



SEEN and HEARD



PROMOTING the RIGHTS OF
DISABLED CHILDREN GLOBALLY

Report of a one day seminar
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Introduction

This Report is based on a one day seminar held as part of the International Disability and Development Consortium (IDDC) meeting in Brighton, October 1999. The seminar brought together over 30 people with different perspectives on disabled child rights, including disabled people (young and not so young), and representatives from a range of organisations including DPOs (DAA and Inclusion International), the UN (UNESCO), Department for International Development, NGOs, networks and International NGO representatives from IDDC. The contact details of those who attended are available at the end of the report.

The articles in this report reflect a wide range of perspectives and approaches in relation to promoting disabled child rights, most of which were presented during this one day seminar. They do not reflect an IDDC view but rather the real and diverse perspectives of people who are working in the world today to promote disabled child rights.

Part I presents an overview of the UN Convention on the Rights of the Child and how its relates to disabled children. Simone Aspis, who defines herself as a disabled woman with learning difficulties, concludes this section with a challenging critique of the CRC and what it means in relation to disabled persons with learning difficulties

Part II focuses in some detail on specific perspectives, for example, issues relating to deaf children, young persons with physical disability from North and South, and also young disabled people attending a special school in the UK.

Part III presents a selection of practical action in the form of programmes and networks promoting disabled children's rights. In addition, individual member agencies of IDDC focusing on children, such as Save the Children UK and Radda Barnen, have a lot more information on programmes not presented in this report, but available from their offices.

The report concludes with examples of two key information networks which can be used to promote disabled child rights globally.

More examples of good practice and innovative programmes can be submitted to the IDDC website (www.iddc.org.uk) by sending to co-ordinator@iddc.org.uk

Copies of this report can be obtained from the IDDC administrator administrator@iddc.org.uk

Sue Stubbs, IDDC Co-ordinator

Part I: The United Nations Convention on the Rights of the Child and Disabled Children

1 The United Nations Monitoring Committee on the UN Convention on the Rights of the Child

An Introduction by Professor Queenie Mokhuane, Committee Member from South Africa

UN Convention on the Rights of the Child and disabilities

The Committee on the Rights of the Child is a body whose mandate is to monitor the implementation of the Convention on the Rights of the Child (CRC). State parties should implement the Convention two years after its ratification. The Committee's mandate is also to examine progress in achieving the realisation of the obligation undertaken in the Convention. This usually happens five years after the submission of the initial report by the State party concerned.

What is required from States parties:

- 1) To indicate measures taken to harmonise national and policy with the provisions of the CRC. In this regard domestic legislation has to be reviewed. State parties have to indicate measures taken to review their existing domestic legislation, harmonising it with the provisions of the CRC and making it an integral part of domestic law.

In this regard the CRC should be “self-executing”, enabling many judges or magistrates to apply it in cases brought before their courts. This necessitates a paradigm shift in most cases from a predominantly ownership mentality to the rights based approach with an emphasis on the child as subject of law including children with disabilities.

- 2) Against the backdrop of the rights approach, goals have to be set in the various areas covered by the CRC. Taking the example of the right to life, survival and development (article 6), all children have an inherent right to life, survival and development. State parties are urged to take active measures to promote the right to life, survival and development. This comprises physical, social, cognitive and emotional development of the most vulnerable groups of children, including children with disabilities, and it means the prevention of their rights to health, education, participation and protection from being marginalised. Specific goals are set to overcome problems that hinder the attainment of these rights. Some of the problems are attitudinal, making disabled people more vulnerable.
- 3) Intersectorial collaboration, co-ordination and service delivery in many areas of social service delivery to children, especially to children with disabilities, facilitates the interaction of complementary programmes divided across health, education, social welfare, juvenile justice and child protection.

To ensure the effective delivery of social services to children in a way that meets their needs and improves their living conditions, policy actions targeted at children need to be costed, translated into budgetary programmes and prioritised in resource allocation.

- 4) Article 4 commits State parties to allocate the resources to realise the objectives and goals of the CRC “to the maximum extent of their available resources and where needed, within the framework of international co-operation”. The CRC does not

stipulate criteria for resource allocation. However, the Committee on the Rights of the Child has consistently in their dialogue with State parties mentioned “disability” as one of the criteria for resource allocation. The Committee on the Rights of the Child usually inquires about the percentage of the budget of inclusive programmes spent on support programmes for children with disabilities.

In this way, the Committee on the Rights of the Child tries to establish the resource commitments to the CRC and, therefore, the political will for service delivery. Sustained appropriate funding and measurement of outcomes is essential to ensure access to quality services, especially in restrictive environments. Thus, developmental approaches, policies and programmes should be pursued and implemented.

- 5) The next point considered by the Committee refers to dissemination of the CRC and the State party report to the Committee on this. The usual question asked is: please indicate languages used, including Braille, and the availability to the general public. The intention here is to assess how widely available the CRC text is and to gauge the awareness and feeling of children about it. Awareness raising is an important part of working with children with disabilities.

General principles of Articles 2,3, 6, 12

The CRC specifically addresses itself to 4 principles, namely:

- non-discrimination (Article 2)
- the best interests of the child (Article 3)
- the right to life, survival and development (Article 6)
- the right to express views freely in all matters affecting the child and the right to participation (Article 12)

Non-discrimination

With reference to, the Committee asks for information on whether the principle of non-discrimination is binding in the national constitution or in domestic legislation pertaining to children. The Committee asks whether the Standard Rules on the Equalisation of Opportunities are implemented, ensuring that organisations of persons with disabilities are involved in the national legislation concerning the rights of persons with disabilities, as well as ongoing evaluation of that legislation. Any discriminatory practice must be eliminated. In addition, opportunities for complaints through accessible mechanisms and redress must be established at national and regional levels.

In its concluding observations the Committee usually highlights its concerns about a number of groups of children suffering discrimination, such as the girl child and children born outside marriage. The law of non-discrimination and its implementation are essential tools in combating discrimination against children with disabilities. Access to health, education, and social services for children with disabilities that are living in rural areas is examined.

This Committee looks at laws and provisions permitting selective infanticide, for example in cases of Downs Syndrome.

Monitoring the situation of disabled children by means of desegregated data and appropriate indicators is usually sought, including the number of disabled children who are institutionalised and the periodic review of the institution.

The best interests of the child

The principle of the best interests of the child is important and has to be considered in all matters and decisions affecting the child. State parties are required to analyse what is the impact of the decision taken on behalf of children. The child's voice should be taken seriously and the influence of children should penetrate decision-making. Financial allocations should be sensitive to this principle. All of the above also has a bearing on the best interests of children with disabilities. Poverty, lack of access to resources at a community level, social isolation and war are not in the best interests of any child. The best interests of affected children and those with disabilities should be at the forethought of programmes. State parties have an obligation to promote these programmes.

The right to life, survival and development

The Committee looks at laws and provisions promoting health and welfare of children allowing them to develop fully, including psycho-social development. Attitudes to disability are explored, including the circumstances that deny children with disabilities the rights to life and development. The CRC gives guidance in this regard and protects children's right to survival and development, without limitations, through prevention, early detection, community based interventions, staff training, improvement of information systems and finally access to health. Domestic legislation has to have provisions and measures in place to ensure the full survival of every child.

Respect for the views of the child

The views of the child must be heard in all legal proceedings dealing with the child and this includes children disabilities. The courts may not, for instance, order an adoption without first hearing the views of a child who is in a position to express his views. The courts should always take cognisance of the evolving capacities of the child. Courts must hear the views of the child in matters of guardianship, authorising acts that involve more than the ordinary management of the child as property. Article 12 allows all children, including those with disabilities, greater freedom of expression and self-representation in matters affecting them. The CRC and the Standard Rules on the equalisation of opportunities for persons with disabilities place great emphasis on the participation of disabled children in decision making. Their voices must influence policy formulation, budget and social programmes as these have an effect on their every day life.

2 Rights for Disabled Children : A project to help make the CRC more effective in protecting disabled children's rights

RDC is a project of the international disability NGOs and the Save the Children Alliance and chaired by Bengt Lindqvist, the UN Special Rapporteur on Equalisation of Opportunities for Disabled Persons. It is co-ordinated by Disability Awareness in Action.

Introduction

Rachel Hurst, Director of Disability Awareness in Action, spoke at the seminar about the horrendous violations against disabled children's rights being perpetrated globally. She particularly focused on the right to survival – as large numbers of disabled children do not even survive. They die through neglect or murder. The following article on the project 'Rights for Disabled Children' can be found on the DAA website ; www.daa.org.uk

Rights for Disabled Children is a project being co-ordinated by DAA and is aimed at giving disabled children throughout the world a voice and a say in the way their lives are run. It is working to promote human rights for disabled children and enforce the **Convention on the Rights of the Child**.

Although all the articles in the CRC are applicable to disabled children, it remains widely ignored in this context, with the result that disabled children remain excluded from society through neglect, abuse and institutionalisation.

Disabled children are always at great risk of discrimination and are particularly vulnerable when there is a shortage of resources. 97% of disabled children in developing countries are denied even the most rudimentary rehabilitation services and 98% are denied an education. Disabled children suffer more violence and abuse than other children - they are imprisoned in institutions, cupboards and sheds and, all too often, starved to death. Even in the wealthy and 'enlightened' developed countries, the birth of a disabled child is almost invariably viewed as a 'tragedy'.

