



“I Am Equally Human”

**Discrimination and Lack of Accessibility for People with
Disabilities in Iran**

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Map



Summary

Alireza, 22, has cerebral palsy. He uses a wheelchair and can only use his right hand. He had to drop out of school at 15 because there was no way for him to reach classrooms on the upper floors of the school or use the toilet. Before that, he relied on other students or cleaning staff to carry him and his wheelchair, but as he gained weight, this became impossible. For his entire life he has relied on his mother, now 65, to use the toilet, shower, and get dressed. His mother suffers from severe backpain that sometimes keeps her in bed for weeks. Alireza said:

I really feel ashamed when she struggles to help me, so I try to minimize my requests for help. I wish I could have someone else to assist me. But the State Welfare Organization, which is responsible for supporting us, does not care about us. They just pay me this monthly allowance [the equivalent of US\$40] with which I can't even buy one meal per day. I think I can survive only while my mom is alive. The day she is not there for me, I will have nowhere else to go...

Though he enjoys exercising, Alireza rarely leaves home and spends most days watching television. For Alireza, just reaching the sports club requires overcoming multiple barriers. Public transport near his home – including buses or metro – are not accessible for someone like Alireza who has a physical disability. Seeing his wheelchair, taxi drivers rarely stop to pick him up, and when they do, charge extra to put his wheelchair in the trunk. “I think most people, and especially those in charge, often forget that we are equally human,” he said.

Like Alireza, people with disabilities across Iran face serious obstacles to participating in daily life activities that most people take for granted, such as going to work or school, gathering with friends or relatives, attending cultural events, shopping for groceries, or visiting the doctor. Inaccessible buildings and public transportation impede independent navigation and participation. People with disabilities confront stigma and discrimination almost everywhere in their daily lives, for example when interacting with state-employed social workers, doctors in hospitals, and public bus drivers. Stigma and discrimination are even embedded in the public policies supposedly aimed to support them. Discrimination

in healthcare is also a persistent problem, including the failure to provide people with disabilities full and accurate information about treatments and available options and ensuring that they give informed consent to treatment.

To live an independent and dignified life within society, people with disabilities should have access to services and devices that facilitate their participation in the community on an equal basis with others. People with different types of disabilities require differentiated services. For example, assistive equipment such as motorized wheelchairs and elevators in public buildings may be essential for some. Others may require personal assistance services, whereby a professional assistant supports an individual with daily tasks such as dressing, bathing, cooking, shopping, and participating in other activities. Social protection programs including disability pensions may also be essential for some to secure services that are not provided by the state.

All people with disabilities have the right to access the physical environment, including buildings, roads, schools, housing, medical facilities, workplaces, and other facilities and services open or provided to the public, in both urban and rural areas, on an equal basis with others. People also have the right to live independently and be included fully in their communities. They also have the right to the highest attainable standard of health, including rehabilitation and services specific to their disabilities. The government also has an obligation to raise awareness about the rights and dignity of people with disabilities and to combat stereotypes, prejudices, and harmful practices.

The Iranian government has taken some steps towards improving rights protection for persons with disabilities in recent years. Iran ratified the United Nations Convention of the Rights of Persons with Disabilities (CRPD) in 2009 and began initiatives to investigate and promote accessibility of public buildings, transportation, and other facilities in Tehran and other major cities including through the establishment of the National Headquarters on accessibility in 2015. Most recently, a new law on protection of the rights of disabled people came into force in 2018. However, much more needs to be done.

Through 58 in-depth interviews with people with disabilities and others, Human Rights Watch and the Center for Human Rights in Iran documented discrimination, abuse, and lack of accessibility. We found that the government has failed to provide sufficient community-based services - including quality and appropriate assistive equipment,

personal assistance, accessible and affordable habilitation and rehabilitation, and other services - thus violating the right of people with disabilities to live independently and participate in the community. It has also failed to take appropriate steps based on all available resources to develop accessible public transportation and to guarantee equal access to health care for people with disabilities.

Negative stereotypes and discrimination, including among state social workers and medical workers, also impede access for people with disabilities to essential services. As a result, many people with disabilities spend their lives isolated at home and totally dependent on family members or relatives for support for the most basic daily tasks.

Iran is an upper middle-income country with a GDP per capita of US\$20,000 in 2016, according to the World Bank. However, senior State Welfare Organization officials have frequently noted that insufficient budgetary support contributes significantly to the lack of services and support for people with disabilities in the country.

There are no official up-to-date statistics on how many of Iran's roughly 80 million people have disabilities. Government agencies providing services to people with disabilities reported 1.8 million people, or 4.2 percent of the population, registered as having disabilities in 2015. The actual number of people with disabilities in Iran is likely much higher. Some officials in Iran have acknowledged that the actual number of people with disabilities is likely between 11 and 14 percent of the population, or about 9 to 11 million people. Globally, according to the World Bank and the World Health Organization (WHO), approximately 15 percent of the world's population have disabilities. Stigma and discrimination, a cumbersome and often long registration process, as well as a lack of awareness about their rights, likely contribute to a reluctance among some people to register or among families to register their children. This may be particularly true for women and girls; only 35 percent of people registered as having a disability with the State Welfare Organization are female.

