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

EDITORS  
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**Allen Moore**  
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**November 2011**

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# Table of Contents

Preface and Acknowledgments.....	5
Project Introduction - Iran and America: A Dialogue on Disability.....	7
<i>Allen Moore and Sarah Kornblet</i>	
An Overview of the Situation of the Disabled in Iran.....	15
<i>Mohammad Kamali</i>	
United States Ratification of the Convention on the Rights of Persons with Disabilities: Would it make a Difference?.....	21
<i>Janet E. Lord &amp; Michael Ashley Stein</i>	
The International Convention on the Rights of Persons with Disabilities and its Applications in the Iranian Internal Regulatory System .....	29
<i>Ali Saberi</i>	
The New World of Inclusive Education: A Review of the Convention on the Rights of Persons with Disabilities and the American Experience .....	35
<i>Allison deFranco</i>	
Let's Disable Her Further, Shall We? The Cast of Gender on Disability Rights in the Iranian Context .....	43
<i>Hengameh Saberi</i>	
Autism and Disability Discourse and Policy in the Comparative Perspective .....	51
<i>Ari Ne'eman</i>	
The Role of Non-Governmental Organizations as Reflected in the Social Movement of the Disabled in Iran: Achievements and Obstacles.....	61
<i>Soheil Moeini</i>	
Assessing the Policy Divide between Veteran and Non-Veteran Americans with Disabilities.....	67
<i>Michael E. Waterstone &amp; Michael Ashley Stein</i>	
About the Authors.....	73
The Stimson Center.....	76



## Preface

The Stimson Center project, *Iran and America: A Dialogue about Disability* (“*The Dialogue*”), held in partnership with the Harvard Law School Project on Disability, BlueLaw International LLP, and Iranian partner organizations, assembled civil society leaders, academics, and other experts for a US-Iran cross-cultural dialogue on disability law and rights. *The Dialogue* laid the groundwork for an enduring community exchange that has culminated in this informational volume, “***Advancing the Rights of Persons with Disabilities: A US-Iran Dialogue on Law, Policy, and Advocacy***” with articles written by participants and intended for use by both countries as they determine how best to implement the UN Convention on the Rights of Persons with Disabilities (“The Convention”).

*The Dialogue* has afforded a unique, open platform for creative thinking on how to integrate the content of the Convention into a country’s policy and legal system. Participants met for two sessions over the course of a year, in Istanbul, Turkey. The first was an initial planning meeting in August 2010, and the second in March 2011. At the March workshop, 11 Iranian and US disability rights advocates and experts from academia, non-governmental organizations, and law and policy organizations convened for an in-depth discussion of matters surrounding disability rights and the status and future of the Convention in both countries. The March Session began with background presentations on the history of disability rights in both countries, including the current status of those rights.

In the course of these meetings, participants from both countries shared personal and professional experiences and offered candid accounts of challenges posed due to a variety of factors. Those factors included ignorance of the law in the general population; weak laws; lack of legal enforcement; and a lack of resources to implement “required” change. Several themes were addressed, including similarities and differences of law and implementation practices among countries; the social debate surrounding disability rights through the lens of an individual’s career, education, or family; and the effects of war on persons with disabilities, including the distinct advantages that disabled veterans in both societies receive relative to other persons with disabilities. Disability support mechanisms were another recurring theme, more specifically, looking at structures already in place, and exploring the effectiveness of forging new advocacy collaborations with organizations working locally, regionally, and globally on issues surrounding disability rights.

Beyond the two sessions in Istanbul, participants continue to utilize important ideas and lessons learned to spread knowledge and awareness to others. This volume is the project’s final product and is produced in both an English and Farsi edition.

The Stimson Center remains grateful for its partnerships with BlueLaw International and the Harvard Law School Project on Disability. Experts from these organizations continue to provide invaluable knowledge and have helped to expand the project’s network and increased visibility on the *Dialogue’s* efforts. Funding for this project was provided by the United States

Institute of Peace. The opinions, findings, and conclusions or recommendations expressed in this publication are those of the author(s) and do not necessarily reflect the views of the United States Institute of Peace.

# Iran and America: A Dialogue on Disability

By Allen Moore and Sarah Kornblat

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:

- њ Respect for the inherent dignity, autonomy, and independence of all persons;
- њ Non-discrimination against any person;
- њ Full and effective participation and inclusion in society;
- њ Respect for differences and acceptance of persons with disabilities as part of human diversity and humanity;
- њ Equality of opportunity;
- њ Accessibility;
- њ Gender equity; and
- њ 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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# An Overview of the Situation of the Disabled in Iran

By Mohammad Kamali

## Prologue

The World Health Organization (WHO) and the United Nations estimate 10 percent of the population of all countries to be afflicted with disabilities. Due to the differences that exist in the various methods of census, such as headcounts, case studies, and registration statistics, reaching an accurate figure regarding the number of people with disabilities is very difficult. Thus, these numbers tend to be much higher in advanced countries than in developing ones. Greater numbers of elderly individuals in these countries is also a contributing reason.

Results for number of disabled in Iran come from two sources. The population censuses of 1986, 1996, and 2006 constitute one of the most important sources but unfortunately lacks validity. In 1986, the disabled people were estimated to be one percent of the population, or approximately 453,090 persons. Since people with mental disabilities were not included and only obvious, observable cases were counted, the statistics were neither valid nor reliable. In 1996, instead of a census of individuals, 479,590 families were counted to include a person with a disability which amounted to approximately 3.9 percent of the total number of families in the country. The mentioned flaws in the census of the previous decade also applied to this second survey as well. However, in 2006, the situation improved through the use of questions focused on function, disability, and health—and was based on a new law on health and disability. This survey revealed an increase in the number of the people with disabilities, which according to this survey, was approximately 1,100,000. More than 60 percent of these individuals lived in urban areas. Accounting for people with mental disabilities is the most prominent difference of this survey from those preceding it. Nevertheless, a more realistic view may be to use a method developed by Professor Eric Hollander in 1994. In this method, a ratio is assigned to each population group. By multiplying this ratio by the number of people in that group, the number of disabled individuals can be determined. Therefore, around five percent of the population of the country have either severe or mid-range disabilities, which equals more than 3,600,000 people. This estimate is closer to reality.

This discussion must consider two important points. First, the numbers of disabled people are increasing. This is due to the increase of life expectancy, improved health and sanitation care, as well as improved nutrition and living conditions in society. The above-mentioned reasons enable people to have an extended life despite their disabilities. An increase in the number of elderly in different countries is another reason for the higher numbers of



people with disabilities in society. Second, there seems to be a vicious, circular relationship between disability and poverty, that being whether the disabled cannot provide for their lives or that the impoverished are bound to become disabled. Either way, this cycle causes the emergence of many other social problems which absorb the resources and attention of social welfare systems.

## **Disability, immobility, and rehabilitation**

Disability is a key phrase in the fields of social sciences and rehabilitation. It is a relative term denoting a barrier that hinders the abilities of a person to perform an action in a natural situation. Currently, within the literature and discussion of rehabilitation in Iran, the terms disabled and handicapped are used interchangeably. This is due to the relative nature of disabilities; any person can suffer some degree of disability during their lifetime. This is why a disabled person is often defined as “an individual that due to different appearance or behavior or limitation in mobility or function, is considered disabled or is considered so legally and formally.”

Individuals with disabilities, before being recognized as disabled, must be recognized as human beings in society. Human beings who are different only in behavior and appearance and function differently than others in society but as humans are entitled to social facilities and active participation in social affairs. Unfortunately, discriminatory presumptions of the past and the present have limited their access to facilities and social presence, even at bare minimums. This is because in planning legislative actions, education, and housing, only the needs of a healthy person have been considered. What creates this issue is the negative presuppositions and general ignorance about the capabilities and potentials of the disabled.

In its academic sense, rehabilitation includes measures taken in order to enable a person with disabilities to return into society. The definition of rehabilitation has undergone much change with time; currently one of the most conclusive definitions is that of Professor Eric Hollander who believes rehabilitation to comprise a set of goal-oriented measures taken over a certain period of time to reduce the effect of the disability on people with disabilities, enabling them to achieve independence, and facilitating social interactions, better life qualities, and further development of the self. Rehabilitation includes not only educating the disabled but also intervention in the foundations of society to make it more compatible with the needs of the disabled and protect the human rights of such individuals. Enforcing human rights through the government of each country is a commitment of every country, society and citizen. The disabled have the same rights to living as other members of society and there should be no exceptions. There may be need for special attention to ensure that the following needs of the disabled are met: access to social and welfare facilities, learning and career opportunities, housing, transportation, access to information and social and cultural life such as sports facilities, entertainment, social appearance, and full involvement in politics.

Thus, as one of the most important subjects in consideration for the disabled, rehabilitation has a humanitarian and social component rather than a mere clinical and medical aspect, which even by its own definition requires intervention within the structure of society to lay the foundations for the presence of disabled people in societies; it requires governments to

pay special attention to the disabled in fields of education, health, rehabilitation facilities, communication, transportation, civil life, independence, and financial independence so that they may join the level of people without disabilities in society. At times this special attention is questioned by some; however the answer is that only if such measures are indeed provided will the disabled be on equal grounds with the rest of the society.

## Rehabilitation in Iran

The appearance of rehabilitation was formalized in Iran in 1968 with the ratification of a law to establish the Rehabilitation Organization, affiliated with the Ministry of Labor and Social Affairs. Of course, before that time activities in this field were carried out by the military, or the Lion and Sun Society (an organization like the Red Cross) in Iran. According to the aforementioned law, the government would establish the Rehabilitation Organization to empower people with disabilities such as loss of limbs to restart their activities, learn skills and live their lives with a boosted morale. In 1969, the operation of the Shafahian Rehabilitation Hospital was transferred to the Rehabilitation Organization. In 1974, with the establishment of the Ministry of Social Welfare, the organization was moved to their jurisdiction and with the dissolution of the Ministry of Social Welfare in 1976, the organization was returned to the Ministry of Health and Welfare.

In the early 1980's, with the ratification of the Islamic revolution council after the victory of the Islamic revolution, the Rehabilitation Organization was among several institutions that merged to create the Welfare Organization. Since then, rehabilitation activities take place under the supervision of the Administration office for Rehabilitation Affairs of the Welfare Organization. The academic measures taken to train professional employees in this area started with the establishment of the Graduate Schools of Rehabilitation in 1973 with degrees in physiotherapy, work therapy, and speech therapy. Currently, there are more than 10 universities in Iran with graduate programs covering rehabilitation fields.

After the eight years of imposed war with Iraq, the necessity to care for those who had lost certain functions due to war grew. Rehabilitation activities expanded through the actions of the Committee for War Veterans, leading to the increase in the number of rehabilitation institutions and further attention to this field. In addition, the limited efforts for the education of the mentally challenged were enhanced with the establishment of the Institution of Special Education in 1991, and its merger with the Rehabilitation Organization. The simultaneous offering of services in rehabilitation, education, medical, and social areas brought about improvements in the situation of disabled and mentally challenged students.

Currently, most rehabilitation services in Iran are offered by the Welfare Organization. The most recent figures show over 650,000 people with disabilities to be registered and supported by these services. Rehabilitation services are also being provided by the Committee for the Affairs of War Veterans, the Special Education Institution, the Red Crescent society, and the Imam Khomeini Aid Committee, among others, as well as non-governmental organizations. With the approval of the Islamic Revolution Council, in May 2004, Iran joined 50 other countries with legal rights for people with disabilities. This number, in comparison with the 200 nations that are members to the United Nations, is very low. "The Comprehensive Disability Rights Act," although still far from being "comprehensive" from a

professional point of view, plays an important role in legally aiding the disabled in achieving most of their neglected rights. Even though it has been years since the ratification of the act, it is still on a long and arduous path to full implementation and is not doing very well at the moment.

The process of ratification of the Convention on the Rights of People with Disabilities in Iran was met with a lot of delays. Despite the timely actions of the specialists and the DNGOs, the governmental processes have been slow. It was expected that because of positive reactions from the Ministry of Foreign Affairs, the Human Rights Committee, the Parliament Research Centre, the Welfare Organization and other authorities, the process would be a rapid one, but unfortunately took over 17 months. In any case, the ratification took place in 2009 and there is hope it will be a pivotal point in the history of the disabled in Iran and that many endeavors to achieve their neglected rights will come to fruition, hence allowing the society of individuals with disabilities in Iran to unite with those around the world to attain those rights.

