morocco shows its commitment towards the human rights promotion, by aligning itself with the international directives. On the other hand, it fosters the foreign funds investments through the non governmental agencies supporting local associations.

In the last years, the process of democratisation in Morocco, triggered by the King himself, saw the implementation of significantly important reforms in the legal field, which are influencing Moroccan culture, even though very slowly. The promotion of a new family law code

(*Mudawana*) in 2004, the promulgation of the law concerning political parties and the law against torture, along with the reforms in the judicial and penal field, represent some instances of this process of modernisation. Despite the above mentioned processes, it must be reminded that Morocco still remains a deeply problematic country and, on a social development level the UN Human Development Report of 2006 put it in the 123rd place². Since the '90s, the poverty rates were increasing especially in the rural areas and showed a tendency to *feminization*, which implies a broader exposition to poverty of the female population, most of them young and without an education (Vermeren 2006). The high rate of illiteracy, the poor condition of both health and education systems and the increasing unemployment rates activate a process of social marginalization that affects the most sensitive part of society, and represent an obstacle to the economic development and the broader improvement of living and working conditions. Moreover, this sense of precariousness and insecurity characterising the status of the lower classes, does not counteract institutional and political stakeholders in charge of improving their marginalized situation or modify it. In the last years in Morocco, only a small part of the society has gained some access to the public sphere, thanks to the latest liberal reforms. On the contrary the lower classes, which constitute the large majority of the population, are still living at the margins, excluded from any real form of citizenship, with no political representations as well as with no institutional means to express their voice (Capello 2008).

Given these circumstances, it is immediately evident how disabled people, especially when living in poverty, can be socially marginalized. The lack of social, political and cultural means leave disabled people in the shadow and reduce their capacity to choose. This capacity is often confined in narrow spaces in institutions where people with disability might appear to be supported, but that sometimes represents the only chance for society to reserve them.

Disability and Children with Disabilities in Morocco

It is only recently that Morocco has laid some emphasis on the problems related to disability, especially in the field of education, on a national level and involving local associations. The Government, indeed, does not limit its intervention (even though still scarce) in the medical ambit, while it rather adopts a socio-relational



attitude towards disability. Morocco ratified the *UN Convention on the Rights of Persons with Disabilities* in May 2009, and it also joined the programme *Education For All* (promoted in 1990 in Jomtien/Thailand and reasserted in 2000 in Dakar), which is mentioning the principle of inclusive education for disabled children. Both these examples are emblematic and represent strong signals of commitment towards the social inclusion of people with disabilities.

In 2004 in Morocco, a national survey on disability was carried out by the national authority in charge of the support for families, childhood and disabled people (*Secrétariat d'Etat Chargé de la Famille, de l'Enfance et des Personnes Handicapées, SEFEPH*). Its outcomes show that 5.12 % of the citizens are made up of people with disability³. It means that 1.530.000 individuals, out of a population of about thirty million, are disabled. Actually, the health conditions and the shortage of medical services have led to a significant incidence of disabling pathologies, especially among children. The survey also illustrates that 76 % of the disabled children do not receive a proper education and, in addition, that the more serious the impairment is the harder it is to find adequate facilities (www.social.gov.ma).

Some parents of disabled children renounce to give them an education, because they are discouraged by schools' refusal to admit them. Therefore, lots of children remain in their private homes instead of receiving either total or partial education.

Since the 1990s, thanks to the intervention of the NGOs, the National Ministry of Education gained a new interesting impulse, owing to the educational project for children with mental and sensory impairments: following the French example, specialised integrated classes (CLIS) were created with the aim of hosting six to eight students with the same kind of disability. Notwithstanding this purpose, though, the CLIS are actually registering heterogeneous and complex situations, with the unique result that families with disabled children are relieved from the difficulties, despite no effective educational project is implemented.

On the other hand, the children with more serious psychological and motor alterations, such as cerebral motor impairment, often remain excluded from the access to schools and, as a consequence, to the entire society. Apart from the aforementioned *integrated classes*, there exists a sort of inclusion that aims at including children with mild disabilities within the ordinary classes. The problem is that this kind

of inclusive education, called *intégration sauvage*, does not imply any kind of didactic support, and consequently it does not really solve the problem of inclusion.⁴

Implications of Exclusion

The political and social marginalisation of people with disabilities is especially visible in the experience of those who act as mediators for the disabled children when entering the broader society. Above all the aforementioned mediators, the mothers are the main actors connecting their children with the external world (Eidelman 2009:436).

