Rights of children and adolescents with disabilities

Newsletter on progress towards the Millennium Development Goals from a child rights perspective

challenges

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Until not long ago, children with disabilities were made fun of, hidden away and, all too often, the victims of violence. Fortunately, this state of affairs has improved thanks to changes in the way disability is viewed and to the ratification, by 23 countries in the region, of the Convention on the Rights of Persons with Disabilities (CRPD).

Disability used to be seen as a physical or medical problem, and so a person with disabilities was expected to adapt to the rest of society. The approach today, however, is about making society offer ways to ensure accessibility and inclusion. This is a society-wide responsibility that must be assumed through the adoption of public policies.

These policies include early detection, inclusion in schools and recreational activities, different types of accessibility, special provisions within social protection systems (e.g. cash support for families with children with disabilities and subsidies for assistive devices), subsidized local production of assistive devices, training of teachers and families regarding care for children with disabilities, measures to combat discrimination, use of technology for education and play, and so forth. These policies promote not only the rights of children in the broad sense, but also economic development.

This issue of CHALLENGES provides examples of such policies and data on children with disabilities specially prepared by ECLAC. It also offers a compilation of the opinions of children with disabilities regarding what they would like to see reflected in the media.
Recent events

**Launch of “State of the World’s Children 2013. Children with disabilities”**
UNICEF will launch this issue of its flagship report in May, in Viet Nam. This year’s report explores and analyses the major issues confronting children with disabilities and their families. It advocates for necessary actions that will enable their full inclusion and participation in society.
http://www.unicef.org/publications/index_67127.html

**Meeting of experts to define strategic priorities of the regional agenda on persons with disabilities**
This meeting will take place at ECLAC headquarters in Santiago on 14 and 15 May, with the aim of analysing the situation of persons with disabilities in the Latin American and Caribbean region in order to propose a regional agenda to underpin joint work by government agencies and civil society organizations.
http://www.cepal.org/id.asp?id=49807

**Seventh international congress on teacher training in primary education**
This congress was held under the theme “Towards the challenge of inclusive education in the framework of equity in the face of diversity” in Guadalajara, Mexico, on 15-17 November 2012.
http://www.congresoberoamericano.net/

**V World Congress for the Rights of Children and Adolescents: Children, adolescents and social change**
This congress was held in San Juan, Argentina, on 15-19 October. The discussions explored the ideas, practices and policies on childhood and adolescence throughout the world.
http://www.vcongresomundialdeinfancia.org/

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**ECLAC, 2013**

**ECLAC, 2011**
http://www.eclac.org/publicaciones/xml/6/43186/lcl3315-P.pdf

**WHO and World Bank, 2011**

**UNESCO, 2011**

How would children with disabilities like the media to portray their reality and experiences?

“I’d like to see deaf children on TV. I’ve never seen any.”

“I’d like to see news on sports for people with disabilities, there are many games for deaf people.”

“I’d like to see news on how to make fewer stairs and more ramps…”

“…”things that are more real and informative, because lots of people don’t know about these problems.”

“I’d like to see even the President helping people with disabilities, as I think he’s not helping us now.”

“I’d like them to show how difficult it is for people with disabilities to study.”

“I’d like them to show that it’s wrong to leave someone with disabilities standing in the bus.”

“I’d like us to be on TV playing, studying.”

“I’d like to see the news in sign language.”

“…”to know more about athletes with disabilities. How they got to be where they are.”

Policies for the inclusion of children with disabilities

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I. What is disability?

The international community has made progress in grasping the experience of people with disability and safeguarding their rights. This article looks at the situation of children with disabilities in Latin America and the Caribbean, with a special focus on what governments are already doing and could do to ensure fulfilment of their rights.

Until recently, children with disabilities were made fun of and faced violence and discrimination, so their families kept them hidden away. Fortunately, this has changed, thanks in part to two parallel developments. One has to do with changes in the way disability is viewed. The other is the broad ratification of the Convention on the Rights of Persons with Disabilities (CRPD).