State Welfare Organization Failures

Our research uncovered serious problems in the work of the State Welfare Organization (SWO), the main agency tasked with providing services to people with disabilities. Interviewees described how state social workers insulted and humiliated them. Many

people we interviewed stated that social workers did not provide them with sufficient information in a timely manner about services and equipment to which they are entitled to and the procedures for obtaining them.

For the most part, those we interviewed who required assistance in fulfilling basic needs—including eating, getting dressed, or daily hygiene—relied solely on the help of family members or close friends. While family members often play important roles in the lives of people with disabilities, people with disabilities have the right to live independently and be included in the community on an equal basis with others. To ensure this, they should have access to a range of in-home and other support, including personal assistance. None of the people with disabilities interviewed for this report benefited from professional personal assistance (PA). A personal assistant is an individual supporting a person with a disability in different aspects of daily life – such as personal care, household tasks, assistance at school, university, or the workplace, driving, interpretation, and other tasks customized to the individual.

People who did hire individuals to help with personal care reported instances of caregivers not providing professional care, such as improperly inserting a catheter and causing injury, or stealing from them. Government officials have acknowledged the need for greater oversight of companies that offer home care services.

The SWO is responsible for providing assistive devices such as wheelchairs, crutches, and hearing aids. However, many people interviewed said that they encountered excessive waiting times, often up to a few years, and complex procedures to obtain free or subsidized equipment. People who did receive assistive devices found that they were of low quality and did not facilitate their independence. For example, the SWO typically only provides manual wheelchairs. People whom we interviewed who cannot use manual wheelchairs independently said that their only choice was to purchase electronic wheelchairs at their own expense, which many could not afford to do.

The SWO implements some community-based rehabilitation programs aiming to make services available within communities, particularly in rural areas. However, interviews with people with disabilities in Iran revealed that many of them face various barriers in accessing essential services such as physiotherapy, speech therapy, occupational therapy, and psychotherapy. Often, these services are not available in the communities where they

live. Where they do exist, the quality may be poor, or services may be cost prohibitive: neither private nor public insurance schemes in Iran cover these services.

Human Rights Watch and the Center for Human Rights in Iran found that the current disability pension program is discriminatory and has serious shortcomings both in coverage and the amount paid. According to the government, 25 percent of persons with disabilities registered with the SWO, or 321,000 people, received “disability pensions” in 2016. However, many people with disabilities who need financial support do not receive the benefit. Unemployment among people with disabilities is 60 percent. Yet, only those with disabilities diagnosed to be “severe or very severe” are eligible. The lack of sufficient funding also limits the number of people who receive the pension. Some people we interviewed mentioned that SWO staff said that they will remain on waiting lists to receive the pension until another recipient becomes ineligible (finds a job, for example) or passes away. The amount of the pension in the most recent Persian year 1396 (March 2017 to March 2018), 1.48 million Iri (US\$39.36), is not sufficient to meet basic needs; by contrast, in the same year, the official minimum wage was six times greater, or 9.3 million Iri (\$247.34), which has also been criticized as being too low.

Discriminatory Laws and Policies

The Iranian government’s approach to disability continues to rely heavily on the medical model of disability, which contributes to discriminate and stigmatize. Until recently, disability was widely understood through the lens of a person’s defect, difference, or illness. People with disabilities were seen as vulnerable, in need of care, or in need of curing. Under the CRPD, disability is understood as an interaction between individuals and their environment, and the emphasis is on identifying and removing barriers in the environment and discriminatory attitudes. This reflects the shift from the “medical model” of viewing disability to a social, or rights-based, model.

The definition of disability under Iran’s 2004 disability law is unnecessarily restrictive and reflects this medical model, focusing on an individual’s health and functioning as determinants of disability, and qualifying disability as “impairments amounting to continuous and considerable deficiency in their health and general functioning to the level that the person’s social and economic independence is reduced.” The law’s language excludes conditions in some way determined to be “less severe” or non-continuous.

For people with psychosocial disabilities, only those who are identified as having “chronic mental disorders” can be registered as people with disabilities. To qualify, a person must have a condition that has been continuous for the past two years and must have been hospitalized for their psycho-social condition at least once in the last two years.

Iranian legislation uses derogatory and outdated language such as “insane,” “retarded,” “eyeless,” and “crippled.” The government has sought to revise some language in recent years, including by using the terms physical disability and mental disability.

In addition, prevention of disability is one of the main priorities of Iran’s disability policy. The idea of preventing disability reflects an outdated approach to disability which regards disability as an impairment that needs to be cured or fixed. While government actions to improve public health, access to health care services and information, and other policies may result in a reduction in the number of disabilities, prevention of disabilities is distinct from the protection of the rights of people with disabilities.