In order to highlight the dire situation of disabled children around the world, and begin a programme of work to bring about change, a number of international NGOs encouraged the Committee on the Rights of the Child to hold its thematic day in, October 1997, on 'The Rights of Children with Disabilities.'

Three areas of particular concern were highlighted:

1. the right to life, survival and development
2. the right to education
3. the right to self-representation

As a consequence of the thematic day, a working group has been set up to take forward the recommendations and promote disabled children's human rights through specific actions that will:

- give disabled children a voice of their own
- collect the horrifying statistics and violations of disabled children's rights
- develop and disseminate good practice

Examples of abuses in relation to disabled children's rights can be submitted to the DAA confidential database ; admin@daa.virgin.net

3 The International Save the Children Alliance Task Group on Disability and Discrimination : Developing an advocacy tool on preventing violations and promoting good practice

By Hazel Jones and Sue Stubbs

Background:

The International Save the Children Alliance consists of 26 independent organisations around the world focusing on the Rights of Children. Save the Children UK and Save the Children Sweden (Radda Barnen) are two members of this Alliance who are very involved in disability work. They established a Task Group to raise awareness on disability issues within the Alliance. SC(UK) and Radda Barnen have between them a substantial body of practical experience of disability programme work in dozens of countries in Africa, Asia, Latin America and Europe. Much of this work is pioneering and overcomes many barriers of lack of resources, negative attitudes, and very challenging environments. The Task Group was also involved in the Theme Day on the Disabled Child mentioned above, and became a member of the CRC Working Group.

The Alliance Task Group felt that its best contribution to the objectives of the Working group, would be to document the very practical field-level experience that was its strength. Firstly, of good practice, or programmes working towards good practice; and secondly violations of disabled children's rights according to each article in the CRC.

The resulting publication will be used to influence primarily other International Save the Children Alliance members to address disability issues, but also as a resource for other agencies focusing on Children's Rights, including Parents and Disabled People's Organisations, and the Monitoring Committee on the CRC.

Save the Children Alliance recognises the importance of all children's rights. The main objective of this project is not to argue that disabled children's rights should take precedence over any other child's rights – children's rights are universal and totally inclusive. But for disabled children, all too often they are **invisible**, and need **bringing into focus**.

What is the situation of disabled children in the world today?

Disabled children....

- live in all cultures, contexts, societies globally,
- include those with motor, speech, visual, hearing, hidden intellectual and multiple impairments,
- globally, there are an estimated 120 million disabled children¹,
- in a typical community with a family size of 6 people, one in four families will have a disabled family member,²
- 80% of these children have mild / moderate impairments,
- but, children with *mild impairments* can be *severely disabled* by lack of access to basic rights,
- most live in countries of the South

¹ Estimate of numbers of children with mild, moderate or severe impairment. Precise statistics depend on local culture and context.

² based on the figure of a least 4% of a population in poorer countries will have moderate or severe impairment (Helender, Prejudice and Dignity, 1995)

- both poverty and affluence can further disable these children. Urban-based middle-classes can discriminate against and exclude these children more than poor communities
- ◆ for 80% of these children, their *local community* could provide all the rehabilitation they need to fully develop their potential and be included in everyday community life.

The key issues for disabled children globally in the experience of SC UK are:

- invisibility, exclusion, discrimination,
- poverty,
- lack of knowledge, skills, information,
- inappropriate or inadequate rehabilitation services,
- inaccessible and poor quality education systems,
- lack of access to health and appropriate welfare support
- war, conflict, refugee and displacement situations,
- institutionalisation,
- lack of early childhood intervention, care, education,
- vulnerability of disabled girls, particularly those with severe/multiple impairments.

Promoting good practice

Some key strategies supported by Save the Children UK are:

- promoting survival and Development through Community-Based Rehabilitation,
- promoting access to appropriate and relevant education through Inclusive Education from early childhood to adult,
- promoting participation through support to Self Help groups of disabled children and adults, and of parents.

Invisibility of disabled children

The most striking issue to emerge when starting to collect data for this project is 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 reports, 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), and less often under other Articles. What's more, it is rare to find more than a passing reference to disabled children in the NGO literature on child rights issues.

Examples of invisibility according to Articles:

Protection in situations of conflict (Articles 38, 39)

Very little documentation refers directly to disabled children (Ahlen, 1997). The stories are there, however, if one looks for them. For example, 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)

Programmes directed at disabled refugees tend to focus on adults, primarily those disabled by conflict.

'In 1994 people in the [Kakuma refugee camp in Kenya] realised that the majority of disabled people living there were not participating in the activities. Women and children with disabilities were not benefiting. The focus of the activities was on men who had been injured during the war and physically disabled.' (Ahlen, 1997).

The right to education (Article 28, 29)

A UNESCO report of 1994 noted that:

- of 65 countries providing information, 34 [over 50%] report that disabled children are excluded from education;
- 18 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

Protection from sexual abuse and exploitation (Article 34)

The limited research carried out in Europe and North America indicates that disabled children are at much 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 comes 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 [sic] 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, unusual for a girl of her age.'

A recent opportunity to address this issue 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* has not included the issue of the sexual abuse of disabled children in either of the initial project stages (training and country research).

What might explain this invisibility?

❑ 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.

❑ Disabled children do not survive

Of 311 examples of violations collected, 56 (18%) are of Article 6: Right to life, survival and development:

- In the Gambia: ‘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.’ (GADHOH, 1999)
- In 1994 in the UK, a man was freed at the Old Bailey after trying to kill his baby son who had Down’s Syndrome. The judge said that he expected him to continue as a responsible parent. (DAA database)
- While 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 Report, 1997)

□ Disabled children are hidden

In Russia, parents are routinely pressured into abandoning a ‘defective’ new-born by medical staff, who warn them about the child’s future life as a ‘social pariah’ (Human Rights Watch, 1998). This is in direct contravention of Article 9: Separation from parents.

□ Disabled children are ignored

On a field trip to an education project in Viet Nam, Hazel Jones visited several families with disabled children. Afterwards, she asked a local education official what was the primary school attendance rate in his Sub-district. He answered proudly ‘100%’. She asked: ‘Is that 100% of all children?’, he replied ‘Yes, 100%’. But, she 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?**³ In calculating the school attendance rate, the number of disabled children, along with unregistered and migrant children, is first subtracted from the total number of children in the District (Bond, 1998). The result is that disabled children may not even be regarded as eligible for education.

□ The prevalence of the ‘medical model’ of disability

It is a common experience of disabled children to be identified by their impairment rather than as children who happen to have an impairment. Consequently, approaches to addressing the needs and rights of disabled children tend to focus solely on treating the impairment rather than on the broader needs and rights of the child.

In Eastern Europe, the legacy of the Soviet era persists in the dominant ‘defectology’ approach to disability. In Georgia, for example, children with impairments are identified and categorised by a Medico-Pedagogic Commission, which allocates the child to a special school or institution based on his/her category of impairment. This tendency to focus solely on the child’s impairments results in segregation and sometimes institutionalisation, which violates many of the child’s other rights, and is therefore in direct violation of Article 3: The best interests of the child. (Jones, 2000)

³ Author’s personal experience.

□ **Lack of information and knowledge**

Violations often occur out of ignorance. A representative from a disabled people's organisation in Swaziland said:

'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.'

(Thomas Mndzebele, President of the Swaziland Association for Visually Impaired Persons)

K is aged 17 and has cerebral palsy. He tells his own story:

"In June 1998, I was going to Maseru. I had Maluti 90 (local currency). Immediately when I got off the taxi at Maseru main bus stop, I met a guy who appeared to know me. I did not mind since I am known by many people. He stood in front of me as he talked to me. I was not aware that they were two, until the other one who was standing behind me, grabbed my wallet from my pocket. I turned and held him tight by the jacket. He tried to pull himself away but I resisted until he threw my wallet on the ground. Then I let him go. When I opened the wallet I found that he had already taken Maluti 70. Fortunately this happened near the police station, then I rushed to report the case. The police asked me what I expect them to do, when that robber has run away. They also told me I was drunk. The question is: How should we, people with disabilities, trust the police? Since I was trying to follow the normal procedure of reporting to them like other people. Have they treated me like this because I have disability?"

Under Article 16, K's right to freedom from unlawful interference with property, and freedom from slander have been violated. And by the very people who are supposed to be there to protect those rights. *(reported by LSMHP)*

Strategies to promote and protect the rights of disabled children

Successfully implementing laws and policies depends not only on governments or organisations, but on individuals: how do they interpret the policy, and how willing are they to adapt to new ideas and ways of working? What do they need in the way of information, knowledge and skills?

1 Raising awareness and understanding of children's rights

Countries that have signed the UN CRC have a duty to share information throughout the country. Many countries do this through a national child rights coalition of NGOs, which monitors the government's implementation of children's rights:

The Lesotho Society for Mentally Handicapped Persons (LSMHP) is a member of the country's NGO coalition and represents the interest of children with learning disabilities.