Disability used to be perceived as a physical and medical problem, referred to in the literature as the “medical model” of disability. Today, however, the emphasis is on the relationship between the individual and his/her context; this approach is termed the “biopsychosocial model”. The medical model centred on restrictions and inability to perform activities considered normal for any individual. The focus was thus on clinical diagnosis and physical rehabilitation, such as providing crutches or wheelchairs for people unable to walk.

Conversely, the biopsychosocial model shifts the locus of the definition of disability to the interaction of the individual with a non-solidary context. It is not, therefore, a matter of finding a “cure” to help the individual to adapt, but of getting society to offer ways of guaranteeing accessibility and inclusion for all, such as by providing ramps for wheelchair-users or people on crutches. This is a society-wide responsibility that must be assumed through the adoption of public policies. This conceptual shift runs parallel to the discussions surrounding the ratification of CRPD. The first article of the Convention states:

“Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.”

This definition is consistent with the biopsychosocial model, as it stresses the interaction, barriers and conditions that prevent persons with disabilities from participating fully in society. This is important in relation to determining who and how many have disabilities.

As the disability concept has evolved, a new understanding has emerged regarding the public policy domains in which opportunities exist to promote the rights of children with disabilities. However, designing and implementing policies and programmes require information and data on children with disabilities.

2. How many children with disabilities are there in Latin America and the Caribbean?

A number of methodological and ethical issues need to be considered for measuring the prevalence of disability among children. First, there are the various dimensions (physical, mental and others) of disability, which must all be taken into account. It is crucial for policy purposes to ascertain the prevalence of each type of disability. Second, the degree of impairment needs to be assessed (for example, being fully blind is not comparable with needing glasses).

In 2001, the World Health Organization (WHO) adopted the International Classification of Functioning, Disability and Health (ICF) for examining and codifying responses to questions on different areas (such as body functions, activities and participation, among others). The Washington Group on

1 During the “Decade of Disabled Persons” (1983-1992) it was recommended that the United Nations General Assembly draft an international convention on the elimination of discrimination against persons with disabilities. In 2000, leaders of five international non-governmental organizations on disability matters issued a declaration, calling on all governments to support such a convention. The approved text, the outcome of a five-year negotiation process, was adopted by the United Nations General Assembly in 2006 and came into force in 2008, following ratification by the twentieth State Party.
Artículo 8, Declaración de Mar del Plata, XX Cumbre Iberoamericana, Argentina, diciembre 2010.
Disability Statistics has addressed degree of difficulty ("some difficulty", "a lot of difficulty", "unable to do it at all") in formulating questions such as those in ICF.

Another challenge in measuring disability is the stigma respondents may feel when answering questions. Few disability surveys collect data on social and demographic circumstances. Questions addressed to adults may not be applicable to children, and vice versa. Also, it may be difficult to distinguish between mild disability and developmental delay, or between what a child can do, does, wants to do and is allowed to do. Moreover, countries use different definitions of disability reflecting cultural differences, which limits comparison and aggregation between countries.

Nevertheless, several attempts have been made to estimate the global number of people and children with disabilities. These range from 5% to 10% for children aged 0-14 and reach 20% among adults (WHO and World Bank, 2011). Recent studies by ECLAC indicate that about 12% of the population in Latin America and the Caribbean has at least one disability –12.4% in Latin America and 5.4% in the Caribbean. Tables 1 and 2 show the distribution of disabilities by age group. Prevalence is seen to be low among younger children, and is mainly due to congenital problems. Detection at young ages is complex and prevalence is often underestimated. Disability rates increase at older ages, owing to illnesses and accidents. Differences between countries may reflect variations in methodologies and the quality of estimations.

Many children with disabilities experience multiple factors of exclusion and discrimination, as illustrated by the example of indigenous girls with a disability in poor, rural areas. Figure 1 portrays the situation in eight countries for which relatively comparable data exist on disability, disaggregated by sex and ethnicity. Afro-descendent children tend to exhibit a higher disability prevalence than other groups.

Lastly, it must be borne in mind that the figures do not fully capture the impact of disability on the whole family or its non-quantitative impact on children’s lives.