In Morocco, the social and political marginalisation is not limited to the adults and children with disabilities, but it broadens including families in their entirety, which are active part in the identity dynamics of society.

Exclusion, showed on different several levels, leads to a sense of frustration and impotence that narrows down one's capacity of choice, as well as one's opportunity of social emancipation. The sense of abandonment on a political and institutional level is translated into everyday practices, as ghettoization, which constantly affects these people.

Within the family relationships, the perception of disabling diseases is to be ascribed to the Muslim religion, which is a key instrument to reality interpretation in this area. To be a Muslim implies the duty to perform precise rituals, to respect the Pillars of Islam and, above all to interiorise any social expression through the channel of the sacred (Destro 1998:167-192).

Connotations of Suffering in Relation to Disability

In Morocco, there exists a patriarchal society, where families are characterised by hierarchical relationships and marked roles, and the reproductive capacity is considered as a peculiarity of women's status. In particular, women are seen as instruments for the delivery of heirs, essential means for laying foundations for one's economic and political standings (Destro 1998:127-166). Consequently, cases of infertility or of birth of a disabled child often create deep disappointment as it is a common belief that such contingencies do not respect the cultural values on the basis of the desire for maternity and paternity. After the birth of a disabled child, families feel destabilized and consider conveniently hiding the baby from the indiscreet eyes of the community. With specific reference to mothers, they experience social



dysfunction and existential problems in everyday life which derive from their child's disability. Despite this, women normally do not passively subject themselves to these mechanisms of power, and often critically react to them by adopting forms of disapproval which are accepted by their community. These reactions generally consist in the establishment of extra-family feminine networks or in the appropriation of Western values, which are slowly transforming the status of the Muslim woman.

Moreover, the neglecting behaviour of the state and the institutions in charge of the care of the disabled make the situation even more complex: disability does not appear as a social problem and, consequently, pietistic and sympathetic attitudes are too common and do not permit to see the disabled person in his entirety and as a human rights holder.

Endeavours Towards Enhanced Inclusion – Mediating Role of NGOs

Along with women, the process of social inclusion of children with disabilities is supported by the Moroccan educational institutions, even though it is not to be taken for granted, especially when dealing with children with severe disabilities. As a result, NGOs intervene between government and civil society by playing the role of activists and promoters of a citizenship that passes through the law, the redistributive justice and the idea of dignity. NGOs' actions uphold the rights of children with disabilities providing them with basic social and sanitary services, implemented by non governmental channels although indissolubly linked to local and international politics.

Despite not going through humanitarian emergency, Morocco currently presents marked social disparities where situations of structural violence⁵, address different groups: the strategies of power of the *Makhzen*⁶ led to a significant damage of Moroccan politics, which comprise the everyday reality of the lower classes. Thus, both national and international humanitarian organisations, such as *OVCI la Nostra Famiglia*, propose themselves as an instrument to foster the affirmation of disabled persons' rights by driving the government in order to promote social inclusion policies. However, very often, by taking the place of the established power, the international NGOs inherit its logics of power and run the risk to nurture the same mechanisms of exclusion and dependence that they attempt to eliminate.