## **Prognosis**

Despite the steady development in the recognition and providing services in Iran, the disabled in Iran are still mostly unable to make a strong social presence, limited by the lack of preliminary facilities, and their families or themselves prefer that these individuals stay indoors. Inaccessibility of buildings and other environments along with the lack of accessibility in sidewalks, public areas, educational, medical, and official buildings, shopping centers, recreational and sports centers and others have created a situation that is far from acceptable and will remain so for years to come. Families and disabled individuals have many issues with housing, employment, public transportation and also limitations, deficiencies, and high prices of rehabilitation equipment and facilities. As a result of low incomes and financial problems for many underprivileged families, the solution offered by NGOs up to now has mostly been to provide pensions, the low amount of which, unfortunately, is not a dependable source of comfort; especially in families with a disabled individual where the factors pertaining to the specific kind of disability are not taken into account. It appears that negative assumptions about disability is a major reason for the insufficiency of financial support, with many arguing about how can the needs of the disabled can be tended to when the needs of even the able have not yet been fulfilled. This is, in itself, a great problem.

Rehabilitation is also one of the undertakings that define the role of NGOs. Despite the increasing growth in this department, the need for serious support of investors in this field is felt which recently has been met with much unkind disregard. In advanced countries, the use of volunteered help to offer services to the disabled has grown greatly. In the Sydney and Athens Olympic Games, the world observed the participation of tens of thousands of volunteers helping and accompanying the disabled competitors in the games. The culture of volunteer services must be fundamentally developed within the field of rehabilitation by those responsible.

Rehabilitation, in the author's opinion, is a specialized service which has the potential to be provided around the above-mentioned three poles. The experience of rehabilitation for more than a decade in society has proved that categorizing rehabilitation services is possible. Furthermore, the services can be offered in accordance with the specific disabilities of the person. On the other hand, if executive policies about rehabilitation services are customized to society, it will also become possible to decentralize the services as is mentioned in the law. In this manner, utilizing family members and volunteers to render such services will be easily achievable. Here, it is necessary to see to the requirements of the Ministry of Health for coordinating a merge between rehabilitation and primary care units in the Iranian society.

One of the problems in rehabilitation is the lack of demographic statistics regarding people with disabilities in Iran. The current figures from the Iran Statistics Center are unreliable due to many reasons and the very few case studies have no academic value. The lack of a reliable and complete database mars the credibility and usability of the current recorded statistics. It seems in this particular case, the only solution is to establish a new center for processing such data using the latest categorization systems by the ICF in tandem with the Iran Statistics Center.

Another point is the increasing presence of the disabled and their NGOs and the role they can take in enforcing the Comprehensive Act on the Rights of People with Disabilities and the International Convention on the Rights of People with Disabilities. It must be noted that only through their hard work and perseverance in social arenas and following their just and deserved rights have disabled people gained a place in society and have been able to partake in the compilation and ratification of the Convention laws.

It appears the main role of the disabled and their NGOs in following the realization of the Complete Disabled Rights Act must be reevaluated by people with disabilities themselves. There are several ways to go about this—from appearing in awareness programs to following up legal prosecution of the negligence or violation of their rights. The history of legal actions in Iran shows there is hope that with the help of the judiciary, complaints can be filed against negligence and refusal to abide by the laws, and justice regarding rights will be delivered where it was ignored in previous years.

In order to expand the culture of disabled people in society, there is a solution to enable disabled children to study in normal public schools with other children. A “partial view” to the matter may cause serious and extensive damage. I wish to point out a new concept in the science of rehabilitation. The term “holistic rehabilitation” has been presented as a leading method in rehabilitation programs for a few years now. Previously, it was the norm to divide rehabilitation into medical, educational, technical and social programs. Nowadays, this interpretation is discarded and holistic rehabilitation is focused on the needs of the disabled person and the family from the moment the disability occurs. Therefore, at the onset of an injury that would cause spinal paralysis, it is necessary to have a social worker, a physiotherapist, and a psychologist alongside with the medical team. In addition rehabilitation programs it is necessary to have an occupational therapist, a psychologist, and a psychiatrist to aid the patient and their family. If the programs are approached in a holistic manner, rather than as isolated, divided tasks, it will be possible to prevent disunity in programs, overlaps, and wasting of resources.



# **United States Ratification of the Convention on the Rights of Persons with Disabilities: Would it Make a Difference?**

**By Janet E. Lord and Michael Ashley Stein**

## **Introduction**

The United States signed the United Nations Convention on the Rights of Persons with Disabilities (CRPD) on July 30, 2010, and the Obama administration has pledged to support ratification and submit its CRPD ratification package to the Senate in short order. America has long held itself out as the global leader in disability law and policy. At the same time, the United States historically has been reluctant to ratify United Nations human rights treaties. Accordingly, possible CRPD ratification is of consequence, not only for disability rights, but more generally for US human rights foreign policy.

## **Legal and political requirements for ratification**

In the United States, treaties require consent by two-thirds of the Senate (US Constitution). The first step in that process is a comprehensive review of the treaty by the governing administration. This review is undertaken in order to determine whether the treaty in question is consistent with United States laws and policies. This assessment is typically led by the United States Department of State, but includes an inter-agency process in which all relevant agencies are given the opportunity to review and comment on the implications of ratification, identify shortcomings in law or policy, and otherwise provide input. The State Department prepares a recommendation for the President, based on its interagency review process and comprehensive legal analysis, on whether the United States should ratify the instrument. The State Department also prepares documentation, inclusive of the detailed legal analysis, for submission to the Senate to request approval of the treaty. A final review of these documents is made by the President's staff. If the President considers that treaty ratification is in the best interests of the United States, the documents—referred to as the ratification package—are sent to the Senate, to start the process of consent (CRS, 2001).

A treaty sent to the Senate for ratification is referred specifically to the Senate Foreign Relations Committee. Typically, there is a hearing on the treaty, to determine if there are any public concerns or to consider the need for special legislative implementation. A political decision is made by the Committee Chair of the Senate Foreign Relations Committee on what the appropriate process should be in each instance. The Chair may thus use his/her discretion in placing the treaty on the agenda and can effectively delay any action on the treaty, sometimes for many years. The final steps for Senate consent are

a recommendation by the Senate Foreign Relations Committee and a favorable vote by the Senate. The Committee is responsive to expressions of support and questions from the public. Human rights organizations, private companies and other organizations may contact the Committee to express their support and ask questions (CRS, 2001).

The submission of a treaty ratification package to the Senate will often include, in addition to the detailed legal analysis, recommend reservations, understandings, or declarations (RUDs). RUDs are intended to address any potential problems or objections regarding ratification of the treaty. For example, there may be United States laws that require change as a result of treaty approval. While a separate legislative bill can be introduced by the administration to accomplish this change, following the standard process for approval of new laws in the Congress, this would likely stall treaty ratification. In such cases, RUDs could be utilized in order to prevent such legislative action. A reservation is designed to alter the terms of the treaty, thus changing the legal obligation undertaken by the ratifying state. Understandings and declarations may be used to clarify the interpretation of a treaty provision (Buergethal, 1995), for example to ensure alignment of a treaty obligation with constitutional understandings.

Following the Senate's consent to ratification, the treaty is returned to the President. Thus, the process is complete once the President signs the instrument of ratification following the Senate's granting its consent. The President's signature on the instrument of ratification binds the US government to the terms of the treaty, subject to any RUDs.

### **Assessing American disability law and CRPD obligations**

The CRPD's aims are consistent with those of American disability law and policy. Overall, United States law can be viewed as either being in alignment with the CRPD, or certainly capable of reaching those levels through more rigorous enforcement and, potentially in some instances, through additional legislative action. Indeed, the core principles articulated in the CRPD are firmly embedded in and drawn from American disability law—respect for human dignity, non-discrimination and autonomy, reasonable accommodation, and participation (Stein & Lord, 2008).

Where gaps arise between the two sets of legal mandates, they do so because United States domestic civil rights laws and international human rights laws operate from distinct, although not mutually exclusive perspectives. Disability laws and policies in the United States are grounded in the social model of disability, as is the CRPD (Stein, 2007). According to the social model, factors external to any given person's impairments determine how disabled she or he will be from functioning in society. Disability rights proponents in the United States view discriminatory attitudes toward citizens with disabilities as the central obstacle to mainstream integration, and have pursued an antidiscrimination approach modeled after previous civil rights statutes, most notably Title VII of the Civil Rights Act of 1964. The most significant result of their advocacy efforts was the 1990 promulgation of the Americans with Disabilities Act (ADA), which signaled the social model's legislative victory in the United States (Stein & Stein, 2007).

The American disability antidiscrimination agenda has exerted powerful influence in revising legal regimes affecting persons with disabilities, yet remains limited in the means by which equality can be achieved. This is because the American approach to disability rights is grounded in rigid formal justice notions that narrowly compel the treatment of similarly situated people as alike. One result of this exclusive focus is the implementation of civil and political rights through antidiscrimination statutes that do not fully encompass economic, social and cultural rights. Accordingly, the ADA provides civil rights protection without advancing robust equality measures. Put another way, civil rights are directed at ensuring equal treatment but not at equal opportunity, or, more comprehensively, robust substantive equality. As a result, the ADA as well as other American statutory protections cannot bring about full social inclusion for persons with disabilities (Stein & Stein, 2007).

To illustrate, consider the example of employment, where an obvious gap exists in coverage between American federal disability law and policy and the CRPD as it relates to the promotion of employment opportunities. Yet there is no reason to believe that by providing measures that support the ADA's strong antidiscrimination prohibitions, the United States could not achieve the CRPD's more comprehensive vision. Necessary measures might include some combination of vocational training, tax subsidies for extra-reasonable accommodations, affirmative action, job set-asides, or contract procurement (Stein & Waterstone, 2008).

Beyond employment, there are several areas in which it may be said that United States disability law and policy falls short of the CRPD's full conception of disability rights. This disconnect arises from the American perception that favors civil and political rights as worthy of strong statutory protection, regarding economic, cultural and social rights as beyond the ordinary normative realm of legislation. While American disability rights law does encompass some components of economic, social and cultural rights, there are clearly some gaps where the Convention appears to require strong equality measures or proactive action. This is the case, for example, in the circumstances of Articles 5 (Equality and non-discrimination); 6 (Women with disabilities); 8 (Awareness-raising); 20 (Personal mobility); 28 (Adequate standard of living and social protection); and 30 (Participation in cultural life, recreation, leisure, and sport). For other CRPD provisions, under-enforcement of United States laws creates a gap between legal requirements (that are otherwise adequate) and reality. This is apparent with regard to obligations set forth in Articles 9 (Accessibility); 11 (Situations of risk and humanitarian emergencies); 13 (Access to justice); and 29 (Participation in political and public life). And for still other Articles, because their province lies in state rather than in federal law, there is reason to suspect that those areas are not adequately protected. Articles 12 (Equal recognition before the law); 23 (Respect for home and the family); and 25 (Health) fall into this last group. With regard to Article 12, for example, it seems clear the progressive nature of a supported decision-making framework requires law and policy reform in most if not all countries around the world (Stein & Waterstone, 2008).

It is important to emphasize, however, that existing gaps in American disability rights law and policy that fall short of the CRPD obligations are capable of being narrowed or eradicated through either more rigorous implementation of existing United States laws and policies, and/or through Congressional legislative action. Importantly, none of these gaps presents an obstacle to ratification of the CRPD by the United States (Stein & Waterstone, 2008).



## **Significance of ratification being considered**

By considering CRPD ratification, the United States has begun a detailed internal review of its currently prevailing disability laws, policies, and practices. One positive result of its consideration of the CRPD is a better understanding of the landscape of disability law and policy. Even if the United States does not ratify the CRPD in the near term, the act of signing the CRPD and commencing the ratification process has triggered dialogue across the federal government that can serve as an impetus for better compliance and policy invigoration. Such dialogue can prompt policy and programmatic shifts in disability laws and policies in anticipation of possible ratification, and in turn can serve to promote and advance specific issues related to disability-based human rights.

There are indications that such triggered responses are already occurring. Concurrent with the CRPD's signing by the United States, President Obama's senior advisor, Valerie Jarrett, announced creation of a new position, special advisor for international disability rights, within the Department of State's Bureau of Democracy, Human Rights and Labor, thereby signaling a renewed commitment to ensuring the human rights foreign policy of the United States is disability inclusive (AAPD, 2010). Two months later, the United States National Council on Disability, an independent federal agency advising the President on disability issues, launched a study to review and assess the extent to which the foreign assistance policy of the United States is disability inclusive and the possible implications of CRPD ratification, especially in the light of Article 32's requirements relating to international cooperation (NCD, 2011). The President's appointment of a senior advisor on disability issues within the Federal Emergency Management Agency (FEMA), which is part of the Department of Homeland Security, is likewise fostering CRPD-related dialogue inasmuch as FEMA is considering the implications of Article 11 for its international humanitarian and disaster response programming (White House, 2011). And most recently, in December 2010, the President appointed a coordinator of disability and inclusive development at the United States Agency for International Development (State News Service, 2011). Indeed the State Department's Quadrennial Diplomacy and Development Review likewise reflects this interest in disability inclusion and commits to ensuring that disability is mainstreamed in all diplomacy and development undertaken by the United States (Quadrennial Diplomacy and Development Review, 2010).