Sometimes disabled children are hidden or segregated, which reinforces the idea that they are different and should be excluded from activities with other children. A way of changing this behaviour is by arranging meetings between disabled and non-disabled children and their families, or by raising their profile through the media:

In Yemen on the International Day for Disabled Persons (3rd December), disabled children gave presentations in schools and had children from regular schools visit theirs. Disabled children were also involved in a Children's Day of Broadcasting. They were given training and support to produce a radio programme in which they expressed themselves to the public about their problems and feelings. (Radda Barnen, 1999)

2 Breaking down barriers

New ideas are difficult to put into practice when struggling against criticism and there is nobody to consult when a problem arises. Meeting and listening to others in support networks, which share ideas openly and in trust, builds up good practices. This can help to break down the barriers, which are common between service users and providers:

In Lesotho, parents of LSMHP have become more aware of their children's needs and can assist and advise teachers on how to help their children at school. They are invited to give talks and to share their experience during teachers' seminars. (EENET, 1998)

3 Learning by doing

New ideas can be introduced using a pilot project, which can provide a vision and be an environment for learning. It allows people to develop skills, make mistakes, become familiar with the unfamiliar, and come to a common understanding about the aims of their work:

A pilot inclusive education programme for children with learning disabilities has been started in Addis Ababa, Ethiopia. The aims are to develop a workable programme, to share lessons learnt, and to promote the rights of children with special needs. The results have been positive: mainstream students help their disabled classmates, teachers welcome more students, and the school administration and Education Bureau are more enthusiastic. (Haile & Bogale, 1999)

In Bosnia, Oxfam supports the Koraci Nade ('Steps of Hope') Centre, which offers support for disabled children with an emphasis 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."

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.*' (Hastie, 1997)

4 Promoting information and knowledge

Even in regular health services and other services, service-users often lack reliable information.

In Viet Nam, until recently the only support available to families with a young disabled child was medical treatment or physiotherapy. As a result, many 'untreatable' disabled children were abandoned or neglected. SC/UK's Care in the Community project aimed to fill 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. 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.' (Chalker, 1998, p.21)

Hung's mother is just one example of a group of parents who are taking control of their families' lives, and becoming increasingly vocal advocates for the rights of their children.

5 Promoting self-advocacy

In the UK, some of the most innovative projects support disabled children's right to make choices and to have their say about decisions that affect them. The PACT Yorkshire Advocacy Initiative is one example. PACT works with disabled children and their families, and aims to *'promote a deeper understanding of individual needs through communication and advocacy. To achieve this it is obviously essential to find out from children themselves what they hope for from life.'* PACT provides training, advice and practical support to agencies wanting to improve their own skills in listening to disabled children and young people.

Faced in the future with increasingly vocal and aware disabled young people, service providers will have no choice but to develop more flexible approaches. As the Chief Executive of a UK NGO points out: *'unless particular attention is paid to the inclusion of disabled children within any 'mainstream' activity – they will remain invisible and their needs and rights unmet.'* (Morris, 1999)

Conclusion

Violations of every Article of the CRC are occurring in all aspects of disabled children's lives. Disabled children, more than any other group of children, are routinely denied the most basic rights. No special or higher priority is being claimed for disabled over non-disabled children; what is needed is simply to *bring disabled children into focus*. The challenge is to raise the profile of disabled children, by sharing our experiences, by recognising them wherever they are, by actively including them and by encouraging them to speak for themselves. The rights of 'All children' means 'all children, including disabled

children'. The invisibility of disabled children is itself a violation: of the right to be heard, to be seen, to be considered a child like any other.

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4 The Right to education

How does the convention on the rights of the child transpire in the Salamanca Statement and framework for action?

By Sai Vayrynen, UNESCO, Special Needs Education

CONVENTION ON THE RIGHTS OF THE CHILD

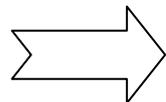
WHAT DOES THIS MEAN IN PRACTICE

WORLD DECLARATION ON EDUCATION FOR ALL (JOMTIEN 1990)

Basic education should be provided to all children youth and adults. The quality should be expanded, and measures must be taken to reduce disparities... The learning needs of the disabled demand special attention. Steps need to be taken to provide equal access to education to all disabled persons as an integral part of the education system (Art. 3.1, 3.5)

(Art.2)

The Rights not be discriminated against

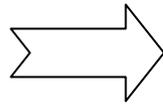


The right for inclusive education

SALAMANCA STATEMENT AND FRAMEWORK FOR ACTION

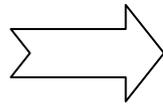
Regular schools with inclusive orientation are the most effective means of combating discriminatory attitudes, creating welcoming communities, building an inclusive society and achieving education for all ; they provide an effective education to the majority of children and improve the efficiency and ultimately the cost-effectiveness of the entire education system (Salamanca Statement, Art.2).

(Art. 9) The right to live within his or her family



The right of the child to attend his/her Community school

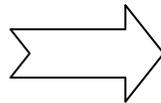
Schools should accommodate all children regardless of their any conditions... Schools have to find ways of successfully educating all children, including those who have serious disadvantages and disabilities (Framework for Action, Art.3)



The right to live and study with His/her peers

Inclusion and participation are essential to human dignity and to the enjoyment and exercise of human rights. All children should learn together and inclusive schools must recognise and respond to the diverse needs of their students. Inclusive schooling is an effective means for building solidarity between children with special needs and their peers.

(Framework for Action, Art.6-8)

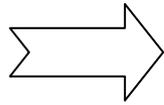


The rights to have access to the same curriculum

Curricula should be adapted to children's needs, not vice-versa (Framework for Action .Art 28-34).

(Art23) A disabled child has the right

*to special care, education and training
to help him or her achieve the greatest
degree of self-reliance and social
integration possible*



**The right to have access to available
support**

There should be a continuum of support and services to match the continuum of special needs encountered in every school. In inclusive schools children with special educational needs should receive whatever extra support they may require to ensure their effective education (Framework for Action, Art. 7 – 8)

5 Article 12 of the Convention on the Rights of the Child: A critique in relation to disabled persons with learning difficulties

By Simone Aspis of Changing Perspectives

“The most beautiful and enriching trait of human life is diversity – a diversity that can never be used to justify inequality. Repressing diversity will impoverish the human race. We must facilitate and strengthened diversity in order to reach a more equitable world for us all. For equality to exist, we must avoid standards that define what a normal human life should be or the normal way of achieving success ...and happiness. The only normal quality that can exist amongst human beings is life itself.” Says Dr Oscar Ariasⁱ (President of Costa Rica)

Article 12 (1) states that *“State Parties shall assure to the child who is capable of forming his or her views the right to express those views freely in all matters affecting the child, in the view of the child being given due weight in accordance with the age and maturity of the child.”*

How Article 12 discriminates against children with learning disability

This Article assumes that not all children’s views should be given equal consideration. It is likely that under this interpretation that for example a child who is able to use the appropriate vocabulary and social interaction skills will have his/her views taken more seriously than someone who acts out theirs. For example, if two 14-year-old children are unhappy with having to take pills for weight control, then the one who is able to use culturally appropriate language and social interaction skills is more likely to have his / her views respected than the one who only spits out the pills. This could mean that the child who is only able to spit out the pills might legitimately be forced to have the medical treatment, as this form of expression would be considered immature.

“Children rights are for all children and we have to keep reminding ourselves that childhood starts from birth, not when babies become old enough to say things for themselves. Babies and young children speak to us in all sorts of ways and it’s up to us to give them time to express themselves. When they can talk we’ve got to learn to listen to them and act on what they’re telling us!”

The implicit view of Article 12 that not all children’s views are of equal value challenges is challenged. It is clear that there is no one way that children tell others how they feel. There are many ways that these young people are telling other people something that is important.

Examples of how behaviour can communicate clear messages:

14 year-old Tanya was living with her foster carers, which she did not like. Tanya made it very clear that she did want to be with her foster carers. “Tanya became aggressive, was very distressed when it was time to return to the foster carers, and indicated strongly that she did not want to go back to them. She then began running away from the foster carers, soiling herself and stealing.”

12-year-old Natasha was attending a special school for children with learning difficulties. Natasha showed how she was sexually abused:

“She displayed anger, cried often, and masturbated constantly Natasha was found to have a vaginal discharge, her hymen was damaged, and there were scars on her hymen that were at least two years old.”

“Niki started to talk less and less, he didn’t smile so much and when he laughed it was a nervous shrill sound that seemed to come from somewhere else... One day I picked him up and he was very subdued, frightened really. Which is not like our Niki at all, well not like he used to be. He was still rigid, he couldn’t talk, couldn’t make sound.... I took off his school uniform and he was covered in bruises, scratches up and down his thigh. They looked like fingernail marks, purple and black. He must have been in a lot of pain. Niki went back to his primary (mainstream) school and the special school was forgotten at least for the time being.”

Anaya Souza, at the age of four was able to tell her mother why she did not want to attend the special school:

“One of the teachers did a stuffed fish and two bunny rabbits, but I took them home and I showed my mother. I think I should have done them myself. In the end I ripped them up because I did not do them. Why do we need schools like that?”

Harre(1970) pointed out that that in everyday life, social experience takes form in whole, meaningful episodes, not isolated acts or actions. We need to look at the whole context, including the people concerned, the ways in which they express themselves, the background to what is going on, the setting in which events are taking place, and so on. Tanya’s mother, for example, understood her daughter’s action of only soiling herself when she returned to her foster carers where she was abused.

“We place a great reliance on non-verbal communication, and if the non-verbal content of a message isn’t congruent with it’s verbal content, as a general rule we tend to ignore the verbal content and believe the non-verbal message. Argyle et al (1971) asked actors to give a verbal style that contradicted their actions. For instance, if the words that they said were friendly, the actions were aggressive; or the other way round. They found that people were four times as likely to remember the non-verbal message than the words that were actually being said.”

