Children’s rights and ICF-CY documentation
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Abstract

In developed as well as developing countries, children with disabilities are vulnerable to deprivation of their rights in the form of denial of treatment, neglect, exploitation, discrimination and lack of access to services and supports. Viewed within the framework of universal standards, the UN Convention on the Rights of the Child (UNCRC) and the ICF-CY complement each other, defining the rights of children and providing evidence of barriers to those rights, respectively. In this context, “...children’s rights generate obligations and responsibilities that must be honoured” (Landsdown, 2000). The ICF-CY can document the child’s limitations and environmental barriers providing evidence for the rights to protection, care and access.

This paper advances the use of the ICF-CY to document major UNCRC articles defining the child’s integrity as a person and inherent right to life and survival, to an identity, to be the first to receive services, to a family environment, to protection and assistance in institutional care, and to protection from exploitation. Article 23 of the UNCRC - access for children with disabilities- (codes e 570, 575, 580, 585); article 28 - participation in education (codes e 125, 130, 140, 585); and articles 5, 9 and 20- family life (codes e 310, 315, 410) are representative UNCRC articles and corresponding ICF-CY codes. The ICF-CY can provide documentation of children’s functional limitations and corresponding environmental barriers that make children’s rights explicit, constituting a universal reference for the development of national policies, legislation and practices pertaining to the rights of children with disabilities.

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Children’s rights and disability

It is only within the last three decades that children with disabilities have gained their rights in Western countries, including the right to education; the right to early childhood intervention is even more recent. In many parts of the world, these rights are yet to be realized. Implementation of the rights of children with disabilities has taken the form of legislative and societal initiatives on behalf of children and adults with disabilities in most of the developed world. A prerequisite for implementing the rights to health, education and services has been to establish criteria for eligibility. From a historical as well as contemporary perspective, it is clear that the approach to classification of children with disabilities not only conveys information but also assign value to their conditions. The significance of naming and classification activities related to childhood disability are that they influence perceptions of children's needs and the way in which those needs should be met (Florian et al., 2006).

ICF-CY and documentation of rights

At a universal level, the ICF may serve as a standard reference for defining the rights of children. Although such rights are often implicit in legislation of Western countries, the ICF may provide the basis for explicit documentation of rights (Corker & Davis, 2000; Landsdown, 2000). This may be of particular significance in developing countries where right to health care and education of children in general is abridged and where children with disabilities are specifically denied access to schooling (Simeonsson, 2003). To this end, documentation of restriction of participation codes of the ICF may serve as evidence of the deprivation of rights at the level of the individual child or a population.

Fundamental to the development and well being of children are rights to health and education. These rights are defined in the U.N. Convention on the Rights of the Child and continue to be advanced in international declarations and national laws. Although well established in most developed countries, such rights are still not realized for many, especially children and girls in the developing world and children with disabilities everywhere.

Nurturing children and promoting their health and development is an implicit responsibility of families and societies. In countries around the world, there is substantial variability of care-giving, with many children experiencing unintentional or intentional neglect, maltreatment or victimization. Such deprivation of rights may be expressed in broad forms of child labor, lack of access to schooling, exposure and infection with AIDS, (Tarantola & Gruskin, 1998) exposure to violence or armed conflict (Gustafsson, 1999) and exposure to toxic or dangerous environments (Powell & Stewart, 2001). At specific levels it may be expressed in lack of personal control in the administration of treatments and giving or withholding consent (Southall, Burr, Smith, Bull, Radford, Williams & Nicholson, 2000).

In every society, children’s inferior role and limited ability to advocate for themselves renders them uniquely vulnerable to deprivation of their rights. That vulnerability is significantly increased for children with disabilities whose heightened dependence on others and need for support exacerbates their inferior role. For children with disabilities, deprivation of rights may take the form of denial of treatment, lack of accessibility to settings and experiences, isolation, neglect, exploitation as well as abuse from caregivers. The recent history of western countries reveals that it was only a few decades ago that children with disabilities were assigned to a lifetime of institutional neglect and deprivation. That situation unfortunately still exists today in various forms of discrimination and neglect in many countries of the world.
Advocacy efforts by and on behalf of adults with disabilities have contributed to a growing awareness of human rights internationally. Awareness of the rights of children while not as extensive is being addressed (Peens & Louw, 2000). The priority of making children’s rights explicit as the basis for policy development, legislation and service provision is reinforced by emerging issues in the developing and developed world. Within a global perspective, disability is disproportionately found in the developing world with children accounting for the largest age group. In developed countries, the rights of children with disabilities and chronic conditions are central to issues about societal responsibilities and resource allocation. If human rights are to serve as the basis for equitable services for all children including those with disabilities, “...human rights ought to begin with the rights of children in our society and in their families” (Westman, 1999; p.315).