## **Significance of ratification beyond the United States**

By signing the CRPD on July 30, 2009, voicing support for its ratification, and providing technical assistance (UN Enable, 2009), the Obama administration has demonstrated the commitment of the United States to rejoining the global community generally (Ogilvy & Ya'alon 2009, 193-94), and to continuing American leadership in the area of disability law and policy. In February 2011, the Obama White House briefed the American disability community on the status of its work on CRPD ratification, indicating the ratification package was nearing completion and that it would soon be transmitted to the United States Senate for its advice and consent. The briefing included a summary of the ratification package consisting of three reservations where shortcomings or differences in American disability law required some modification of CRPD obligations, five understandings regarding the

interpretation of various CRPD provisions and one declaration clarifying the application of the CRPD in domestic courts. The RUDs reflect the conclusion reached by the inter-agency review process that CRPD implementation is readily achievable.

Many in the United States human rights movement find hope in the promises undertaken by President Obama during his campaign to sign and support human rights treaty ratification, including ratification of the CRPD. At the same time, it bears noting American resistance to participating in human rights treaties (Nash, 2009)—and indeed international law in general—originates more than half a century ago (Foot 2008, 720), thus making an exceedingly challenging environment for CRPD ratification. Two factors nevertheless differentiate and improve prospects for CRPD ratification from that of other human rights instruments. First, disability rights has always been viewed as an across-the-aisle issue and benefited accordingly from bipartisan support (Bagenstos, 2003). Second, unlike other human rights issues, the United States has long held itself out as the global leader in disability rights (Stein & Lord, 2011). Hence, CRPD ratification is necessary to continue the aspiration voiced by President George H.W. Bush when signing the ADA, that America can be “a model for the choices and opportunities of future generations around the world” (Bush, 1990).

## **Conclusion**

Ratification of the CRPD is ostensibly readily achievable in view of the highly developed state of American disability law and policy, the traditional bipartisan nature of disability politics and the commitment by the United States to advance disability rights through its foreign policy. And yet American intransigence with regard to human rights treaties-and treaties in general-is a hurdle that supporters of ratification cannot ignore. It remains open to question whether the Obama administration is willing to spend much political capital on pressing for CRPD ratification. Equally unclear is whether the American disability community is willing to allocate the time and attention needed to press 67 United States Senators on participation in an international treaty.

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# The International Convention on the Rights of Persons with Disabilities and its Applications in the Iranian Internal Regulatory System

By Ali Saberi

## Abstract

For any government to accede to an international convention, there are specific procedures to be followed according to their internal system. In some systems, conventions, upon ratification, are considered as a part of their constitution and are immediately effective in legislature and are enforceable in court. In other systems, especially those with two councils, most conventions must go through an extensive legal process. In this article, the legislature of Iran, which is in the first category, is observed for further research, in a realistic and academic manner, the effects of the country's ratification of the Convention on the Rights of Persons with Disabilities (CRPD).

## Preamble

While the formalities of all announcements to accede and ratify a convention in the global arena are almost identical, transforming the convention into a part of the constitution of any country has its own specific procedure. These procedures, aside from political and social influences, have a purely legal format, and face issues of compatibility with other legal ratifications and procedural processes of the parliament in each country. In courts, there is the question of whether the convention should be handled as an individual international law or be added to the already existing internal constitution of the country. Therefore, it can be said that there is an important legal question on the matter of whether an international convention, ratified by the parliament, should be considered part of the internal law of the country. Another question is if the articles of the new law differ from previously legalized articles, are the original articles considered automatically annulled? Or should there be more alterations made to make the convention compatible with existing laws? If this is the case, what is the point of acceding to the convention?

CRPD, which is short for the Convention on the Rights of People with Disabilities, is the 8<sup>th</sup> instrument of international human rights in the 21<sup>st</sup> century. Due to religious sensitivities, the Islamic Republic of Iran has refused to accede to some of these eight treaties. However, a lack of religious and cultural barriers has facilitated the ratification of the CRPD in Iran, making accession to the convention seem rather simple. This instrument, according to its designers and authors, does not create new rights for the disabled, but its goal is to obligate governments who join it to alter their internal system in a manner that does not discriminate

against the disabled. Therefore, when analyzing internal laws, whether to determine legality or from a legislative perspective, the aim is that as soon as the convention is joined, all previous discriminating laws are considered ineffective. This is so that from then on, when settling disputes in court about discrimination, the convention can be referred to directly without the need to rely on any other internal laws, possibly annulling certain executive decisions or rulings for the compensation of damages.

In the legal system of Iran, Article 9 of the civil law, which dates 80 years back, governs issues regarding the current topic. Passed in 1928, this article states that: according to constitutional law, obligatory regulations between Iran and other countries are to be considered as the law. The regulations of the current constitutional law and its comparison to that of the previous political regime are not the concern of our discussion.

What is important is that the ratification and accession of the Islamic Republic of Iran to any international convention is equivalent to adding the treaty to the national laws of the country; therefore, if it is ratified, it must be enforced and obeyed in the same way as it would be if ordained in the country. Thus, if the international law is ratified and is in contradiction with laws preceding it, it nullifies and replaces those laws and there is no need for new legislature. Aside from this being accepted legal procedure, it also follows logic. If it were required to alter the convention after a country joins and add it to its national constitution, or go through extensive legal procedures to alter other national laws to be compatible with the convention or their own cancellation, in reality, the legal value of the convention would be compromised. It would be left without legal sanction and would be considered merely advisory for governments rather than law. In this case, considering it as part of the law also damages the legal system, as what has been accepted into the legal system has no sanction and does not render its preceding laws ineffective. Obviously, no legal system would accept this unreasonable situation. It is necessary to remember that the legislature of Iran considers all international conventions, after being ratified through legal procedures in parliament, as internal law, unlike governments whose legislature demands yet another procedure in order to legalize these conventions. The latter process is more customary in governments with two councils.

However, it is not enough that after ratification, conventions are considered as law in Iran's legal system and to rely on the fact that the process followed is that of a country with a single legislative council; there are certainly other legal issues at hand. We will observe an example of these practical and theoretical issues by choosing one article from the CRPD. It is stated in the convention that governments are obligated to aid the disabled by providing equal career opportunities in the society by removing discrimination and obstacles and applying this anti-discrimination policy to all career venues. On the other hand, Article 28 of the electoral law in Iran forbids blind and deaf individuals from running for parliament. Upon ratification the convention is added to the Iranian constitution and all discriminating laws are automatically superseded. However, in Iran, a council exists that aside from ensuring the compatibility of legal regulations with religion, also examines the eligibility of candidates in parliament elections. Therefore, even if Article 28 of the election law is considered ineffective in legislature and executive regulations, it is not clear how the aforementioned "council of guardians" would respond to the application of a blind or deaf candidate. Another point is that the decisions of this council are irrevocable and closed to complaints, and no claims on

the basis of violation of Article 28 can be made before another council. This is an example of theoretical and practical issues that arise in the application of the convention. However, by considering the international convention as internal law, the legal procedure protects the convention law against contradictory regulations.

All that was said is with the supposition that we disagree with the common verbal interpretation of Article 9 of civil law and do not take the stance that “international treaties” cover bilateral or multi-lateral conventions, and that international/regional treaties are not included. Of course this interpretation does not have many subscribers and more lawyers prefer to interpret convention regulations to include all international affairs. To consider the convention as an internal law and leave it bereft of international support, considering all that was said of international conventions, is not free of a danger.

This is illustrated by the fact that before joining the civil-political rights and social-cultural rights charter in 1975, the government of Iran tried to prepare national laws for accession to conventions. Consequently, the law banning arrest of citizens with civil debts was passed. Convention regulations also necessitated this ban as well, and with its ratification in parliament the legal procedure was reinforced. However, 23 years later, in 1998, a law was passed that directly orders the arrest of citizens with civil debts! It is usually said that conventions after ratification are considered part of the internal law of the country and the national law is subject to alteration by the legislature. This example highlights that the CRPD does not guarantee anti-discrimination rights for the disabled upon inclusion in national laws. Even with its addition to the constitution, the contradictory laws are rendered ineffective. For example, if Article 28 of election laws against the participation of blind and deaf people in parliament elections were to be annulled, and if we overlook the irrevocable decision-making abilities of the council of guardians, the legislative power still has the authority to pass a law against the convention. In the legal scene, it may defend the decision on the grounds of conflict with internal law and is irrelevant to the international obligations of the government since it is now a national law. Therefore, accepting the regulations of the convention as part of the internal law and considering its preceding laws automatically ineffective is a double-edged blade and the wrong side of it must not be allowed to impinge negatively upon the spirit of the international interactions of the government. That is not possible except by keeping the international aspect of the convention—at least in the executive obligations of the government.

Perhaps political sensitivities, and more so the fact that any convention upon ratification is a part of constitutional law and previous contradicting laws are automatically annulled and no future ratifications may conflict with them, have caused the government of Iran to be cautious about the CRPD, as it has been with other human rights charters it has eventually ratified. The Iranian government has accepted this convention with reserved rights, which have been considered for ratification with a statement that is inclusive in most human rights documentation: “if it is not in direct contradiction with national laws.”

In the opinion of its designers and authors, the new convention, which is an extension to the United Nations charter of human rights, might not add anything to the rights of the disabled, but its focus is removing discrimination. If the convention is to be accepted as law under the condition that it does not contradict previous discriminating laws in the legal system,



then its main purpose is lost. The convention itself prohibits the right of reserve and this is an intrinsic characteristic of human rights treaties and their anti-discriminatory nature. Lawyers hold that stating rights of reserve in international conventions is not credible and holds no legal effect. With this analysis, the main struggle of people with disabilities in our legal system is to compel the government to annul the right of reserve stated in the conditions of joining the convention and not hinder its enforcement. This effort, of course, will be coupled with much activity that will eventually resolve the practical and theoretical issues mentioned in previous paragraphs. Another point, which seems to be theoretically problematic, is that Iran has not joined some of the human rights conventions in the past such as the convention to forbid discrimination against women, wherein the current convention, discrimination against disabled women is strictly prohibited. Analysis of this duality in fundamentals is beyond the scope of this article and requires a study of its own.

### **Conventions in the legal system**

Now we consider the convention in the legal system of Iran from another standpoint and the manners in which international conventions are referred to in the legal system of Iran. Unfortunately, research in this field is difficult, since access to court rulings is nothing short of impossible. That is perhaps due to the Roman-Germanic nature of Iran's legal system and its underdeveloped structure. Although references to international conventions are not abundant enough to be researched extensively, they are in the process of being compiled. As the CRPD is a recent addition to our legal system, and there is no traceable reference to it in our legal proceedings yet, through other examples we may observe the orientation of judges towards such cases.

The Iranian legal system is recorded history and the procedure is that cases are typically not referred to unless in special circumstances or for exceptional persons. Perhaps for any or each of these reasons, the Honorable Judge Yazdani, in compliance with the convention on the rights of children, which states that they have the right to receive education, and with emphasis on the fact that the convention is part of the internal law, ruled an elementary school in Tehran be obligated to register a child despite the lack of identification documents. This was itself because of a case in progress regarding the child's identity, which could take very long to resolve and deprive the child of the chance to be educated. His Honor insisted on this statement in his ruling, stating that "based on the content of the convention, education is one of the rights of any child, whether legitimate or illegitimate."

As another example, during the proceedings of what came to be known as the Hemophiliacs Case, involving people who had been afflicted with Hepatitis and HIV through the use of contaminated blood products, the Honorable Judge Nasirayee sentenced the government to pay financial and spiritual compensation to those affected. The ruling was made on the basis of the charter of political, economical, social and cultural rights, and with the Judge's insistence that upon joining the conventions, they are now a part of Iran's internal law.

Considering the insignificant amount of experience in the matter and the understanding and experience one gains in the legal system, it seems that the part of anti-discriminatory actions where it concerns the civil and political rights, is less relied upon in the courts of Iran. However, considering economic, social and cultural rights, and prohibition of discrimination

in issues of welfare, (and the fact that the legal system of Iran has had a comprehensive law regarding the welfare of the disabled since 2004—an instrument solely focusing on welfare) it can be assumed, with reliance on this law and the records that have been produced in courts, particularly those of the Administrative Justice Court, that parts of the convention that pertain to these issues will be referred upon in courts. At any rate, according to the cases of such reference that have occurred in our legal rights cases, the activities and labors of disabled individuals in this field can be the right support and the sanction that is needed to fully enforce this convention.

The fact that Iran has not acceded the additional protocol, (the government has used the optional nature of the protocol and has not signed it) may also cause problems in the administrative sense for enforcement. In the prologue of a document written in the parliament, which permits accession to the convention by Iran, the executive institutions are the same as administrative ones. It seems the lack of development in NGOs dilutes the effects of unofficial reports as well. Investigating the issues of DNGOs (NGOs for people with disabilities) and offering guidelines to work specifically in accordance with the new convention, is the discussion for another paper.