If it has been established that it easier to tell lies using words rather than through body language.

Article 12 should, therefore, be rewritten to acknowledge the importance of reading children’s feelings, which may or may not be expressed in words.

Article 12 and making use of appropriate aids and support

“The provision of special technology, interpreters (for example signing for the deaf and partial hearing children) and special training, including of other children, parents and other family members” is acknowledged in Article 12.

Not all disabled young people are non-verbal. Indeed some young people are assumed as being non-verbal because of the nature and degree of physical or cognitive impairment. Some disabled young people need to have communication aids or sign language interpreters to assist their ability to communicate with words.

Example of child needing a communication aid:

Stephen Mark an autistic child was being sexually abused within a special school. Stephen was unable to say how he was abused until he was given a communication aid, which he used with a television link from home.

Article 12 and legal proceedings

Article 12 also highlights the importance for disabled young people to have their voice heard during any legal proceedings, which affects their day-to-day lives.

Lorraine Downer who appealed on behalf Andrew to the Special Educational Needs Tribunal said, *“It was all about Andrew. I think it would be unfair if he did not know what was going on. There are probably lots of parents who would have kept their children out of it. It was all about Andrew so he needed to be involved.”*

Andrew said “We go to court to fight for Castle High. I showed the court what I could do and let the court check who will win and see what is best. I gave all my work I do at Woodsetton (Primary) School. They (Dudley Council) say I can only count up to 10. This is not true. I can count very well, take away, times and do some algebra. I can measure and do mental arithmetic, I cannot see why they say I cannot do this. I am a quiet boy but I listen to the teachers and adults in what they say. I work on my own and I ask for help from a teacher when I do not know. I cannot help being quiet, that is how I am. I want to go to Castle High because I will learn better with my English, Maths and Technology. My cousins and friends are there so I will be able to mix with them.”

Andrew did not want to only say to the Special Educational Needs Tribunal Panel what Dudley Council said was wrong about him but also what school he wanted to attend and why.

Participation but not self-determination: does Article 12 go far enough?

The aim of the article is the emphasis on participation rather than self-determination of decision making. For example, Andrew Downer was able to express his views during the Special Educational Needs Tribunal hearing. However, Andrew would not be able to make his own decision to appeal to the SENT in his own name in education law. Generally, a young person under the age of 18 would need to appoint an adult (usually parent) if wanting to take legal action in any other aspect in his/ her life. There is no support for a child's self-determination.

All Children Together is a parents group that asked young disabled people with learning difficulties to find out what they think about their schools. ACT's researchers found that 17 out of 21 children interviewed said they should make the decision between special and mainstream schooling for themselves. The Young And Powerful also stated that “Children should have rights that are separate to their parents.”

PART II: Key Issues and Different Perspectives

6 Voices of young disabled people: The PACT Project from Yorkshire

Liam Flanagan, Andrew Green (disabled young people) and Arnie Tweddle (teacher)

Introduction

The PACT project in Yorkshire is a social work project of the Children's Society. Its aim is to empower and support children and young people with disabilities and their families, particularly by promoting self-advocacy. Two young disabled people involved in this project attended the seminar with their teacher, and spoke of their different projects to raise awareness on disability. One of these was a play called "I May Be Different But..." which they performed around different schools.

Liam Flanagan writes:

The York Youth Forum: Since the presentation in Brighton we've organised lots of different and interesting things and events. I gave a presentation about our Youth Forum to different groups from around the York area... Me, Jenny our co-ordinator, and Tom who's another volunteer made our presentation together – we wrote it all, and though we were nervous, we did a good presentation.... We organised an event called 'Shout About' to promote the forum in rural areas. We have also done events in York's internet cafes and also a consultation event on transport called 'Train-spotting'. With each event we emphasise the Rights of Children!

The play "I May Be Different But..." has finished touring. We had lots of positive feedback. It was very interesting to hear some feedback from Manor School (where I do GCSE English). After they'd watched us, their teacher and also mine talked to them about it for a whole lesson, and I'm told they were very impressed by the fact that we stood up and talked about our disabilities. They didn't think that they'd be able to do that sort of thing. It gives me a great buzz to hear things like that and also to hear that some children knew people with disabilities and knew what they were. The audiences all understood the message of the play which was to enforce the fact that we might have a disability but we are the same as everyone else inside. It was a fantastic experience to do the play... it was easier to see people's reactions than in the Youth Forum. I've talked enough about both of these projects and now sadly its time to say good bye until next time maybe?

7 Global Deaf Issues

Doreen Woodford (Initiatives for Deaf Education)

Article 23 has a grave omission. It talks “of physical and mental” but not “sensory ” disability. Deafness and deafblindness are sensory disabilities, as is blindness.

All I can do is give you a “taster”, which I will do under four headings.

I shall concentrate on situations in the South, but that does not mean that all deaf children in the North have full access to their rights! (an earlier speaker talked about things that might be through admirably progressive in one country being seen as progressive in another. Any attempt to transfer a successful practice to one group, without first ascertaining that the groups are similar in composition, environment, culture, and many other factors is to be deplored. Progressiveness in any one place is helped by my key word, which is “appropriate”.)

1 Deafness is a disability with its own language

This language is a language of movement, space, time, and has no relationship to speech. It employs the whole body and relies on facial gestures. The hands are an important, but not the only important part, of sign language. It is not finger-spelling, which is transliteration of spoken words.

Sign has no words.

Sign languages are national and different, just as spoken languages are. A child has the right to know the language of the country. The deaf community is the bearer of that language.

It is sensible to involve the national deaf community in all planning for the children, and to use them in the carrying out of the education. The children also need access to the written, and as far as possible, the spoken language of their community. A bilingual education gives the best opportunity for this, with sign language as the first.

However, there has always been tension in deaf education as to methodology. A country, (or, where there is autonomy, a school or a family) need to be provided with full and adequate information in order to make a choice. The choice must be theirs, not imposed. They will then be able to meet difficulties if they arise.

Situations that have arisen, for example, in Ethiopia, and are arising in Swaziland are to be avoided, where children have had their communication changed two, three or four times, because of outside experts,

Where deaf teachers have made their own plans, as in The People’s Democratic Republic of Congo, there is continuity and excellence. Very experienced outsiders, such as one or two working for example, in Uganda and Ethiopia, are likely to be very careful as they share their expertise and convictions.

Children need a language to think, to learn, to develop a faith to live by, to participate in society, to build a moral code. (I would like particularly to talk about faith communities and deaf children, but must not take the time).

2 Deafness is a disability with its own culture

This culture is both international and national. Deaf people are the guardians and bearers of the culture.

The culture has its own ways of behaving and thinking. Both deaf and hearing culture need to respect and understand each other.

Culture is formed by language and this fact needs careful consideration when planning education.

The World Federation of the Deaf has considerable information, literature, experts, to help in this, as in most other situations. It is sensible to consult them as well as the National Associations of Deaf people. These vary in strength from country to country.

The progressive activities of the Uganda National Association of the deaf are a model, backed by a supportive government, of what such an association can do to further the rights, not only of children, but of deaf people of all ages. (I wish I had more time to talk about their activities).

3 Deafness is a diverse disability

It is very difficult to find, in any group of similar children, any two that match exactly. If you match the audio-gram, they will differ over use of the hearing; match cause, they will differ over resulting impairment, and so on. Some children are born profoundly deaf and others acquire profound deafness. Some are born partially hearing, which in itself varies. It may be static, fluctuating, increasing. Some acquire partial hearing. (I do not have time to talk about deafblind children, who are a very much-neglected group, needing specialised programmes to meet their needs. I commend the efforts of SENSE International to you)

Hearing loss affects language acquisition and comprehension.

It is very sad when all children are treated the same. I have seen, and tried to help remedy, children in Afghanistan who had spoken language and had retained speech but after experiencing trauma, they were put into a school for the deaf. They were never expected to speak or be spoken to, in the mistaken belief that sign was all they now needed.

I have seen deafened young teenagers, who could read and write and had a lot of educational knowledge put in large classes of deaf children in Uganda. The deaf children need a lot of explanation and visual material. Their progress is slower, their background knowledge less, but the deafness children, who understood a sentence as soon as it was written on the board, had to wait while it was carefully explained to the deaf children.

There are many children deafened by war, AIDS, illness, accident in many income-poor countries. What I have mentioned does not have to happen. There is better arrangement in parts of India, in a school in Thailand, and, to a lesser extent, in the Philippines. Diverse, appropriate programmes are a necessary key feature of provision.

4 Deafness is a disability but need not be a handicap.

Deaf children are able to do what other children do, learn what other children learn, and achieve what other children achieve.

Hearing people deprive them of their rights by underestimating the possibilities, setting the targets too low, and planning for too little. (I heard only yesterday, and will not identify the country, as I have not had time to make sure my information is correct, of a school where English is taught as a second language, as governments are increasingly obliging teachers of all children, even deaf children, to do. Throughout the classes, at all stages, the same single tense is taught. The rationale being that verbs are too hard for deaf children. A deprivation of rights indeed, if this is so).

The present lack of opportunity for secondary and higher education throughout income-poor countries and the poverty of vocational training are well known to us all here.

The difficulty of many teachers is gaining appropriate training, in continuing education, affect the children as well as the teachers. For deaf teachers, who are essential in deaf education, it is even harder (Initiatives facilitates appropriate training).

