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**Advancing the Rights of Persons with Disabilities:
A US-Iran Dialogue on Law, Policy, and Advocacy**

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Iran and America: A Dialogue on Disability

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Experts on disability policy from Iran and America have come together for the express purpose of sharing experiences and perspectives on how best to advance the interests and rights of persons with disabilities in the two countries and elsewhere. The interest is grounded in the fact that persons with disabilities virtually everywhere suffer from stigma, social exclusion, discrimination, and various forms of abuse. The barriers to inclusion, education, employment, and acceptance can be physical, attitudinal, legal and economic.

Efforts to improve the rights of persons with disabilities have been underway for decades, but they began to accelerate in the 1970s. Most countries have made advances in improving access and opportunity, but results vary tremendously. It was the combination of growing interest and uneven progress that led directly to the United Nations Convention on the Rights of Persons with Disabilities (CRPD).

The CRPD is the newest UN human rights treaty, coming into force in May 2008, in a historically short period of time. It is testament to the high level of international interest in enhancing the rights of persons with disabilities. The US has signed, but not yet ratified, the CRPD while Iran ratified it in 2009. The US has a well-developed series of laws delineating and protecting the rights of disabled persons, while Iran is at the early stages of strengthening its legal and regulatory regime. Both countries are in an ongoing struggle to make further progress. The CRPD was an important catalyst for the Iran-America dialogue.

Participants in the *Dialogue* had an opportunity to share their knowledge and experience on marginalization, along with ideas for strategies that could alter circumstances using the framework of the CRPD.

After the *Dialogue's* two meetings had been completed, an important report related to the CRPD was issued jointly by the World Health Organization (WHO) and the World Bank. The World Report on Disability was prepared, in part, to assist countries in implementing the CRPD. Issued in June, 2011, the new report finds that about one billion people in the world live with a disability. The report shows a correlation between disability and poverty. About 20 percent of the world's poorest people live with a disability, and an estimated 80 percent of those with disabilities live in low-income countries. The report highlights the fact that significant progress on meeting the UN Millennium Development Goals (MDGs) requires more action and attention to addressing the health, education, employment and other needs of people with disabilities (WHO, 2011).

Background

The WHO estimates about 14 percent of the world's population has some form of physical, mental, or developmental disability. Definitions and survey methods vary, leading to estimates of disability in America in the 13-16 percent range, while the Iran government estimates that about four percent of the population is disabled (WHO, 2011). What does not vary is the historical marginalization of persons with disabilities. Only the details differ—and the evolution of public policy.

Disability rights in the United States

The rights of disabled persons in America have grown in fits and starts through the nation's history. As in most societies, the primary responsibility for care rests with family members. That was true in the America of the 1600s, and it is true today.

However, families struggling with the special challenges of family members began to join together to push for broader community and societal responses. In 1817, the American School for the Deaf was founded in Hartford, Connecticut. It was the first special school for disabled children in the entire Western Hemisphere (Disability History Timeline, 2002). In 1864, Congress authorized the first college in the world specifically for disabled persons, the Columbia Institution for the Instruction of the Deaf and Dumb and Blind. It would later become Gallaudet University (Disability History Timeline, 2002).

In 1918, concerns for disabled soldiers returning from World War I led to the first federal law granting rehabilitation services and civil employment rights to these veterans, the Smith-Sears Veterans Rehabilitation Act (Disability History Timeline, 2002). It is worth noting that only disabled veterans were covered by the new law, thus creating a divide among disabled veterans and all other disabled persons that lives to the current day. Iran, and many other countries, also has very different rights and privileges for disabled veterans vs. all others. This divide presents both challenges and opportunities for advocates for disabled persons.

The 1970s are sometimes thought of as the coming of age of the disability rights movement in the United States. It is clear though, that much of the groundwork for the progress made after 1970 was laid well before that. Here are a few noteworthy events:

The Social Security Act became law in 1935. Intended primarily to provide old-age benefits, it also made funds available for blind individuals and disabled children.