### 3. What is the impact of disability on children?

The biggest and most immediate impact is that children suffer the limitations imposed on them by a non-inclusive society, context and setting which do not offer them opportunities to develop their potential and enjoy their life to the fullest. Mitigating and avoiding this impact constitutes the moral imperative upon which the CRPD and the Inter-American Convention for the Elimination of All Forms of Discrimination Against Persons with Disabilities (1999) were adopted.
Excluding children with disabilities from school and play not only violates their rights but also harms society, because these children can, with the appropriate support, become full and productive members of society, as well as wonderful friends to other children.

The economic losses occur not only in the long term, but in the medium term as well. This is because discrimination and inequity jeopardizes the achievement of social development goals, which cannot be reached if somewhere between 5% and 15% of the population are being excluded.

The economic costs concern not only potential aggregate losses, but short-run losses, too. Families that must bear the direct and indirect costs of medicines, devices, special treatments and transportation can slip below the poverty line in the absence of social protection mechanisms. And families which lack preparation or support in dealing with the care needs of a child with disabilities may be at increased risk of breaking up, or of experiencing intra-family violence and abuse.

Lastly, parents can sometimes overprotect a child with disabilities and, by failing to recognize the child’s real capacities and potential, they can in fact violate his or her right to enjoy an age-appropriate degree of autonomy and independence.

4. What are the countries doing?

There has been a very positive initial response from countries in the region in terms of signing and ratifying the global convention (CRPD). By late 2012, 28 countries in Latin America and the Caribbean had signed the CRPD, of which 23 countries were in the process of ratifying it. However, ratification does not always translate into legislation, policies, programmes, and activities, often because of lack of awareness or of coordination between the proposals and activities necessary. For instance, it is often believed that merely building ramps at the entrance of a mall or school is sufficient. This is certainly not the case, however, because accessibility has many dimensions. Ramps and similar changes to physical structures or transportation address only architectural accessibility. There are also communicational barriers that need to be overcome through speech therapy, hearing aids, or special equipment.

In education, sports and recreation, it is important to address methodological and instrumental accessibility, i.e. use of all types of learning, assessment and teaching resources to ensure that children with different abilities learn in the classroom. The Latin American and Caribbean region has made progress in promoting inclusive education, understood not as a philosophy or educational approach only for children with disabilities, but one that is fundamental for fulfilling the right to education for children from all marginalized groups. Instruments, tools and activities adapted to the needs and abilities of different children should be available (e.g. learning software and computer games for visually impaired children). Lastly, social and cultural barriers must be removed —what is known as “attitudinal accessibility”, eliminating prejudice, discrimination and stigma. Legal or normative barriers, too, must be overcome for what is termed “programmatic accessibility”, affording careful attention to rules or provisions which are seemingly neutral but which allow or perpetuate barriers (Lumpkin, 2012).

Besides ratifying CRPD, more specific laws, policies, programmes and actions may need to be implemented to ensure the full enjoyment of these rights. An early screening and detection system is also crucial for implementing the necessary public policies. Such a system must include an appropriate early intervention plan, including support for parents and active engagement of parents and other family members as well as anyone else involved in the child’s care and education.
There are various entry points for early detection: for example, at regular well-child check-ups in the first few years of life, in the framework of immunization schemes, through specific community-based screening processes, and as part of strategies of primary health care or early childhood development. Chile, Colombia, Costa Rica, Guyana, Jamaica, Nicaragua, Panama and Suriname have implemented integrated packages of early identification combined with the provision of family support. Until recently, however, less than half of the region’s countries had implemented early detection programmes.

In line with CRPD commitments and Education for All (EFA) initiatives, it is a basic right to have services cover not only early childhood development but also—and throughout—inclusive primary education. Several Latin American and Caribbean countries have made headway in this regard and provide a greater number of inclusive services in education. The imperative of fully respecting the educational rights of children and adolescents goes beyond primary education to include adequate preparation for full participation in society. Employment laws must prevent discrimination in the labour market and provide specific employment schemes to foster a context of inclusion.

Technology can be used to promote and improve accessibility and inclusion. Community centres, schools and libraries should have learning software for special needs children. In Cuba, over 600 youth clubs offer the use of computers with open-source software for recreational and academic purposes. These also offer classes and certificates for children, including those with disabilities. The Dominican Republic and Brazil provide similar alternatives using open-source software.

