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Project CHILD



Children and the International Landscape of Disabilities United Nations Disability Policy Analysis

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Children and the International Landscape of Disabilities

United Nations Disability Policy Analysis

Prepared for

The Doha International Institute for Family Studies and Development (DIIFSD)

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Doha International Institute for Family Studies and Development (DIIFSD)

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The Doha International Institute for Family Studies and Development (DIIFSD) is an interdisciplinary global research institute that conducts research and scholarship on the legal, sociological, and scientific basis of the family as the natural and fundamental group unit of society. Through the development of mutually supportive relationships with an international network of family specialists, the DIIFSD promotes family-supportive policy initiatives while reinforcing effective programs that assist the family in successfully fulfilling its numerous roles.

The Doha International Institute for Family Studies and Development was established in 2005 under the patronage of Her Highness Sheikha Mozah Bint Nasser Al Missned and the Qatar Foundation for Education, Science and Community Development. The DIIFSD serves as a global center for providing academic research, interdisciplinary studies, and policy initiatives in support, development, and implementation of family-friendly policies and programs around the world.

Public Policy Research Institute (PPRI)

Texas A&M University

The Public Policy Research Institute (PPRI) at Texas A&M University serves as a key collaborative partner of the Doha International Institute for Family Studies and Development (DIIFSD). The Institute has been recognized as a leading interdisciplinary social policy and family research organization for more than 25 years. During this time, PPRI has successfully completed research projects totaling \$110 million in competitive grants, while continuing to provide scientific research and evaluative services to inform more than 90 public and private sponsors engaged in formulating public policy.

The PPRI is a social problem research institute, focusing on critical societal issues such as education, health, and the welfare of families and children. The Public Policy Research Institute possesses the analytical as well as technical capacities to engage in large scale database development and management, family policy examination, and research on the impact of disability on family functioning. The PPRI staff includes experts on women and children with disabilities and their families including United Nations policies and best practices around the world. The PPRI has worked effectively with DIIFSD on several prior projects including development of the world's top online library for family research (Global FAMIS) and Project CHILD, a worldwide study of children with disabilities and their families.

Introduction

In continuing the implementation of its mission to promote research on, and advocacy for the family, the Doha International Institute for Family Studies and Development (DIIFSD), in partnership with the Public Policy Research Institute (PPRI), at Texas A&M University, initiated a study on the status and needs of children with disabilities and their families around the world. Entitled *Children and the International Landscape of Disabilities (Project CHILD)*, (2009 – 2010), this study embodies a unique and comprehensive world-wide analysis comparing cultural and national responses to children with disabilities and their families. Project CHILD investigated the identification, causes, treatment, education, and transition to adult life of children with disabilities, as well situational impacts upon their families as reported by experts on disability around the world.

Project CHILD is composed of three distinct components: *International Disability Resource Guide*, *Voices from Around the World – Special Report* (both issued separately), and this *United Nations Disability Policy Analysis*.

The *International Disability Resource Guide* is a directory presently containing over 760 entries including national and international disability agencies, professional organizations, scholarly journals, foundations and conferences in 124 different countries complete with descriptions and contact information. Resources were identified through internet searches, in various on-line databases and through recommendations from experts. The *International Disability Resource Guide* is a valuable tool for practitioners, researchers, and families of children with disabilities that serves as a reference of available disability resources.

Voices from Around the World – Special Report integrates findings from 57 countries representing 71% of the world's population. The findings are based upon more than 100 interviews conducted with experts whose experiences capture the realities confronting many of the world's children with disabilities and their families. In this report,



through the voices of experts interviewed, the myriad of issues surrounding the care of children with disabilities throughout the world are detailed. While there are many difficulties involved in serving children with disabilities and their families, there exist several best practices that were shared by experts and policy makers from every corner of the globe. These valuable ideas are placed in their proper perspective and shared in this report—making a solid contribution to all who are involved with children with disabilities: their families, educators, policy-makers, and practitioners.

The *United Nations Disability Policy Analysis* serves as the backdrop for examining the current status of children with disabilities and their families. This historical review shows that the United Nations (UN) initiated leadership efforts through its documented actions in establishing disability policy.