The Role of OVCI

I had the chance to reflect on the role played by OVCI in Morocco throughout the development of my research, both on a theoretical and practical point of view. I reckon OVCI's intervention can partly disengage itself from the categories of interpretation⁷ broadly adopted for the implementation of interventions in the South of the world. While OVCI is influenced by Italian shared cultural meanings, at the same time the everyday practices of intervention intervene with the social and cultural framework of Morocco and by this opening itself to dialogue. This attitude fosters and supports the organisation of initiatives, such as the *Handifilm*, a cinematographic festival on disability promoted by the parents' Organization *Casa Lahina* (promoted by OVCI itself). These interventions testify the promotion of an active citizenship. OVCI action is thus oriented towards awareness raising about the issue of disability, both on a community and on an institutional level. It is given evidence of this new tendency by the concrete operativeness on the field of the *Académie Regionale d'Education et Formation (AREF)*⁸ in the area of Rabat, a governmental Organisation (under the Ministry of Education) that actively collaborates with OVCI for the promotion of the Social-Educational Centre in Temara. In addition, along with the path of social inclusion, the inclusion of some children with severe disability into ordinary classes turned out to be an important example, as well as the promotion of the medical and social training of their parents and the dialogue established with the mothers of the children hosted in the aforementioned Centre. In particular, such dialogues are conducted in form of *focus groups*, useful instruments for an effective communication able to unveil the experiences of suffering and uneasiness, in the respect of culturally accepted dynamics.

Insights into Families with Disability

Such a research approach was chosen along with the whole team. It was my intention to enter the private spheres of Moroccan society (in particular the feminine one) and I well knew I had to delicately tiptoe in their lives. I reckon I gained the access because I am a woman and I can be carefully observed by them, sometimes even indiscreetly.

The disabled children's mothers' stories of life brought out a deep sense of frustration and impotence. Some of them cannot bear the psychological burden that characterises their status



and, therefore, most of them suffer from forms of depression. Broadly speaking, they often are trapped to a conception of *cure* considered as solutions for problems and, at the same time, they are also aware to be bound to confinement and existential insecurity, if socially excluded along with their children. The physiotherapy, which was proposed since the very first OVCI interventions, is now welcomed and acknowledged by the families as an opportunity to "hope for a better quality of life". The possibility of a son or a daughter to walk again thanks to rehabilitation, is often welcomed as a solution to the social exclusion of his/her mother. Therefore, this kind of care might be a possible solution to the social dysfunction caused by the birth of a disabled child, a tactic of resistance triggered by the mothers with the goal of managing the alteration of their role, which generates existential insecurity.

Conclusion

In conclusion, the issue of child disability implicates multiple complexities which are strictly linked not only to the individual ambit but also to the social, cultural and political one.

In Morocco, the humanitarian interventions play a fundamental role, but constitute a multi-faceted and multidimensional reality. In other words, in the study of the humanitarian practices, it becomes evident that there does not exist a homogeneous way of considering *help*. Of course, nobody can play the mere role of spectator and not taking any action would be worse, but surely the early assumption of help should be deeply reflected. If we consider the cause of unease or personal suffering as the object of intervention, there exists the need of implying the social and political fields and also assume an anthropological viewpoint when dealing with the concept of care itself, until the inclusion of the issue of human rights, not only civil and social but also social and economical, by promoting equity and social justice (Quaranta 2006:12). Analyzing its diverse forms, it is to be considered that a simplistic idea of assistance, seen as vertical and hierarchical, has necessarily to be overcome by giving voice to the marginalised, so that people are really listened to and retrieve their capacity of action.

I believe that a honest reflection on one's own perception of disability and categories of intervention could create a critical sense not only in view of practitioners in the field, but also to the donors. Often, a donation, seen as the only form of intervention as a response to social injustice, tends to discredit the people to

support, as well as the complexity of the problems they face.