Inaccessible Public Transportation

As a result of poor accessibility to public transportation, roads, and buildings, many people with disabilities in Iran we interviewed remain trapped in their homes, unable to live independently and participate in society on an equal basis with others. For example, although there are some buses with ramps accessible for people who use wheelchairs or walkers, some people reported that drivers often do not know how to open the ramp. In larger cities with metros, there are elevators in some stations, but they are often out of service. Some wheelchair users resorted to using escalators, despite the dangers.

For people who are blind, bus stops are not announced, and regular buses may stop outside of designated stops, hindering the ability of a blind person to count stops as a means of orienting in the absence of announcements. At least one blind person has died and several others have been injured while trying to board a train in the Tehran metro in recent years, according to media reports.

People living in smaller cities and rural areas faced particular difficulties in accessing transportation, since public transportation in these locations is either very minimal or does not exist at all, and where it does exist, it is overwhelmingly inaccessible.

Inaccessible Public Buildings

Iran is a highly centralized country and the government regulates nearly all activities. Basic requests can require complex forms, administrative processes, and official stamps. To access most public services in Iran, people need to go in-person to governmental offices. According to SWO, only thirty percent of public buildings in Iran are accessible for persons with disabilities. Even State Welfare Organization offices are typically inaccessible, despite the fact that people with disabilities must visit them in order to receive various services.

People with disabilities interviewed, especially those who use wheelchairs, said that they find the entrances of most public buildings inaccessible, due to stairs without alternative ramps or elevator access. Even when an elevator is available, interviewees said that many elevators were too small to fit most wheelchairs. Blind people or people with low vision reported inaccessible elevators in many public buildings. In some cases, the elevator floor designators or call buttons are not accessible because they do not have braille or vocal indicators.

The Iranian government has made some progress toward making public infrastructure and transportation more accessible, particularly in the capital, Tehran, and some larger cities. It also established the National Headquarters to Follow-up on Accessibility in 2015, which requests reports and information from different government bodies about their efforts to improve accessibility. In recent years, many municipalities around the country have appointed advisors on “citizens with disabilities” or “urban accessibility” some of whom have been people with disabilities themselves.

Lack of Accessibility and Discrimination in Healthcare

Human Rights Watch and the Center for Human Rights in Iran documented multiple barriers impeding the ability of people with disabilities to access health care services on an equal basis with others. The lack of accommodations as well as discriminatory attitudes and a lack of awareness among doctors and medical staff are serious concerns. Further impediments to accessing medical and personal care include a lack of assistive services and equipment, a lack of financial means due to inadequate government support as well as inaccessible transportation and physical infrastructure, including in health care facilities.

Quality and specialized health care services are not provided in some provinces, particularly in remote and rural areas, and people must often travel long distances to reach a medical facility. Upon reaching a hospital or clinic, persons with disabilities often cannot access them because many do not have ramps or elevators. Blind people and those with low vision said that they do not go to health care facilities alone because the buildings are not accessible, and staff do not provide them with accommodations. Deaf and hard of hearing people interviewed said that they cannot use health care services independently due to the lack of sign language interpreters.

Many people with disabilities interviewed said that they faced discrimination from health care personnel, including denial of care. There is no publicly available information regarding any training doctors and other medical personnel receive regarding the rights of people with disabilities.

Access to sexual and reproductive health care and information is difficult for most of the population in Iran. Due to additional barriers, people with disabilities experience particular difficulties accessing these services and information. Women with physical disabilities told us that they rarely visit gynecologists or undergo sexual health preventative care due to financial and mobility restrictions, lack of professional assistance to facilitate doctors' visits, or lack of information about the importance of this care.

We documented many cases in which doctors and other healthcare professionals did not seek or obtain the informed consent of their patients and did not provide them with comprehensive information about the treatment or potential side-effects in a fully understandable format, or often at all. For adults with disabilities, medicine and treatment should be delivered with the consent of the individual being treated. The CRPD requires health professionals to provide care of the same quality to people with disabilities as to others, including on the basis of free and informed consent.

For example, according to mental health professionals in Iran whom we interviewed, Electroconvulsive Therapy (ECT) is often carried out unnecessarily, or for conditions in which ECT is not likely to be helpful, and without the informed consent of the person receiving the treatment. ECT consists of passing electricity through the brain to induce a

seizure and is used in mental hospitals in many countries to treat bipolar disorder and severe depression.

People with psychosocial disabilities interviewed said that they learned about ECT by experiencing it several times. For example, Jafar, a man with psychosocial disabilities, said, “The first time I had electroshock, a heart physician visited me the day before. Then, they took me for the shock and it was only then that I learned how it was. I forgot many things after that. They did it every other day. Now, I know how it is and what happens afterwards.”

