Disabled Children's Rights and the UN Convention on the Rights of the Child

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Introduction

The United Nations Convention on the Rights of the Child (UNCRC) is the most widely ratified international convention[1] and it is now ten years since it was unanimously adopted by the UN General Assembly in 1989. Every Article of the CRC applies to all children, without exception. However, it cannot be assumed that initiatives to improve children's rights in general will automatically benefit the most marginalised children. In order to raise awareness of the rights of one such group - disabled children - the International Save the Children Alliance (the Alliance) has initiated a project `Disabled Children's Rights and the UNCRC: an Advocacy Tool.' This article will describe this project and some of its underlying principles, highlight key issues emerging from the research, and suggest a range of strategies which are already making improvements in practice.

Project background

In October 1997, the UN Committee on the Rights of the Child held a Thematic Day on the rights of disabled children.[2] An International Working Group on the Rights of Disabled Children was subsequently established on which the Alliance is represented. With a view to contributing to the aims of the Working Group, an Alliance Task Group on Disability and Discrimination was set up. One of its first projects has been to document examples of violations and good practice in relation to disabled children's rights and the UNCRC.

Begun in August 1999, the main objectives of this project are: to raise awareness and reinforce the fact that every Article of the CRC applies equally to disabled children, not only Article 23; to provide concrete examples to help the UN Committee on the Rights of the Child to monitor implementation more closely; to provide an advocacy tool for local and international organisations, parents' and disabled people's organisations in promoting the rights of disabled children.

A memo was sent out to potential respondents world-wide and posted on relevant web-sites.[3] A wide variety of respondents have contributed examples of both violations and good practice, including disabled young people, parents, international and local non-government organisations (NGOs) and advocacy groups. To date, over 450 examples have been collected.

Criteria for violations and good practice

It may be useful at this point to clarify some of the underlying assumptions and definitions adopted by the Alliance, and presented for guidance to contributors.

What is good practice/working towards good practice? Good practice is not fixed and absolute. What may be considered progress towards good practice in one country would be a backward move in another. Any initiative that results in improvements in disabled children's lives may be included. Ethiopia is moving forward, from previously totally excluding disabled children from education system, to accepting that they can be educated "as the resources of the country permit." (Haile & Bogale, 1999)

What is a violation? A violation is when a right has been either breached or simply not implemented. For a disabled child, the violation may be in comparison to the treatment of others in the community/family, e.g. all children in the family go to school except the disabled child. On the other hand, the violation may be one that a disabled child faces alongside other children, e.g. lack of basic health care facilities, but which has a greater adverse impact on the disabled child. In Zimbabwe, a survey of two poor communities shows that health and education services for the general population are inadequate. Although a few disabled children attend school, teachers do not have the skills to help many more. These children are denied not only an education, but also the opportunity for integration into society. (Save the Children/UK, 1999)

What constitutes discrimination? For the disabled child, the principle of non-discrimination outlined in Article 2 underlies all Articles of the CRC. Discrimination is not always easy to identify, however.

Direct discrimination is the most obvious, i.e. where a disabled child is treated in an inferior way to non-disabled children. For example, an education policy which specifically excludes disabled children from attending mainstream schools. In Buenos Aires, Argentina, disabled children must meet certain criteria in order to be eligible for education. One admission requirement to schools for pupils with severe learning disabilities is that the child must have a diagnosis and prediction of educability suited to school's curriculum targets. To be able to stay at school, a student "must show progress in his learning process."[4]

Indirect discrimination is more subtle, but equally damaging. It can result from an absence of law or policy. Contributors from Swaziland emphasised the lack of policies on disability issues and services for disabled people.[5] It can happen when equal rights are misunderstood to mean equal treatment. One definition of indirect discrimination is 'identical treatment which has a disadvantageous effect on disabled people' (DPI, 1998, p.11). One Swazi woman with severe physical impairments remembers her schooling: "Some teachers had a negative attitudes towards me. They expected me to perform like the non-disabled, e.g. walking fast, and not understanding why I sometimes came late for school."

For example, education policy may state that mainstream schools are open to all children. In reality, disabled children may still not be able to attend school because nothing has been done to make education more accessible: the curriculum is still as rigid, buildings have too many steps, teachers lack skills and awareness, etc.