At the end of World War II, nations were searching for ways to maintain international peace, promote social progress and human rights, and improve living standards. Out of this search for improved order and progress, the United Nations was formed. Founded in 1945 by 51 nations, the UN advocates for and implements measures on a broad range of issues including education, human rights, armed conflict, and progressively more throughout its history, disability.

Since the United Nations first addressed disability in 1948, numerous changes in perspective can be observed. For example, the basic definition of disability has shifted over time along with the approach to the treatment of people with disabilities. Schools of thought on education have also shifted from segregated education of students with disabilities in the home or specialized schools to inclusive education in the classroom alongside typically developing students. As UN policies are reviewed, these changes will become evident.

Prevalence of disability

Reliable data on the prevalence of disabilities worldwide are difficult to obtain. However, available data indicate that people with disabilities

represent a significant portion of the global population. At present, 10% of the world's population is estimated to be a person with a disability.ⁱ One quarter of persons with disabilities are children with a disability and eighty percent live in developing countries.ⁱⁱ

What is a disability?

The United Nations currently uses the definition of disability adopted by the World Health Organization (WHO) in 1980. The WHO makes a distinction between three concepts: *impairment*, *disability* and *handicap*. *Impairment* is a person's diagnosis; for example, a person diagnosed with a visual impairment.ⁱⁱⁱ *Disability* is the limitation a person experiences.^{iv} An individual with a visual impairment would be unable to or have difficulty seeing printed material. A *handicap* is the circumstance surrounding the person and their impairment.^v In this instance, a person with a visual impairment would be unable to read newspapers, books and magazines unless they were available in an accessible format such as Braille.

In addition, before examining UN policy on disability, clarification of the terminologies used at the United Nations is needed. The four main types of documents through which the UN communicates are *resolutions*, *covenants*, *declarations* and *conventions*. A General Assembly resolution is the formal opinion of the UN.^{vi} Covenants are formal agreements between two parties to take or not take some action or position.^{vii} A declaration made by the UN General Assembly is a formal statement regarding a topic.^{viii} Conventions are legally binding international treaties.^{ix} Disabilities have been addressed in each of these types of documents.

The Early Years (1945-1955)

Referred to as *The Early Years*^x, 1945-1955 were significant years for the development of human rights at the United Nations. The first landmark human rights policy is the 1948 *Universal Declaration on Human Rights*. The introduction of disability is made in this declaration alongside the important concepts of security, protection and education.

- Article 16 (3) states that “the family is the natural and fundamental group unit of society and is entitled to protection by

society and the State.”^{xi}

- Article 25 (1) declares that “a person has the right to security in the event of unemployment, sickness, disability...”^{xii}
- Article 26 (1) ensures that “everyone has the right to education.”^{xiii}

The implications of these Articles are important to emphasize; disability should not prevent anyone from enjoying their basic human rights, including family involvement, security and education. However, the reality of daily life for many children with disabilities and their families can be quite different. Findings from *Voices from Around the World* indicate that children are often excluded from school and social activities in their communities due to lack of awareness and information regarding disabilities. Many times this is exacerbated by cultural beliefs placing blame on the child or their family for the disability.

Social Welfare Perspective (1955-1970)

From 1955-1970, the *Social Welfare Perspective*^{xiv} emerged as a different approach to human rights. Individuals with disabilities were viewed as less fortunate. Although well intended, this perspective was aimed at assisting people with disabilities because of the belief that they could not help themselves. This is evident in the *Declaration on the Rights of the Child* (1959), which is one of the first UN policies to recognize the rights of the child and include children with disabilities:

- Principle 2 ensures that the child “shall enjoy special protection, and shall be given opportunities to develop physically, mentally, morally, spiritually and socially in a healthy and normal manner and in conditions of freedom and dignity.”^{xv}
- Principle 5 states, “the child who is physically, mentally or socially handicapped shall be given the special treatment, education and care required by his particular condition.”^{xvi}
- Principle 10 calls for the special protection of children from practices that foster discrimination.^{xvii}

While some might argue that children with disabilities do not require special treatment, but rather access to the same protection and rights as any other child, this Declaration was an important

first step in recognizing children with disabilities.