Notes

- * Translated by Maddalena Colzani
- 1 The Volunteer Organisation for International Co-operation la Nostra Famiglia (OVCI la Nostra Famiglia) is an Italian Non Governmental Organisation, registered by the Italian Ministry of Foreign Affairs. Our motto is "per tutti i bambini del mondo", which means "for all the children of the world": since OVCI is mainly dedicated to the improvement of the life conditions of children in vulnerable social circumstances and/or disability. It is currently operating in several Developing Countries, such as the Federal Republic of Sudan (in the cities of Khartoum and Juba), Morocco (in the capital city of Rabat), Ecuador (in Esmeraldas Province) and the People's Republic of China (in Beijing District). OVCI achieves its humanitarian goals through: physical, mental and social rehabilitation, training of local people in developing countries, social assistance, primary health, education, awareness campaigns in Italy. OVCI implements and supports activities such as Primary Health Care Centres and other medical services, Rehabilitation Units and Centres, Nutritional Units, Orthopaedic Workshops, Community Based Rehabilitation Programmes, Ordinary and Special Education Activities and, finally, Academic Courses on disability-related subjects.
- 2 The abridged version of the Report is downloadable from the site of the United Nations Development Programme (UNDP): <http://hdr.undp.org/en/media/frontmatter2.pdf>
- 3 *Enquête Nationale sur le handicap* was carried out thanks to the technical collaboration of the French consortium CREDES/Handicap International, with the European Union financing. It is downloadable from the site of the Moroccan Ministry of Social Development: www.social.gov.ma
- 4 The survey 2004 demonstrates that 84 % of disabled children are inserted in classes according to the so-called *Intégration sauvage*. Whereas, integrated classes can just host 4 % of disabled children who come from urban areas.
- 5 The concept of *structural violence* was developed by Johan Galtung. This kind of violence has to do with institutional political choices. A sort of structural violence might emerge, for instance, by a low investment in social and health policies. This misdeed determines deficiencies in the system that affect the population or



- a part of it.
- 6 *Makhzen* is the term that identifies the Governmental élite.
 - 7 The *categories of interpretation* are mental constructions that every individual possesses and depend on one's culture of reference. They are functional to the interpretation of reality.
 - 8 The *Académie Regionale d'Education et Formation* are regional institutions of education and training in charge of the promotion of school integration on a regional and district level.

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Zusammenfassung: Gemäß der UN-Konvention über die Rechte von Menschen mit Behinderungen entwickelt sich „das Verständnis von Behinderung ständig weiter. Behinderung entsteht aus der Wechselwirkung zwischen Menschen mit Beeinträchtigungen und einstellungs- und umweltbedingten Barrieren, die sie an der vollen und wirksamen und gleichberechtigten Teilhabe an der Gesellschaft hindern“. In den Studien zu Behinderung ist es von fundamentaler Bedeutung zu fragen, wie die kulturelle Karte der Interpretation des Phänomens Gestalt annimmt. Das Ziel ist es, Leiden oder Diskriminierung aufzuzeigen, welche Menschen mit Behinderung tagtäglich erfahren, während sie mit der jeweiligen Gesellschaftsordnung interagieren. Dies impliziert unweigerlich politische, soziale und kulturelle Angelegenheiten.

Résumé: Selon la Convention des Nations Unies sur les Droits des Personnes Handicapées, "le handicap est un concept évolutif et résulte de l'interaction entre les personnes porteuses de handicaps et les barrières comportementales et environnementales qui empêchent leur pleine et effective participation dans la société sur une base égale aux autres". Dans les études sur le handicap il est dès lors fondamental de se demander comment est dessinée la "carte culturelle" pour l'interprétation du phénomène. L'objectif est de laisser émerger l'expérience de "souffrance" ou de discrimination que vivent les personnes handicapées au quotidien lorsqu'elles interagissent avec l'ordre social de référence. Cela implique forcément des questions de nature politique, sociale et culturelle.



Resumen: Dentro de los "Estudios sobre Discapacidad" (Disability Studies) es fundamental de preguntar a sí mismo, como se constituye el "mapa cultural" de las interpretaciones del fenómeno de la discapacidad. La meta es de reconstruir la experiencia del sufrimiento o de la discriminación que viven las personas con discapacidad diariamente interactuando con el orden social de referencia. Eso inevitablemente implica asuntos políticos, sociales y culturales.

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carried out in Morocco and entitled "The issue of socialization for child disability in contemporary Morocco. Analysis of an international cooperation project in Rabat". In 2010, her thesis was awarded the scholarship "René Cassin" of the Emilia-Romagna Region, and was published online (on the website: www.paceediritti.it), she continues her studies as well. At present, she is reading the Specializing Master in "Peace Studies: International Cooperation, Human Rights and E.U. Policies" of the Roma Tre University in Rome.

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HANDICAP INTERNATIONAL für Menschen mit Behinderung weltweit

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Handicap International setzt sich in über 60 Ländern mit 250 Projekten für Menschen mit Behinderung ein, insbesondere in Kriegs- und Krisengebieten. Einen Schwerpunkt bildet das Engagement für die Opfer von Landminen und Streubomben.