Parents need other parents, as well as skilled and informed advice. Encouragement of the slowly increasing parents' organisations will help the parents to increase their children's opportunities. Progress in Zimbabwe, Uganda, Tanzania, and other places is worth watching and encouraging.

I could go on and on. But I must not.

Conclusion

I want to close with a brief reference to information.

People involved with deaf children often know too little about what is going on in their own country. They often know less about what is going on in neighbouring countries. There is tremendous expertise and a lot of good practice in countries in the South, still thinly spread, yet those looking to set up new projects do not look for it there but seek it in the North. Governments are often the worst offenders, (but deaf people are being more persistent about this).

There is much good literature produced, in appropriate terms, using local language, notably in India, Zimbabwe, Nepal to name only a few. Yet often Northern literature is translated rather than literature more culturally appropriate.

“ Initiatives ” provides an information service widely used by North and South. Many of my responses to letters from the South, after the usual courtesies, go on with information about local experts and advisors who can be consulted.

I have one horrid fear. That is that, in this increasing use of the internet, sufferers in the South who look for information about schools in the North, but find nothing about the education in the South. I would appreciate your re-actions to my fear.

8 Global Issues for Children with Learning Disability

Nancy Breitenbach, Chief Executive Officer, Inclusion International

World Wide Issues for Children with Learning Disabilities

Inclusion International is the former International League of Societies for Persons with Mental Handicap, a type of disability which goes by many names: mental handicap, mental retardation, learning disability, intellectual disability... but the issue today is not one of terminology, rather that of acknowledgement.

Unlike people with impaired mobility, people with intellectual disabilities are often invisible. When they are not, people tend to look past them as if they weren't there. Unlike those with impaired vision, they get little sympathy. Like those with impaired hearing, they are frequently misunderstood.

But unlike all of the above, they are the only people with disabilities whose very humanity is questioned. Can they be ignored? Not really, since the WHO currently estimates their numbers at some 60 million.....100 million in the coming years. Thus, contrary to popular belief, intellectual disability is not something that will soon disappear.

In developed countries, scientists and leaders of public opinion have led many to believe that the primary cause of intellectual disability is genetic. Via pre-natal detection techniques and germ-line therapy, doctors already can and feel they should be able to eradicate intellectual disability by stopping the development of fetuses destined to be intellectually disabled.

They forget that in so doing, they are violating a basic human right: the right to exist, not to speak of Article 6 of the CRC: the right to optimum chances for survival. What they are also forgetting is that in developed countries, genetic aetiologies are no more prevalent than acquired syndromes caused by the environment, and that for a great many children who are assessed as intellectually disabled, there is no identifiable cause. No matter what measures are taken in laboratories and surgeries, malnutrition during the mother's pregnancy or in the early childhood years, toxic substances, viral infections and traumatic accidents will continue to take their toll. Intellectual disability is not going to go away.

Is the situation identical in developing countries? To be perfectly honest, we don't really know. But the limited information to which we have access leads us to believe that things are not the same. Survival rates for children born with severe and visible forms of intellectual impairment are probably quite poor. Parents may not know how to provide them with the specialised care they need to survive; social pressures may encourage them to abandon the child or commit it to an institution, condemning it to a miserable existence if not a slow death.....which, again, is a violation of Article 6.

The predominant causes of acquired intellectual disability and the moment of incidence may be quite different in developing countries. Poverty and deprivation, for instance, can produce large numbers of stunted children with intellectual disability, caused specifically by under-nutrition (brain development lags behind for lack of protein) and micro-nutrient deficiencies such as iodine and iron.

What happens to the intellectually disabled children who survive? They and their parents are disregarded by society, if not blamed for having produced such children because of some grave error in the past. Their needs may be ignored: a sick child with intellectual disability may be considered not worth saving; he or she may be deemed ineducable and blocked off from any form of training. In any case, the child is often separated from society (isolated at home or relegated to special settings) and the parents disenfranchised (since “specialists” decide thereafter what is best for them).

There are close to 200 member organisations of Inclusion International; they have fought for 40 years and continue to fight to counteract this dehumanisation.

Our basic objectives for people with intellectual disability and their families are full citizenship, inclusion in society, appropriate supports and self-determination.

Sue Stubbs has asked me to present examples of good practice, which I hesitate to put forward because “good practice” implies a value judgement inevitably coloured by one’s culture. I prefer the formula: “examples of actions leading to better practice”.

They range from the sublime to the heart-rendin:

Efforts to improve quality of life: Inclusion International’s involvement in the field of bioethics; efforts by its member organisations to make East European institutions more humane and to help mothers in India provide a more balanced diet for themselves and for their children;

Self-determination: Inclusion International promotes self-advocacy for people with intellectual disability, providing training and supports so they can speak for themselves; Parent mobilisation: seminars develop self-affirmation (as exemplified by an information package called *My Rights* created by parents from a number of African and Caribbean countries) and recognition of conflicts of interest (a Spanish member has recently published a manual called *Discrimination by Love* which clarifies issues within the family). Inclusion in society: Inclusion International is widely known for its commitment to inclusive education, and the quality of its work is such that UNESCO distributes Inclusion documents to encourage “Education For All”.

Adequate supports: parents are taught how to use the UN Standard Rules in order to obtain the support services they need; in Asia, Inclusion correspondents have developed a 3-day curriculum called *Inclusion, Involvement, Individuality*. It is about “normal people who happen to be slow” so that parents and professionals can learn to provide care for these people within the community. As for full citizenship, Inclusion International supports self-help seminars, which educate parents, professionals and policy-makers about people with intellectual disability, their human rights and their potential. And on the global scene, Inclusion International lobbies actively to defend the rights of people with intellectual disability in a number of UN agencies, notably the High Commission on Human Rights, the World Health Organisation, UNESCO, UNICEF, the ILO and ECOSOC.

In order to intensify these efforts, a Task Force on Human Rights composed of some 20 experts from around the world has recently been created. These experts will unite their efforts in order to ensure that people with intellectual disability will continue to occupy a place in the world, and be acknowledged as having every right to do so.

9 Disabled Children Become Disabled Adults: Some Implications

Beverley Ashton, Action on Disability and Development

First and foremost, disabled children are children who are going to grow into adults. The two halves of this statement encapsulate my two points.

Disabled children have the same basic needs as all children – adequate food, shelter, security, nurture and social contact. They are as good, or as naughty as all children. They are as brave or as fearful as their lives demand that they be. They need security but they also need to be able to play, take risks, have triumphs and experience mishaps. They need support but also to have expectations placed upon them to prepare them for adulthood.

Most disabled children will become disabled adults but few of them know this. As they learn that little boys become men and little girls become women, many disabled children believe that they will grow up non-disabled.

As they progress through childhood and prepare for their future it is important for them to have appropriate role models. They need to learn the skills demanded of disabled adults and to feel good about their identity. For this reason, it is important that disabled children meet the disabled adults from their own societies.

Marginalisation of disabled children

Exclusion and marginalisation of disabled people starts very early. Infants who are noticeably impaired by illness or deformity are often simultaneously overprotected but yet offered a much less favourable start in life than their healthy siblings.

Disabled children have fewer demands placed on them. They may not be able to perform some of the simple household tasks other small children do to contribute to the household economy, but then their mothers may not teach or ask them to do others that they could. Disabled children are likely to be fed last and may have to survive infections as best they can without medical intervention as their fate is seen to be "the will of god". Later, disabled children are less likely to be sent to school for fear that they will not cope, will face ridicule or that their disclosure will affect the marriage prospects of their siblings.

Even at this early stage in life, a disabled child is often seen as the passive recipient of whatever fate delivers.

Having not attended school, disabled young people are at a significant disadvantage in obtaining apprenticeships and job training placements. This in turn makes it difficult for them to obtain work, earn an income or financially support a family. Even those who have been to school are not easily able to find paid work or gain access to the credit they need to begin a business.

As disabled girls are deemed unmarriageable, they are not able to secure their future through a husband's income.

Reduced capacity to support the family

As society excludes disabled people the pay-back, or social security, disabled children can offer their parents later in life is severely reduced. They are not seen as a worthwhile investment by the family, who speak of them as a “useless mouth to feed”.

This early lack of investment in disabled children is not just a reflection of ignorance. In situations of poverty this is a desperate but rational economic decision by the family. Excluded from job-training, employment, and access to credit disabled young people are not in a position to financially support elderly parents. Indeed unmarriageable disabled women and their illegitimate children often remain dependent on family support themselves.

Self-help approach to change

Disabled people want to change their situation. They have formed self-help groups to press for legislative protection of their rights. “Action on Disability and Development” (ADD) works with these self-help organisations of disabled people to form the newly formed village level groups finding their voice for the first time, through to the more powerful federations at national level who are engaging directly with their governments regarding inclusion of disabled people in poverty alleviation strategies and constitutional reform.

ADD believes that disabled people themselves are the most powerful advocates for changing attitudes and breaking down the barriers created by society. We continue to work with disabled people’s organisations in Africa and Asia, supporting their campaign for the rightful inclusion of all disabled adults and children in society.

10 Young People with Physical Disability : Extracts from a One Day Seminar by PHOS

Pierre Mertens, Chairman of PHOS

Introduction to the theme day: “Young Persons With a Physical Disability”.