In 1966, two Covenants were added to the *Universal Declaration on Human Rights*, which completed the *International Bill of Human Rights*. Almost twenty years after the *Universal Declaration on Human Rights*, the *International Covenant on Economic, Social and Cultural Rights* and the *International Covenant on Political and Civil Rights* both reaffirm that the family is the fundamental group unit of society.^{xviii, xix} The *International Covenant on Economic, Social and Cultural Rights* goes on to ensure the widest possible protection and assistance for the family, particularly for its establishment as it is responsible for the care and education of dependent children. This Covenant also recognizes the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.^{xx}

The next policy that addressed disabilities emerged three years later. In the *Declaration on Social Progress and Development* (1969), Article 19 emphasizes the need to protect the rights and welfare of people with disabilities, especially children and youth.^{xxi} It also encourages their full integration into society.^{xxii}

While the United Nations encourages education and access to healthcare in several human rights policies, *Voices from Around the World* indicates that many children with disabilities still lack these basic rights. Expert interviews in this report confirm that the integration of children with disabilities into society remains a challenge, but find integration to be more successful when the family is a strong advocate for the child.

The Human Rights Approach (1970s)

The Human Rights Approach to disabilities began in the 1970s.^{xxiii} By this time, the perspective on disability was no longer that of a case for charity, but rather a human rights issue. This shift is reflected in much of this decade's language. In the early 1970s, "mentally retarded" was a common term used in reference to people with intellectual disabilities. Toward the end of the 1970s, "disabled person" became the more accepted term. However, putting the word "disability" before person emphasizes the disability rather than the person. This terminology would not change until 1993 when "person with a disability" became the standard term. The *Declaration on the Rights of Mentally Retarded Persons* (1971) is the first policy specifically devoted to people with disabilities. It

calls for national and international action to ensure its use as a common basis and framework for the protection of the rights of people with disabilities. Article 4 states that:

"...whenever possible, the mentally retarded person should live with his own family or with foster parents and participate in different forms of community life. If care in an institution becomes necessary, it should be provided in surroundings and other circumstances as close as possible to those of normal life."^{xxiv}

This Declaration never mentions the option of living independently. It is only recently that the concept of independent living has emerged as a viable option for people with all forms of disability. However, *Voices from Around the World* provides multiple accounts of the general underestimation of the capabilities of people with disabilities as a major obstacle to independent living.

Many people, including women and children, have acquired disabilities as a result of warfare and armed conflict. In 1975 alone, there were 22 instances of armed conflict around the world.^{xxv} This spurred the UN General Assembly to adopt the *Declaration on the Protection of Women and Children in Emergency and Armed Conflict*. Article 5 of this Declaration states, "all forms of repression of women and children shall be considered criminal."^{xxvi} Repression, in this instance, includes imprisonment, torture and shooting, which often result in permanent disability.

More policies specific to disabilities followed in 1975 including the *Declaration on the Rights of Disabled Persons*, which represents the first time the term "disabled person" is defined by the United Nations. Article 1 defines disabled person as:

"any person unable to ensure by himself or herself the necessities of a normal individual and/or social life, as a result of a deficiency in his or her physical or mental capabilities."^{xxvii}

This definition implies a deficiency of the person, whereas the current WHO definition identifies disability as a deficiency of society. In other words, societies should adapt to persons with disabilities, not the reverse. However, further steps need to be taken to communicate this distinction more clearly to society. As experts reflected in *Voices from Around the World*, many people continue holding the view that persons with disabilities are in some way deficient and in need of special

assistance. Article 2 continues with “individuals with disabilities shall have equal rights without distinction or discrimination.” The policy also recognizes that people with disabilities have the right to education, medical care, economic and social security, and employment.

World Programme of Action and Decade of Disabled Persons (1980-1992)

The *World Programme of Action (WPA)* and *Decade of Disabled Persons* began in the 1980s. In 1981, the *International Year of Disabled Persons* sought to define the relationship between a person with a disability and their environment.^{xxxix} In 1982, the *World Programme of Action (WPA)* resulted from the *International Year of Disabled Persons* and served as an international framework for disability policy on prevention, rehabilitation, and equalization. Further, the WPA encouraged national governments, the United Nations and non-governmental organizations to cooperate on the issue of disabilities. Changing views of disability from the medical model or charity perspective to a social model or human rights perspective was also emphasized as well as the importance of examining disability issues in the settings in which they occur.