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Kurzmeldungen/Announcements

UN-Deklaration zu HIV/AIDS

Vom 8. bis 10. Juni 2011 fand in New York das hochrangige Treffen der Vereinten Nationen zu HIV/AIDS statt. Eine *Political Declaration* ist das sichtbarste Ergebnis der Konferenz (www.un.org/ga/search/view_doc.asp?symbol=A/65/L.77). Sie enthält viele und anspruchsvolle Ziele. Bis 2015 sollen die Mutter-Kind HIV-Übertragung vollständig gebremst, eine 50 %-ige Reduzierung der Übertragung durch sexuelle Kontakte und intravenöse Medikamente erreicht und mindestens 15 Millionen Menschen mit Antiretroviralen behandelt werden. Zum ersten Mal wird in der Erklärung (Absatz 23) die Anerkennung der UN Konvention über die Rechte von Menschen mit Behinderungen, ihre Integration, Erziehung, Gesundheit, Barrierefreiheit und Zugang zu Information für die globale Antwort zu HIV/AIDS berücksichtigt.

Damit die Ziele erreicht werden können, müssen die HIV/AIDS Programme in die Gesundheitsprogramme integriert werden, z.B. die HIV-Infektion bei Kindern bremsen und sich gleichzeitig um die Gesundheitsverbesserung der Mutter kümmern. Auch die Gesundheitssysteme müssen verstärkt werden. Die Medikamente für die Behandlung müssen in allen Ländern zugänglich (Flexibilisierung des Trips-Abkommen) gemacht werden. Im Bereich der Prävention ist es wichtig, weiter gegen Stigma und Diskriminierung intensiv zu arbeiten und eine aktivere Rolle der Jugend in der HIV/AIDS-Bekämpfung zu fördern.

Die Erklärung hat positive Ansätze aber auch erhebliche Schwächen. Wie das Ganze finanziert wird, ist nicht klar. Allerdings ist wichtig, dass alle Länder mehr Entschlossenheit zeigen und ihre Verpflichtungen erfüllen. Die afrikanischen Länder haben sich verpflichtet, 0,15 % ihres Bruttonationaleinkommens (BNE) zur Entwicklungsarbeit beizutragen, das Gleiche gilt für die Industrieländer, die 0,7 % ihres BNE beitragen müssen.

World Report on Disability wurde veröffentlicht

Anfang Juni haben die Weltgesundheitsorganisation (WHO) und die Weltbank den *World Report on Disability* veröffentlicht. Mit diesem wird die Zahl der Menschen mit Behinderung mit mehr als 1 Milliarde Menschen drastisch nach oben korrigiert.

Der Bericht soll Regierungen und der Zivilgesellschaft auf Basis einer wissenschaftlichen Basis eine umfassende Beschreibung und Analyse von Behinderung weltweit geben. Darauf aufbauend werden Empfehlungen für nationale und internationale Akteure gegeben. Aufbauend auf einer aktuellen Definition von Behinderung und den Bezügen zu Armut, Entwicklungszusammenarbeit und Menschenrechte (Kapitel 1) führt der Bericht über Ausführungen zur Häufigkeit von Behinderung weltweit (Kapitel 2)

hin zu speziellen Themen wie Gesundheit (Kapitel 3), Rehabilitation (Kapitel 4) und unterstützende Dienste (Kapitel 5). Die folgenden Kapitel gehen auf umweltbezogene Aspekte sowie Barrierefreiheit (Kapitel 6), Bildung bzw. Erziehung (Kapitel 7) und Beschäftigung von Menschen mit Behinderung (Kapitel 8) ein. Abschließend werden Empfehlungen und praktische Aspekte diskutiert.

Der Bericht zeichnet sich besonders durch einen mehrperspektivischen Zugang zu Behinderung und der Anerkennung der sozialen Wechselwirkungen aus. Es wird festgestellt, dass Behinderung ein individuell stark unterschiedliches Phänomen ist und besonders durch behindernde Barrieren kreiert wird. In den Empfehlungen werden hier unangemessene politische Planungen, negative Einstellungen, wenig verfügbare angemessene Dienste, behindernde Barrieren, mangelnde Einbeziehung behinderter Menschen und fehlende Daten als Faktoren erwähnt, die die Teilhabemöglichkeiten von Menschen mit Behinderungen am gesellschaftlichen Leben langfristig erschweren. Der Zusammenhang zwischen sozialen Bedingungen und Behinderung wird durch die Darstellung des bi-direktionalen Zusammenhanges von Armut und Behinderung besonders betont.