Instead of summing up the results by recapturing the essence of what was said, I prefer to shortly discuss a matter with reference to a newly established law in Iran, which holds great importance in the matter of international conventions in the legislature of Iran. Perhaps mentioning it would end this paper with an open ended question and hopes for further research in the matter. Article 62 of the law on Patenting Inventions, Industrial Plans, and Marketing Brands, established in 2007, states that in the case of the contradiction of these laws with those stated in international treaties regarding business ownerships that the Islamic Republic of Iran has acceded or will accede, the aforementioned treaties take precedence. It must be noted that treaties regarding business ownership and trades have an economical aspect, and the sensitivities that surround human rights all around the world, and especially Iran, do not apply there.

In any case, the question remains whether Article 62 is a general regulation that has always existed in our legal system and is merely being restated by the legislature? Or is it specific to this particular law? Lawyers, by gathering legal views and expanding on the essence of Article 62 and its effect on all treaties and conventions, can insist that a convention, upon ratification and addition to internal law, automatically annuls its preceding laws, and from that time forward laws contradictory to the international conventions cannot be passed. Even if they were passed, they would not have any legal effect. The sensitivity of the government of Iran about the CRPD was much less than other human rights conventions, and so within a reasonable amount of time the government urged the NGOs to accept the convention within their working charter. The reasons for this ease in acceptance and its effects are beyond our current discussion; however, whatever they are, with reference to the fundamentals of Article 62 of the aforementioned law, at least within the context of our discussion of the CRPD, it can be assumed that in the world of theory and legal knowledge, the convention has rendered all of its contradictory laws, in the past and the future, ineffective. Prohibition of discrimination can truly be achieved, although there is a great gap between theory and reality; a great gap that lawyers, and more importantly activists for the rights of people with disabilities can surely fill.



# **The New World of Inclusive Education: A Review of the Convention on the Rights of Persons with Disabilities and the American Experience**

**By Allison deFranco<sup>1</sup>**

## **Introduction**

Children with disabilities throughout the world are often marginalized and excluded from mainstream society. In many countries, children with disabilities are sent away to institutions where they receive no education and are isolated from society for their entire lives. In other countries, children with disabilities are forced to attend separate schools instead of general schools in the community. The vast barriers children with disabilities face in accessing education in most societies has led to a low employment rate for persons with disabilities and a disproportionately high rate of poverty. The Convention on the Rights of Persons with Disabilities (CRPD) addresses these issues and specifically outlines the right to education for persons with disabilities. This paper will discuss the CRPD's inclusive education provision and the benefits of inclusive education, and then will review the special education laws in the United States to provide lessons learned from the American experience.

## **The right to inclusive education**

Article 24 of the CRPD employs the concept of “inclusive” education for the first time in international law and sets out an important obligation for States Parties to ensure education programs are inclusive of persons with disabilities. In particular, Article 24 states:

[1] States Parties recognize the right of persons with disabilities to education. With a view to realizing this right without discrimination and on the basis of equal opportunity, States Parties shall ensure an inclusive education system at all levels and lifelong learning directed to:

- a) The full development of human potential and sense of dignity and self-worth, and the strengthening of respect for human rights, fundamental freedoms and human diversity;
- b) The development by persons with disabilities of their personality, talents and creativity, as well as their mental and physical abilities, to their fullest potential;
- c) Enabling persons with disabilities to participate effectively in a free society.

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<sup>1</sup> The author would like to thank Kathryn Carroll, St. John's University School of Law, J.D. Candidate 2013, for her research assistance.

[2] In realizing this right, States Parties shall ensure that:

- a) Persons with disabilities are not excluded from the general education system on the basis of disability, and that children with disabilities are not excluded from free and compulsory primary education, or from secondary education, on the basis of disability;
- b) Persons with disabilities can access an INCLUSIVE (emphasis added), quality and free primary education and secondary education on an equal basis with others in the communities in which they live;
- c) Reasonable accommodation of the individual's requirements is provided;
- d) Persons with disabilities receive the support required, within the general education system, to facilitate their effective education;
- e) Effective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion (CRPD, 2006).

The obligation of inclusive education is unfamiliar to many international law and education experts alike, and thus it is important to review further.

### **The benefits of inclusive education**

The CRPD requires States Parties to implement inclusive education systems that ensure reasonable accommodations for children with disabilities. Inclusive education promotes the education of children with disabilities in general education programs. Research suggests all children benefit from inclusive education programs, and therefore every child is better afforded their essential right to education. Inclusive education benefits communities, families, teachers, and students by providing knowledge and understanding of disability related issues. Inclusive education ensures children with disabilities attend school with their peers and teaches them life skills (CRS Vietnam, 2008). Communities also benefit from inclusive schools by gaining more knowledge and understanding about disabilities. The inclusion of children with disabilities in general schools introduces children with disabilities into the local communities and neighborhoods and helps to break down barriers and prejudice. Communities become more accepting of differences, and everyone benefits from a friendlier, open environment (CRS Vietnam, 2008). Schools benefit from inclusive education programs as well.

The concept of inclusive education focuses on each individual child's ability to learn rather than treating all the children the same. Teachers are able to instruct each child in a more individualized way. All children, with and without disabilities, benefit from a teaching style catered to their individual way of learning. Inclusive education also features different teaching techniques such as drawing, singing, and participatory activities. Studies suggest young children retain more information when they are "involved" in learning rather than just lectured at by teachers. Inclusive education also allows teachers to become more dynamic in the classroom, and thus makes school more enjoyable for children and teachers (CRS Vietnam, 2008).

## The United States model of including children with disabilities in education

The United States offers an interesting case study to conceptualize the definition of inclusive education as outlined in the CRPD. The United States has implemented “special education” laws and policies that protect the rights of students with disabilities to attend public schools for over thirty years. Although the United States has a long history of educating children with disabilities in comparison to many other countries, the United States still has not created an inclusive education system. The CRPD is thus an important tool to guide the development of a fully inclusive education system in the United States. In addition to reviewing the American experience to better understand the CRPD’s call for inclusive education, the American experience also serves as a useful lens for other countries to review and consider lessons learned as they work to develop and implement inclusive education systems in accordance with international law. A basic understanding of the development of the American system, as well as the inherent shortcomings in the system, may assist other countries to create comprehensive inclusive education systems that do not lead to the same issues that exist in the American system.

### Brief overview of American laws and policies for educating children with disabilities

In its 1954 landmark decision, *Brown v. Board of Education of Topeka*, the United States Supreme Court found that “[s]eparate but equal is inherently unequal in the context of public education.” (Brown, 1954). Although the facts in *Brown* dealt with racial segregation in public schools, the Court’s interpretation of the Constitution serves as the legal foundation for the rights of children with disabilities to attend public schools with their peers in the United States. Almost 20 years after *Brown*, two class action complaints invoked the *Brown* decision to bring successful Constitutional challenges of state and local laws that denied children with disabilities the opportunity to attend public schools (PARC, 1971; Mills, 1972).

In follow up to these cases, Congress enacted the Education for All Handicapped Children Act (EHA) in 1975, which has subsequently been renamed the Individuals with Disabilities Education Act (IDEA). IDEA requires public schools to provide qualified students with disabilities a Free Appropriate Public Education (FAPE) in the least restrictive environment (LRE). The LRE requires school districts to educate students with disabilities in the regular classroom with appropriate supports to the maximum extent possible. School districts must work with parents and children to develop an individualized education plan (IEP) that details appropriate supports and aids for children with disabilities. The adoption and implementation of IDEA marks an important step towards educating all children with disabilities in the United States, but there is still a great deal of progress to be made before the phrase “separate but equal” is fully removed and replaced with a phrase supporting an inclusive education system in American schools that is equal for all children.

## Mainstream education in the United States

To truly understand the meaning of inclusive education in the United States, it is important to distinguish the difference between “inclusive” education and “mainstream” education. Mainstream education is merely placing children with disabilities in the general classroom with their peers as opposed to putting them in a special classroom for the day, or sending them to a separate school for children with disabilities (Ferguson, 1995). Although mainstream education is an improvement to older segregation models of educating children with disabilities, or worse not educating children with disabilities at all, it does not traditionally provide students with the supports they need to succeed in the general classroom. Instead, many mainstream education systems in the United States allow students to be “pulled out” at various times throughout the day so they can receive the supports they need in particular subjects such as math or reading.

The option to pull out students is problematic as it continues to segregate children with disabilities from their peers for varying periods of time and for an array of reasons. Students with disabilities are often pulled out of the mainstream classroom for strikingly inappropriate reasons such as learning how to use a pencil eraser. Further, many students with disabilities still spend most, if not all, of the day in segregated special classrooms working on basic skills. The IDEA requires students to be educated in the “least restrictive environment” and this gives school districts the option to place children in segregated classrooms if that is found to be the best option. The existence of segregated classrooms is problematic and does not effectively fit into a mainstream education model because simply placing child with a disability in the same building as other children is not mainstreaming. Further, segregated classrooms represent an unfortunate step in the wrong direction for developing inclusive education systems.

## Inclusive education in the United States

Inclusive education, by comparison, places students with disabilities in the general classroom to learn with their peers and provides adequate supports for students to participate and learn in the general classroom. The resources and supports that have typically been found in resource rooms or special education classrooms are available in the general classroom. For example, if a child who is blind is learning to read Braille in school, the Braille teacher would be placed in the general classroom to teach the child. To further illustrate, if a child with a learning disability needs extra support in math the resource teacher who used to provide support in a separate room now is in the general classroom working with that child and the other children. This helps all children learn as it provides for more teacher support to be in the general classroom.

The concept of providing appropriate supports in the classroom as opposed to pulling out children to work on certain skills outside the classroom is often hard for Americans to grasp. In American schools, many children who do not have disabilities are pulled out of elementary classrooms to work on certain skills such as reading or writing, and thus American society does not see the problem with pulling children out of the general classroom to further develop certain skills. This lack of understanding is a product of an outdated American philosophy as it is problematic to remove one or two young children from the

general classroom to go learn in a separate room whether or not they have disabilities. It is not an inclusive learning environment if a teacher asks a student to leave his/her peers to go work on some skill they can work on in a collaborative manner with their peers in the classroom. Children mimic each other and learn from each other and all children learn at different levels and speeds.

For true inclusion to work, society must understand these differences are real and part of human experience—and that it is not productive to remove children from a positive learning environment. As for developing a student's self-esteem, no one likes to feel "different" from their peers and standing up in the middle of the classroom to head down the hall does not help any student gain confidence and in many cases it does not help the student further develop their academic or social skills. The feeling of being made fun of when a child leaves the classroom does not promote a positive, inclusive atmosphere to learn in, but rather it impacts a child's self esteem and self worth. The most successful inclusive education models in the United States have been implemented from the top down. If the school principal advances inclusive education in his or her school, teachers and staff are much more likely to implement inclusive strategies. School authorities who understand the concept of inclusion can provide a better education for all students.

### **Framing the legal issues for students with disabilities in the United States**

Society's awareness and understanding about inclusive education is necessary to implement a good education framework, but the framework itself is structured by education law. This section reviews the legal issues under IDEA to illustrate why the United States does not have an inclusive legal framework in line with the CRPD. Notably, IDEA articulates the importance of reviewing each student on an individual basis in the same manner as called for by the CRPD. However, as the following discussion points out, issues have arisen and been fleshed out over the years in the American implementation of individual student review under the IDEA. These issues can provide important guidance to other countries as they develop inclusive education systems focusing on individual student needs.

One major issue to consider is that IDEA allows for children with disabilities to receive a Free Appropriate Public Education (FAPE) in general schools, but what constitutes an "appropriate" education is unclear. This question has been heavily debated in the United States. When a child is receiving average marks in school and progressing from grade to grade, does that constitute an "appropriate" education, or should a child with a disability receive every accommodation necessary to reach their full potential?

A parallel issue that arises under IDEA is the question of who qualifies under the law. The law names certain disability groups that may be eligible for the law's protections if the child is otherwise qualified. The concept of "otherwise qualified" presents an issue for children who have one of the listed disabilities but receive passing marks in school. In one instance, a child with autism was not considered "otherwise qualified" despite the fact the child needed certain educational services to succeed in school. The particular child tested very well, but refused to do homework or in class assignments. Because of his high test marks the school district refused to provide an individualized education plan (IEP) for him, and thus he was not entitled to the protections and remedies afforded under IDEA. The school psychologist



who evaluated him noted that one-on-one attention would greatly benefit him in school, but did not recommend an IEP. The child recently started to fail courses due to his lack of homework completion, and now the school must pay for the child to be evaluated by an independent evaluator. If IDEA was interpreted with a more inclusive education lens, the law would ensure all children with disabilities are provided the reasonable accommodations they need to not only get by in school, but to succeed both academically and socially.