Key Recommendations

The government of Iran should:

- Implement a comprehensive review of legislation and policies to ensure that they are in line with the requirements of the Convention on the Rights of Persons with Disabilities;
- Establish effective and independent monitoring systems as well as confidential, accessible complaint mechanisms to ensure that any alleged abusive or negligent treatment by SWO staff or home care providers is adequately addressed;
- Ensure that disability prevention programs are funded and implemented separately from policies designed to ensure the rights of people with disabilities. The State Welfare Organization, as the main implementing agency of the CRPD, should not have responsibility for disability prevention. Any disability prevention policies should be designed and implemented with full respect for the autonomy and right to private and family life of people with disabilities;
- Develop and publish a time-bound detailed plan to ensure, using maximum available resources, that public transportation including in rural and remote areas, as well as public roads, facilities, buildings and information would become equally accessible for people with disabilities;
- Introduce and enforce meaningful penalties for non-observance of accessibility requirements and denial of reasonable accommodation to people with disabilities;
- Ensure that medical care for people with disabilities is of the same quality and equally accessible for people with disabilities on an equal basis with others. Medicines and treatment should only be given on the basis of free and informed consent.

Terms

Autism: A developmental condition present from early childhood characterized by difficulty in communicating and forming relationships with other people and in using language and abstract concepts. The cause of autism in children is unknown, but researchers generally believe that it stems from a problem in the central nervous system.¹

Cerebral palsy: An impairment of muscular function and weakness of the limbs caused by lack of oxygen to the brain immediately after birth, brain injury during birth, or a viral infection. Often accompanied by poor motor skills, it sometimes involves speech and learning difficulties.²

Child: The word “child,” “boy,” or “girl” in this report refers to anyone under the age of 18. Although the Iranian civil and penal codes consider 15 lunar years and 9 lunar years as the age of maturity for boys and girls, respectively, the 2013 Law on Protection of Children without Guardians or with Incompetent Guardians as well as the State Welfare Organization’s rules and practice define a child as anyone under 18.

Organizations of People with Disabilities (DPOs): Organizations in which people with disabilities constitute the majority of members and the governing body and who work to promote self-representation, participation, equality, and integration of people with disabilities.

Down syndrome: A condition in which a person is born with an extra copy of chromosome 21. People with Down’s syndrome can have hearing problems and problems with the intestines, eyes, thyroid, and skeleton, as well as intellectual disabilities.³

¹ *Merriam-Webster’s Medical Dictionary*, 2007, <http://dictionary.reference.com/browse/autism> (accessed April 27, 2013); *The American Heritage New Dictionary of Cultural Literacy, Third Edition*, 2005, <http://dictionary.reference.com/browse/autism> (accessed April 27, 2013).

² “Cerebral palsy,” *Collins English Dictionary: Complete & Unabridged 10th Edition*, 2009, <http://dictionary.reference.com/browse/Cerebral+Palsy> (accessed April 6, 2013); *The American Heritage Stedman’s Medical Dictionary*, 2002, <http://dictionary.reference.com/browse/Cerebral+Palsy> (accessed April 26, 2013).

³ “Down’s syndrome,” *MedLine Plus*, <http://www.nlm.nih.gov/medlineplus/downsyndrome.html> (accessed April 6, 2013).

Electroconvulsive therapy (ECT): A psychiatric shock therapy that consists of placing electrodes on the patient’s head and passing electricity through the brain to stimulate an artificial seizure. ECT is generally prescribed for severe depression, mania, schizophrenia, and other mental health conditions when other treatment has failed to work or for quicker results. In its modified form, ECT is administered under general anesthesia, with muscle relaxants, and oxygenation and can result in headaches as well as short-term memory loss. A typical course of ECT involves six to twelve sessions given two to three times a week.

Intellectual disability [formerly labeled “mental retardation”] is a disability characterized by variations in reasoning, learning, problem solving and in adaptive behavior. Adaptive behavior can include comprehension and participation in a conversation, understanding and following social norms, and performing activities such as getting dressed and using the restroom.

Psychosocial disability is the preferred term to describe the experience of persons with mental health conditions such as depression, post-traumatic stress disorder [PTSD], bipolar disorder and schizophrenia. “Psychosocial disability” relates to the interaction between psychological differences and social/cultural limits for behavior as well as the stigma that society attaches to persons with these conditions.

Methodology

This report is the outcome of a joint project by Human Rights Watch and the Center for Human Rights in Iran (CHRI, formerly the International Campaign for Human Rights in Iran).

For this report a researcher working for both organizations conducted 58 interviews with people living in Iran. We interviewed 36 people with different disabilities, including 15 women and 21 men, some of whom are disability rights advocates. Interviewees also included: 10 parents of people with disabilities; 3 health care professionals; and 9 specialists including staff of the State Welfare Organization, NGO activists, and other service providers. Names of the cities where interviewees live are often withheld to ensure anonymity, out of concerns for their security.

For the last 30 years, the Iranian government has rarely allowed international human rights organizations—such as Human Rights Watch—to enter the country and conduct independent investigations. Iran’s record on independent criticism and free expression more broadly has been dismal, particularly over the past decade. Hundreds of activists, lawyers, human rights defenders, and journalists have been prosecuted for peaceful dissent. Iranian citizens are often wary of carrying out extended conversations on human rights issues via telephone or email, fearing government surveillance which is also widespread across social media platforms such as Facebook, Twitter, and the Telegram messaging application. The government often accuses its critics inside Iran, including human rights activists, of being agents of foreign states or entities, and prosecutes them under Iran’s national security laws.⁴

Where available, Human Rights Watch and the Center for Human Rights in Iran incorporated government statistics and officials’ statements into this analysis.