A child born with a physical disability is confronted from the beginning with obstacles. From the start, more attention is given to what is wrong than to what is positively possible.

Parents receive a special child that is craving to be approached in a normal way. The child grows up with a body that is different. With some luck, at home, in a normal school, in a normal youth movement.

Young persons with a physical disability bear a whole history with them. Their “being different” has also given them another life. It has strengthened them or it has marked them.

Many young people are tired of being provided with medical care. They throw their appliances in a corner of the room and prefer to sit in their wheelchair and try to pick up something that is worth experiencing on this clod of earth.

Living is friendship, is experiencing something, is enjoying, is being somebody, and therefore no operations exist. How do they experience this, young persons with a physical disability? How do they consider the world that created special places for them? What are their rights? How do they themselves consider their duties? What keeps them busy? How do they see their future?

What does it mean now, to be young with a physical disability in a developing country? How does their situation differ from ours and what are the similarities?

We want to examine these issues in relation to the Children’s Rights....we listen to young persons from North and South, young people with a physical disability.

Panel Discussion with Young Disabled Persons from North and South

In a panel discussion, young persons from North and South give their own view of the world in which they’re living. The participants to this panel were:

- Nimal Jayawardene, accompanied by Mrs. Sunethra from Sri Lanka
- Idriisa Kiraga from Uganda
- Ani Zaharia from Romania

Aim of Panel Discussion

The right to participate and to have one's own opinion, as well as to voice that opinion, are important rights. This debate stems from there: to interpret opinions and exchange experiences about three questions/themes:

- What do I have at my disposal, what choices can I make? Where am I dependent on others, and where can I make my own choices?
- How important is it to have one's own income?
- How important is it, as a disabled person, to want and to have children?

Summary of Panel Debate

At the end of the debate we can say that the following matters attracted the attention:

- All over the world big efforts are made to interpret human rights in general into rights for children and young persons, including young people with disabilities. But it is not very easy.
- When comparing with countries as Uganda and Sri Lanka, who are also different from each other, we realise that financial and economical factors play quite an important role, so it seems that we only talk about luxury problems.
- But there are also similarities: we have the right to earn an income, the right to live as normally as possible, the right to marry and to have children etc. But the mentality in the society certainly does not stimulate this, even if it is for different reasons in each continent.
- A striking difference - that could possibly have something to do with these reasons - is that the foreign hosts lead a rather personal fight, or through organisations, to obtain certain things, whereas from the public here we hear things like: there should be a service that helps us with such and such, society should provide us with this or that... Is that so, or don't all of us have to fight in a modified situation?

Part III: Practical Programming Examples on Promoting Disabled Children's Rights

11 Preventing Blindness and Early Intervention

By Gisa Paul-Mechel CBM – Christoffel Blindenmission

THE DISABLED CHILD'S RIGHT TO EARLY INTERVENTION

With CBM's emphasis on CBR, early intervention has become a major focus in the majority of CBR projects.

Aims :

To prevent the escalation from the original impairment to a serious disability

To motivate authorities to incorporate early Intervention and prevention of impairment into the framework of education/rehabilitation services.

To involve the parents/families of children with disabilities to better understand the potential and the needs of their child.

To obtain commitment of the health and education professionals to carry out screening and early detection and refer to existing services.

Example :

- In Poland CBMI, the Polish Association of the Blind and a German group of experts operated a 3 year training programme for 35 teachers from schools in all parts of the country. The curriculum was set by a German Special Education Resource NGO. The programme was shared financially between CBMI and the Polish Association of the Blind. After completing their approach in modern methods of special, the Polish teachers opened early intervention programmes in their respective schools.

DISABLED CHILDREN'S RIGHT TO HEALTH

Every minute one child in the world becomes blind

1.5 million children are blind

Approx. 250 million children of pre-school age suffer from vitamin.A deficiency

350 000 children go blind every year.2 million children die for want of vitamin A

On the vision 2020 campaign children are given The Right to Sight.

Christoffel Blindenmission Bensheim, Germany is a Christian, Inter- denominational aid organisation.

Operation : over 1000 projects in 109 countries
(Africa, Asia, Latin America, Eastern Europe)

Mandate : Prevention of disability, treatment of hearing and eye diseases, Disability Programmes.

12 A Community Programme in Ethiopia

By Mark O'Kelly, Leonard Cheshire International

I am going to say a few words about a community disability programme in Entoto, a poor area on the edge of Addis Ababa in Ethiopia. This actually started as a feeding centre during the famine in 1980s and has since developed into a community programme which includes health education, immunisation programmes, installing water points and pit latrines, skills training and loan schemes. As part of this wider community programme, there is a disability programme.

Some parents of disabled children simply do not know what to do with their children. Sometimes they keep them hidden away and are unwilling to accept help. It is therefore necessary to raise awareness of disability within the community and parents of disabled children already receiving support from the community programme are often the best people to do this, depending on how their child has developed and how the family has benefited.

The local field workers help the family understand the child's impairment and also their capabilities.

Practical help can include basic physiotherapy help with seating, advice on helping the child to eat, low cost aids and equipment. Parent groups can also be a source of support.

Going to school is an important part of the child's development and an important factor in social inclusion.

However there are problems to be overcome for the children to attend school.

These can include physical problems such as access to the building and transport, and, more importantly, the attitude of teachers and others at the school, many of whom are suspicious of disability.

Cheshire Ethiopia is therefore working with the schools to improve physical access and change attitudes. Currently over 70 disabled children are attending school through this programme. This may not be an enormous number, but it is a start, and it does show a change in attitude of the schools and the parents.

I just want to leave you with a quote from a mother of disabled child.

“I wanted to give my child to the government - I just did not know what to do with her. But then the CBR people came. They encouraged me to treat her like a human being”.

13 Disabled Children and Conflict Situations

13.1. Children with Disability in Federal Republic of Yugoslavia: disabled children's rights in conflict and war.

Dragana Stretenov, Save The Children UK, Federal Republic of Yugoslavia

During the six years of the presence of SCF in FRY, which includes both the emergency and developmental projects covering the whole territory of the country, extensive knowledge of the situation of children has been gained.

Children with disability are probably the most disadvantaged group of children faced with many barriers preventing proper satisfaction of their needs and their development on the basis of equality. These barriers are obstacles to their education as well as to the integration into local communities.

Their needs and rights were at risk before the war started in three major areas.

- ◆ Within the family, due to the chronic poverty, lack of information and constraints imposed by the predominant, traditional patriarchal culture
- ◆ Within the community, because of lack of appropriate services and in addition because of unequal access to education.
- ◆ Within wider society that is still generally intolerant and ignorant towards accepting children of marginalised groups as equal members of the society.

Many roads and railway bridges damaged during the war are still not operational and, in addition to shortage of fuel, are creating problems in supplying institutions with basic food, hygienic and medical items. The Social Welfare system is faced with daily problems to maintain basic living condition of children in institutions.

Medical institutions for assessment and treatment of children with disability were nearly closed during the war because of parents' problems of organising transport of severe disabled children. The effect of this sudden, unplanned termination of therapy and stimulation for the majority of children produced regression in their functioning. Shelters were inaccessible for most of physically disabled children because of barriers and inappropriate for children with disability who reacted with high level of distress when they were forced by their parents to spend time there. Most parents decided to stay at home with their children in spite of additional life risks.

Due the collapse of health services and chronic poverty there is significant shortage of drugs necessary for daily needs of children in institutions. Children in the community with epilepsy, who are dependent on specific drugs not available in the country, are already without these medicines and their condition has dramatically deteriorated with threat to their lives.

Professional staff capacity to deal with war and post war situation is very limited. Their motivation is very low and they have many more duties than they can handle in coping with new situation. The result is a deterioration in the care of children.

Only parents of children with disability in the towns already involved in the project approached us with clear idea that they have to act urgently. They developed a proposal for an emergency Community Support Project. It was aimed at children with disability and their parents in 8 locations. The project is still operational and it will give us comprehensive information about coping mechanism of parents and children with disability that are exposed to conflict. Clearly, the war produced violation of all children's rights starting from the most basic right to live, survival and development.

An analysis of the situation facing children with disability and the extent to which they enjoy their rights gave us examples of violations of these rights. This was particularly in relation to the best interest of the child, right to special care, education and training, right to highest level of health and medical services, right to live with their parents and particularly right to inclusive education and play and leisure opportunities.

We can say that the situation for children in FRY is exceptional for a long time now and that the war continues to undermine the rights of all children including certain groups that will continue to be particularly vulnerable such as disabled children who may become refugee or displaced children.

War has a tremendous impact on children with disabilities who are already heavily deprived of the rights advocated by the UN Convention.

All special play-schools, elementary and secondary schools were closed since the beginning of the war until the beginning of new school year (five and a half months). The situation was the same with all Day Care Centres caring for children with moderate, severe and profound disability. This situation has terminated education for children, caused complete family exclusion and additional pressure on parents to organise 24 hours care for children.

A number of institutions for children have been damaged during the war, which decreased the already modest living standard for children. Repairs will not be possible without major humanitarian support.

Major destruction left institutions without electricity and water for nearly a month. This situation will probably cause problems with heating during the winter which will altogether put in question the physical survival of a huge number of children (more than 500 children in some institutions)

13.2. A Perspective from Handicap International

Claude Simonnot, Handicap International

I Victims of war?