There are also clear limitations built into IDEA's enforcement mechanism. IDEA does not have any complaint mechanism allowing for systemic change, and the only means of redress is on an individual basis. This means if two or more children have the same grievance, there is no means to address the grievances collectively through a class action complaint. This is an interesting omission to consider, as the two cases that were catalysts for the law were both class action complaints alleging violations under the United States Constitution. When Congress drafted IDEA it provided for individual procedures and processes within the law, but this has led to disparity of services among students with disabilities for reasons Congress did not envision. Cases are reviewed on a case-by-case basis, which in theory makes sense, but in practice has serious shortcomings. For example, children who are blind in the United States often receive their books in accessible format weeks after school has started, and thus they are behind their classmates. While there have been numerous individual challenges to account for the disparity of services, it remains a major problem throughout the United States and there is no way to challenge this issue holistically under IDEA. The lack of systemic change makes it difficult to quickly transition from the current American education system to a more inclusive education system that provides all children with the accommodations they need to succeed in the general classroom with their peers.

## **Conclusion**

The CRPD has stimulated an important discussion throughout the world about inclusive education for children with disabilities. There is no best practice model of inclusive education and there are many countries that have never educated children with disabilities, so there is a great deal of progress to be made in fulfilling the obligation of inclusive education for children with disabilities. The United States has long been a leader in providing children with disabilities a public education. The American legal system and practical experience have much to offer the world as the inclusive education discussion continues.

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# Let's Disable Her Further, Shall We? The Cast of Gender on Disability Rights in the Iranian Context

By Hengameh Saberi

## Introduction: Setting up the question

Contemporary human rights regimes afford individuals a myriad of identity choices to frame domestic and international rights claims. The diversity of internationally recognized claims to a decent and dignified life translates into fragmented modes of interaction between identity and recognition. At times, a single identity may impose similar demands on multiple international human rights fora and instruments. At other times, a particular identity may give rise to substantively different claims addressed to multiple human rights frameworks. The fluid function of identities, by virtue of which an individual can claim recognition and protection on the basis of her multiple identities, appears to attest to the optimal advancement of international human rights. But once one lifts the halo from universal protection of the individual, this hybridity presents difficult questions about the implications of the pervasiveness of entitlements for the very individual such rights are intended to protect.

This essay briefly examines the interaction between gender and disability, two identities that render women with disabilities a suspect group for enhanced discrimination. Specifically, it will consider the legal protection of the rights of women with disabilities in the Islamic Republic of Iran through two international human rights instruments, one resolutely opposed by Iran and the other acceded to on October 23, 2009: the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW), and the Convention on the Rights of Persons with Disabilities (CRPD). The pervasive identity traveling between the two instruments here is gender defined as being a 'woman', for CRPD distinctly regards disabled women as vulnerable to higher levels of discrimination resulting from the compounding function of the twin factors of gender and disability.

It is precisely this assumption of compounded discrimination that this essay will call into question in the following way: gender and disability in disabled women, like any other combination of suspect identities in a particular individual, intersect and may lead to different forms and levels of discrimination. Yet such intersectionality does not necessarily have a compounding impact on the level of discrimination it brings about. The exact way in which suspect identities of gender and disability intersect, and the implications of that intersection, vary among different particular cultural, economic and legal contexts. The gender-specific provisions of CRPD, however, build on a universal assumption that gender

and disability always work in a compounding fashion, resulting in exponential discrimination against disabled women. This, this essay suggests, is a questionable assumption.

Absent reliable statistics, it is difficult to determine to what extent, if any, gender in fact results in compounded discrimination against women with disabilities in various local contexts with unique cultural, legal, and economic specificities. This is so because the historical and universal forces of gender discrimination and its manifestations are not absolute, and because the manifestations of disability discrimination are context-dependent too. So any disparate impact of disability on women in each context ought to be proven, rather than assumed.

That being said, this author's skepticism about the compounding function of gender and disability does not deny the possibility women with disabilities are disproportionately disadvantaged as compared to men with disabilities. Yet, even if clear empirical evidence confirms a disparity of opportunity in education, employment, health care and so on among people with disabilities solely based on gender, it does not automatically follow that gender and disability in fact work in a compounding way to negatively impact the status of the disabled woman and leave her worse off than the general population of able-bodied women and disabled men.

Put more clearly, given the long history of repression and exclusion on the basis of both gender and disability, it is not surprising that the twin factors are generally assumed to necessarily and universally reinforce one another in an impairing manner, leaving the disabled woman in the most vulnerable position of all four poles divided by gender and disability (the other three poles being the disabled man, the able-bodied woman and the able-bodied man). Yet, once this assumption of the compounded impact of gender and disability is relaxed, we may in fact be better able to acknowledge that the real interest of the affected group becomes meaningful only in relation to that of the other poles around the divide rather than as an abstract, compensatory response to the group's historically assumed vulnerability.

In the particular case of Iran, this recognition is of both practical and theoretical significance. From a practical viewpoint, Iran's blanket reservation to CRPD, to the extent that it contravenes Iranian law and relates to women's rights, may appear to deserve much less lament than what is generally held by human rights discourse, once it is acknowledged that gender-specific rights in this context may neither be necessary nor desirable.

By the same token, from a more foundational perspective—albeit with practical implications, an *a priori* placement of the disabled woman on the extreme end of vulnerability on the spectrum of gender and disability forecloses the possibility of recognizing her as a social and legal agent and understanding her interest as something that takes shape in an active interaction with the interests of all the other poles. In the interest of expanded human rights protection based on multiple suspect identities, human rights discourse tends to myopically consider disabled woman's interests relative to her immediately opposite pole, disabled man, leaving out the complexity of her direct or indirect interaction with the other two poles—able-bodied women and men. In doing so, it in effect reduces her to further passivity and understands her as one who has little agency in the dynamic process of forming interests, demands, and entitlements.

The remainder of this essay brings this point home by first reviewing CRPD's gender-specific provisions to determine how much of what Iran rebuffed in CEDAW, it has also rejected in CRPD by means of a blanket reservation.

With the reservation to CRPD's gender-specific provisions in place and the Convention in force, the next question is whether a CRPD devoid of gender protection is in fact a loss. Three venues, corresponding to a juxtaposition of the interests of disabled women with those of the other three poles, ought to be kept in mind to answer this question and demonstrate the scant likelihood of gender and disability functioning in a compounded manner to leave women with disabilities at the bottom of vulnerability spectrum. Disentangling the discriminatory effects of gender and disability will also provide further insight into some of the ways in which a heightened focus on gender and disability in fact masks the gains and losses of other participants as well as those of the disabled woman, the main object of protection.

### **Gender and CRPD: A minimalist solution in the absence of CEDAW?**

Advocacy for Iran to join CEDAW has been an ongoing project for Iranian secular feminist movements. These voices have at times found allies in the more moderate religious establishment who, relying on dynamic Islamic jurisprudence, concede that “[c]hanges can be made in many of the laws that are considered discriminatory ... [and] that the rights that currently exist for women in Shi'i jurisprudence are not fixed, and can be changed ...” (*Ayatollah Boujnourdi*, *Azad Newspaper*, 17 Bahman1380/ February 6, 2002). Official sectors have entertained various assessments of the compatibility of the Convention with Islamic laws, although the government's official position since the latter part of the 1990s has been almost consistently antagonistic. In 2001, the reformist government of President Khatami went so far as to approve a bill for Iran to join CEDAW provided that it did not violate Islamic Law (*Zanan magazine*, no. 84, 18). Although the Cultural Commission of the Sixth *Majlis* (the reformist Parliament) subsequently endorsed the government's bill to join the Convention, the bill was not ultimately passed. Under the best circumstances, the Convention would have been accepted with conditions and reservations. Arguments to the contrary notwithstanding, sophisticated activists were under no illusion that a restricted CEDAW would either eliminate gender discrimination or quell international pressure on the government.

Notably, Articles 2 and 3 of CEDAW would require major constitutional, civil, and penal reforms based on a new reading of Islamic law. Suffice it to say that the Iranian Constitution fails to even pay a lip service to formal sex equality. Article 19, which guarantees equality for all regardless of color, race, and language, (with an ambiguous analogue of ‘the like’), excludes any reference to gender. The Constitution's reference in Article 3(14) to “securing the multifarious rights of all citizens, both women and men, and providing legal protection for all, as well as the equality of all before the law” as government's responsibilities, and its emphasis in Article 20 on the equality of all citizens, men and women, in the enjoyment of “all human, political, economic, social, and cultural rights” must be read in conjunction with the proviso in the latter part of the same Article that qualifies equality protection to “conformity with Islamic criteria.”

These same domestic obstacles to formal gender equality again arouse in the context of the CRPD. This time, however, disability rights being much less politicized than women's rights, the baby was kept and only the bathwater thrown out through the magic of a general reservation. The CRPD incorporates gender as a basis of further protection on two grounds: first, as an identity that in fact exacerbates discrimination on the basis of disability—what is referred to here as the consequence of the compounding function of two identities—and second, as a general basis of discrimination that calls for enhanced human rights protection. Both of these perspectives are clearly introduced in the Preamble of the CRPD: the former in Paragraph Q: “[r]ecognizing that women and girls with disabilities are often at greater risk, violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation,” and the latter in Paragraph S “[e]mphasizing the need to incorporate a gender perspective in all efforts to promote the full enjoyment of human rights and fundamental freedoms by persons with disabilities.” At first blush, there seems to be a balanced emphasis on both perspectives throughout the Convention. While “equality between men and women” constitutes one of the general principles of the CRPD (Article 3(G)), and state parties agree to raise awareness about “stereotypes, prejudices and harmful practices relating to persons with disabilities, including those based on sex and age” (Article 8(1B)), the only provision in the Convention that specifically addresses the case of women states that “women and girls with disabilities are subject to *multiple* discrimination...” (Article 6(1)) (emphasis added). It is true that a reference to “multiple discrimination” in and of itself does not indicate a compounding interaction between gender and disability. However, when read in conjunction with Paragraph Q of the Preamble, in the last analysis, it speaks of the CRPD’s objective to target discrimination resulting from the compounded effect of gender and disability.

Iran’s generic reservation to the CRPD states that “... with regard to Article 46 [which disallows reservations that may be incompatible with the object and purpose of the Convention], 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.” Gender equality, therefore, does not pose any more substantial complications for domestic law beyond some fresh ground for criticism by human rights activists and international groups. Just like with any general reservations to human rights instruments, the debate revolves around the implications of the reservations. If Iran’s reservation is in fact against the purpose and object of the Convention, as Belgium so holds, according to the CRPD’s Article 46(1) and also Article 19(C) of Vienna Convention on the Law of Treaties, it is null and should not be permitted. Plausible options in response to Iran’s reservation would be to either (1) accept the reservation as compatible with the spirit of the instrument, or (2) consider the reservation null and hold the reserving party bound by the entire instrument including what it has declined to commit to via a reservation, or (3) for the objecting party, to reject the reservation and refuse to consider the instrument binding between the objecting and reserving state.

Finding an answer to this question is not the interest of this essay. It is, in fact, the very posing of this question that must be challenged if we are to see beyond formal gender equality. It is one thing, and quite plausible, to deplore Iran’s resistance to the CRPD’s attempt to promote and reaffirm gender equality as a general principle—although it is hardly realistic to expect

Iran would have done otherwise given its history with the CEDAW. But it is a completely different position, and one that begs serious questions, to believe gender-specific rules deriving from assumptions about the compounding function of gender and disability will necessarily improve the welfare of women with disabilities. Under a minimalist approach, one could contend that if the CEDAW has been politicized beyond redemption, something might be salvaged through the CRPD's gender-focused rules. But as demonstrated below, that outcome is elusive, a hope in it illusory, and its underlying project potentially counterproductive.

### **What is at stake? Vulnerability and empowerment**

As mentioned before, an accurate sociological assessment of the severity of discrimination against women with disabilities calls for statistics—a hard find in political climates where institutionalized transparency is a rare commodity. But even in the face of confirmed evidence of greater discriminatory treatment of women with disabilities, it is still necessary to unravel, so far as conceptually possible, the sources of that discrimination. In a legal culture of substantive gender discrimination, one would suspect there are obvious and identifiable forms of discrimination based on gender alone. Furthermore, there is no denying that despite undisputed progress in disability rights—both before and after Iran's joining the CRPD, full substantive equality for individuals with disabilities remains an unrealized ideal. So the disabled woman is naturally subject to the sum of the ill consequences unjustifiably and independently implicated in each of her two identities—sex and ability. What is questionable, however, is the underlying assumption of dominant human rights discourse that the two forms of discrimination necessarily compound one another to produce harms greater than the sum of their parts. The compounded assumption of discrimination casts the disabled woman as subject to exponential levels of discrimination that work in unison.

What is needed in order to open new windows onto the precise interaction of gender and disability in each societal context is cultural and anthropological observation, a keen understanding of social and economic development problems and prospects, insight into the details of existing domestic and international legal structures, and a recognition of the potentials of and impediments to progressive political change.