The UN Human Rights Committee recognises that: "the principle of equality may require affirmative action in order to diminish or eliminate conditions which cause...discrimination." In other words, a disabled child may need something different, in order to access the same as others. For example, in order to access her same right to education, a child with a visual impairment may need something different: a magnifier, class-mates to read aloud for her, or to sit at the front the class, depending on her needs.

Non-implementation. It can happen when the laws and policies exist, but are not translated into practice. The 1984 Accessibility law in the Philippines sets out detailed minimum design criteria for public accessibility, but any visitor to Manila will recognise that these are not widely followed and that the streets of the capital remain an obstacle course for most people, but especially for disabled people.

In Uganda, human rights for disabled people are enshrined in the Constitution and is to be applauded as the first country in the world to recognise Sign as an official language in its constitution. Meanwhile, however, a letter from a disabled Ugandan secondary school student tells a woeful tale of his struggle to meet his most basic rights: "Despite the fact that I am a lame orphan in senior three, the government still requires me to pay school fees... I have a right to good health but whenever I go to a hospital or clinic, money is needed for treatment and I do not have any. I am demobilised because I lack a wheelchair. I am simply surviving on crutches." [6]

Issues arising from the data

Invisibility of disabled children

Once data started to be collated, the first and most striking issue to emerge was the overall invisibility of disabled children. A search of recent Country Reports to the UN Committee on the Rights of the Child indicates that, in most cases, disabled children are mentioned under Article 23 only, with the focus on rehabilitation and `special care.' Occasionally disabled children are referred to under Article 28 (the right to education); very rarely under other Articles. It is rare to find more than a passing reference to disabled children in the NGO literature on child rights issues. The following currently high-profile areas of children's rights show how little disabled children feature.

Protection in situations of conflict (Articles 38, 39)

Very little documentation refers directly to disabled children (Ahlen, 1997). However, the stories are there, surrounded by a conspiracy of silence.

The Happy Home Centre in Lebanon works with families to provide care and education for children with learning difficulties. The majority of these families are either refugees or internally displaced as a result of Israeli attacks. Staff at the Centre have reported: "three cases of disabled girls attending the centre [who were] raped by men in the area where they live. The rapists were members of armed militias, and the families were scared to press charges. Not only would this carry the risk of reprisal from the offenders but would also bring more shame to the family which is already stigmatised for having a disabled daughter." (Boukhari, 1997)

The notable exception is the publicity given to one impairment-specific group - amputee survivors of landmines, usually to the exclusion of other disabled groups, the implications of which are discussed below.

The right to education (Articles 28, 29)

In spite of the World Education Forum in April, the Framework for Action on Education For All and the commitment of UNESCO to "reach the unreached" (UNESCO, 2000), disabled children remain largely unreached by education. In a report to the UN General Assembly (UN, 1996), the Special Rapporteur on Disability noted that: of 65 countries providing information, 34 [over 50%] report that disabled children are excluded from education; 18 countries report that they are excluded by law from the public education system; 10 countries report no legislation on education for disabled children; and in some countries less than 1% of disabled children receive education.

On a field trip to an education project in Viet Nam, I visited several families with disabled children. Afterwards, I asked a local education official what was the primary school attendance rate in his sub-District. He answered proudly 100%. I asked: "Is that 100% of all children?" and he replied "Yes, 100%." But, I asked, what about that deaf child we just visited, she's never been to school? He looked confused: "Oh! You mean all children, including disabled children?"[7] In Viet Nam, in order to calculate the school attendance rate, disabled children, along with unregistered and migrant children, are first subtracted from the total of primary age children (Bond, 1998). The result is that disabled children are not even regarded as part of the equation.

Protection from sexual abuse and exploitation (Article 34)

Research carried out in Europe and North America indicates that disabled children are at higher risk of sexual abuse than non-disabled children (Berglund, 1997). Anecdotal evidence suggests that this is also the case in Asia. The following example is from the Philippines: "Maria, a 12 year-old grade 4 student, considered by her teachers as a slow learner, is a victim of sexual abuse... during class days, she takes her lunch at her mother's house where she is frequently in contact with her cousin who impregnated her. Maria kept her affair with her cousin a secret from her parents as her cousin threatened her. Until one day, her parents were taken by surprise when Maria was rushed to the hospital to give birth. As a result, Maria decided to quit school because her parents do not want her to be harassed by what her classmates would do and because she now has a baby to attend to for a girl of her age."[8]

Sadly, a recent opportunity to address some of the questions raised in this account appears to have been missed. A three year UN/ESCAP project on the Elimination of Sexual Abuse and Sexual Exploitation of Children and Youth in Asia and Pacific does not appear to have included the issue of the sexual abuse of disabled children in the initial project stages which have focused on training and country research.