The *Decade of Disabled Persons* spanned from 1983-1992.^{xxx} During this time, the number of activities recommended for improving the situation and status of persons with disabilities increased. Financial resources, education and employment opportunities were of great importance. The United Nations itself began opening all employment opportunities to people with disabilities.^{xxxi} A 1987 mid-decade review concluded that due to slow progress, efforts would continue after the end of the decade.^{xxxii}

Cooperation and support of national governments are examined throughout *Voices from Around the World*. Often, government officials overlook children with disabilities and their families, resulting in a lack of policy implementation and low funding.

The *Convention on the Rights of the Child* (1989) is the first internationally binding treaty that discusses in detail the treatment of children with disabilities.

- Article 1 begins by stating that the Convention’s ratifying State Parties must respect the rights of the child without

discrimination because of the child’s or parent’s disability.^{xxxiii}

- Article 23 addresses several rights in regards to children with disabilities.
 - .1 “State Parties must recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child’s active participation in the community.”^{xxxiv}
 - .2 “State 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 child’s condition and to the circumstances of the parents or others caring for the child.”^{xxxv}
 - .3 “Recognizing the special needs of a disabled child, assistance shall be provided free of charge, whenever possible, taking into account the financial resources of the parents or others caring for the child.”^{xxxvi}
 - .4 “State Parties shall promote the exchange of appropriate information in the field of preventative health care and of medical, psychological and functional treatment of disabled children.”^{xxxvii}

Article 23 takes many steps for ensuring that children with disabilities receive equal rights, but there are many ambiguities allowing State Parties a reprieve if the financial resources are not available.^{xxxviii}

Shortly after the passage of this Convention came the United Nations’ *Tallinn Guidelines for Action on Human Resources Development in the Field of Disability* (1990). These Guidelines encourage the recognition of persons with disabilities as agents of their own destiny rather than dependent objects of governments.^{xxxix} The Guidelines also encourage the inclusion of children with disabilities in the regular school system. This is the first time that it is referenced internationally that children with disabilities should be able to attend the

regular school system. Inclusion of children with disabilities in the regular education classroom is reviewed at length in *Voices from Around the World*. However, in many places where inclusive education exists, physical barriers, such as stairs and lack of support by teachers and school officials often prevent children with disabilities from attending school.

The *Tallinn Guidelines* also suggest that the training of people with disabilities should include socialization and self-help skills to prepare them for independent living.^{xi} The Guidelines recognize that people with disabilities can live independently, whereas earlier policies only recognize the options of residing with the family or in an institution. While the rights of children with disabilities transitioning to adulthood are encouraged in policies like the *Tallinn Guidelines*, *Voices from Around the World* finds there are often few resources available to aid in this process. Programs to assist adults with disabilities in securing employment, independent living, or continuing their education are few. Often the family is left to bear this burden alone, leading to one of the main concerns of most families of children with disabilities: What will happen to my child when I die? This was expressed universally by experts interviewed in *Voices from Around the World*.

Similarly, the United Nations' *Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care* (1991) defines fundamental freedoms and basic rights of people with mental disabilities. This document served as a reference for national legislation.^{xii} These twenty-five Principles address issues such as the protection of minors, life in the community, the determination of mental illness, confidentiality and consent to treatment.^{xiii} While the document is not legally binding, there was an expectation of application.^{xiii}

The Standard Rules on the Equalization of Opportunities for Persons with Disabilities (1993-1999)

The *Standard Rules on the Equalization of Opportunities for Persons with Disabilities* (1993) dominated the early 1990s. The United Nations' development of the *Standard Rules* was based on knowledge gained during the *Decade of Disabled Persons*. The purpose was to ensure that people with disabilities have the same rights and obligations as others.^{xiv} The Rules provide

guidelines for increasing awareness, medical care, rehabilitation, support services, accessibility, education, employment, income maintenance and social security, family life and personal integrity, culture, recreation and sports, and religion.^{xlv} They also call for the appointment of a Special Rapporteur to monitor the implementation of the *Standard Rules*. Mr. Bengt Lindqvist of Sweden was appointed as the first Special Rapporteur on Disability from 1994-2002. Sheikha Hissa Khalifa bin Ahmed al-Thani, Qatar, served as Special Rapporteur from 2003-2009. In August of 2009, Mr. Shuaib Chalklen of South Africa was appointed as Special Rapporteur on Disability for 2009-2011.