The case of Iran is no exception. How does, for instance, the peculiar commingling of tradition and modernity, Islamic convictions and Western ideals, secular feminism and religious-inspired gender reform impact the lives of women with disabilities? In what ways do social norms rooted in Islamic culture, if not necessarily in Islamic jurisprudence, produce and reinforce the physical, mental, and social vulnerability of women and the disabled? And, how does vesting responsibility for protection (and manipulation) in able-bodied men affect disabled women's sense of agency? How should one approach this culture of responsibility based on vulnerability, which ironically enough, as day-to-day life is concerned, may be more congenial to accommodating the needs of disabled women as compared to disabled men? In what sense do economic variables, possibly higher unemployment rates among the disabled, and hence their choice to continue higher education for a longer time affect the balance of power between disabled women and disabled men and also against able-bodied men and women? What about the stronger recruitment rate of disabled women



(and women in general) due to their presumed lower wage expectations and its bearings on the social organization and power relations?

These are all merely exemplary questions, but they remain entirely unnoticed so long as one has not questioned the common assumption of the compounded effects of gender and disability. If we shift away from the phenomenological questions of gender and disability studies to the legal domain, this interaction does not become any less complex. At any particular time, policies of preferential treatment for disabled women to ameliorate compounded discrimination might seem a sensible compensatory balancing measure. But such policies and regulations may reflect and reinforce a narrow view of the long-term interest of all stakeholders, including women with disabilities.

Consider, for instance, the post-Revolutionary reforms of Iranian family law. A series of ebbs and flows in women's rights through the evolution of family law has reflected an often questionable image of minimum gender equality in family law without any acknowledgement of the successes, as little as they might have been, along the way. A myopic focus on an ideal image of equality has cast a blinding shadow on the potential long-term costs to women – costs embedded in some of the much-applauded progressive reforms. An illustrative example is the *mahr* or dowry, which since the early 1990s evolved into a more strict and enforceable obligation for the husband towards the wife. The *mahr* as a legal enterprise is intended to increase women's financial security and bring balance to the husband's discretion in divorce. But in fact, it can become a sort of monetary iron-force in the hands of women used at will, eventually switching the power position from one to the other without a trace of balance. The upshot is an entirely new, complex map of the family economy, in which it is more straightforward to determine the winners and losers of the financial contest than those in the distribution of substantive equality and, ultimately, dignity.

Now considering the concern about compounded discrimination against disabled women and their vulnerability in family relations, disability rights activists might demand that the regulation of the *mahr* must take into account the imbalance which has historically favored men—disabled or not—in their relationship with disabled women. Such a proposal will not only ignore the above-mentioned complexities that the *mahr* brings to the institution of family, but also could skew the economics of marriage contracts with disabled women in contrast to able-bodied women in ways that in fact negatively bear on their access to the institution of marriage (confirmed by the CRPD in its Article 23). Rather than a pre-determined, absolute and abstract concept, as this example illustrates, the interest of women with disabilities is shaped and ought to be determined in an active interaction and juxtaposition with that of the other three poles around gender and disability.

The case of the *mahr* and disability is just a hypothetical exercise, but the spirit and reality of such protection are not. Mindful of disabled women's difficulty to exercise their right to marry, Iran's current law on the rights of individuals with disabilities, the Comprehensive Act for the Protection of the Rights of the Disabled (CAPRD), in the addendum to its Article 6 provides: "Spouses who support their disabled spouse, for the time that they are providing support, are exempt from military duty." All this disgrace of a law is meant to do is to offer an incentive, one that in the Iranian social context is strong, to men (the only subjects of

military duty) and to the society generally to ensure that more women with disabilities can marry.

With this last example, one hardly need say more on the unintended but inescapable consequences of gender-specific rules in the disability context designed to respond to compounded discrimination. To make matters more complicated, however, it should also be noted the definition of disability in the CAPRD is much more limited than the CRPD. The CAPRD plainly adheres to a medical definition of disability by recognizing “disability as any physical, mental or psychological disorder—or all three together—that have a permanent and considerable impact on the general function and health of the person and affect her social and economic independence” (Article 1(Addendum)). Post ratification, the CRPD stands on the same level of domestic legal status as the CAPRD, and being the latter of the two, it should take precedence over the former in the cases of inconsistency. So in effect the enforceable definition of disability must be the CRPD’s broader definition. Yet if the CAPRD’s Addendum to Article 6 were to apply to the subjects falling under its narrower definition of disability, a wide array of women qualifying as disabled under the broader approach of the CRPD would in effect not be afforded the same privileges in Marriage provided by the CAPRD’s Addendum to Article 6 given to women who are medically recognized as disabled. Although given the larger scope of gender inequality and disability discrimination, this may be only neglect rather than negligence, the question from a theoretical perspective so far as the consequences of gender-specific rules in the disability context are concerned is not moot.

Ultimately, this is all about empowerment, as Article 6(2) of the CRPD reaffirms. Just exactly how much protection is progress and how much would be an impediment is a work of trial and error. If this were how the human rights discourse on gender and disability viewed itself, all that is said in this essay would be no more than a trivial reminder. But the fact is we are so ingrained in fluid identities and multiplication of rights that a reminder such as this about what is at stake for stakeholders can scarcely be avoided. This is not merely a voice against paternalism—that is only a small part of it, but rather a question of functional norms that deliver what they promise. While institutionalizing over-protection leaves the objects of protection worse off in a further disabling manner, avoiding protection for the fear of a perplexing scheme of gains and losses among subjects also speaks of a desire to find the right answer prior to action. The right answer is nowhere but in the action itself, so long as there is a door open to get out of the prison house of old assumptions.



# **Autism and Disability Discourse and Policy in the Comparative Perspective**

**By Ari Ne'eman**

## **Introduction**

Over the course of the last decade, the public profile of the autism spectrum has grown at a far quicker pace than that of any other disability category. Public Service Announcements, celebrity charity events, fundraising walks, and all manner of other means of raising money and “awareness” associated with the autism spectrum have increased markedly, tracking rising incidence statistics for the autism spectrum provided by the Centers for Disease Control and Prevention (CDC). It is difficult to think of a television show that has not had a “very special episode” or a movie star that has not lent their name to some facet of “the cause” at one point or another. Over the course of the last decade, hundreds of millions of both public and private dollars have been invested in autism research and autism has been one of only a select few disability categories to have legislation pass Congress specific to a particular diagnosis.

Yet, despite the rising public attention to this particular developmental disability, the national and international conversations on autism have been largely segregated from other disabilities and developmental disabilities. As autism’s public profile has risen, the likelihood of autism issues being considered separately from those relating to the broader developmental disability category has drastically increased. This raises the question: has the relatively high profile autism has received relative to other disability categories within the “developmental disability” space resulted in greater quality of life for individuals on the autism spectrum? This paper aims to answer some of these questions by outlining the major differences in American policy and public discourse with respect to the autism spectrum as compared to policy and discourse related to other disability categories and seeks to ascertain if individuals on the autism spectrum enjoy improved life outcomes as a result of these differences.

## **How does the discourse on autism differ from the general disability discourse in the United States?**

On January 18, 2011, the Inter-Agency Autism Coordinating Committee, a federal advisory committee tasked with providing recommendations to the Secretary of Health and Human Services, met in Rockville, Maryland (Interagency Autism Coordinating Committee). Among the tasks of the Committee on that particular date was to review and finalize its annual Strategic Plan for Autism Research, one of the few duties statutorily mandated

to the IACC by its authorizing statute, the Combating Autism Act.<sup>1</sup> As the discussion commenced, one of the issues under debate was whether or not to include the idea of self-determination—the idea that people with disabilities should be able to make decisions about their own services, supports and public policies—as a cross-cutting theme in the plan. The idea of self-determination is well established in the developmental disability community—in fact, the Developmental Disabilities Assistance and Bill of Rights Act makes reference to it throughout the text of the legislation. Despite this, the concept was resisted by several members of the IACC. In fact, the final vote came very close to defeating the measure—only two defections would have been required to turn the 12-8 vote into a deadlock. How did a concept so universally acknowledged in one part of the disability community become so controversial in another part?

Some explanation may be found in the different character of the public discourse on autism as compared to the general developmental disability and broader disability discourse. The national conversation on autism which has emerged in the United States is very much distinct in tone, values and inclusivity of the population being discussed from dialogues associated with other disabilities. Such distinctions can be observed clearly in American political, policy and legislative proceedings as well as in the character of language around autism and disability at the United Nations.

An instructive example of the disconnect between general disability and autism policy can be found in a cursory review of successful and unsuccessful disability and autism legislation in the United States Congress. The Americans with Disabilities Act of 1990 (ADA) is generally considered the nation's landmark disability civil rights law, outlining not only clear and specific legal non-discrimination protections for people with disabilities, including a right to reasonable accommodations, but also providing a conceptual framework for disability policy writ large. The findings of the ADA clearly communicate the intent of Congress that disability be viewed as a civil rights issue. To quote the last two findings of the ADA's text upon initial passage:

- 8) The Nations proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic self-sufficiency for such individuals; and
- 9) The continuing existence of unfair and unnecessary discrimination and prejudice denies people with disabilities the opportunity to compete on an equal basis and to pursue those opportunities for which our free society is justifiably famous, and costs the United States billions of dollars in unnecessary expenses resulting from dependency and non-productivity.

Such language clearly places the onus for change on society and identifies the problems associated with disability as caused by discrimination and prejudice, rather than necessarily by particular medical conditions themselves. Contrast this approach with the language surrounding autism legislation. In 2006, Congress passed legislation known as the “Combating Autism Act,” allocating funding primarily to the National Institutes of Health

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1 Full Disclosure: The author is a member of the IACC and participated in this discussion, as reflected in the minutes of the meeting on that date.

around medical research aimed at developing a “cure” for the autism spectrum. In the words of one ardent advocate for the legislation, the co-founder of Cure Autism Now, a national parent group which would later merge with Autism Speaks, “this bill is a federal declaration of war on the epidemic of autism” (Autism Speaks, Inc., 2006). The bill focused almost entirely on research and epidemiological surveillance, with few investments in improved service-provision. At least part of the explanation for this singular focus on medical cures can be found in how those advocating for the Combating Autism Act defined the problems associated with autism. To quote the Autism Speaks website, “Autism costs the nation over \$35 billion per year, a figure expected to significantly increase in the next decade.” This approach, unlike the ADA approach which defines costs on society as resulting from “the continuing existence of unfair and unnecessary discrimination and prejudice,” leads to an exclusive emphasis on eliminating autism rather than improving the lives – and thus the opportunity to contribute to society – of individuals on the autism spectrum. Indeed, while subsequent autism legislation taking a civil rights focus, such as the Expanding the Promise for Individuals with Autism Act of 2007, was introduced, it failed to advance through the Congress in part because of the lack of interest in advancing it from the autism non-profit establishment as compared to priorities relating to medical research.

To further explore the comparison, it may be valuable to compare the Combating Autism Act and the Developmental Disabilities Assistance and Bill of Rights Act (heretofore referred to as the DD Act). Unlike the ADA, the DD Act is a funding bill rather than one creating legal rights—as is the Combating Autism Act. Furthermore, both the autism spectrum and the developmental disability categories include significant numbers of individuals with significant impairments in communication and intellectual capability. In fact, the autism spectrum is generally considered to fall within the scope of the developmental disability category. The DD Act, first passed in 1970, created a network of public interest law firms (called “Protection and Advocacy programs”), Planning Councils and university-based research programs aimed at enhancing the quality of life of individuals with developmental disabilities from childhood to adulthood. The DD Act also makes available funds for “projects of national significance,” typically used for innovative research and service-provision with the ability to develop models that can make a practical impact on the lives of people with developmental disabilities and family members. In short, the DD Act is focused on both research and services and explicitly acknowledges the needs of individuals with developmental disabilities across the lifespan.

By contrast, the Combating Autism Act is far more limited in its goals and scope. The act primarily funds research and surveillance activities aimed at identifying causes and etiology of the autism spectrum. In so far as the act does focus on services—through the expansion of the Leadership and Education in Neurodevelopmental Disorders programs (which existed prior to the CAA)—it does so only in the context of young children. Indeed, the Health Resources Services Administration’s autism work is done within the context of its Maternal and Child Health Division – meaning that addressing the needs of adults on the autism spectrum is outside of its mandate. This is a marked difference from the policy direction set out by the DD Act.

These distinctions have emerged in international forums as well. The United Nations Convention on the Rights of Persons with Disabilities (CRPD) is structured around eight guiding 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.

These abstract concepts are carried out in specifics through the various articles of the Convention, including Article 8—which calls for public awareness campaigns promoting positive perceptions of and greater recognition of the skills, merits and abilities of people with disabilities, and Article 29—promoting the inclusion of people with disabilities in non-governmental organizations and in self-advocacy organizations run by and for people with disabilities (CRPD). Although the majority of the convention deals with more concrete matters of policy such as the availability of reasonable accommodations or the provision of services and supports in integrated community settings, the Convention also addresses the importance of including people with disabilities in all aspects of the public discourse on them and stresses the need for public conversations on disability which are respectful, inclusive and in keeping with the values of the Convention.

