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International Human Rights to Early Intervention for Infants and Young Children with Disabilities: Tools for Global Advocacy

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Abstract

With almost universal ratification of the Convention on the Rights of the Child and the growing number of States Parties that have signed or ratified the Convention on the Rights of Persons with Disabilities, the majority of countries in the world have now committed to implementing the human rights articulated in these treaties. In this article we first provide an overview of both Conventions, highlight the articles in the treaties that are relevant to early intervention for infants and young children with disabilities, and describe the specific duties required of States Parties to ensure compliance including international cooperation. Second, a series of early intervention action principles are put forward that can help States Parties translate the underlying values of the Conventions into practice.

Keywords

global advocacy; early intervention; United Nations Conventions

The most recent estimates suggest that approximately fifteen percent of the global population, or over a billion people, experience some type of functional limitation and two million of those individuals live with a significant disability (World Health Organization, 2011). The United Nations Development Programme reports that eighty percent of individuals with disabilities live in developing countries (United Nations Enable, 2012). Although the number of infants and young children (those under the age of five) with disabilities worldwide is not well documented for a variety of reasons (Olusanya, 2011), there is now concerted effort by numerous international organizations to improve the documentation of disability status for this group of children, especially in low and middle-income countries (Britto & Ulkuer, 2012). Nevertheless, available evidence indicates that nearly a quarter of young children in developing countries are at risk for or have established developmental delays or disabilities (Walker et al., 2011).

The many benefits of early intervention for children, families, and communities have been well-documented where adequate resources are available (see Guralnick, 2005; Heckman, 2006). A recent review of studies from a diverse group of low and middle-income countries also provides evidence for positive outcomes, although much more work is needed for children with established disabilities (Engle, et al., 2011). Accordingly, early intervention

can be effective in developing countries but special attention will be required to address local conditions as well as numerous other issues.

In addition to the need for well-designed early intervention research and evaluation studies in the developing world, it is critical that investments in early childhood intervention programs have priority in resource allocation; a task that is particularly challenging in current stressful economic environments. When resources are limited, funding for early childhood services and supports, particularly for infants and young children with disabilities, may have low priority (Olusanya, 2011). Yet, when establishing priorities, one must consider that the United Nations has adopted two international human rights treaties that, when taken together, articulate a human right to early intervention for infants and young children with disabilities. These treaties, the Convention on the Rights of the Child (CRC) and the Convention on the Rights of Persons with Disabilities (CRPD), also describe the standards by which all States Parties can guide the development of programs, services, and laws necessary to comply with the Conventions.

The global community is familiar with the CRC and recognizes that the standards of the treaty have achieved customary law status; in other words, they document a global consensus on children's rights. The CRPD is similarly becoming accepted throughout the world as the comprehensive articulation of the rights of all individuals with disabilities including infants and young children. The rights of infants and young children and the duties of governments as articulated in these two international treaties, the knowledge that early intervention can yield important benefits, and the economic incentives to investing in early intervention for the long term benefit of a country, have set the stage for a global mobilization of activities supporting early intervention advocacy.

The CRC and the CRPD provide not only the theoretical human rights underpinning for the provision for early intervention but also the concrete reporting and monitoring mechanisms to ensure that governmental attention is directed towards compliance. In this article, the authors review the rights and duties articulated in the Conventions that are relevant to early intervention and outline a series of action principles to guide implementation of early intervention services and supports from an international perspective.

International Human Rights Conventions: Background

Although civilians have always been victims of war, the violence and widespread nature of World War I brought the extent of suffering experienced by women and children to the attention of the international community. Concurrently, interest was growing to create a world body that would focus efforts on resolving disputes peacefully and prevent another global war. As a result, the League of Nations was created. It was this body that adopted the first major international agreement protecting specific rights for children known as the Declaration of Geneva (League of Nations, 1924). The Declaration has been characterized as "substantively unfocused and essentially an aspirational document" (Bennett, 1987, p. 18. n.93). In spite of the criticism, the document stands out as the first formal international recognition of the vulnerable legal status of the world's children and addresses the duty of

the world community to provide for children “the best that it has to give” (Bennett, 1987, p. 18, n.93).

The League of Nations was unable to achieve its goal of ensuring world peace and not until after the Nuremberg Trials following the Second World War in 1945 was there sufficient commitment to creating the body we know as the United Nations (UN). The horrific human rights atrocities that occurred during World War II led to concerted efforts to develop and enforce international human rights standards (Glendon, 2001). One of the early achievements of the UN was the creation of the Universal Declaration of Human Rights in 1948 (United Nations General Assembly, 1948). This document along with the UN Charter establishing the UN set the stage for a series of human rights treaties that articulate a global consensus on the rights that all human beings have simply by being. The most recent of these human rights treaties are the CRC and the CRPD.