Also, in 1993, the United Nations adopted the *Vienna Declaration and Programme of Action* developed by the World Conference on Human Rights, reaffirming the *Universal Declaration on Human Rights*. Article 22 of the *Vienna Declaration* states that steps needed to be taken to ensure non-discrimination, and the equal enjoyment of all human rights and fundamental freedoms by people with disabilities, including their active participation in all aspects of society.^{xlvi}

The United Nations' World Summit for Social Development, held in 1995, adopted the *Copenhagen Declaration on Social Development*. This Declaration attempts to respond to the material and spiritual needs of individuals with disabilities, their families and communities.^{xlvii} In 1995, the United Nations' 4th World Conference on Women adopted the *Beijing Declaration*, which affirms equal rights to women and girls who face barriers such as disability.^{xlviii}

Millennium Development Goals and the Convention on the Rights of Persons with Disabilities

The new Millennium brought about a new focus for the United Nations. The *Millennium Development Goals* (MDGs) are eight goals to be achieved by 2015 that address critical issues worldwide.^{xlix} While disabilities are not the focus of the MDGs, experts argue that disabilities are a cross cutting issue and must be addressed in order to achieve the goals. For example, children with disabilities who are excluded from school must be addressed to meet the MDG of 100 percent of children receiving a primary education.

At the 2000 World NGO Summit on Disability, attendees called for an international treaty on the rights of people with disabilities.¹ This led the

General Assembly to appoint an Ad Hoc Committee to consider proposals for an international convention focused on the rights of persons with disabilities in December 2001. The Ad Hoc committee met during 2002-2006 and developed the current disability policies. The *Convention on the Rights of Persons with Disabilities* (CRPD) is the first legally binding treaty specifically dealing with disabilities. The Convention aims to promote, protect, and ensure the full and equal enjoyment of all human rights by persons with disabilities. It focuses on key areas of accessibility, personal mobility, health, education, employment, habilitation, rehabilitation, participation in political life, equality and non-discrimination. The implementation of the CRPD is monitored by the Committee on the Rights of Persons with Disabilities. To locate the most current information on signatories and ratifications of the CRPD visit <http://www.un.org/disabilities/>.

While both developed and developing countries alike can agree on the importance of disability policy, evident by the more than 145 signatories to the CRPD, it is vital to discuss unique differences in types and causes of disabilities. In developing countries, the types of disabilities diagnosed tend to be more visible, such as people who are deaf, blind, or have severe physical or intellectual disabilities. Less visible disabilities are often overlooked. Developed countries tend to diagnose all types of disabilities, bringing a greater awareness to less visible disabilities, such as learning disabilities, milder intellectual disabilities and behavioral disabilities.

In developing countries, disabilities often result from disease, malnutrition, lack of prenatal care, and injuries. Because of medical advances around the world, more children who would have died in the recent past are now surviving, many of whom have lifelong disabilities. More children in developed nations are born with a disability than those who acquire them. Also, in all countries, as life expectancy increases so does the number of elderly persons with acquired disabilities. Because of these differences, each country will have to determine how they can best implement UN policies on disability.

In examining the UN policies on disability through time, several changes in the conceptualization of disability and what it means to be a person with a disability come to light. The early approach to people with disabilities was that of charity. The concept that they need assistance and could not