Why are disabled children invisible?

Disabled children do not survive. A letter sent from a DPO in the Gambia states bluntly: "[severely disabled children] do not survive childhood ... The lack of rehabilitation facilities coupled with fear of the difficult responsibility of rearing and bringing up an invalid... results in negligence and eventual death of these children."[9]

The violation of the right to survival is not confined to income-poor countries however. Of 54 violations of Article 6, the right life survival and development, 14 are from middle or high-income countries. In Japan: "parent-child suicide, in which parents kill themselves along with their children, often occurs. The motivations include disease or weakness of the parent or his/her spouse, family troubles, and weakness or disability of the child. Though this phenomenon is nothing but an act of murder of children by parents, it is often tolerated out of sympathy for the parents." (Japan NGO Coalition, 1997)

Disabled children are not seen as children. Disabled children tend to be viewed differently from non-disabled children. Practices and behaviour which would provoke outrage in the case of a non-disabled child, are more likely to be accepted where a disabled child is concerned. Merry Cross describes abusive practice as "based on the attitude that disabled children don't matter as much as non-disabled children. If disabled children are seen as `less human,' then their abuse is `not that inhumane'" (Cross, 1998).

For example, a report commissioned by the UK Down's Syndrome Association cites a case in which a six month old child was given no pain relief after undergoing heart surgery because according to the doctor "Down's children don't feel any pain" (Rutter & Seyman, 1999).

Disabled children are hidden. This happens throughout the world, nowhere more so than in countries with a long tradition of institutionalising disabled children. Human Rights Watch reports that in Russia, medical staff routinely pressure parents to abandon a disabled child at birth to an institution by warning them about the child's future life as a "social pariah." This is in direct contravention of Article 9: separation from parents. In the institution, the child is likely to be "denied virtually every right to medical care, education, and individual development... officially classified as `ineducable,' and excluded from opportunities to learn to read, write, and in some cases, to walk" (Human Rights Watch, 1998).

The "medical model" of disability. It is a common experience of disabled children to be identified by their impairment rather than as children first who happen to have an impairment. Consequently, approaches to working with disabled children tend to focus primarily on treating the impairment rather than on addressing the broader needs and rights of the child. Landmine survivors, commonly referred to in publicity campaigns as victims, tend to be seen solely in terms of their medical needs, out of context of their social and educational needs. Further, post-conflict responses tend to focus resources on the medical needs of landmine survivors, to the detriment of children with other impairments.

Whilst not denying the necessity for orthotics, many agencies focus exclusively on this aspect in conflict zones. This may have the effect of even further marginalising children with Down's syndrome or cerebral palsy who find that all physiotherapy and assistive aid production is targeted to those who have lost limbs. It would be very easy for some of these clinics to also become involved in making braces and other types of equipment for children with other types of impairment, but this is rarely the case (The International Save the Children Alliance, 1999).

In the UK, the medical model of disability persists, especially among service-providers, where "disabled children are seen to be in need of `care' rather than in need of respect for their human rights" (Morris, 1998, p.7). One mother describes her struggle to get local services to meet her child's needs as follows: "I don't want Susie to go to residential respite twice a week. ... What I'd like would be for her to go to the after-school club down the road with her friends. But the taxi won't vary the route, the club says it isn't insured and they invent barriers. It would be so good and so cheap for her to go to that club... But it seems that local authorities can afford respite care and they can't afford the kind of play and leisure opportunities that would give Susie independence and the chance to make friends" (Russell, 1998). The medical model of disability seems to function as a strait-jacket on the thinking of ordinary people when faced with a disabled child.