A United Nations declaration is not a legally binding document, albeit one that a country (State Party) may sign acknowledging agreement with the standards contained within. A treaty or convention, however, is considered legally binding once ratified by a State Party’s legislative body. By ratifying a treaty, a State Party commits to working towards the standards within and to reporting regularly to the UN on its achievements and plans for future action. The distinction between the document types is important in terms of the protections afforded to individuals within their respective country, the degree of State Party commitment, and the duty to report on implementation efforts.

United Nations Convention on the Rights of the Child

Historically, the United Nations thematic human rights treaties have been preceded by declarations and/or other “soft” law documents articulating standards and principles for States Parties to follow. This was the case for the CRC. The Declaration of the Rights of the Child was passed by the United Nations in 1959 after lobbying by the Polish Government to address numerous child related problems resulting from World War II (United Nations General Assembly, 1959). Although this document attempted to comprehensively cover children's rights, it never had the force of law and Poland continued to push for a legally binding instrument. The Declaration of the Rights of the Child has been criticized because it speaks of "principles and entitlements" as opposed to the "rights" of children. The specific criticism is that the Declaration is concerned with economic and social issues rather than civil and political rights (Bennett, 1987, p. 18-19).

The instrument which came to be known as the United Nations Convention on the Rights of the Child (CRC) was first proposed by Poland in 1978. It was originally intended to put into treaty form the earlier non-binding Declaration of the Rights of the Child. However, after a decade of drafting, it evolved into a more complex and distinctly separate instrument consisting of forty-one substantive articles. The CRC was adopted by the General Assembly in November 1989 and entered into force in September 1990. One hundred and ninety-two nations have signed and/or ratified the treaty stating their commitment to adopt the internationally accepted standards when drafting national children's rights legislation. Somalia and the United States are the only two nations that have not ratified the CRC although both have signed it (United Nations Enable, 2012).

The CRC includes civil and political rights as well as economic, social, and cultural rights, thereby addressing the criticism of the Declaration of the Rights of the Child. It adds to international children's rights law in significant ways. First, it includes rights omitted from previous international agreements—e.g., the right of a child to preserve his/her identity and the right of indigenous children to practice their own culture. Second, the CRC provides more comprehensive coverage in some areas—e.g., the rights of children with disabilities and safeguards in adoption procedures. In addition, it requires affirmative duties by states to abolish traditional practices prejudicial to the health of children and to provide for rehabilitative measures for victims of neglect, abuse and exploitation. Finally, the CRC facilitates the development and establishment of international children's rights law and an international consensus on acceptable standards.

Underlying the CRC are four general principles that must be considered when implementing all the articles of the treaty. These articles are summarized as follows:

- **Article 2:** Children must not suffer discrimination irrespective of child or parents' race, color, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability, birth, or other status.
- **Article 3:** The best interests of the child must be a primary consideration in all actions that affect the child.
- **Article 6:** Children have the inherent right to life and the right to survival and development in all aspects of life.
- **Article 12:** Children have the right to express his or her opinion freely and to have that opinion taken into account in all matters affecting their lives.

Each of these articles has relevancy for infants and young children with disabilities. The discrimination on the basis of disability that is well documented around the world is specifically addressed in Article 2; the CRC was, in fact, the first human rights treaty to specifically include disability. The article clearly includes children with disabilities among those recognized as especially vulnerable and marginalized and requires nondiscriminatory treatment by State Parties. Articles 3 and 6 in particular speak to the rights of infants and young children and bring attention to the services that will help them achieve their full potential. Early intervention services clearly meet the definition of activities that would help children with disabilities "achieve their full potential." Article 12 is recognized as a standard that will be applied with the developing capacity of children in mind. For infants and young children the application will be less relevant than for older children.

The CRC provides standards in health care, education, legal and social services. The standards are those that States Parties can use as "goals" and by which their progress towards compliance can be measured. The obligations of States Parties to the CRC are clearly articulated in Article 4. They include aligning national legislation to the CRC standards and committing sufficient national budget to ensure that rights can be realized. The budgetary amount will differ depending on the economic status of a States Party, but in all cases must reflect a commitment to children.

States Parties must also submit reports periodically to the UN documenting progress towards compliance. Articles 43-45 of the CRC describe the Committee on the Rights of the Child's role in this reporting. This Committee is the monitoring arm of the CRC consisting of children's rights experts elected by the States Parties, although they serve in their individual capacity. Those nations that ratify the Convention are required to submit periodic reports on the measures they have taken to implement the treaty. The initial report is due to the Committee two years following ratification, and then every five years. In addition to the State Party's government report, the Committee considers reports by local non-governmental groups, often called shadow reports. These shadow reports document compliance with the CRC also and provide Committee members with additional information from civil society. Government representatives are invited to meet with the Committee to discuss the report and a final Committee report including findings and recommendations for future action is subsequently issued.