“Don’t look at us like looking at “poor people” we are not only “poor””

Salif Keita, Griot, singer and albino, from Mali

War is a “survival” situation where rights are neglected, spoiled, forgotten. But we believe that there is room to preserve the human link in these specific situations. Our experience shows that taking care of disabled persons under war situation is an emblem of the survival of humanity within the whole community.

But ten minutes to talk on “children and conflict” is quite a challenge. That is why I don’t want to describe in details the war effects on children and childhood, as most of you have great experience of it.

Having to think about situations where childhood is severely affected will knock on the door of our personal memory. That’s why I will briefly start with my own history. I was born in Algeria, in a remote place during the war. One day, a soldier was killed in front of our front door. Our house was shelled. I was caught up in the panic when a terrorist threw hand grenade at the Ramadan event; people were injured and killed around me.

Believe it or not, at that time, my biggest trauma was when the moon was suddenly masked by a cloud or when my father had to left the house for a long three-day mission.

What I’m trying to say is that, even if children are emblematic victims, their behaviour is quite far away from what adults (and so called specialists) are able to imagine. Knowing that, we must be careful when labelling people with stickers such as “war victim’s” or “traumatised children”, or “Post Traumatic Syndrome Disorder” (P.T.S.D. for the eminent specialist).

Our suggestion is to pay more attention to people. We are concerned and involved with people living, thinking and suffering, not with victims. We have to avoid spreading the status of victims in the population that we wanted to help.

It doesn’t mean we can’t have empathy with the people. It means that, even if people have faced terrible events, it is their stories and they will have to give a sense to that, with some help, time and respect.

When we were in refugee camps in Bosnia, we were surprised to see how lying down was important for mothers and how hyperactivity of the kids was important. In fact, children were involved in taking care of adults.

It means that their childhood has been stolen from them. It proves true what was said by Winnicott: “A child alone does not exist”.

The most important thing to preserve is the links across generations, the attachment to a family, a group.

In war situations, a relationship with stranger is dangerous and the alter ego is a danger and can be a killer. A relationship with a relative can become suddenly painful, or even killed.

It is of a major importance to work on these human links in order to restore humanity in the human relationship if possible inside in the country. In this respect, sheltering people, "victims", in another country, far away from their living place, without paying attention to the destruction of the remaining links can be, in some way, criminal.

II MINE VICTIMS ASSISTANCE

1 Awareness

" I saw beautiful and clear water in a hole in the middle of the road, I went to wash my foot and the mines blew me up. I knew that this road was mined, I have been informed before but I believed that nothing can happen to me". A child does not believe he can die.

No one is able to support limits in his daily life : "*don't do that, don't go there, don't play in this forest...*" In this respect, how is it possible to inform kids without their participation ? Awareness of people, and especially children is a difficult, long-term process, difficult to evaluate and time consuming.

2 Who are the mine victims ?

- ◆ Are they people killed ?
- ◆ The survivors of mines accidents ?
- ◆ The family of the people who were killed ?
- ◆ The family of the people who became disabled ?
- ◆ The people who lose house, land and property ?
- ◆ The population living under stress of having a family member blown up by a mine?

We found that a lot of money was involved in de-mining land when 5 to 10% only is channelled in mine victims assistance, the biggest part of it going to artificial limb production.

3 What does this mean?

When someone is disabled in a family, the whole family is "disabled".
Global approach is an urgent need and orthopaedic workshop is only part of it.

Mines victims do have special needs but must be included in a general public health service for all the disabled persons.

Work must be done in recognition of the rights of these people, in order to move from "charity" to "rights".

14. Inclusive Education and Rights of Disabled Children

14.1. Rights of children with disabilities in Ovci La Nostra Famiglia work The Work of 'La Nostra Famiglia'

By Elisabetta Gaiatto and Elena Media, LNF La Nostra Famiglia - ITALY

Ovci La Nostra Famiglia is born by an Italian association that from over forty years is operating for children with disabilities.

When the association La Nostra Famiglia has begun his activity (1954), in Italy the child with disabilities and his family missed in the most total way of juridical guardianship and services: the Association therefore has always fought because the rights of the children with disabilities were recognised.

Today La Nostra Famiglia manages a net of centres of medical rehabilitation (around 40 on the Italian territory) primarily for the childish age. Also as international organisation (OVCI), it has therefore an approach that privileges the defence of the right to health. According to the style of La Nostra Famiglia, in Italy and in the world, **health** must be interpreted as global harmony of the person and as search of the highest level of compatible welfare with its personal and family situation.

All the children, and in particular all the children with disabilities, have the right to this: therefore in his job La Nostra Famiglia has a global approach, facing the search of the maximum welfare and the maximum level of development of the potentialities of every child.

All the activities respond to this finality: from the "simple" rehabilitative treatment to the research, for which a Scientific Institute has been created.

Today in Italy La Nostra Famiglia has the difficult task to reconcile his vision of the health as global welfare, of the child as unique and unrepeatable person, of the value of the child with disabilities, with a sectorial and specialistic concept of health; with a prevailing mentality for which the rehabilitation is a trial that has to normalise the child with disabilities; with the expectation of the families that the "broken" child comes "repaired" from the physician rehabilitator; with the strong tendency to the reduction of the Health expense that goes to strike above all those bands of population that need cares for the whole life.

In the job in the developing countries, the principal problem is to raise in the place economic resources to sustain the costs of the activities of rehabilitation. In general, a work of awareness of the families and the politicians is necessary, because there is not a perception of the health as a due right, above all for the people with disabilities.

Another important slope, working with children with disabilities, it is the defence of the right to **education**.

Italy, already from the years 70, has undertaken with a lot of decision the road of the scholastic integration of the children with disabilities in the ordinary system.

According to our experience, the Italian system – that in the time is enriched with a lot of normative forecasts – shows that:

- The scholastic integration is a system that, before everything, requires a strong work of awareness of the families and the whole scholastic environment: otherwise, also using all the most interesting tools for the integration, the insertion can easily become a form of “integrated segregation” for the child with disabilities.
- In the ordinary school exists a strong risk to penalise the special educational needs of the child with serious disabilities: if, at the end of the education career lived in situation of integration, the boy with disabilities has not acquired the basic notions that would serve him for a positive social integration, the struggle for a scholastic integration can become a boomerang
- Often the ordinary school “absorbs” more easily child with an impairment, in comparison to children that doesn't have impairments but even only ability of learning slightly inferior to the average, or problems of psychological nature.

For these reasons we are very interested into the concrete development of “inclusive education” approach, untied by ideological conditionings concerning the choice among ordinary schools, special schools, support classrooms etc., and more correctly careful to the centrality of the child.

On the basis of the walk done up to now, we can say that:

- Introducing the idea of the inclusive education in Italy, great scepticism is found in general: both for snobbery (possible that the so integrated Italian system has something to learn from the system of the Lesotho) both because, for now, we are able to give only reflection and not practical indications of job
- The educational programs not only have to be flexible to suit for every child: the same implementation of the programs of inclusive education has to be flexible and to conform to the existing normative picture in a datum country, that not always and not necessarily have to change. It is the case of Italy, but also of countries that less inclined choices of integration have done (cf. Ecuador) but however they have basted a national system to guarantee the right to the education of the child with disabilities. This requires more imagination and a lot of patience in comparison to the ideal situation in which a new system is applied by zero
- It is very important that the construction of an inclusive scholastic environment is combined to the growth of an inclusive social environment, able not only to guarantee to the child with disabilities the guardianship of the right to a scholastic education formal type, but also the right to the game, the right of association and every other right recognised to all the children

To finish, an issue on which Ovcì La Nostra Famiglia works a lot is the awareness of parents so that they are the first actors of the positive integration of the child with disabilities, protagonists in an organised way on the political scene for the defence of their rights. In Italy as in the developing countries, the organisation proposes “schools for parents” and it supports the birth of groups and associations of parents.

A sector of more recent interest is the empowerment of the same children with disabilities, so that from the infancy they are accustomed to be an active subject of the social life.

14.2. Exclusion and Marginalisation in Schooling

By Felicita Velura, AIFO – Associazione Italiana Amici di Raoul Follereau (AIFO)

The following are key issues arising out of AIFO's work in the sphere of inclusive education. They demonstrate how exclusion and marginalisation are linked to schooling in general :

Inconvenient school hours: Children from poor families have responsibility for household work and for supplementing their families' incomes. Schools with rigid school hours become inaccessible for them because of these needs.

Differences in skills: "Dalit" (low caste) girls in India grow up in a different subculture, socially, culturally and linguistically. They may not have the same stimulation for learning oral speech skills as children from other backgrounds. Thus children come to the primary school with different skills. In school they may be considered "slow" or "problematic" and may be "forced" to leave the school.

Choosing a culture: children talking in dialect or other mainstream language may be forced to feel that their way of speaking, dressing, etc. is inferior. When they go back to their homes and with their companions, they may need to adjust back to their original culture and way behaving. Thus, they may choose to be like their peers in their home surroundings and drop off from the school.

How true are these considerations for other slum areas and ethnic minority groups? Do others also similar experiences and insights? Can such children be considered as children with intellectual impairment? I am interested in receiving your feedback on these questions.

15 Information and the Rights of Disabled Children

15.1. The Enabling Education Network

Susie Miles, EENET

EENET is an information-sharing network that supports and promotes the inclusion of marginalised groups in education world-wide.