In contrast, autism discussions at the United Nations have proceeded from a very different framework. While the General Assembly Resolution establishing April 2<sup>nd</sup> as World Autism Awareness Day did make reference to the UN Convention on the Rights of the Child and the UN Convention on the Rights of Persons with Disabilities, the content of much of the autism conversation at the United Nations has been through a public health rather than a civil rights framework. In addition, it seems that the standards of respectful discourse are very different when discussing autism as compared to other disability groups. For example, in September of 2009, a gathering of First Spouses at the United Nations were shown a video pulled together by Autism Speaks, the largest and best-funded autism advocacy group in the United States, entitled, “I am Autism” (Autism Speaks, 2009). The video consisted of a disembodied voice announcing:

“I am autism. I'm visible in your children, but if I can help it, I am invisible to you until it's too late...I speak your language fluently. And with every voice I take away, I acquire yet another language....I work very quickly. I work faster than pediatric aids, cancer, and diabetes combined. And if you're happily married, I will make sure that your marriage fails. Your money will fall into my hands, and I will bankrupt you for my own self-gain. I don't sleep, so I make sure you don't either. I will make it virtually impossible for your family to easily attend a temple, birthday party, or public park without a struggle, without

embarrassment, without pain.... I am autism. I have no interest in right or wrong. I derive great pleasure out of your loneliness...I will fight to take away your hope. I will plot to rob you of your children and your dreams.” (Autistic Self-Advocacy Network, 2009).

The video sparked a horrified response amongst autistic adults and youth, leading to nationwide protests of Autism Speaks fundraisers, and an advocacy campaign utilizing bloggers, social media and on the ground advocacy leading to the successful removal of the video from the internet (Biever, 2009). However, it is surprising and instructive to see that a video which could spark such a strong response from the individuals with the disability it aimed to represent would have been placed in such a position of honor in an international forum. One possible explanation may relate to the different processes that autism and general disability policy conversations have taken at the United Nations and elsewhere. While a wide array of different non-governmental organizations, including many run by people with disabilities, participated in the United Nations Convention on the Rights of Persons with Disabilities, most autism discussions at the UN have been driven by a single parent organization, Autism Speaks, which lacks any autistic individuals on its board of directors or amongst its senior leadership (Wallis, 2009).

### **What does the data tell us about the outcomes of autistic people in the United States?**

The National Core Indicators Consumer Survey Report is designed to provide data on the experiences of individuals with intellectual and developmental disabilities receiving publicly financed service-provision in twenty states. The NCI Survey reveals a number of concerning differences in the service-provision experiences of adults on the autism spectrum as compared to those with other developmental disabilities. For example, while the percentage of autistic persons with a co-occurring diagnosis of mental illness (18 percent) was far lower than that of persons without an autism diagnosis (28 percent), autistic people were vastly more likely to be taking every variation of psychotropic medications. The percentage of autistic adults under guardianship was twenty-one percent higher than people with other developmental disability diagnoses (NCI Data Brief, 2011). Autistic adults were also significantly more likely to receive labels such as “uncooperative” and “disruptive behavior” than individuals with other developmental disabilities and had substantially less choice and control over their own day- to-day lives (NCI Data Brief, 2011).

The aforementioned inequities also exist for younger autistic individuals. According to US Department of Education data, over a third of autistic students spend less than 40 percent of their day inside the general education classroom, as compared to under 10 percent of students with other disabilities (IDEA Data, 2011). Indeed, a national survey of high school students with disabilities found that autistic students spent over 70 percent of their academic courses in segregated settings (Institute of Education Sciences, 2007). Despite far greater public attention and political capital, autistic adults and youth face significantly worse educational and service-provision outcomes than other groups of people with disabilities in the United States. What can explain this inequity and is it related to the differences in societal approaches that exist when comparing autism to other disabilities?



## **What are some possible causes for the divide between autism and general disability discourse, policy, and outcomes?**

At this point, it may be worth considering the ways in which autism and disability policy have been shaped by the process of their development, specifically, the constituencies they were intended to serve. Passage of the ADA—and its predecessor the Rehabilitation Act—was the result of a broad-ranging effort which included family members, professionals and a wide range of supportive allies but was primarily led by disabled individuals. Section 504 of the Rehabilitation Act of 1973—an earlier law applying only to entities receiving federal funds which the ADA extended to the public at large—was enforced only by virtue of mass direct action led by groups of disabled people in 1977 to pressure the federal government into promulgating strong regulations implementing the law (Shapiro, 1994). While the Developmental Disabilities Act was passed mainly due to strong family advocacy, the community of families who led the effort was broad-based and included many who had adults with developmental disabilities in their families rather than just children.

The Combating Autism Act's passage can be traced back to the founding of Autism Speaks, an advocacy group mentioned earlier in this paper run near-exclusively by the parent and professional constituencies within the autism community. Autism Speaks was founded in 2005 by the then Vice Chair of General Electric and Chairman and CEO of NBC Universal Bob Wright and his wife Suzanne, who were motivated primarily out of a desire to cure their recently diagnosed autistic grandchild—one of the Wrights' first pronouncements upon forming Autism Speaks was, "I want my grandson back" (Wright, 2005). A review of the statements of Autism Speaks' founders show an almost exclusive interest in causation and cure research, as well as interventions aimed at young children. Furthermore, the tactics of the autism movement's most well-financed organization differ significantly from that of the broader developmental disability movement as well. Often, they have more in common with the corporate boardrooms from which Bob Wright emerged. Shortly after its founding, Autism Speaks swallowed up via mergers the two largest autism research organizations prior to its emergence—Cure Autism Now and the National Alliance for Autism Research (Gross & Strom, 2007). Soon after, NBC's television and print media served as effective mechanisms to amplify the organization's message, focusing primarily on the views and experiences of its founders, such as "Suzanne Wright Discusses New Autism Speaks Awareness Campaign on Today Show, MSNBC." (Autism Speaks). The media blitz elevated autism above other diagnoses in the popular mind, leading—along with the lobbying power of Autism Speaks more generally—to the passage of the Combating Autism Act soon afterwards.

This history helps clarify the disconnect outlined earlier. Much of the divide between the disability and autism narratives in the United States can be attributed to the lack of inclusion of Autistic people themselves in the policy and public discussions around the autism spectrum, in contrast to the generally more inclusive discussions in the world of general disability policy. People with disabilities—by virtue of experiencing the challenges of interacting with a world all too frequently designed for the non-disabled—are much more likely to prioritize the gains in quality of life that can be acquired through the civil rights and services/supports framework adopted by the UN Convention on the Rights of Persons with Disabilities. In contrast, parents—particularly parents of young children, who are over-represented in the autism world as compared to in other developmental disability

parent communities—are more likely to prioritize basic medical research and services focused on early childhood. The historic exclusion of self-advocates from autism policy discussions has shaped policy away from the needs of Autistic people living today, with the exception of young children, and towards a focus on causation and prevention. This is reflected in both the autism policy agenda, as described earlier in this paper, as well as in the autism research agenda, where the bias can be reflected statistically.

The IACC's 2009 Research Portfolio, an annual report which tracks the direction of all autism research dollars both public and private, found that only three percent of 2009 research dollars relating to ASD went to research focused on improving services and supports for individuals on the spectrum. A similar inequity existed for research focused around the needs and characteristics of adults on the autism spectrum, which only garnered less than one percent of research funding—as compared to 32 percent for research oriented around causation and prevention (Interagency Autism Coordinating Committee). In light of these inequities, it is unsurprising a recent study found as many as 40 percent of young adults on the autism spectrum lack access to any service-provision, even as public attention to ASD is at its highest (Shattuck et al., 2011). Indeed, reflecting the dominance of the parent narrative in autism policy, the few legislative and policy advances relating to the autism spectrum in recent years have been focused around insurance coverage for interventions in early childhood rather than improvements in service-provision across the lifespan.

In closing, an analysis of the practical results of the increased public attention to the autism spectrum in the United States yields very mixed outcomes and results in terms of meaningful improvements in quality of life for autistic adults and youth. The difference between political and social capital and results can be attributed at least in part to the marginalization of self-advocate voices from the United States' national autism policy conversation and the resulting differences in focus, priorities and values from the general disability and developmental disability movement. As the autism movement in the United States and internationally evolves and grows to reflect a changing population and demands by self-advocate stakeholders for a greater voice, it would be wise for greater consideration to be given to the positive role a more inclusive conversation has played in general disability rights and policy movements.

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# **The Role of Non-Governmental Organizations as Reflected in the Social Movement of the Disabled in Iran: Achievements and Obstacles**

**By Soheil Moeini**

## **The disabled people of Iran, past and present**

The history of the disabled in Iran is quite similar to that of any other country. Initially they were observed as flaws in the system of creation, always in need of assistance and care, the responsibility of which would naturally fall on their parents who had no choice but to provide the means necessary to relieve their primary needs. At this stage the disabled did not socialize or were not able to do so. The second stage of development in the social life of the disabled was through religious and charity foundations, which enabled these individuals to leave their homes and acquire some primary education by clergy men and charitable people. The presence of the disabled in community centers, mostly in small areas and villages to learn the Qur'an and memorize the Shahnameh (an epic poetic masterpiece written by Ferdowsi), was the result of this new-found social freedom.

In the third stage of social development, the disabled were empowered by society, supported and sponsored by charities and allowed to acquire preliminary educational abilities and crafts. In the fourth stage, which spans the past 40 to 50 years, the very first modern non-governmental organizations (NGOs) in the country were formed. These organizations recognized the rights of the disabled to learn crafts and skills, earn a living, and have a respectable life in accordance with social norms, and placed these rights within their working charters. The main feature of such organizations was that they were managed by wealthy charitable people or specialists in aiding the disabled, while the disabled themselves had no part in the matter. The fifth stage of social development was the origination of the very first self-help organizations for the disabled, formed through the many endeavors of the first group of educated disabled people in the 1960s. However, it was only since the 1970s that this movement has taken on more permanent forms through organizations such as the Disabled Society of Iran (DSI).

Even in this period, despite the sudden growth of government assets through oil production, the social interaction of the disabled was limited to their participation in newly established special schools for the disabled and governmental rehabilitation centers. There was no visible ground for the development and expansion of NGOs for the disabled (DNGOs). It was not until the 1980s and the increasing presence of educated people with disabilities in society that the circumstances existed, including general and cultural awareness, to establish DNGOs which would be managed by disabled for the disabled. Following this were steady improvements in such organizations, including the White Cane Foundation in 1990 and the Blind Society of Iran in 1995. In the second half of the 20<sup>th</sup> century there was

a considerable boost in the establishment of NGOs, consisting of disabled activists, to the point that over the period of five years the number of such organizations reached 250, albeit only in smaller areas, rural areas, and provinces. The establishment of such organizations has had a significant effect on the quality of activities and services of the disabled in Iran, some of which will be discussed below.

## Achievements

The most important and direct influences of NGOs on the morale and living conditions of the disabled are outlined below.

1. **Shaping the group identity of the disabled.** Establishment of such NGOs has resulted in the formation of a group identity of sorts among the disabled as people with common rights and needs; this is the first base for the rise of conscious social efforts of the disabled as a recognized social minority.
2. **Increasing self-esteem and confidence.** Through these NGOs, the disabled have come to a common belief they can change their destinies and improve their own lives and social affairs by willingness to do so.
3. **Enabling the public and social presence of the disabled.** DNGOs have empowered more disabled people to have reasons to leave their homes and to be present in the public. This is especially true for women who, due to cultural and tradition limitations, had no social presence before.
4. **Filling voids in the governmental service system.** One of the most prominent achievements of the disabled self-help organizations in Iran was the improvements in services that government-supported organizations either did not provide or provided with sub-par quality and quantity, such as teaching Braille and navigation skills to the blind, providing wheelchairs and other means for facilitated accessibility to individuals with physical disabilities and movement impairments, teaching arts and crafts to the mentally disabled and etc.
5. **Voicing the needs of the target group to the decision-makers.** One of the significant accomplishments of the DNGOs was their role in enabling the needs of the disabled to become clear to the executive and decisive authorities or bureaus such as the Islamic parliamentary council.
6. **Offering specialized consultation to the ministries and public sectors.** Another vital achievement of the DNGOs was offering consultation for fulfilling the needs of the disabled and improving the management of their affairs such as prioritizing accessibility in urban environments and assigning budgets to institutions for the social welfare of the disabled.
7. **Raising public awareness.** The DNGOs educated the public through different methods such as the media to recognize the needs of the disabled and introducing the social rights of these people.

Following on the above-mentioned achievements, this essay next explains the social and legal rights of the disabled as established within the DNGOs.