As well as monitoring States Parties reports, the Committee on the Rights of the Child also provides additional guidance on general issues of importance to children's rights. The Committee has issued General Comments on a variety of topics. General Comment #7, Implementing Rights in Early Childhood, was issued in 2006 (Committee on the Rights of the Child, 2006). In this General Comment, the Committee included the following paragraph that has particular relevance for the rights to early intervention:

Early childhood is the period during which disabilities are usually identified and the impact on children's well-being and development recognized. Young children should never be institutionalized solely on the grounds of disability. It is a priority to ensure that they have equal opportunities to participate fully in education and community life, including by the removal of barriers that impede the realization of their rights. Young disabled children are entitled to appropriate specialist assistance, including support for their parents (or other caregivers). Disabled children should at all times be treated with dignity and in ways that encourage their self-reliance (Committee on the Rights of the Child, paragraph 36(d)).

The CRC itself and the Committee's interpretation of the treaty standards, clearly support the rights of infants and young children with disabilities and their families to receive early supports and services. The General Comment also provides a wealth of additional information for States Parties on implementation measures, is a valuable tool for advocacy particularly in capacity building and resource allocation for all States Parties, and provides recommendations particular to global advocacy (Committee on the Rights of the Child, paragraphs 38-43).

There has been criticism of the United Nations treaties generally due to the lack of sanctions available if a State Party does not adhere to the relevant standards. However, most human rights advocates believe that the value of these treaties lies in articulating a global consensus of rights and providing a process by which governments are required to investigate and document compliance in their particular country and be available for international inspection. Currently, the Convention itself lacks a mechanism for an individual child to bring a complaint that his/her rights have been violated, although a new Optional Protocol does allow this. Therefore, the CRC is probably most important not as a tool for individual

advocacy but as a statement of principles on the value of children and the articulation of an ideal world that we can work to create. Because the CRC is now considered international customary law, it is an invaluable framework for global advocacy. Compliance to the standards within the CRC (and other human rights treaties) provides both goals for States Parties to work towards and a monitoring opportunity for the UN Committee. Tied to this in some countries has been a clear relationship between the deficits identified (either by States Parties and/or the Committee) and funding. Ultimately, however, public humiliation or embarrassment and possibly withholding of fiscal aid would be the only repercussions for failure to follow any of the international human rights treaties.

Articles of Particular Importance For Rights to Early Intervention

The preamble to the Convention on the Rights of the Child establishes the premise on which the whole treaty is based—i.e., that children, because of their vulnerability, need special supports and protection. In addition to the four principles central to all the articles of the Convention as described briefly above, other specific articles address rights relevant to early intervention services for infants and young children. The main ones are described below, beginning with the rights of children with disabilities.

Article 23: Rights of children with disabilities to a full and decent life—Children with disabilities are the focus of Article 23 of the Convention. The article states that a child with a mental or physical disability should enjoy a full and decent life in conditions that ensure dignity, promote self-reliance, and facilitate the child’s active participation in the community. The article acknowledges the holistic needs of the child.

The CRC unequivocally states that children with disabilities have the right to special assistance and requires that States Parties extend aid, upon application, to any eligible child, taking into account the circumstances of the child and those responsible for his or her care. However, the article lacks the full commitment of any guaranteed level of assistance. During drafting negotiations, the belief that affirmative measures should be taken to ensure that children with disabilities are integrated into their communities was always an important principle. However, there were disagreements among the drafters on how to facilitate this. The primary difference concerned whether the care of children with disabilities lay with governments and should be provided free of charge or whether parents and relatives are primarily responsible with state and private organizations filling in when needed. In addition, some believed that although government should be responsible for the assistance, the CRC should recognize the needs of poor countries and should mandate some level of assistance for them. These differences are reflected in sections 1, 2 and 3 of the article stating that assistance should be provided free of charge where possible, taking into account the financial resources of those responsible for the child. This has been characterized as a “clumsy and disingenuous attempt to avoid taking positive measures which would improve the lives of children with disabilities” (Van Buren, 1995). Although arguments can be made that this standard does not reflect the “best interests of the child” expectation of the CRC, these sections are the guidelines provided regarding assistance to children with disabilities within the context of available family resources augmented by national and international assistance (LeBlanc, 1995).

Article 23(4) binds States Parties to the duty to promote the exchange of information, particularly with developing nations on preventive health care and on the medical, psychological, and functional treatment of children with disabilities. This will be a potentially important benefit to children with disabilities to the extent States Parties actually participate in the exchange of information.