The researcher sought to interview people from a range of socioeconomic backgrounds, but the majority of interviewees were living in urban settings enjoying a relatively good quality of life, largely due to family support. The researcher conducted all of the interviews in Persian (Farsi) over secure messaging applications. Due to communication and security

⁴ “Iran: Flawed Convictions for Journalists, Human Rights Watch,” Human Rights Watch news release, May 3, 2016, <https://www.hrw.org/news/2016/05/03/iran-flawed-convictions-journalists>.

barriers, deaf persons and persons with intellectual and developmental disabilities are less represented among the interviewees compared to people with other types of disabilities. Deaf persons were interviewed in writing through secure messaging applications.

The researcher asked interviewees to suggest a time slot and asked them to feel free to interrupt the interview any time if they felt uncomfortable either with the questions or due to any perceived threat to their security.

All participants were informed of the purpose of the interview and the ways in which the information would be used and were assured anonymity. This report uses pseudonyms for all interviewees and withholds other identifying information to protect their privacy and security. None of the interviewees received financial or other incentives for speaking with the researcher.

In February 2017, Human Rights Watch sent letters to the State Welfare Organization, the National Headquarters to Follow-up on Accessibility, the Ministry of Health, and the Vice-Presidency on Women and Family. We received a written response from the State Welfare Organization to some of the questions posed. In May 2018, Human Rights Watch wrote to the State Welfare Organization, the National Headquarters to Follow-up on Accessibility, and the Ministry of Health requesting information related to the findings of this report. This correspondence is included in the online annex to this report.

I. Overview: Disability in Iran

Scale of Disability in Iran

There are no official up-to-date statistics on how many of Iran's 80 million people have disabilities.⁵ Based on 2015 data from the three government agencies providing services to people with disabilities, more than 1.87 million (4.2 percent of the population) were registered as having disabilities.⁶ The 2011 national census found that just 1.35 percent of the population has a disability, but experts, including officials from the State Welfare Organization, questioned the accuracy of the data.⁷

The actual number of people with disabilities in Iran is likely much higher. Some public officials have acknowledged that the number of persons with disabilities in Iran is likely between 11 and 14 percent.⁸ According to the World Health Organization and the World Bank, 15 percent of the world's population lives with a disability.⁹

⁵ The Iran Statistics Center decided to remove all disability-related questions from the 2016 census questionnaires, claiming a lack of adequate financial resources. Hossein Nahvinezhad, Rehabilitation Director of SWO, "Around two per cent of the society are disabled" (حدود دو درصد جامعه معلول هستند) Special News Debate, Islamic Republic of Iran Broadcasting News Agency (IRIB) December 4, 2016, <http://www.iribnews.ir/fa/news/1405196/> (accessed July 24, 2017). Official website of the Iran Statistics Center (درگاه ملی مرکز آمار ایران) National Census of Individuals and Housing, general outcome, 2016 (1395 in Persian calendar), <https://www.amar.org.ir/> (accessed June 10, 2017); and "Detailed results of 1395 individuals and housing census" (نتایج تفصیلی سرشماری نفوس و مسکن 1395) Iran Statistics Center, <https://www.amar.org.ir/> (accessed July 21, 2017).

⁶ The SWO reported 1.3 million people with disabilities registered with the organization. Roughly 565,000 war veterans with disabilities were registered with FMVA. A small number of persons with disabilities, roughly 7,500, are under coverage of the Imam Khomeini Relief Center (IKRC). UN CRPD Committee, Replies of Islamic Republic of Iran to the List of Issues, January 13, 2017, CRPD/C/IRN/Q/1/Add.1, paras. 156-158, http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fIRN%2fQ%2f1%2fAdd.1&Lang=en (accessed February 15, 2017).

⁷ Yahya Sokhangooie, then Deputy Director of SWO on Rehabilitation, interview with Jamejam Press, "Disabled persons statistics are not up-to-date," (آمار معلولان به روز نیست) October 23, 2014, <http://press.jamejamonline.ir/Newspreview/1691561724465684273> (accessed May 6, 2017).

⁸ In 2014, Keivan Davatgaran, director of SWO's "Disabled Persons Empowerment Office," estimated the number of people with disabilities to be around 11 percent. "11 per cent of country's population have some degrees of disability" [درصد جمعیت 11 درصد جمعیت] Iranian Students News Agency (ISNA), November 10, 2014, <http://www.isna.ir/news/93081909011/> (accessed April 18, 2017). Rasool Khezri, a member of Iran's parliament and secretary of the parliamentary group for persons with disabilities, puts the number at 12 to 14 percent of the population. "Shocking number of 12 to 14 per cent of disabled persons in the country" (آمار تکان‌دهنده 12 تا 14 درصدی معلولان در کشور), Khaneh Mellat News Agency, April 8, 2016, <http://icana.netiran.ir/Fa/News/296467/> (accessed April 18, 2017).