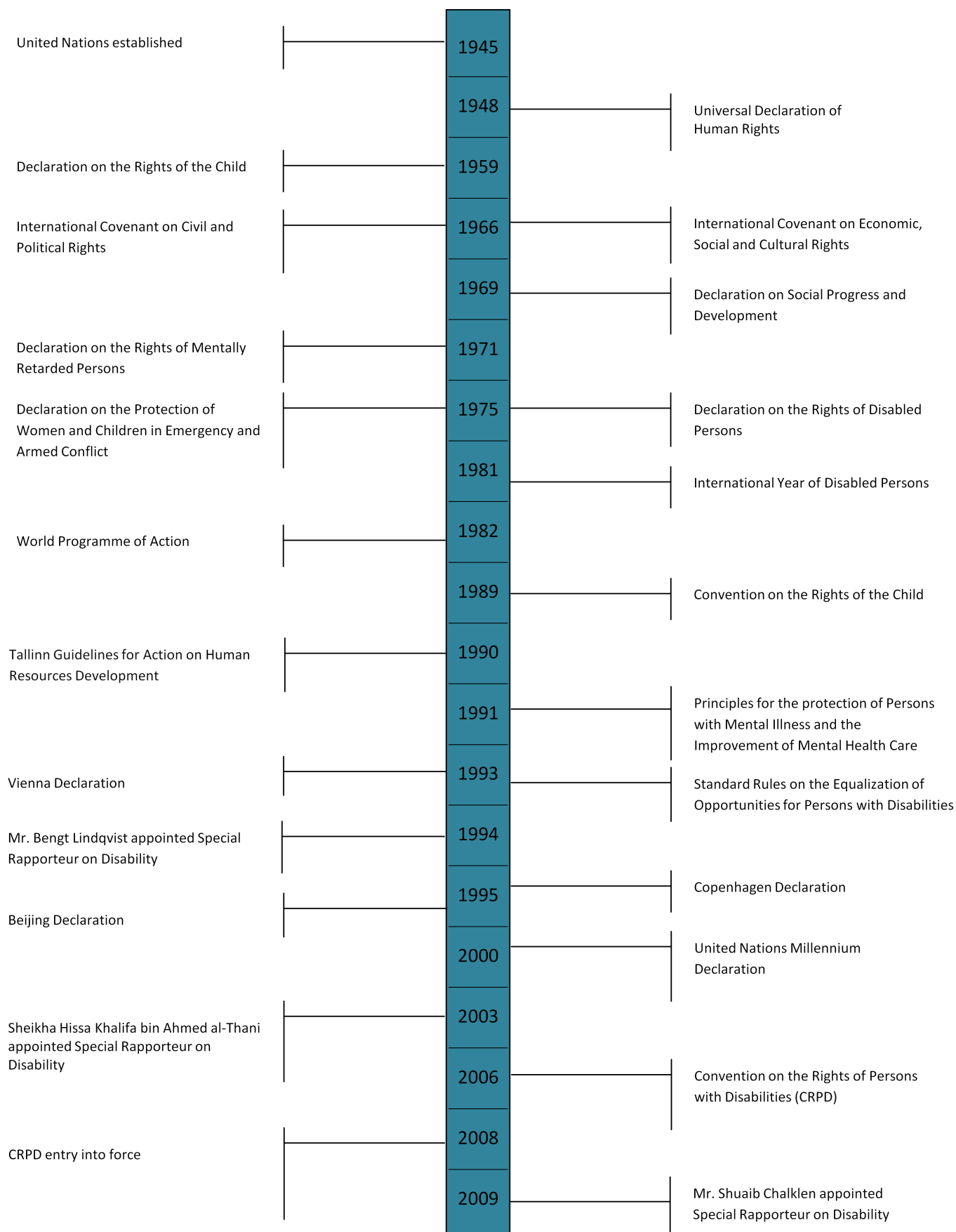
help themselves was dominant. In the 1970s, views shifted to a more human rights-oriented perspective and brought about the recognition that people with disabilities should have equal rights and can contribute much to society when the barriers to participation are removed.

Other major changes include shifts in terminology, acceptance of a greater degree of independent living, and the recognized right to an education. Early phrases such as “mentally retarded” and “disabled person” have been replaced with people first language. In the early 1990s the terminology shifted to acknowledge the person first and the disability second. Phrases such as “children with disabilities” acknowledge that the child is more than the disability.

Another shift in thinking occurred in living situations for people with disabilities. In early policies, the available options for a person with a disability included living at home or in an institution. The *Tallinn Guidelines* (1990) introduced the concept that people with disabilities should be provided training and self-help skills that can prepare them for independent living. Similarly, approaches to education have also changed over time. Early on, children with disabilities either received no education or were educated in special schools. This shift also occurred with the adoption of the *Tallinn Guidelines*, which first called for inclusive education.

While great strides have been made in regards to perception and treatment of people with disabilities, particularly children with disabilities, many will agree that there is more work to be done, especially in developing countries. As seen in the past with the *Decade of Disabled Persons*, an increase in awareness and funding can be a catalyst to bring about future change in the field of disabilities. However, more work needs to be done to determine how these policies effect children with disabilities and their families.

UNITED NATIONS TIMELINE



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