Communities can also organize games and sports for children with disabilities. The Paralympics and Special Olympics are examples of this approach. Moreover, a truly inclusive approach should offer a variety of opportunities for children with disabilities to participate in sports and recreational activities along with other children. These should always be done with a view to the child’s best interests, in other words, avoiding exposure to bodily or emotional harm. In Argentina, several municipalities have built and financed inclusive playgrounds, where children with disabilities can play in safe areas especially adapted for their recreation.

Once children with disabilities have been identified and parents have received early training and support, families will require care and assistance for several years. This carries costs that should be covered within the framework of comprehensive social protection for children (UNICEF, 2012), including monetary transfers and other measures. In Ecuador, the Joaquin Gallegos programme provides caregivers of persons with severe mental or physical disability with medicine and a cash transfer of US$ 240. Caregivers may also receive training in health, hygiene, nutrition and rehabilitation. To date, almost 15,000 caregivers have received this transfer and the total budgeted amount is US$ 41.8 million (0.78% of the GDP).

Another element in the social protection system should be universally free or subsidized assistive aids such as glasses, hearing aids, wheelchairs and prostheses. Provision such as this is already in place in Argentina, Chile, Colombia, Costa Rica,
Panama and Trinidad and Tobago. Poor families, especially, often refrain from buying their children assistive devices because the fact that they will be outgrown make the purchase seem wasteful. A simple lending scheme could provide children with essential devices cost-free, with parents committed to returning the outgrown devices in due course for another child to use, and receiving another in exchange. Policies should also be implemented to promote the local design and production of assistive devices. This will improve the availability of appropriate aids, lower the cost to families or governments and provide employment opportunities.

Social protection should also include specific procedures and services for all families through its linkages with the health system: rehabilitation, simple medical procedures (such as cleft lip surgery) and speech therapy, for example. While government support programmes of this sort have increased, few make specific provision for children with disabilities living in poverty or in rural areas. Antigua and Barbuda runs a residential care programme for a limited number of children with disabilities, as does Colombia in the framework of its primary health programmes. Ecuador offers integrated care programmes in special centres for children up to age 5, and Uruguay does so up to age 18.

While many children with disability face discrimination not from the intrinsic nature of their disability, but from rejection of difference, poverty, social isolation, prejudice, ignorance and lack of services and support (Lansdown, 2012), many others are better off thanks to the CRPD and recent policy changes. Moreover, policies for children with disabilities have a broader effect: they improve the quality of life of all children.

**BIBLIOGRAPHY**


What are the main challenges that children with disabilities face in the Caribbean countries?

Children in the English-speaking Caribbean face many of the same challenges as children with disabilities around the world. These include inaccessibility to buildings and information, stigma, negative stereotyping, discrimination, social exclusion and inadequate human and community resources for rehabilitation and recreation. Many also feel a sense of helplessness and rejection by peers and society. Parents of non-disabled children do not want their children to be in the same class as children with disabilities. It is therefore necessary for society to have an appreciation of the value of including persons with disabilities in all aspects of life, thus reducing the prejudices and stigma linked to disability. This can be achieved through widespread practice of disability studies.

In addition to issues shared with differently abled children internationally; Caribbean children with disabilities also experience challenges relating to the implications of small island development, poverty, vulnerability and risks of abuse.

Caribbean countries have to choose between many desirable goals for development because children with disabilities are only one competing choice. This is, in my opinion, the main challenge of children with disabilities in the Caribbean; to be able to receive priority or even equal attention amid limited resources. Changing this would require holistic approaches to community development which would address the diverse needs of all children and provide community-based resources.

What are governments doing in terms of public policies for children and adolescents with disabilities in the Caribbean?

All Caribbean countries have some programme of special education. Segregated education and separate services remain very much the norm on most islands. However, there are moves in Jamaica and Trinidad and Tobago to include children with disabilities in the mainstream educational services. This applies to the hearing impaired and the blind at secondary level. These efforts will help children to be better prepared for the real world.