Der Bericht geht auf die Frage nach dem Anteil von Menschen mit Behinderungen weltweit ein. In einer detaillierten Gegenüberstellung verschiedener Erhebungsmethoden und unter Berücksichtigung unterschiedlicher Herangehensweisen gibt der Bericht an, dass 15,6 % der Weltbevölkerung eine Behinderung haben. Einschränkend hält er aber fest, dass dies keine endgültige Zahl sein kann, sondern nur die bestmögliche Annäherung nach dem gegenwärtigen Forschungsstand.

Der Bericht bietet LeserInnen eine fundierte und aktuelle Grundlage, um sich mit der Situation von Menschen mit Behinderungen im globalen Kontext auseinander zu setzen. Durch die differenzierten Darstellungen einer Vielzahl von AutorInnen wird der Bericht als Ganzes oder in Auszügen lesenswert. Er legt sich nicht auf abschließende Feststellungen fest, sondern gibt Denkanstöße, zeigt unterschiedliche Ansatzpunkte und unterstützt ein Verständnis von Behinderung im Sinne der UN-Konvention über die Rechte von Menschen mit Behinderung. Weitere Informationen unter: www.who.int/disabilities/world_report/en/index.html

Disability on the World Bank Education Agenda

The World Bank Education Strategy was launched in April 2011, outlining an inclusive education system that takes into account the more marginalised groups of society, including persons with disabilities. The aim of the strategy is to encourage donors, employers and governments to pro-



vide education preparing future employees for the challenges of the labour market. The strategy outlines an inclusive education system that takes into account the more marginalised groups of society, including persons with disabilities. According to the strategy, specific resources should be allocated in order to directly target these groups, and stakeholders such as civil society should be part of the design process of programmes in order to ensure a system that embraces all groups of society.

Inklusiver Freiwilligendienst (weltwärts)

Die Bewerbungsfrist für das weltwärts-Freiwilligenprogramm endet im September!

bezev entsendet seit 2008 über das weltwärts Programm Freiwillige in Projekte mit Menschen mit Behinderung in Afrika, Asien und Lateinamerika. Gesucht werden junge Erwachsene bis 28 Jahre, die pädagogische oder therapeutische Erfahrungen mitbringen. Einige Projektpartner wünschen sich besonders SchulabgängerInnen, Studierende oder Auszubildende mit Beeinträchtigung.

Mehr zu den Einsatzstellen unter www.bezev.de im Be-

reich *Freiwilligendienst*. Die Bewerbungsfrist für eine Ausreise im Sommer 2012 endet am 15. September 2011.

Neustart für Website Landmine.de

Handicap International, medico international und Misereor führen seit Mai 2011 die bewährte Internetpräsenz Landmine.de weiter. Die neue Landmine.de bietet Nachrichten über die Ächtung, die Produktion, den Einsatz und die Folgen von Landminen und Streubomben. Sie berichtet außerdem über Hilfsprojekte vor Ort sowie Kampagnenaktivitäten – wie im Moment die weltweiten Aktionen gegen die Finanzierung von Streubombenproduzenten. Auch wer eigene Aktivitäten plant oder z.B. in Schulen über das Minenthema informieren möchte, findet auf landmine.de Anregungen und Material. Nachdem die Verträge über ein Verbot von Minen und Streubomben und damit wichtige Ziele erreicht waren, hat sich das Aktionsbündnis Landmine.de Ende 2010 aufgelöst. Zentrale Informationen aus den früheren Jahren der Kampagnenarbeit werden im Archiv der neuen Website zur Verfügung gestellt. Weitere Informationen unter: www.landmine.de



Literatur/Reviews

World Health Organization

World Report on Disability

June 2011

Launched on 9 June 2011, the World report summarizes the best available scientific evidence on disability and makes recommendations for action to support the implementation of the Convention on the Rights of Persons with Disabilities (2006).