Article 24: Right to highest standards of health and health services—The importance of access to health services for children with disabilities cannot be overstated as many disabilities or secondary consequences can be prevented or minimized with appropriate preventative and other health care. Article 24 guarantees that children with disabilities receive both preventative health care and treatment if a disability occurs. Access to general health care is a critical component of the effort to ensure that children with disabilities are integrated into the mainstream of their community. Moreover, like Article 23 addressing children with disabilities, Article 24(4) also requires States Parties to “undertake to promote and encourage international co-operation with a view to achieving progressively the full realization” of the right to the highest standard of health and medical care available. The needs of developing countries are highlighted.

Article 18: Parental responsibilities—Article 18 on its face appears to focus on the rights of parents to be equally responsible for the upbringing and development of their children and the recognition of the child-care assistance many working parents require. Article 18(2) mandates that States Parties provide “appropriate assistance to parents and legal guardians in the performance of their child-rearing responsibilities” and develop institutions, facilities, and services for the care of children. However, it also recognizes the importance of family in the overall development of children and that families may need assistance in order to provide appropriate parenting. For children with disabilities, the needs of the parents and families may require different and/or additional supports.

Article 4: International Cooperation—The CRC also addresses the importance of international cooperation in the implementation of children’s rights. In the Preamble itself, the Convention articulates the important role of international cooperation for “improving the living conditions of children in every country, in particular in the developing countries.” As stated in Article 4, a State Party must do all it can to implement the rights contained in the treaty. This includes aligning national legislation to the standards of the Convention and carrying out administrative and policy initiatives to fulfill the goals of the CRC. Article 4 goes further requiring that social, economic, and cultural rights implementation activities must be undertaken “to the maximum extent of . . .available resources, and where needed, within the framework of international cooperation.”

The second United Nations treaty of importance in advocacy for infants and young children with disabilities is the newest of the human rights conventions—the Convention on the Rights of Persons with Disabilities (CRPD). A brief history and overview of the CRPD including those articles of particular importance for infants and young children with disabilities is presented next.

Convention on the Rights of Persons with Disabilities

The United Nations has addressed disability issues from the beginning of its history by actively promoting social welfare activities during the 1940s and 1950s—i.e., funding efforts to end diseases that cause disability, end birth defects, improve basic health indicators, and develop rehabilitation centers and trained personnel around the world. The approach began to shift during the 1960s towards efforts ensuring individuals with disabilities could participate in society. Applying a human rights analysis to the situation of individuals with disabilities and advocating for equal opportunity to participate in society became the focus in the 1970s (United Nations Enable, 2012).

Like the CRC, the Convention on the Rights of Persons with Disabilities resulted from concepts developed in numerous earlier UN documents addressing the rights of individuals with disabilities. These documents included the 1971 Declaration on Rights of Mentally Retarded Persons and the 1975 Declaration on the Rights of Disabled Persons. Although as declarations, neither was legally binding, both were instrumental in the evolution of international disability rights advocacy. Although significant for covering disability, children with disabilities were not specifically addressed. Probably most influential of the United Nations precursors to the CRPD was the Standard Rules for the Equalization of Opportunities for Persons with Disabilities that was drafted following a decade (1983-1992) of international focus on disabled persons (U.N. General Assembly, Standard Rules, 1993). The Standard Rules is a detailed framework of principles and implementation strategies that the UN hoped would be used by States Parties to make disability rights a global reality. Although efforts towards drafting a specific convention addressing the rights of individuals with disabilities began in the 1980s, it was the Special Rapporteur on Disability's reports on the implementation efforts in those countries adopting the Standards Rules that kick started the process. According to the Special Rapporteur, little progress was made following adoption of the Standard Rules (U.N. General Assembly, 2000). Despite the fact that all the international human rights conventions included people with disabilities, even if not specifically addressed, and the adoption of the Standard Rules by many States Parties, it was recognized that the application of human rights to individuals with disabilities was going to require something more substantial. Accordingly, calls for a stand-alone Convention were renewed (Degener & Quinn, 2002).

The UN General Assembly created an Ad Hoc Committee with the specific mandate to draft a Convention addressing the rights of individuals with disabilities. The Committee met eight times in New York between 2002 and 2006. In that short period of time, following very contentious debates over fundamental questions, the Committee drafted an international human rights treaty that identifies the rights of persons with disabilities as well as the obligations on States Parties to promote, protect, and ensure those rights. It is modeled after earlier thematic human right treaties, including the CRC. The purpose of the "Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity" (Article 1).