⁹ This figure refers to the adult population, aged 18 years and over, among the 59 countries surveyed. It ranges from 11.8 percent in higher income countries to 18 percent in lower income countries. World Health Organization (WHO), "World Report on Disability," 2011, http://whqlibdoc.who.int/publications/2011/9789240685215_eng.pdf (accessed July 21, 2017).

The discrepancy between official data and actual numbers may often be linked to stigma and bureaucratic hurdles. Stigma is especially strong in rural areas, according to those interviewed, particularly for people with intellectual or psychosocial disabilities and girls with disabilities.¹⁰ Some families hide family members with disabilities at home and prohibit them from participating in social activities or education. In 2015, the director of Iran's Special Education Organization stated that while there are roughly 110,000 children with disabilities attending primary and secondary education in Iran, there are likely two to three times more children with disabilities, given that many families hide their children at home.¹¹

Far fewer women and girls with disabilities are registered with state agencies than men and boys. According to the SWO, only 35 percent of registered persons with disabilities are female.¹² The entrenched stigma about females with disabilities, as well as broader restrictions on independence for women and girls in Iran, likely contributes to this.¹³

Low registration rates are also prevalent for persons with psychosocial disabilities. According to a 2011 Ministry of Health study, 23.6 percent of 15 to 64-year-olds in Iran (12.5 million people) had some form of mental health condition.¹⁴ In order to qualify as having a psychosocial disability and to register with SWO, a person must be diagnosed as "having chronic mental disease." In 2017, only 8 percent of persons with disabilities registered with the SWO were considered to have mental health conditions.¹⁵

¹⁰ Researcher interviews with Negar, social worker for persons with psychosocial disabilities, May 5, 2017; Mahin, a parent of a person with intellectual disability and disability advocate, December 6, 2016; and Mohammed, parent of a person with intellectual disability and disability advocate, December 6, 2016.

¹¹ "Cultural barriers deprive special students from education," (مشکلات فرهنگی موجب محرومیت کودکان استثنایی از تحصیل می‌شود) Iran News Agency, February 3, 2015 <http://www.irna.ir/rkhorasan/fa/News/81490703/>

¹² Hossein Nahvinezhad, rehabilitation director of SWO, "Need to improve disability identification system in Ministry of Health" (ضرورت تقویت نظام شناسایی معلولیت‌ها در وزارت بهداشت), Iranian Students News Agency (ISNA) February 19, 2017, <http://www.isna.ir/news/95113021296/> (accessed June 29, 2017).

¹³ "It's a Men's Club" Discrimination Against Women in Iran's Job Market, Human Rights Watch, May 25, 2017, <https://www.hrw.org/report/2017/05/25/its-mens-club/discrimination-against-women-irans-job-market>.

¹⁴ Ali Akbar Sayari, deputy of Health affairs of the Ministry of Health, Treatment and Medical Education: "23.6 percent of the 15 to 64-year-old population suffer from mental disorder- 23.6 درصد جمعیت 15 تا 64 سال کشور از اختلال روانی رنج می‌برند" Iran News Agency (IRNA) October 21, 2015, <http://www.irna.ir/fa/News/81808077/> (accessed May 3, 2017).

¹⁵ Hossein Nahvinezhad, rehabilitation director of SWO, addressing specialized meeting to evaluate SWO performance regarding people with "chronic mental disease," official website of SWO Alborz province, October 22, 2017, <http://alborz.behzisti.ir/Portal/home/?news/235053/264206/274662/> (accessed April 16, 2018).

In many of the provinces and cities where we were able to access information, there was a considerable difference between the number of persons the Organization of Persons with Disabilities (DPOs) and advocates identified as having disabilities and the number of those registered and supported by the SWO's offices. For example, in Piranshahr, a town in northwest Iran with a population of around 130,000, disability advocates have identified 640 persons with disabilities with high support needs who are not registered or supported by any government agency.¹⁶

Domestic law mandates the Iran Statistics Center to collect data on the number of persons with disabilities in every census and to disaggregate the data on the type of disability.¹⁷ Yet, there is no government system in place to collect and make public data about persons with disabilities in Iran, or the barriers they face exercising their rights. Furthermore, existing data is not disaggregated based on age, sex, gender, ethnic, religious, or linguistic background, migrant, asylum seeking or refugee status.¹⁸ Following the 2011 census's low reporting of persons with disabilities, rather than strengthening their data collection system, the Iran Statistics Center removed all questions on disability in the 2016 census.¹⁹ During its March 2017 review under the Committee on the Rights of Persons with Disabilities, which monitors states' compliance with the CRPD, Iranian officials provided updated statistics on the number of persons with disabilities registered, but the Committee concluded that this data did not meet the CRPD's requirements for data that states are required to collect, disaggregate, and openly publish.²⁰

¹⁶ Rasool Khezri, Piranshahr representative in Iran's Parliament (Majles), interview with Jamejam press, "Disabled persons statistics are not up-to-date," (امار معلولان به روز نیست), October 23, 2014, <http://press.jamejamonline.ir/Newspreview/1691561724465684273> (accessed May 6, 2017).