Turning rights into reality

The UNCRC is a valuable tool in promoting the rights of children. It can be useful in both helping to formulate child-related legislation and in supporting and monitoring practical implementation of children's rights in practice. Relevant laws and policies related to disability are a pre-requisite for long-term and sustainable improvements in disabled people's lives. However, implementation in practice depends often on individuals, their interpretation of policy, commitment to new ideas and willingness to adapt to new ways of working. As expressed by one Bulgarian parent of a disabled child: "no matter the system, it all comes down to individual people and how supportive they are."[10]

An analysis of examples collected by the project indicates that one of the most common factors contributing to a violation is a lack of information, knowledge and skills. This is illustrated by a comment from a DPO representative in Swaziland:

"The [blind] child's rights are often violated, not because the parents intentionally do it but due to ignorance... The parents themselves need support and education." The majority of examples of good practice, conversely, promote the dissemination of information, knowledge and skills.

Promoting awareness and understanding of children's rights. The 191 countries that have ratified the UNCRC have a duty outlined in Article 17 to disseminate information about children's rights. How are they doing this? Many countries have a National Child Rights Coalition of NGOs which monitors its government's implementation. It is important that the concerns of disabled children are represented on this Coalition.

The Lesotho Society for Mentally Handicapped Persons (LSMHP) is working with local NGOs and government agencies in awareness-raising and lobbying for the rights of the disabled. The LSMHP is represented on the NGO Coalition on the Rights of the Child whose purpose is to monitor and promote practical implementation of the UNCRC thus ensuring that disabled children are not forgotten (LSMHP, 1999).

Promoting self-advocacy. One of the most effective ways of combating ignorance about disabled children is by enabling the children themselves to talk about their lives, whether individually, or through the media. In Yemen, disabled children have been involved in a Children's Day of Broadcasting. Thirty disadvantaged children, including disabled children, were given support to produce a radio programme in which children expressed themselves to the public about their problems and feelings. The initial programme was a success and led to further programmes with children speaking for themselves (Radda Barnen, 1999).

In the UK, the social services department has a statutory duty under the 1989 Children Act to "ascertain the wishes and feelings [of children in care] and take these into account when making decisions" (UK Children Act, 1989, quoted in Morris, 1998). Sadly, for many children with difficulty communicating, there is a tendency on the part of adults to make decisions for them, believing that they do not have opinions.

The PACT Yorkshire Advocacy Initiative provides training, advice and practical support to agencies wanting to improve their own skills in listening to disabled children and young people, with a focus on children with no verbal communication. It aims to "promote a deeper understanding of individual needs through communication and advocacy. To achieve this it is essential to find out from children themselves what they hope for from life" (PACT, 1999).

Challenging the medical model. Some of the most successful projects are based on a social model of disability which provides an alternative to the more widespread medical approach. The aim of these projects is to address barriers to participation in the community. These barriers may be in the physical environment, or to do with attitudes and behaviour of family and community, or with lack of access to existing services.

In Viet Nam, until recently, the only support available for a family with a young disabled child was medical treatment or physiotherapy. The Ho Chi Minh City Care in the Community project is filling this vacuum. The project works with parents and volunteers, providing them with information, encouraging them to meet and share their experiences and to support each other with advice and practical help (Jones, 1998). One local government official admits: "In the past we would advise parents of disabled children to keep their children at home - hidden away. We see now that was a mistake. Now we encourage them to bring them out" (Chalker, 1998, p.22).

Parents are helped to teach their children new skills. Many feel more confident about encouraging their child's independence in the community: "Hung is an 11 year-old, with problems walking, who attends his local kindergarten. [Previously] his mother focused only on his mobility, hoping some day that he would walk. As a result of the project's training, she realised that Hung needed to develop in all areas simultaneously, and that she should not wait until he walked to teach him other things. Hung's mother feels very strongly about this issue, and is very keen to share it with other mothers" (ibid, p.21).

In Bosnia, Oxfam supports the Koraci Nade (Steps of Hope) Centre which offers support for disabled children. The emphasis is on development through play in a relaxed environment where parents can get advice and meet and support each other. A physiotherapist describes the difference the centre has made to one child: "Martina... had problems sleeping and going to the toilet, and was really scared of other children. ... Once she started coming to the Centre and mixing with other children, she started to progress almost immediately - the group-work approach that the physiotherapist introduced really worked much better than individual work. Children need to be with other children. The doctors with white coats in cold rooms frighten the children. Here they get physiotherapy surrounded by toys, laughter and their friends" (Hastie, 1997, p.35).

This project is influencing practice at the nearby Faculty of Defectology. Students from the Faculty say that the Centre is "where they have learnt most about how to work with disabled children. They will be the professionals of the future and are seeing a whole new approach in practice" (ibid, p.84).