The General Assembly adopted the treaty on December 13, 2006 and it was opened for signature on March 30, 2007. Currently there are 115 States Parties that have ratified the

CRPD and are legally bound to implement those standards. One hundred and fifty three (153) States Parties have signed the treaty which for some is the first step towards ratification. An Optional Protocol provides an avenue for complaints by individuals and/or groups claiming discrimination under the CRPD. As of June 2012, the Optional Protocol has been signed by 90 States Parties and ratified by 65 (United Nations Enable, 2012). The Convention also establishes two implementation mechanisms: the Committee on the Rights of Persons with Disabilities, established to monitor implementation in Article 34, and the Conference of States Parties established to consider matters regarding implementation in Article 40.

One of the most debated aspects of the CRPD was defining the covered group—i.e., who is disabled. After various proposals and language revisions, the Committee did not include a definition of “disability” or “persons with disabilities” as such. However, elements of the Preamble and Article 1 provide guidance. According to the Preamble, “Disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.” In Article 1, “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.”

These statements are remarkable for documenting an evolution in thinking about disability that is very recent. First, the CRPD recognizes that “disability” is an evolving concept resulting from attitudinal and environmental barriers hindering the participation of persons with disabilities in society. Consequently, the notion of “disability” is not fixed but can change, depending on the time and place in which the disability occurs. Second, disability is not considered as a medical condition (impairment) exclusively, but rather as a result of the interaction between negative attitudes or an unwelcoming environment with respect to the condition of a particular individual. The CRPD reflects the belief that by dismantling attitudinal and environmental barriers—as opposed to treating persons with disabilities as problems to be fixed or not fully human—individuals with disabilities can participate as active members of society and exercise the full range of their rights (WHO, 2011). Finally, the CRPD does not restrict coverage to particular persons. It does identify persons with long-term physical, mental, intellectual, and sensory disabilities as covered under the CRPD. However, the reference to “include” assures that this need not restrict the application and States Parties could also ensure protection to others—e.g., persons with short-term disabilities (United Nations Enable, 2012).

This broad and ambiguous definition of “disability” within the CRPD is welcome from many perspectives including those of early intervention specialists who routinely identify children who may not have a specific diagnosis or qualify for intervention services, yet who may well benefit from early therapy or other preventative interventions. The CRPD is not focused on strict definitions or criteria for eligibility; rather, the focus is on ensuring that individuals with or at risk for disabilities are afforded their rights as articulated under the CRPD.

The CRPD, like the CRC, articulates guiding principles that “underlie” the Convention and all of its articles. Article 3 includes the following principles: (1) Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons; (2) Non-discrimination; (3) Full and effective participation and inclusion in society; (4) Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity; (5) Equality of opportunity; (6) Accessibility; (7) Equality between men and women; and (8) Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities. Some of these principles are very similar to the CRC statements on the rights to equality, inclusion, independence and the evolving capacity of children, as reviewed earlier.

Articles of Particular Importance For Rights to Early Intervention

The following section highlights the CRPD articles that have particular relevance for infants and young children with disabilities and their rights to early intervention.

Article 4: General obligations—It is common practice in the UN human rights treaties to include an article that describes the broad obligations of States Parties; the CRPD calls for “full realization” of all human rights and fundamental freedoms in Article 4(1). Further, individuals have access to all rights without discrimination of any kind based on disability. States Parties are obligated to: (1) To adopt all appropriate legislative, administrative and other measures for the implementation of the rights recognized in the present Convention; (2) To take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs, and practices that constitute discrimination against persons with disabilities; (3) To take into account the protection and promotion of the human rights of persons with disabilities in all policies and programmes; (4) To refrain from engaging in any act or practice that is inconsistent with the present Convention and to ensure that public authorities and institutions act in conformity with the present Convention; and (5) To take all appropriate measures to eliminate discrimination on the basis of disability by any person, organization, or private enterprise.

Article 4(1)(i) confirms the need for training of those working with individuals with disabilities on the Convention rights to ensure that individuals have access to those rights. Article 4(2) is particularly important for early intervention service implementation. This paragraph of the Article states that:

With regard to economic, social and cultural rights, each State Party undertakes to take measures to the maximum of its available resources and, where needed, within the framework of international cooperation, with a view to achieving progressively the full realization of these rights, without prejudice to those obligations contained in the present Convention that are immediately applicable according to international law.

The CRC, Article 4, also recognizes the difficulty States Parties may have implementing aspects of the CRC because of both financial and professional limitations. Progressive realization – a process of setting priorities and engaging in activities to the “maximum” of

available resources and with international assistance as needed – is not an excuse for non-compliance but a realistic strategy for eventual compliance.

Article 7: Children with disabilities—Article 7 of the CRPD was debated during drafting because some felt that it was unnecessary given the emphasis on children with a disability that was included in the CRC, particularly Article 23 of that convention. However, ultimately it was decided that highlighting the particular needs of children and in essence reinforcing Article 23 of the CRC was important. The concepts of “best interests of the child,” as a primary consideration in all actions regarding children and “right to express their views” are all concepts found in the CRC. In addition, the right to “full enjoyment of all human rights and fundamental freedoms” on an equal basis with other children is also repeated here.