EENET's underlying values and principles

EENET :

- believes in the equal rights and dignity of all children
- prioritises the needs of countries which have limited access to basic information and resources
- acknowledges diversity across cultures and believes that inclusive education should respond to this diversity
- seeks to develop partnerships in all parts of the world.

In conducting its work, EENET:

- adheres to the principles of the Salamanca Statement,
- believes that access to education is a fundamental right,
- recognises the intrinsic value of indigenous forms of education.

EENET is committed to:

- encouraging the effective participation of key stakeholders in Inclusive education,
- engaging with the difficulties caused by the global imbalance of power,
- encouraging a critical and discerning response to all information and materials circulated.

WHY ?

- IE Practitioners lack opportunities for networking
- there is a severe shortage of relevant and appropriate resource materials, particularly in local languages
- there are many excellent examples of good practice in the South – however they are little known and little published.

PERHAPS BECAUSE:

- The flow of information tends to be from North to South,
- Northern debates and practices are too often exported to the South,
- International research, literature and conferences tend to be dominated by a Northern perspective.

EENET is committed to:

- Promoting South-South networks
- Encouraging the South-North flow of information
- Creating conversations – which help to encourage the sharing of ideas and experiences
- Making the familiar unfamiliar
- Promoting the development of critical thinkers in the South.

WHAT ?**Newsletter**

- Easy-to-read, non-academic, free,
- Available in Portuguese, Braille and on Web site,
- Targeted at and written by policy makers, parents, teachers, teacher educators, young people - a page each -Voices from the south.
- Gives information on useful publications.

Web site

- News and events,
- Reports and discussion documents,
 - Case studies and training manuals,
 - Deaf issues.

Information dissemination

- “Preparing Teachers for Inclusion” a video training package from Lesotho,
- Agra seminar report and video
- Posters, leaflets, newsletters,
- Individual queries answered.

Seminars

EENET seminars – Manchester 1997, Oslo 1999
 Agra Seminar 1998 – IDDC and EENET,
 Inclusion and Deafness – Manchester 1999,

Family Involvement in Inclusive education

EENET is in the process of collecting stories from parents and their organisations – of how they have campaigned for the inclusion of their children in education.

Regionalisation

In the long-term EENET aims to regionalise its activities by building partnerships with key regional organisations.

15.2. Promoting Rights Through Information

by Heather Payne, Healthlink Worldwide

Information has an essential role in the promotion of disabled children's rights.

1 All disabled people including older children, need information on their rights

These are set out in:

- Declaration on Rights of disabled Persons 1975,
- Convention on the Rights of the Child 1989,
- UN Standard Rules on Equalisation Opportunities for People with Disabilities 1994

The information must be produced so that is:

- attractive, colourful, illustrated, humorous
- print and other media
- low-cost
- plain language
- easily available

People need to know their rights in order to:

- be equipped for self-advocacy
- hold service-providers accountable
- benefit from adequate goods and services
- lobby for better legislation, policies and resources,
- have higher expectations of life opportunities,
- work for social change.

Examples of good practice:

- CRC rewritten for children by Radda Barna,
- Newsletters on child rights:
 - CRIN Newsletter - CRIN - general child rights issues
 - Innocenti Digest - UNICEF - general child rights issues
 - CBR News 23 on rights of disabled children - Healthlink Worldwide international and Amar Jyoti Indain newsletter
- Websites on child rights:
 - Childhouse www.childhouse.uio.no
 - CRIN website, www.crin.org/disability.htm
 - Links to other sites, eg EENET, SCF, Child Health Dialogue.

2 Organised information provides a base for advocacy

- It establishes evidence, records experience and research and documents the current situation to inform legislation reform, policy review and allocation of resources for equal opportunities.
- Organisation of information requires a suitable classification & technology.

Examples of good practice :

- DAA collects reports of violations and their newsletter, *Disability Tribune*, highlights violation of Universal Human Rights.
- Working group on rights. Focuses on rights in three areas : right to life and development : rights to education, right to self-representation,
- Working group also asks for information on projects with disabled children,
- Yugoslav Child Rights Centre - *Monitor Child Rights*, newsletter with a global focus, no just Yugoslavia.

3 Self-advocacy

- Information materials are vital for training in campaigning, communication skills, training peers & organisational capacity building
- Accessible information on rights and services in various formats and media enables choice and control.

Examples of good practice:

- DAA manuals “ consultation and influence ”, “ Campaigning ” and “ International Day of Disabled Persons Information Kit ”,
- SCF, Radda Barna materials for working with children - manuals for children’s participation - visual methods, drama, video, journalism, etc.
- DSI (Danis Council Organisations of Disabled People) developed a NGO Index - a measure of the level of implementation of the Standard Rules (World Disability Report 1999 pp 19-22). It includes:
 - 25 questions based on the 22 Standard Rules,
 - Degree of fulfilment rated on a scale of 0 to 6,
 - Questionnaire completed by panels of disabled people at national and local level in 46 countries
 - Ministry of Health Rehabilitation Services, Bulawayo, Zimbabwe aims to provide information for service-users.

4 Advocacy by allies and contracted specialists

Support is offered by others to disabled people to swell the voice, rather than replace it.

Examples of good practice :

International Disability Foundation produced situation analysis, World Disability Report 1999 with DPOs as editorial consultants.

BBC World Service produced radio series on disability in 1998 in 6 countries with printed magazine supplement.

5 Information leads to strategies

Forming strategies is a current challenge for many and need for information is pressing, Documentation of impact evaluation of present practice urgently required.

Poverty alleviation must focus on disabled people with inclusive development strategies.

Documentation of impact evaluation of present practice urgently required,

Poverty alleviation must focus on disabled people with inclusive development strategies.

Example of good practice :

SCF Alliance working group project in progress

6 Information networks share good practice

These are being established but are in their infancy.

Networks between sectors of state & civil society combine and co-ordinate resources, overcome competition and close gaps between :

- policy and practice,
- understanding of poverty, health and disability,
- health, disability and rights to create equitable access to services,
- disabled people and rehabilitation practitioners to gain understanding of
- self-determination and independent living,
- DPOs in urban areas and disabled people in remote rural areas to build DPO capacity.

Example of good practice :

Child Health Information Network - CHIN, India - supported by DFID and Healthlink Worldwide

7 Information envisions policy-makers, reinforces practice, forces social change

Bold statements, clear messages, shocking facts and sound rationale all influence our hearts, will and actions.

Example of good practice:

Department of Education and Employment recent giant poster campaign.

8 Information is a two-way flow

- Children's voices can influence decisions, consultations are possible even under 4years of age
- Debate can question dominant views, especially in sensitive areas like disabled children

Examples of good practice:

Newsletter *Pikkin Palaver* - Children, Environment and Society Focus - promoting participatory research with children.

M. Miles : *Some on going crossed-wires in disability service development*. Puts forward the cultural / religious relevance of rights over charity. Also highlights how an over-emphasis on rights overlooks cultural acceptance of interdependence. In many societies, duties (to siblings, spouses, parents, extended family, age-mates, etc...) outweigh personal freedoms.

Quote from a South African disabled activist :

“ We have rights but we also have responsibilities. The right to development requires us to take on board the responsibility of ensuring that our organisations are effective and efficient. The right to self-representation - the right that only disabled people should speak for the disabled - implies also the responsibility to create democratic structures which are representative and accountable ”.

What is the role of information in realising this responsibility?

PARTICIPANTS IN SEMINAR ON RIGHTS OF DISABLED CHILDREN Tuesday 5th October 1999 Brighton

Organisation	Name	email	Phone/fax	Brighton Seminar
Action on Disability and Development	1. Beverly Ashton, Advocacy Officer	add@gn.apc.org	Tel: 44 1373 47 30 64 Fax: 44 1373 45 20 75	Chair, Speaker IDDC member
AIFO	2. Felicita Velura 3. Roberto Giorgetti, Vice Chairperson	aifo@iperbole.bologna.it anrogio@iol.it	Tel: 39 051 43 34 02 Fax: 39 051 43 40 46	Speaker IDDC member
Centre for International Child Health	4. Sally Hartley	s.hartley@ich.ucl.ac.uk		guest
Changing Perspectives	5. Simone Aspis	simone@disabilityissues.freemove.co.uk	+44 (0)181 459 5717	Speaker
Christofel Blinden Mission	6. Gisa Paul-Mechel, Education and Rehabilitation Co-ordinator	Gisa.Paul-Mechel@CBM-I.ORG	Tel: 49 62 51 13 1215 Fax: 49 6251 131 165	Speaker IDDC member
Comic Relief	7. Peter MacFayden	petermac@gn.apc.org		Guest
Committee on the Rights of the Child,	8. Queenie Mokhuane	mokhuane@mcd4330.medunsa.ac.za	Tel 0027 12 521 4632 Fax: 0027 12 521 4632	Speaker
Department for International Development	9. Julia Chambers, assistant to Social Development Advisor	juliachambers@hotmail.com		Guest
Diana, Princess of Wales Memorial Fund	10. Olivia Dix		+44(0)171 902 551	Guest
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Inclusion International	19. Nancy Breitenbach, Executive Director	Inclus@club-internet.fr	Tel:+33 (0)450 400197 Fax:+33(0) 450 400107	Speaker
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La Nostra Famiglia	21. Dr Elisabetta Gaiatto 22. Elena Medi	Ovci@pl.inf.it	Tel: 39 0434 842711 Fax : 39 0434 842797	Speaker IDDC member
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