¹⁷ Comprehensive Law on Protecting the Rights of Disabled Persons, Islamic Consultative Assembly, *Official Gazette*, no. 17264, 1383 (2004), Art. 11, <http://rc.majlis.ir/fa/law/show/94044>.

¹⁸ UN CRPD Committee, Concluding Observations on Initial Report of Islamic Republic of Iran, adopted by the Committee on its 17th session, CRPD/C/IRN/CO/1, May 10, 2017, para. 58.

¹⁹ National Yearbook on Statistics 1390 (2011), Iran Statistics Center, Results of the 1,390 Individuals and Housing Public Census, Tehran, <https://www.amar.org.ir/مجازي-فروشگاه-اصلي-صفحه/خانه/ProdID/143> (accessed June 27, 2017).

²⁰ UN CRPD Committee, Concluding Observations on Iran, para. 58.

Agencies Providing Social Services to People with Disabilities

The State Welfare Organization (SWO) serves people with all types of disabilities across the country, as well as other socially vulnerable groups.²¹ The SWO has offices in all major cities and most towns. For people with disabilities the SWO focuses on disability prevention, rehabilitation, and empowerment.²² This includes providing rehabilitation services and equipment, running and monitoring residential institutions, paying disability pensions and nursing allowances to those found eligible, and reimbursing education tuition for some students with disabilities.

The Foundation of Martyrs and Veterans Affairs (FMVA) has a narrow mandate to serve the roughly 565,000 veterans with disabilities.²³ Both the SWO and FMVA serve as government focal points for matters relating to the implementation of the United Nations Convention on the Rights of Persons with Disabilities (CRPD).²⁴ In addition, the Imam Khomeini Relief Committee (IKRC) is a government charity mandated to support the poorest and most disadvantaged populations including some persons with disabilities.

²¹ Shortly after the 1979 Islamic revolution, the Revolution Council passed legislation to establish the SWO by dissolving and merging 16 governmental and non-governmental bodies, organizations and associations. The SWO was first placed under the Ministry of Health but was moved to then Ministry of Welfare and Social Security in 2004. The SWO currently lies under the Ministry of Cooperative, Labor, and Social Welfare; its mandate includes “fulfilling needs of persons with disabilities, older people, public child care systems, women heads of households, abandoned children, street children, children who subject to child abuse, women and girls who leave their families and have nowhere to live, and people who use drugs.” Official website of SWO, “Missions of the Organization,” (ماموریت‌های سازمان) <http://behzisti.ir/Modules/ShowFramework.aspx?TemporaryTempID=538> (accessed February 27, 2017).

²² Hosein Nahvinejad, rehabilitation director of SWO, Special News Debate on International Day of Persons with Disabilities, broadcast by Iranian governmental television 2nd channel, December 3, 2016, http://www.monazereh.ir/images/Bank/Movie/Ejtemaie/95-09/11_vijeh_khabari_2230/01_vijeh_khabari_2230.mp4 (accessed September 22, 2017).

²³ The FMVA is “a public non-governmental organization,” which means it is independent from the executive power in financial and administrative affairs and receives funding directly from the national budget. It is not accountable to the Islamic Consultative Assembly (parliament). The head of the organization is officially a deputy of the president, but in practice the position is under supervision of the supreme leader. Official Website of the FMVA, Introducing the Foundation, <http://www.isaar.ir/vsdgp,9eki5arjar!9pre5.4r.html> (accessed September 22, 2017); and UN CRPD Committee, Replies of Islamic Republic of Iran to the List of Issues, January 13, 2017, CRPD/C/IRN/Q/1/Add.1, para. 158, http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fIRN%2fQ%2f1%2fAdd.1&Lang=en (accessed February 15, 2017).

²⁴ CRPD, art. 33(1). See Law on Ratification of the Convention on the Rights of Persons with Disabilities (قانون تصویب کنوانسیون حقوق افراد دارای معلولیت), adopted by Islamic Consultative Assembly (Parliament of Iran known as Majlis), December 3, 2008, <http://rc.majlis.ir/fa/law/show/134833>.

II. State Welfare Organization Failures and Abuses

In order to live an independent and dignified life within society, persons with disabilities should have access to individualized means and services including, for example, assistive equipment and technologies, comprehensive habilitation and rehabilitation services, personal assistance services, as well as adequate disability pensions, if needed. However, our research found serious shortcomings on the part of the State Welfare Organization in providing these services. Interviewees described how some SWO social workers insulted and humiliated them and often failed to provide adequate information about available services and equipment and how to access them.