Article 8: Raising awareness—This article emphasizes the importance of addressing systemic discriminatory attitudes towards individuals with disabilities, a reality that exists around the world. To that end, the CRPD calls upon States Parties to raise awareness thorough out society, including within the family, regarding the rights of individuals with disabilities in order “to combat stereotypes, prejudices and harmful practices,” as well as to develop positive media campaigns and other awareness programs.

Article 10: Right to life—States Parties are obligated in Article 10 to “reaffirm that every human being has the inherent right to life and shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others”. In many ways this article is similar to other “right to life” statements in other human rights documents. However, the language “to ensure its effective enjoyment” is unusual and reflects the importance of ensuring a right to more than simply survival but also a life of quality. For infants and young children with disabilities this article reinforces the right to development in the early years to ensure the highest quality of life.

Article 23: Respect for family—The importance of family and the rights to participate fully in family life for children with disabilities is highlighted in numerous United Nations documents including the CRC and the Standard Rules on the Equalization of Opportunities for Persons with Disabilities (United Nations General Assembly, 1993). Article 23 of the CRPD reiterates the rights contained in those earlier documents and highlights in Article 23(3) the discrimination often faced by children with disabilities that results in “concealment, abandonment, neglect and segregation” of these children, often in institutional settings. To address these practices, the CRPD, Article 23(4) requires States Parties to provide “early and comprehensive information, services and support” to both children with disabilities and their families so that separation from parents and/or family only occurs when necessary for the best interests of the child.”

Article 24: Education—Although Article 24 of the CRPD primarily addresses access to primary and secondary education, the first paragraph does clarify that the right to education must be without discrimination on the basis of disability and on the basis of equal opportunity. Further, the CRPD states unequivocally that States Parties shall ensure an “inclusive education system at all levels.” The right to education is included in numerous

other human rights treaties; the CRPD goes further than any of these in several respects, including the guarantee of inclusive education. As stated in the Salamanca Statement, regular schools with the “inclusive orientation are the most effective means of combating discriminatory attitudes ... building an inclusive society and achieving education for all” (UNESCO, 1994). However, it should also be noted that although the intent of the CRPD is that there be an inclusive educational opportunity throughout the lifespan for persons with disabilities, this may not be the only option when “effective individualized support measures” require a different setting (Article 24(2), (3)). Moreover, Article 24 has particular relevance for early intervention “education” for infants and young children with disabilities. Specifically, the article requires that States Parties provide: (1) reasonable accommodation to individual needs; (2) supports to facilitate effective education within the general education system; (3) opportunities that enable individuals to learn life and social development skills that facilitate their full and equal participation in education; and (4) training for professionals and staff who work at all levels of education.

Article 25: Health—Like the CRC, the CRPD Article 25 calls upon States Parties to ensure that individuals with disabilities have the “right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability.” In particular, States Parties are mandated under this article to “provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children....” This Article, although placed in a health rather than a broader context, nevertheless directly addresses the importance of early intervention services to minimize or eliminate the effect of a disability as the infant or young child develops, and/or prevent secondary consequences. .

Article 26: Habilitation and rehabilitation—Article 26 calls for a broad commitment from States Parties to “enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life.” Included in this duty is the requirement in Article 26(1)b that these services begin “at the earliest possible stage, and are based on the multidisciplinary assessment of individuals needs and strengths.”

Article 32: International cooperation—Article 32(1) recognizes “the importance of international cooperation and its promotion, in support of national efforts for the realization of the purpose and objectives of the present Convention, and will undertake appropriate and effective measures in this regard, between and among States and, as appropriate, in partnership with relevant international and regional organizations and civil society, in particular organizations of persons with disabilities.” This focus on international cooperation is not unique in human rights treaties; rather it reflects the realities of the importance of assistance for many low income countries in complying with human rights standards. However, the CRPD “should not be understood as only applying in a North-South dimension, but also South-North, South-South and North-North” (Schulze, 2010). Nonetheless, the importance of sustainable development and addressing global poverty as

methods to address discrimination on the basis of disability as well as a cause of disability was highlighted in the discussions of the Ad Hoc Committee (UN Enable, 2012).

It is the intent of the CRPD that both developed and resource rich countries will share their expertise and knowledge with those in the resource poor nations in the implementation of the standards. There are numerous ways, in addition to formal government funding allocations, to offer assistance to those States Parties seeking best practice guidance. Offering consultation assistance at the request of both government and non-governmental entities is one way. Article 32 of the CRPD considered in tandem with Article 23(4) of the CRC discussed earlier provide the avenue for early intervention specialists to offer their expertise to create positive change, particularly in developing countries. The human rights treaties are typically considered valuable for the protections provided to the individual covered; in addition the CRC and CRPD are tools to advocate for global early intervention services and resources.