- HB **Ratification of the comprehensive law on the rights of the disabled in Iran.** Through the efforts of the activists and the support of the NGOs, the comprehensive law on the rights of the disabled was presented to the parliament and after being reviewed by a committee of five disabled rights activists, it was completed and ratified as the most important document to defend the legal rights of the disabled in Iran since 2004 and the most important reference for disabled rights in Iran.
- HB **Ratification of the Convention for the Rights of People with Disabilities (CRPD) in Iran.** After the acceptance of the convention by the United Nations, the translation and publication of this great global achievement of the disabled was placed on the agenda of DNGOs in Iran. Efforts in convincing the legislature to sign and accede to this convention led to its ratification in the parliament in 2008; ratification of international treaties in the parliament of Iran is equal to their addition to the legal constitution of the country.
- HB **Establishing a committee for the accessibility of the city of Tehran.** The second amendment in the comprehensive law by the NGOs led to the establishment of the committee for the accessibility of Tehran, a division of the current municipality, with representatives from the DNGOs to supervise and execute the accessibility plans for Tehran.

## Obstacles

In the first section, this essay reviewed the stages of social life development of the disabled citizens and the emergence of NGOs, which were similar to that which occurs in many other countries. In this section, it will look at the significant obstacles in the process of developing DNGOs. It takes a general look at the internal flaws in the main functions of these organizations, as well as observe a number of external limitations in the cooperation of the NGOs with administrative and executive sectors and governmental institutions. These obstacles are only general observations and do not necessarily apply to all DNGOs.

1. **Insufficient professional human resources.** Even though the establishment of self-help organizations by activists represents an improvement in the social functioning of the disabled, the intention to establish such an organization, and the actual managing and optimal administration of one are very different issues. Many managers of public liability institutions do not have the management know-how and skill to run the facility and this reduces the quality of the services they provide.
2. **Lack of professional structure.** Many of the organizations for the disabled in Iran lack professionalism in both structure and services. Since their executive qualities are solely dependant on the management skills rather than academic



and professional criteria, the quality of their services, if at all acceptable, cannot be long-lasting.

3. **Lack of financial stability.** Many of the self-made organizations for the disabled lack stable funding options, therefore their service qualities suffer a variance and more importantly the lack of fiscal material leads to the loss of professional resources.
4. **Lack of democratic succession of management.** Many NGOs suffer the lack of democracy in both electing and transferring management positions and the board of directors. There is no guarantee that management will be transferred to reliable, dependable and worthy candidates. This issue has caused many disabled rights activists to forfeit their positions within DNGOs.
5. **Lack of clear executive procedures, and methods for evaluation and inspection.** The lack of a solid evaluation and inspection procedure for the activists in DNGOs, insufficient supervision and reports and unclear executive and financial plans have caused some ethical management issues where certain NGOs were literally turned into money-making machines. These cases not only waste monetary resources designated for the improvement of the lives of the disabled but also damage the unity of other DNGOs that strive to serve and hinder the legal support of the rights these NGOs aim to uphold.
6. **Dependence of most institutions on government budgets.** The focus on oil production resources within the government has caused institutions to seek budgets from state authorities rather than utilizing the skills they have to leverage earning potentials within the government. This dependence not only lowers the level of professionalism but also causes the next important issue.
7. **The anomalous control of the government over DNGOs.** The monetary dependence of DNGOs on the government enables the government to control the activities of the institutions which can eventually only damage the individual claims to the legal rights of the disabled.
8. **Lack of national linking channels.** Despite the soaring increase in the number of DNGOs and even improvement of executive and management qualities, organizations in Iran are not nationally connected to each other. This reduces their chances of effective action and staking claims as a national unit with governmental authorities.

## Conclusion

This article highlights the general achievements of DNGOs and obstacles that alter their activities. However, a comprehensive overview shows the social movement of the disabled in Iran and DNGOs has admittedly had a significant growth, especially over the past two decades. The tangible result of that has been the increasing prevalence of the belief among the disabled of Iran that they must unite to claim their rights in an organized body. There are two factors that encourage the development of DNGOs. First is the inability of the

government to fulfill the needs of the disabled which leads them to seek aid and support from NGOs. Second is the increasing presence of the educated disabled and professionals in matters pertaining to disability in positions of management, office, and social activities within the DNGOs, who greatly contribute to dealing with issues and pathologies of such organizations.



# Assessing the Policy Divide Between Veteran and Non-Veteran Americans with Disabilities

By Michael E. Waterstone and Michael Ashley Stein

Disabled veterans historically have been accorded social welfare support and been viewed as an integral part of their societies at a level above that of the general population of persons with disabilities (Gerber, 2000). Present in most countries, such preferential treatment is grounded in moral responsibility felt towards those who have sacrificed their well-being on behalf of the State, despite variation between States in the extent of their respective disabled veteran policies (Cohen, 2001). This divergent treatment, predicated on the origin and consequent inherent “worthiness” of disability, is bolstered by deep seated notions that veterans with disabilities are expected to return to the workforce while persons otherwise disabled are exempt from labor market participation (Waterstone, 2009). The United States has a two-tier system of disability law and policy, one for veterans with disabilities and one for the general disability population. The government framework towards veterans with disabilities has greater coherence; however lessons can be drawn from both schemes.

## A two-tier system

Federal disability law and policy for people with disabilities is multifaceted. Most prominent is the Americans with Disabilities Act (hereafter ADA), an antidiscrimination law adopted in 1990 that contains the express right to be treated equally without regard to disability (ADA, 1990). One of the most prominent—if not the preeminent—priorities of the ADA was to create conditions under which people with disabilities can work. Moving people with disabilities into the labor force was a proposition that had support on both sides of the political aisle (Bagenstos, 2003). The importance of employment to a previously marginalized group is a bedrock principle of antidiscrimination law generally, and is a proposition that has gathered popular academic support (Schultz, 2000).

Separate from antidiscrimination law, and operating from a very different set of premises, are more direct forms of assistance that the government provides. Categorized loosely as a “social safety net,” “social welfare policy,” or even “positive rights,” the focus is on affirmative ways the government can help people with disabilities. These federal laws and programs either directly or indirectly provide goods and services to certain people with disabilities, including cash payments, medical goods, and diverse services. The programs are eligibility driven, and the criteria for acceptance rests on medical assessments made of the individual. Would-be participants are evaluated “objectively” by medical professionals and government bureaucrats who in turn make gate-keeping determinations as to whether an individual’s medical condition makes them eligible to receive benefits. The bulk of American federal disability welfare spending goes to four programs: Social Security Disability Insurance

(SSDI); Supplemental Security Income (SSI); Medicare; and Medicaid (Waterstone, 2009). SSDI and SSI provide income support while Medicare and Medicaid provide medical benefits. SSI and Medicaid are restricted to persons with low incomes; SSDI is available only to those with a work history who become disabled. Medicare is the national health insurance program for persons over age 65, but is also available for persons who have received SSDI benefits for at least two years.

This historical model of conceiving disability, referred to as the medical model, casts people with disabilities as the passive recipients of public welfare or charity. For fear of frauds or cheats (or extending the social welfare net further than is politically acceptable), most of these programs are designed to be restricted to people who at least at some point are so disabled that they cannot work. They therefore contain significant work disincentives or require some distance and detachment from the labor market to obtain entry into the system. Accordingly, the four assistance programs, and the interaction between them, have been criticized for creating incentives for people to not return to work (Burkhauser, 1997).

Partially in response to criticism of an emphasis on non-work, legislators have begun to enact some revisions. In 1999, Congress passed the Ticket to Work and Work Incentives Improvement Act (hereafter TWWIIA), which allows people with disabilities who leave the SSDI rolls to retain Medicare eligibility for eight and a half years (TWWIIA, 2006). After that point, Medicare eligibility is lost. TWWIIA also provides for an expedited reinstatement of Medicare or Medicaid benefits to recipients who, after a period of time in the labor market, become unable to work again. Finally, TWWIIA limits the degree to which work activity can be used to prove that a recipient no longer has a disability (TWWIIA, 2006). Similarly, if an SSI recipient with a disability returns to work, medical benefits under Medicaid are not ended until the recipient's monthly income exceeds the sum of the monthly SSI cash benefit, any impairment-related work expenses, and the monthly cost of Medicaid benefits and publicly funded attendant care services previously paid to the recipient (Waterstone, 2009). Although positive steps, these patchwork attempts at overhaul have not yet moved large numbers of people off the SSI or SSDI rolls. In large measure this is because job training and support has traditionally not held a prominent place in the American policy scheme, there being little in the way of a national job training program for people with disabilities (Stein & Stein, 2007).

By contrast, since the time of its founding the United States has had a stated commitment to care for its wounded warriors. Veterans with disabilities historically have been viewed by the public as the "deserving" disabled (Hubbard, 2006), and more recently stories of returning veterans with disabilities acclimating to their new lives have been quite prevalent in the media. In step with public opinion, politicians and policymakers have operated from a stated desire to care for returning veterans of foreign wars (Liachowitz, 1988). Perhaps the seminal statement regarding veterans with disabilities came in President Lincoln's second inaugural address, when he challenged a divided nation to "bind up the nation's wounds, to care for him who shall have borne the battle and for his widow and his orphan" (Lincoln, 1865). This is still the operating principle of the Department of Veterans Affairs. Politicians and policymakers have not wanted to be on the wrong side of veterans with disabilities. In consequence, veterans with disabilities have had access to favorable laws, programs, and services not available to the general population of people with disabilities (Gerber, 2001).

Veterans with disabilities can proceed with employment discrimination claims under the ADA. However, they have additional and expanded protections under the Uniformed Services Employment and Reemployment Rights Act (hereafter USERRA) which include a broader category of reasonable accommodations, and employer mandated training or retraining for employment positions (USERRA, 2006). Veterans' disability benefits are more generous than SSI and SSDI, tax free, and not subject to reduction based on future employment (Veterans, 2007). Moreover, the Veterans Administration Pension system renders veterans with disabilities with low incomes eligible for monetary support; the Veterans Administration Health Care system provides primary and secondary medical care; and veterans with service-connected disabilities are entitled to important transportation benefits (Waterstone, 2010). Finally, veterans with disabilities have access to the Vocational Rehabilitation and Employment Program which assists veterans with service-connected disabilities to obtain and retain employment (Waterstone, 2010).

In sum, veterans with disabilities have access to favorable laws, programs, and services that are limited to their ranks and deploy both antidiscrimination law and social welfare policies in a more integrated manner than does general disability policy.

## **Lessons drawn**

Veterans with disabilities are a discrete population the United States government and the public have pledged to support. In contrast, the general population of people with disabilities is larger and more diffuse. Although at various points the federal government has undertaken the task of creating equal opportunity for this broader group, important pieces of their welfare have been left to individual states or completely unattended.

This is not to infer the status of veterans with disabilities as the “deserving disabled” has meant that targeted employment-based strategies have worked perfectly. Veterans with disabilities have not been able to escape many of the problems that have infected the general disability landscape. Veterans programs and commitments are chronically underfunded, poorly administrated, and bureaucratically inefficient. Nor do veterans with disabilities escape stigma and suspicion. Indeed, there is a sad reality at work here for the neglect of veterans with disabilities by policymakers that has historically outlived the public's immediate embrace of their service and sacrifice.

Nevertheless, veterans programs offer important insights on what types of policies could be more effective at moving people with disabilities into the workforce—a goal the federal government has continuously identified as worthy of a federal response. To this end, veterans programs provide support for both a broader conception of antidiscrimination law and associated social welfare programs that reduce structural barriers to employment.

Although wholesale implementation is unlikely, veterans-specific disability measures have at times benefited the larger disability community. At a systemic level, veterans programs can serve as a template that could be applied, with modifications, to a larger community of people with disabilities. Thus, for example, the United States' first foray into workers' compensation was similar to compensation already provided to veterans with disabilities (Scotch, 1993). Similarly, SSDI was initially based on aspects of the civil war pension scheme

(Stone, 1984). While vocational rehabilitation may have had its roots in the desire to help workers who had been injured on the job, its overall development was equally influenced by a desire to reintegrate veterans with disabilities into the workforce (Drimmer, 1993).

Veterans with disabilities can also increase overall acceptance of the disability classification. Returning veterans have favorably influenced how the public and policymakers view disability (Liachowitz, 1988). The shift away from treating people with disabilities as inevitable wards of the state and toward rehabilitation was spearheaded by veterans returning from World War I (Scotch, 1993). The Vietnam and Gulf Wars created recognition of war-related disabilities like post-traumatic stress disorder and disease based on environmental exposure, which were aided by understanding chronic disease in civilians (Hubbard, 2006). And, more generally, veterans with disabilities helped gain acceptance of the social model of disability, which took hold as social policy for all people with disabilities in the enactment of the ADA (Stein & Stein, 2007).

Finally, because history shows that the popularity of veterans fades over time as they gradually become subsumed into the general disability community, it is in the veterans with disabilities' self interest to use their unique political status to advocate for measures that have wider benefit to the disability community.

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