- Several advocacy organizations were formed in the 1940s: the National Federation of the Blind, the American Federation of the Physically Handicapped, the National Mental Health Foundation, the Paralyzed Veterans of America, and the National Paraplegia Foundation. These groups sought to end employment discrimination, challenged the institutionalization of persons with disabilities, and pursued specific interests closely associated with those they represented. They individually and collectively contributed to changes in law.
- Through the 1950s and 1960s, existing vocational rehabilitation programs were expanded while new ones were created, and Social Security was expanded in

multiple steps to include benefits for disabled workers. Various public awareness campaigns focused on employment played an important role.

- President Kennedy, influenced by his own sister's developmental issues, pushed for the de-institutionalization of disabled persons and embraced a law to help fund community mental health centers as an alternative. In 1963, a new law was enacted requiring that all disabled children be educated and provided federal financial assistance to that end (1963).
- Medicare and Medicaid were established, bringing federally subsidized health care to disabled and elderly Americans covered by Social Security (1965).
- The Architectural Barriers Act required that all federal buildings be accessible to disabled people (1968). (Disability History Timeline, 2002).

In the early 1970s, disability rights groups, inspired by prior victories and informed by the Civil Rights movement, began to seek strength in numbers. A major turning point towards greater cooperation among different disability groups occurred in 1977 when hundreds of protestors demonstrated inside the building that housed the office of Joseph Califano, the Secretary of Health, Education, and Welfare, insisting that he sign regulations to implement a 1973 law expanding vocational rehabilitation rights and programs (Disability History Timeline, 2002). Their ultimate success inspired still more activism. Progress continued through the 1980s with a multitude of legal changes to assure greater access to programs and benefits, court decisions in favor of disabled persons, and widely publicized stories that increased public awareness.

Access to education, employment, and independent living were the unifying issues. Persons with physical disabilities emphasized physical accessibility and safety; persons with developmental disabilities emphasized acceptance—in the workplace and society generally; and persons with mental illness (and their advocates) focused on self-determination and independent living.

Finally, momentum fed by scores of smaller measures of progress led to the 1990 passage of the Americans with Disabilities Act (ADA). This was a watershed moment. The law provided comprehensive civil rights protection for people with disabilities, much as the Civil Rights Act did for racial and religious minorities. The ADA requires all governmental facilities and programs be accessible; that all but the smallest businesses make “reasonable accommodations” for disabled workers; that public accommodations (stores, restaurants, hotels, etc.) make “reasonable modifications” to ensure access; and that public transportation and communication are made accessible.

Over the next 18 years, an enormous amount of progress occurred. Building codes were changed to assure access in new construction. Older buildings were renovated with the ADA requirements in mind. Employers changed. Schools changed. Laws assuring access to education for some disabled children were expanded into the Individuals with Disabilities Education Act (IDEA).

ADA spawned many lawsuits in the following years, and a number of court decisions narrowed the definition of eligibility for many programs and services. Eventually, there was

a critical mass of support to have another look at the ADA. The ADA Amendments Act of 2008 broadened the scope of who was considered disabled under the law.

The US now has a legal and regulatory regime that is the envy of many countries; nevertheless it is still full of shortcomings and faults. A major challenge is the lack of resources—for the individualized care that disabled children often need to succeed in schools; for independent housing with associated attendant care to fulfill the promise of independent living for developmentally disabled persons; for support services to permit persons with physical disabilities to live independently; and for support services to employers or educators who wish to comply fully with the law.

Disability rights in Iran

The road to equal rights for persons with disabilities in the Islamic Republic of Iran has been a tumultuous one—just as it has been in most countries. Stigma and lack of recognition of the needs of this population, both by the general population and the government, are major impediments to change. But the country has made important progress for decades. An early breakthrough occurred in 1920 when a German missionary and priest pioneered the first education center for the blind (Salenhpour & Adibsereshki, 2001). A handful of other specialized institutions followed, laying the groundwork for disabled persons, family members, and civil society to start seeking more legal rights.