The second section of this article outlines specific action principles to assist States Parties along with international and local non-governmental organizations in the implementation of policies that reflect the values of the CRC and CRPD. Policies that reflect these principles can then guide implementation of programs benefiting individual children, their families, and communities.

Action Principles: International Consensus

The principles, values, and recommended practices articulated by these Conventions provide an overarching framework for professionals in the international community concerned with the well-being of young children with disabilities. Taking this one step further, the professional community has established a related set of principles consistent with those of the Conventions but providing more specific guidance with respect to developing and refining early intervention programs that will yield the most optimal outcomes. Of importance, consensus has been achieved for these “action principles” despite the considerable diversity found in the international community with respect to culture, politics, resources, and a society’s commitment to vulnerable young children and their families (Guralnick, 2008). Each of these action principles is briefly described below and, in many respects, can be viewed as a bridge between policy and ideology on the one hand, and direct services and supports to young children and families on the other.

Principle 1: A Developmental Framework Informs all Components of the Early Intervention System and Centers on Families

Influences on children's development and associated developmental processes are understood to apply equally to *all* children and the developmental approach establishes the foundation for the design and implementation of early intervention programs (Landry & Smith, 2008). This is an important point and reaffirms the full humanity and dignity of all children despite extensive variations in developmental progress. Central to this approach is to assist families with a child with a disability to adjust their patterns of everyday interactions in order to optimally support their child's development (Guralnick, 2011). This can be accomplished by meeting a family's needs in numerous ways including enlisting the

aid of professionals in different fields to assist families to establish developmentally supportive relationships that enhance their child's social and cognitive competence, encouraging participation in culturally relevant family and community-based experiences that further support and expand their child's learning opportunities, and working with the family and larger community to establish initiatives that maximize their child's health and safety. Other efforts can be designed to mitigate the level of any interpersonal or family distress that may emerge, provide material and social resources to the extent possible, and minimize confidence threats with respect to parents' ability to carry out their parenting roles. Assessment tools to gauge risk and protective factors at the levels of the child and family as well as intervention strategies are available that can be organized within and are consistent with this developmental framework. The developmental approach can also be applied to preventive intervention programs for children at risk for delays or disabilities, including children born preterm (Guralnick, 2012)

Principle 2: Integration and Coordination at all Levels of the Early Intervention Program are Essential

Successful early intervention efforts must find ways to organize supports and services around the child in a holistic fashion. Coordinating and integrating health and developmental resources require a commitment to collaborate by service and community teams gathered as part of a process that includes close working relationships with families (Bruder, 2005; Dunst & Bruder, 2006). Cross-sectoral involvement is crucial and strongly encouraged by the Conventions.

Principle 3: The Inclusion and Participation of Children and Families in Community Programs and Activities are Maximized

The Conventions, legal/legislative mandates in numerous countries, and developmental frameworks converge to establish this action principle; one that encourages maximum inclusion of children with disabilities in all family and community activities. Full participation in social, recreational, cultural, and educational activities not only creates a sense of belonging but enhances a child's development by providing access to stimulating learning opportunities available in typical community settings (Dunst, Bruder, Trivette, & Hamby, 2006). Of importance, the experience of inclusion during the early childhood period sets the course for future expectations for full community participation at later stages for both children and their families. Accordingly, each transition point, including child care and educational programs, provides a new opportunity to maximize inclusion.

Principle 4: Early Detection and Identification Procedures are in Place

It is essential for families to understand the meaning and implications of their child's developmental status as early as possible (Marks, Page, & Macias, 2011). Moreover, supportive programs initiated at the earliest stages can minimize the cumulative impact of a child's disability. Although further refinements are needed, well established, reliable, valid, and feasible screening tools along with information to establish risk registries are readily available (Macy, 2012).

Principle 5: Surveillance and Monitoring are Integral Parts of the System

Parental concerns about a child's development must be taken seriously. Correspondingly, some form of ongoing surveillance and monitoring along with a means of regularly disseminating information to parents and communities in general with respect to age appropriate expectations and warning signs should be in place (Marks, et al., 2011). Health care professionals play an essential role in this process (American Academy of Pediatrics, 2006).

Special attention should be given to children and families who exhibit risk factors (e.g., preterm birth, parental mental illness) likely to result in later emerging child disability. The extensive array of risk factors for developmental delay affecting large numbers of children in low-income and middle-income countries has been well documented and poses a unique set of problems (Walker, et al., 2011). Nevertheless, as noted, some preventive interventions appear promising even under circumstances in which resources are severely limited (Engle, et al., 2011). A key to success will be the construction of coordinated and integrated systems.