The Barbados Education Act provides for special education for persons who are mute, deaf, blind, physically or psychologically disabled or mentally retarded. In Trinidad and Tobago the Ministry of Education and Ministry of Health collaborate to ensure that all students are screened in the areas of sensory impairments on entering the primary school system. This early identification of children with disabilities facilitates the implementation of intervention strategies to increase the chances of future success for children with disabilities in education.

What is your long term vision for the education of children and adolescents with disabilities?

To receive a quality, appropriate education in the school of his/her choice where there can be enhanced learning, improved self-esteem and good socialization for good citizenship. Education should focus on children developing their abilities and not emphasize their disabilities and dependence. Children with disabilities should have the same opportunities as every other child. They should not be singled out but be treated like other children. This includes improved universal accessibility to important buildings, transport, schools, and so forth.

Parents of children with disabilities should be empowered so that they can be better advocates for their children and promote better inclusion. Resources should facilitate the development of diagnostic and prescriptive services, appropriate teacher education and availability of the new technologies in education.
Empowering blind and visually impaired children and youth in Saint Lucia

In Saint Lucia, over 1% of the population has a visual impairment. The NGO Saint Lucia Blind Welfare Association (SLBWA) developed a model of integrated care for the needs of the blind population and those with visual impairments. SLBWA offers eye tests to guarantee early detection of visual impairments in children between ages 3 and 5. In 2007, 2,411 ophthalmological examinations were conducted. Trained nurses provide this service in public hospitals and schools located in poor communities across the country. Children who are diagnosed with visual problems are referred to the SLBWA clinic, where they receive treatment and a subsidy for glasses and visual aids. This service is complemented by the Kids Insight project (SLBWA and the Lions Club) which offers pediatric eye treatment in Saint Lucia (where there are no pediatric ophthalmologists). Since 2003 a team of specialists from the West Virginia Eye Institute (United States) travels to Saint Lucia once a year to perform tests and surgeries.

Another important pillar of this programme is inclusive education in the 24 schools in the island, which allow thousands of sighted and blind children to learn together. Rotating teachers coordinate their work with teachers in other schools and with the parents of children with visual impairments. The programme also provides materials in braille and textbooks designed for the blind. Training is offered for the appropriate use of these materials.

There are four special education, rehabilitation and recreation centres. Training for labour market integration is based on computer workshops, jointly with the Poverty Reduction Fund (PRF) and the Caribbean Council for the Blind with SLBWA. There is a lab equipped with adapted software for use by the blind, the sighted and persons with visual impairments. Sporting and recreational activities are also organized. These are specially designed for those with visual impairments and include, for example, cricket for the blind. The project strategy articulates sectors and develops an integral model combining education, labour market training and recreation. This allows for children and adolescents with visual deficiencies to have a normal life in terms of study, work and leisure—to have, in fact, what they are entitled to.

A beach for everyone

Villa Gessel, a very popular seaside village in Argentina, has taken measures to make one of its beaches accessible for people with disabilities and their caregivers. The beach has tents, amphibious wheelchairs—designed and produced locally—that can be taken to the beach and float in the sea without risks, as well as access ramps, accessible bathrooms and other amenities.

The beach is part of a package of inclusive policies implemented by the municipality, which also includes a pedestrian street without architectural barriers for wheelchair-users, street names and menus in Braille, and three accessible parks. The beach accessibility scheme has been in operation for four years, providing opportunities for recreation and play for children with disabilities and their families.

Source: Experiences in social innovation in Latin America and the Caribbean [online], http://www.cepal.org/dds/innovacionsocial/eproyectos/sl/juventud [date of reference: 1 April 2013].

... that children with disabilities experience violence 3.7 times more often than children without disabilities.


... that only between 20% and 30% of children with disabilities in Latin America and the Caribbean attend school.


... that around 20% of schools in Brazil and less than 10% of schools in Mexico are accessible for children with disabilities.


... that, for six countries in Latin America, disability is most prevalent in adolescents aged 12 to 18.

Source: Latin American and Caribbean Demographic Centre (CELADE) – ECLAC Population Division, on the basis of special processing of census microdata.