The Report addresses the need for better research and data on disability. It includes the first update of WHO's disability prevalence estimates for more than thirty years. The Report also explores evidence about discrimination and barriers, identifies needs and provides an analysis of what works to improve the lives of people with disabilities in the areas of health, rehabilitation, support services, information, infrastructure, transportation, education and employment.

Bezug: www.who.int/disabilities/world_report/en/index.html

International Disability Alliance

Guidance Document: Effective Use of International Human Rights Monitoring Mechanisms to Protect the Rights of Persons with Disabilities

May 2010; 83 pages

This guidance document provides practical strategies and advice to disabled people's organisations (DPOs) and DPO coalitions on the international human rights mechanisms. It provides details on the reporting process of the UN Convention on the Rights of Persons with Disabilities (UNCRPD), raises awareness on the need to establish national DPO coalitions, and offers assistance for DPOs on producing effective reports for submission to the UNCRPD Committee. It also provides guidance on the monitoring process and includes information on the use of other human rights mechanisms. This document would be useful to global, regional and national DPOs engaging in the UNCRPD reporting process. Available in Word and PDF formats in English, Spanish and French, and in Word format in Arabic.

Bezug: International Disability Alliance Secretariat, WCC Building, 150 route de Ferney, PO Box 2100, CH - 1211 Geneva 2, Switzerland

www.internationaldisabilityalliance.org/projects-and-events/guidance-document-on-parallel-reporting

World Health Organization

Mental Health and Development : Targeting People with Mental Health Conditions as a Vulnerable Group

2010; 108 pages; ISBN: 9789241563949

This report on mental health and development is a call to action to all development stakeholders - governments, civil society, multilateral agencies, bilateral agencies, global partnerships, private foundations, academic and research institutions - to focus their attention on mental health. The report presents compelling evidence that persons with mental and psychosocial disabilities are a vulnerable group but continue to be marginalized in terms of development aid and government attention. It makes the case for reaching out to this group through the design and implementation of appropriate policies and programmes and through the inclusion of mental health interventions into broader poverty reduction and development strategies. The report also describes a number of key interventions which can provide a starting point for these efforts. By investing in persons with mental and psychosocial disabilities, development outcomes can be improved.

Bezug: World Health Organization (WHO), Marketing and Dissemination, CH-1211 Geneva, Switzerland, E-mail: bookorders@who.int, www.who.int oder http://whqlibdoc.who.int/publications/2010/9789241563949_eng.pdf

Handicap International

Supporting Persons Living with Trauma by Rebuilding Social and Community Links: An Example of a Community-Based Mental Health Approach after the Rwandan Genocide of the Tutsis

2010

The genocide of the Tutsis in 1994 had significant ramifications, both on the community and on the individual level. In 2007, Handicap International initiated a project aiming to promote mental health by strengthening community mechanisms for the preventative and curative care management of children and adolescents experiencing psychological suffering. This project was rooted in a participatory approach which brought together both public and private-sector stakeholders. The report provides an overview of the lessons learned, certain limitations as well as recommendations for the continuation of the project.

Bezug: www.handicap-international.org.uk/Resources/Handicap%20International/PDF%20Documents/HI%20Associations/SupportingPersonsTrauma_2010.pdf



Office of the United Nations High Commissioner for Human Rights

Working with the United Nations Human Rights Programme

A Handbook for Civil Society

The United Nations human rights system provides civil society actors with a unique democratic space in which to participate: contribute expertise, raise awareness about issues; participate in monitoring and implementation of human rights standards, as well as in the development of new standards. The Handbook for Civil Society is a publication of the Office of the United Nations High Commissioner for Human Rights (OHCHR), which explains in a simple way what the different UN human rights mechanisms are, how they work, and how you can contribute and benefit from their work.

Bezug: The Handbook is available online in pdf in the six official UN languages - Arabic, Chinese, English, French, Russian and Spanish: <http://goo.gl/BOZgB>, and in Farsi: <http://goo.gl/zUvBT>, Georgian: <http://goo.gl/7ZiND>, Nepali: <http://goo.gl/Loaxh>, a DAISY talking book version in English is available on CD-ROM.