The Iranian Constitution contains no broad reference to the rights of persons with disabilities, but the section on “Welfare Rights” (approved in 1979; amended in 1989) states that those with disability should benefit from Iran’s social security system. These rights had their origins in legislation from 1959 that first granted some vocational rehabilitation rights to persons “whose prospects of securing and retaining sustainable employment are substantially reduced as a result of physical and mental impairment...” (International Labor Organization, 2011).

Like most countries, Iran wrestles with the challenge of defining disabilities that trigger eligibility for rights and benefits. The State Welfare Organization (SWO) is the arm of government that provides welfare benefits to those who qualify. The SWO defines just four types of disabilities: physical, hearing, visual, and mental (Alaedini, 2004). Then, after the Iran-Iraq War, which resulted in a newly disabled population of 400,000 persons, the government created a new category—*janbaz*—“those who were willing to lose their lives” (Alaedini, 2004). The government created the Janbazan Foundation to assist these war veterans. As is common elsewhere, disabled war veterans received special treatment.

Since 1959, there have been numerous laws and regulations passed to address disability related issues leading up to the Disability Protect Act, passed in 2003, which is Iran’s most progressive and comprehensive legislation concerning disabled persons. Obviously informed by the laws of many other nations, the Disability Protect Act includes 16 articles providing legal protections for disabled persons in areas such as public building access, education, housing, and finance. Some sections relate to employment and inclusion of disabled persons in the workforce. For example, organizations receiving state funding must hire three percent of their workforce from the general disabled population (and 10 percent

veterans) (Alaedini, 2004). The law's reach is broad, but there is no monitoring system to ensure compliance, and no sanctions are enforced. For example, the law requires public buildings to be fully accessible; in practice, little progress has been made (Bahreini, 2007). Similarly, most public transportation is not accessible to the majority of persons with disabilities.

A legal regime is very important, even if it is not yet enforced in a meaningful way. Currently, benefits provided through the SWO are even more important. The SWO offers services through three different branches: social support, prevention, and rehabilitation. Unfortunately, bureaucratic and other obstacles, and financial constraints, limit the number of people served (Bahreini, 2007). More governmental response is required. Advocates may have a real opportunity to influence events in this area.

Advocacy organizations, especially the trail-breaking Iranian Rehabilitation Society and the National Society for the Protection of Children, both founded in the 1960s, have made a huge difference. They have inspired the creation of nearly 250 disability-related NGOs throughout the country (Salenhpour & Adibsereshki, 2004).

Employment continues to be a major challenge, as always, but the situation in Iran is especially complex. The nation's population of about 73 million is young—the median age is 25—and the unemployment rate is about 15 percent. The unemployment rate for disabled persons is estimated to be twice as high. Whatever degree of willingness there may be to assisting persons with disabilities, unemployed young people and their families are not likely to act so charitably when it comes to making the difficult job market even more competitive. Furthermore, notwithstanding new laws that require better access to public buildings, schools, and housing, the lack of compliance limits the potential for progress.

Employers' attitudes continue to be a significant barrier as well. Studies show ongoing prejudices and misconceptions about the quality of work that can be expected of persons with disabilities. The most isolated and marginalized group continues to be persons with intellectual disabilities, whose education opportunities are severely limited, thus circumscribing their future chances for employment. Employers are largely ignorant about legal requirements (not enforced, as noted) and incentives available for hiring the disabled. Change is slow, but positive, aided in part by the presence of so many disabled veterans from the Iran-Iraq War.

The problem of definition: who is disabled?

This question bedevils policy makers and researchers. International comparisons are impossible if no common definition is used. It defies logic that 15 percent of Americans could be disabled while only 4 percent of Iranians are disabled. The most logical explanation is a difference in definition.

The World Health Organization wrestled with this question in the early 1970s when it was attempting to develop estimates of global need for rehabilitative services. It brought forward many questions: should malnutrition count? At what point should an elderly person slowing down both physically and mentally be considered disabled? What about severe mental disorders? Debilitating pain? Alcohol or drug abuse? Morbid obesity? Disabling conditions that improve or are cured? WHO's earliest effort in 1970 estimated that 10 percent

of the world's population was disabled. Mental health was largely absent from those early numbers (Heilander, 2006). The new World Report on Disability opts for a broadly inclusive definition, thus suggesting a significant increase from earlier estimates to its current estimate that approximately 15 percent of the world's population lives with a disability (World Health Organization, 2011).