Principle 6: All Components of the Program are Individualized

This principle recognizes the uniqueness of children and families. Translating this principle into practice requires gaining a thorough understanding of children's developmental and behavioral characteristics and how families and other significant adults interact to build relationships to promote children's social and cognitive competence. The general framework for individualizing assessments and interventions can be found in the first principle. Additional information is needed with respect to barriers to appropriate community experiences and opportunities, threats to their child's health and safety, and constraints in the personal and material resources available to families. The information gathered through such a comprehensive process allows early intervention programs operating within a developmental framework to be tailored closely to existing risk and protective factors at all levels (Guralnick, 2001).

Principle 7: A Strong Evaluation and Feedback Process is Evident

Being as explicit as possible with respect to goals, strategies, and techniques intended to support a child's development, and evaluating progress even informally, is a powerful mechanism for achieving change. This has been apparent since the earliest formal evaluations of early intervention programs (Shonkoff & Hauser-Cram, 1987). Different forms and different levels of sophistication for accountability and evaluation systems have been developed and tested, and each contributes to the effectiveness of early intervention programs.

Principle 8: True Partnerships with Families Cannot Occur Without Sensitivity to Cultural Differences and an Understanding of Their Developmental Implications

This principle recognizes that unless early intervention recommendations and activities are compatible with a family's goals and values, programs will achieve minimal effects. A community's culture, especially the transmission of its values and expectations, are further modified by the family nexus and expressed in family routines and rituals (Fiese &

Spagnola, 2007; Gallimore, Weisner, Bernheimer, Guthrie, & Nihira, 1993). Extensive cultural diversity, including attitude and belief systems about disability, must be factored into the entire early intervention process. Apart from cultural issues related to the meaning of disability, it is also the case that children's development and the transmission of cultural values and expectations are best served by maximizing children's social and cognitive competence.

Principle 9: Recommendations to Families and Intervention Practices Must be Evidence-Based

The field of early intervention has produced a sound body of knowledge with respect to those intervention practices that are likely to produce important benefits for children and families. Guided by a developmental framework, extensive intervention strategies based on research at many levels are available (Spiker, Hebbeler, & Mallik, 2005). As noted, the Conventions emphasize the importance of information sharing and international cooperation. Fortunately, mechanisms for organizing and disseminating current knowledge are becoming increasingly sophisticated. Most materials can be adapted for use in communities with limited resources, although bringing programs to scale in any community remains an ongoing problem (Engle, et al., 2011). Training of professionals, the formation of professional networks, and the availability of materials have been greatly facilitated by internet access (see Professional Training Resource Library of the International Society on Early Intervention: http://depts.washington.edu/isei/ptrl/PTRL_Purpose.php).

Principle 10: A Systems Perspective is Maintained, Recognizing Interrelationships Among all Components

Ultimately, States Parties, regions, and communities that actively promote early intervention programs to a sufficient degree will form a recognizable system with an identifiable infrastructure and corresponding resources. Indeed, for a systems framework to develop there must be a vision integrating the previous principles and adapting that system to changing priorities, resources, knowledge, and possibilities. At whatever level such systems are formed, the identification of leadership groups charged with maintaining a systems perspective is essential. Developmental principles should be at the core of every level, including the family system.

The Conventions and corresponding action principles provide the framework and initial guidance for organizing a truly international effort to enhance in a systematic way the well-being of young children at risk for and those with established disabilities. As indicated in the last principle, leadership is required for early intervention systems to develop, especially in low-income and middle-income countries. Fortunately, the United Nations, in recognition of the significance of the early childhood period to all aspects of children's development and their full participation in family and community life has established early intervention for vulnerable children as a high priority.

Conclusion

There are two achievable and interconnected early intervention advocacy efforts required to address the needs of infants and young children with, or at risk for, disabilities around the world. The first is to convince policy makers to allocate adequate resources to implement best practice, quality programs. The second is to translate what research has taught us about best practice into national policies and programs that will actually be implemented and be effective in a particular country. In addition to the developmental and economic justifications that can be used to advocate for increased resource allocation and the moral arguments that attention to the early intervention needs of infants and young children is the “right” thing to do, the CRC and CRPD provide tools for change, particularly in the establishment of clear and high standards for compliance. These two Conventions mandate substantive action by States Parties to protect both the health and well-being of infants and young children and provide needed special services and supports to maximize the opportunities for community participation and a quality life. Moreover, these human rights treaties also recognize that achieving the goals of both the CRC and CRPD is a global effort —i.e., knowledge and resources must be shared across national boundaries to ensure that all States Parties comply with the Conventions.

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