Learning by doing. The pilot approach to implementing new ideas can provide both a vision and a learning ground where people can develop skills, make mistakes, familiarise themselves with the unfamiliar, and come to a common understanding about the aims of their work. In Ethiopia, a pilot inclusive education programme for children with learning disabilities has been started in Addis Ababa. The aims are to develop a workable programme, to share lessons learnt, and to promote disabled children's rights. So far the results have been positive: regular students have been helpful to their disabled classmates, and teachers, school administration and Education Bureau are increasingly enthusiastic (Haile & Bogale, 1999).

Information, knowledge. In this era of instant and endless information, a common complaint plaguing many parts of the world is lack of information and knowledge. In Swaziland, CBR workers work closely with primary school teachers in schools. They use Child-to-Child methodology to encourage children to compose songs and perform plays which raise school and community awareness of issues such as safety on the roads and in the home, HIV and AIDS and disability. Children and community workers have been actively involved in educating communities about the need for inclusion by challenging existing negative attitudes towards disabled people (EENET, 1998a).

Disabled people themselves are often the most effective communicators about disability. In the US, the Keys to Introducing Disability to Society (KIDS) Project worked with disabled and non-disabled young children in school: "In the projects I have been involved in, if you show [children] other ways of communicating messages, such as Braille or sign language, they take it in their stride and are frequently enthusiastic about learning what they see as just new modes of expression... [We] used games, stories, and short discussions and activities to demonstrate what life with a disability is like on a basic level. It is not necessary to spend a lot of money - with my cane, a Braille writer and a couple of children's books with both Braille and print, I have worked with dozens of classes over the years, to help create positive images and impressions of disabled people" (Martinez, 1997).

Practical Support for implementation. New ideas are difficult to put into practice when maybe struggling against criticism and there is nobody to consult when a problem arises. Support networks which share ideas and examples of good practice are very important. In Lesotho, parents of LSMHP have become more aware of their children's needs and are able to assist and advise teachers how to cope with their children at school. They are invited to give talks and to share their experience during teachers' seminars (EENET, 1998b).

Conclusion

Throughout the world, disabled children, more than any other group of children, are routinely denied the most basic rights. The aim of this Advocacy Tool project is to raise the profile of disabled children by acknowledging their presence in all communities, by actively including their experiences and views, and by encouraging them to speak for themselves. No special or higher priority is being claimed for disabled over non-disabled children. Instead, it is said that they be included wherever there are services and activities for children. It is hoped that by turning the spotlight on disabled children, we can ensure that all children means all children, including disabled children.

Disabled Children's Rights: Advocacy Tool Project. Please send contributions to Hazel Jones, 41 Trafalgar St, York, YO23 1HX, UK; e-mail: <hazel.j@btinternet.com>; or to Ulrika Persson, Radda Barnen, Torsgatan 4, S-10788 Stockholm, Sweden. Tel: +46 8 698 9190; Fax: +46 8 698 9012; e-mail: <ulrika.persson@rb.se>.

Useful Sources on Children's Rights:

The Child Rights Information Network (CRIN) is an invaluable source of information on children's rights with a regular newsletter and a website: <http://www.crin.org.uk>.

International Save the Children Alliance website on Child Rights: <http://www.savechildren.or.jp/alliance/crc-intr.html>.

International Save the Children Alliance, UN Convention on the Rights of the Child: Training Kit. Training pack aimed at NGO/GO staff, programme/service implementers.

Endnotes

1. The UNCRC has been ratified by 191 countries; not ratified by two: Somalia and the US.

2. Minutes and papers presented at the Thematic Day can be found on: http://www.crin.org.uk Rights of Disabled Children desk.

3. Full background to the Alliance Disabled Children's Rights project can be found in English and Portuguese on: <http://www.eenet.org.uk>.

4. Letter from a member of a Parents Association, mother of a child with severe and multiple learning difficulties.

5. All quotes from Swaziland were collected by Save the Children Swaziland and include representatives of disabled people's organisations, CBR and health workers, NGO staff, teachers.

6. Letter from a disabled student.

7. Author's personal experience.

8. Letter from a community health worker.

9. Letter from the Gambia Association of the Deaf and Hard of Hearing.

10. Group of parents interviewed by the author.

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