In 1959, the United Nations published the first Convention on the Rights of the Child. Thirty years later, in 1989, the second UN Convention on the Rights of the Child was published and went into force in 1990. The convention consists of 54 articles with 41 articles specifying the nature and conditions of the rights of children and the remaining 13 articles pertaining to implementation of the convention. Major principles underlying the convention are based on the premise of the child’s integrity as a person (Articles 1-3); inherent right to life and survival (Article 6); right to an identity (Articles 7-8); right to a family environment (Articles 9, 18); right to be heard (Article 12-13); protection in institutional care (Articles 20, 25); protection from exploitation (Articles 19, 23 24); right to education (Article 22) and right to highest allowable health (Article 24).

Of particular relevance to the rights of children with disabilities are the paragraphs of Article 23 define the responsibilities of member states. Paragraph 1 declares that States Parties recognize “that a mentally or physically disabled child should enjoy a full and decent life in conditions which ensure dignity, promotes self reliance and facilitates the child’s active participation in the community”. Paragraph 2 reads, “States Parties recognize the right of the disabled child to special care and shall encourage and ensure the extension, subject to available resources, to the eligible child and those responsible for his or her care, of assistance for which application is made and which is appropriate to the circumstances of the parents or others caring for the child”. Paragraph 3 further specifies that the assistance “...be provided free of charge, whenever possible,... and shall be designed to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child’s achieving the fullest social integration and individual development, including his or her cultural and spiritual development”. The principles of access are also addressed in a related UN document, the Standard Rules for the Equalization of Opportunity published in 1994.

While these principles are often implicit in policies and practice, the convention makes them explicit, constituting a universal bill of rights for all children. As Melton (1991) has noted the Convention provides “...the blue print for policy making on children’s issues” (p.343). In this context, the contribution of the Convention is its use as a guide in the development of national policies, legislation and practices pertaining to the rights of children (C0x, 2000; Lowden, 2000). A significant challenge in the translation of human rights into services and supports for all children, including those with disabilities is finding a consistent means to document deprivation of rights (Schultz, 1996). The challenge is reflected by the lack of a consistent approach to document that a child’s rights to health care, support and education. In many cases, having a medical condition, a diagnosis or meeting eligibility criteria serve as proxy means to document a child’s rights to services and supports. These and related approaches are indirect and do not document the functional nature of the deprivation the child is experiencing.
The concepts of health, disability, well-being and quality of life are frequently interchanged in defining policies and practices on behalf of individuals with disabilities. Saracci (1997) has advanced a concept of health that is consistent with a broad view of human rights. The overall framework and content of the International Classification of Functioning, Disability and Health - ICF-CY are consistent with this inclusive definition of health. In this context, a child’s experience of limitations of access to the physical, social or psychological environment or equality of opportunity, constitute deprivation of rights. The International Classification of Functioning, Disability and Health - ICF-CY may contribute to the documentation of children’s rights in two major ways. Conceptually, the dimensions of body function and structure, activities and participation are defined as variation of human functioning within adequate environmental factors. Adequate environments are those that are available and accessible to the child, are accommodating of the child’s needs, affordable in time and cost and accepting of the individual. In practical terms, the availability of the Environmental Factors dimension provides the opportunity to document those aspects of the environment, whether physical, social or psychological, that constitutes barriers or denial of access. Constraints, barriers or limitations of access experienced by a child could thus be documented with appropriate ICF-CY codes. With reference to the list of rights described earlier, the following Environmental Factors codes could be used to document deprivation of rights experienced by a child: Integrity as a person (e-570 social security); right to life/survival (e 1100-1101 medicine); identity (e550 legal); family environment (e310 family); protection from exploitation (e545 civil); protection from institutional care (e340 personal care); education (e585, 586 education); and highest allowable health (e580 health). Such documentation could be made to insure the rights of an individual child or documented for a population as an “epidemiology of rights”.

The publication of the International Classification of Functioning, Health and Disability (ICF) by WHO in 2001, followed that of the Convention on the Rights of the Child by more than a decade. Viewed within a framework of universal standards, the UN Convention on Rights for Children and the ICF complement each other. One defines the rights of children and the second provides the framework for documenting the deprivation of rights and the conditions under which those rights can be realized. These two universal documents are in turn consistent with Rule 2 (#3) of the U.N. Standard Rules for the Equalization of Opportunities, indicating that a common level should serve as the basis for equalization of opportunity for children as for adults. To the extent that the principles defined by the Convention are expressed in national laws and policies, the ICF holds promise as a means whereby the lived aspects of those rights can be documented. This means that in practice, the unique, developmental needs of children with impairments of function, activity limitations and restrictions of participation in community life should have those needs documented and met through accommodation and the provision of support. The availability of the ICF may thus serve as a standard for documenting the nature and severity of the child’s disability and thereby formalize the child’s rights and protection from discrimination, abuse, neglect and denial of access. In addition, it may serve as an informational resource defining dimensions of the Convention on the Rights of the Child applicable for all children.

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