The definitional question is critically important every time a nation wants to consider granting rights and privileges. Programs that afford funded benefits are carefully drawn so policy makers will know how much things cost. Eligibility is determined by definitions, so they are critical to program design. The Disability Insurance Program in the Social Security Act is proportionately the fastest growing part of the system, especially since the recession of 2008. Promises of federal financial support to meet commitments made in the IDEA law have never been met. The funds were never forthcoming because the needs greatly outstripped the estimates. When the ADA was enacted into law, enormous care was given in circumscribing the responsibilities of business owners and employers.

The ADA would evolve through regulations, behavior, and the courts. A steady stream of court cases served to more narrowly define eligibility at a time when society was realizing that more and more people had disabling conditions previously unrecognized. Abused and neglected children are a prime example. Compromised elderly people are another. So, in the ADA Amendments, a more comprehensive definition was advanced and enacted into law.

The ADA Amendments expanded the definition of disability to include the following:

- Having a physical or mental impairment that substantially limits one or more major life activities;
- Having a record of such an impairment; or
- Being regarded as having such an impairment.

The ADA Amendments expanded the definition of “major life activities” to include caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating, and working. It also added a new category of “major bodily functions” that includes such things as a functioning immune system; digestive, bladder, and bowel functions; neurological and brain functions; respiratory and circulatory functions; and reproductive functions. Furthermore, these determinations are made as if any mitigating measures—medication, medical equipment, prosthetics, hearing aids, etc.—did not exist.

These new definitions went into effect on January 1, 2009, and continue to be refined in the courts.

The UN Convention on the Rights of Persons with Disabilities (CRPD)

First proposed in 2001, the CRPD was developed over five years by an Ad Hoc Committee. Final language was adopted by the UN General Assembly in December, 2006; the documents were opened for signature in March 2007; and the convention first entered into force in May, 2008, after 20 countries signed on.

According to the UN, the CRPD has been signed by 153 countries (and counting), of which 103 have also ratified it. Iran is one of nine countries that skipped signing and went immediately to ratification, while the US is one of 59 countries that have signed but not yet ratified the treaty. An “Optional Protocol” that was developed concurrently with the CRPD has been signed by 90 countries and ratified by 63. Neither the US nor Iran is in this group.

The US signed the CRPD in October, 2009. President Obama has not yet sent a formal request for ratification to the US Senate, but is expected to do so before the 2012 elections. Iran’s Parliament ratified the CRPD on October 23, 2009. It is important to note that various countries, including Iran, have included “reservations” in their ratification. Iran’s reservation: “... with regard to Article 46, the Islamic Republic of Iran declares that it does not consider itself bound by any provisions of the Convention, which may be incompatible with its applicable rules,” has raised concern that such a broadly written statement could negate the Convention’s legal impact in Iran.

The US mostly stayed on the sidelines during the development of the CRPD. The administration of George W. Bush reportedly believed these issues were best left to national governments rather than a multi-lateral treaty process. Furthermore, with its own extensive legal regime relating to rights of persons with disabilities, the Administration apparently saw little benefit in a UN convention. US inaction was a great disappointment to disability rights organizations.

At the same time, a remarkably broad coalition of nations did come together to develop the CRPD in a very short period of time. The CRPD was the first human rights convention process that saw active and supportive participation from across the Islamic world. Iran was one of those countries.

Eight principles form the basis for the CRPD:

- Respect for the inherent dignity, autonomy, and independence of all persons;
- Non-discrimination against any person;
- Full and effective participation and inclusion in society;
- Respect for differences and acceptance of persons with disabilities as part of human diversity and humanity;
- Equality of opportunity;
- Accessibility;
- Gender equity; and
- Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

It is the desire to incorporate these principles into the laws and behavior of the societies and peoples of Iran, the United States, and elsewhere that motivated the US-Iran Dialogue.

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