Save the Children

See Me, Hear Me : A Guide to Using the UN Convention on the Rights of Persons with Disabilities to Promote the Rights of Children

2009; 178 pages; ISBN: 9781841871233

See Me, Hear Me looks at how the UN Convention on the Rights of Persons with Disabilities (CRPD) can be used to support disabled children, alongside the Convention on

the Rights of the Child. The guide analyses the inter-relationship of the two Conventions and provides examples of good practice on how both Conventions should be implemented by governments with regards to children.

Bezug: Save the Children, 1 St John's Lane, London, EC1M 4AR, UK www.savethechildren.org.uk/en/docs/See_Me_Hear_Me_internals_final.pdf
www.savethechildren.org.uk/en/docs/SCUK_See_Me_Hear_Me_AR_May-09.pdf

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Bezug: Harald J. Kolmar, Referat Internationales, Bundesvereinigung Lebenshilfe für Menschen mit geistiger Behinderung e.V., Leipziger Platz 15, 10117 Berlin, E-Mail: harald.kolmar@lebenshilfe.de, www.lebenshilfe.de



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VERANSTALTUNGEN EVENTS

- September 2011 Exploring Inclusive Education: An EENET workshop in Bandung, Indonesien
Information: Ingrid Lewis, E-mail: ingridlewis@eenet.org.uk
Fax: +44 1457 763356, Mobile: +44 7929 326564, www.eenet.org.uk/events.php
- 09.09.2011 Workshop Entwicklungszusammenarbeit und Menschen mit Behinderungen in Frankfurt/M.
Information: Entwicklungspolitisches Netzwerk Hessen, Vilbeler Str. 36, 60313 Frankfurt,
E-Mail: e.V.info@epn-hessen.de, www.epn-hessen.de.
- 15.09.2011 Workshop *Inklusive humanitäre Hilfe* in Berlin
Information: VENRO Sekretariat, Stefanie Rühl, Tel.: +49 228 946 770,
E-mail: sekretariat@venro.org
- 17.09.-21.09.2011 TRANSED 2012: The 13th International Conference on Mobility and Transport for Elderly and
Disabled People in Delhi, Indien
Information: www.transed2012.in
- 23.09.2011 Seminarreihe Inklusive Entwicklung: Evaluierung und Monitoring inklusiver Projekte
Information: Behinderung und Entwicklungszusammenarbeit (bezev), Wandastr. 9, 45136
Essen, Tel.: +49 201/17 88 963, Fax: +49 201/17 89 026, E-Mail: info@bezev.de,
www.bezev.de
- 10.10.-13.10.2011 Disabled Peoples' International 8th World Assembly in Durban, Südafrika
Information: The Conference Company, Tel: +27 31 303 9852, Fax: +27 31 303 9529
- 11.10.-13.10.2011 ESCAP meeting on a New Asian and Pacific Decade to Promote the Rights of Persons with
Disabilities in Bangkok, Thailand
Information: www.unescap.org/sdd/meetings/meetings.asp
- 17.10.-21.10.2011 World Mental Health Congress in Cape Town, South Africa
Information: E-Mail: info@wmhc2011.com, www.wmhc2011.com
- 28.11.-23.12.2011 International Course on Disability & Development an der VU University Amsterdam,
Niederlande
Information: [http://siteresources.worldbank.org/DISABILITY/Resources/
280658-1298502475589/Information_DD_Module_I_2011_110311-1.pdf](http://siteresources.worldbank.org/DISABILITY/Resources/280658-1298502475589/Information_DD_Module_I_2011_110311-1.pdf)
- 29.11.-01.12.2011 2nd Asia Pacific CBR Congress in Manila, Philippinen
Information: www.ncda.gov.ph
- 02.12.2011 Seminarreihe Inklusive Entwicklung: Inklusive Entwicklung als Menschenrecht
Information: Behinderung und Entwicklungszusammenarbeit (bezev), Wandastr. 9, 45136
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1/2012 Terminologie/Terminology Stefan Lorenzkowski Stefan.Lorenzkowski@web.de)

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