In many areas in Iran, there are insufficient numbers of SWO social workers. Although national standards establish that each social worker should have no more than 150 cases, in practice many social workers have much heavier caseloads. For example, in the southern part of Kerman province, each social worker has around 1,500 cases.²⁵ In Ghazvin province, there are fewer than 20 social workers for approximately 20,000 persons with disabilities.²⁶ The low number of social workers has a direct impact on the quality of social work service. For example, Fatemeh, a woman with physical disabilities in Tehran, described one of the difficulties in interacting with the social worker in her local SWO office: “My social worker has so many cases to handle that she rarely remembers anyone. Their system is not electronic, so they cannot take proper notes. Each time I have to tell my story again to convince her that I really need support.”²⁷

People with disabilities also noted the lack of access to personal assistants and quality assistive devices and obstacles to obtaining affordable services such as physiotherapy, speech therapy, occupational therapy, and psychotherapy, which the SWO has the mandate to provide. Many people reported that the state disability pension of 1.48 million

²⁵ Alireza Asadi, rehabilitation director of Welfare Organization Kerman provincial office, Iranian Students News Agency (ISNA), January 28, 2018, <http://kerman.isna.ir/default.aspx?NSID=5&SSLID=46&NID=56190> (accessed February 6, 2018).

²⁶ Hassan Hesami, rehabilitation director of the Social Welfare Organization in Ghazvin province, “Welfare Organization’s insufficient budget in disability field” (بودجه ناکافی بهزیستی در حوزه معلولان), Hamshahri, 20/9/1395, December 10, 2016, <http://ostani.hamshahrilinks.org/Ostan/Iran/Qazvin/Contents/> (accessed March 28, 2017).

²⁷ Researcher interview with Fatemeh, woman with physical disabilities, Tehran, December 5, 2016.

Iri (\$39.36) per month was not sufficient to meet their basic needs. Others stated that they did not receive the pension at all, due to overly strict and discriminatory eligibility criteria.

Abusive Treatment by State Welfare Organization Staff

Many persons with disabilities told our researcher that SWO staff had been disrespectful toward them and verbally abused them.²⁸ For example, when Shahla and her husband, both deaf, were considering having a baby, their friends told them that with a reference letter from SWO, they could receive free genetic counseling and testing. When Shahla visited the SWO office near her home, she faced what she described as “insulting and heartbreaking behavior” from a social worker:

My mom was busy that day and couldn't accompany me to interpret. But I thought it would be easy. I said to myself that I was going to the [State] Welfare Organization and they would understand. But the lady working there literally got mad at me. I'll never forget that day. I tried to talk to her by writing on a piece of paper, but she started shouting, and I could tell she was insulting me. I cried so much.

The social worker continued insulting her, asking why a deaf couple wanted to have a child, and claiming that Shahla and her husband “just wanted to add another deaf person like ourselves to the world.”²⁹

Other persons who are deaf or hard of hearing and their family members recounted similar examples of insulting and humiliating behavior by SWO staff, especially by social workers, who are their primary point of contact.³⁰ For example, Narges had been in a SWO office in Tehran to request services for her daughter, Mahsa, who is hard of hearing. Narges said that when she asked the social worker to help expedite the delivery of hearing aids to her

²⁸ Researcher interviews with Hamed, man with physical disability, small town in northern Iran, November 11, 2016; Bahram, blind man, Karaj, May 11, 2017; Nasrin, blind woman, city in northern Iran, May 21, 2017; and Sajjad, man with physical disabilities, city in southeastern Iran, May 16, 2017.

²⁹ Researcher interview with Shahla, deaf woman, Tehran, November 29, 2016.

³⁰ Researcher interviews with Shahla, deaf woman, Tehran, November 29, 2016; Narges, mother of a deaf girl, Tehran, November 29, 2016; Sohrab, deaf man living in Tehran, April 17, 2017; Foroogh, hard of hearing woman living in a city south Iran, December 9, 2016.

daughter, because she couldn't hear anything with her old hearing aids and was really struggling, "[the officer] became angry and said she didn't care at all that my daughter couldn't hear and that we had to wait as long as necessary."³¹

Sohrab, a 30-year-old deaf man, said, "They speak to us very disrespectfully in the [State] Welfare Organization offices. Once I went to get a disability certification to give to the university I was attending. After I waited for a long time for the letter, the social worker told me, "You guys [who are deaf] are always nagging. You shouldn't be coming here so often.' It was an absolute insult. My question is that if they don't want to see us, why have they accepted this job?!"³²

Akbar, the father of a man with psychosocial disabilities, described his experience trying to get services for his son. "State Welfare Organization staff often speak to us in a rude and even threatening way," he said. "Once I asked one official in our local SWO [office] to explain to me what his responsibilities and roles were. He shouted back at me and said that he didn't have to explain anything to me. Witnessing such behavior makes me believe that if a person with a disability in Iran has a family to support them, they can survive and develop. But if not, they would be left on their own [without state support] to suffer until their lives end."³³

SWO staff's offensive behavior has led some people to limit their visits to the organization's offices to only the most essential requests, such as obtaining disability certificates.³⁴ Banafsheh, a 37-year-old blind woman living in Tehran, said:

Among the worst experiences I've had in my life in terms of dealing with public bodies are those interactions I had with the [State] Welfare Organization. It's a real torture for me if I have to go there. So I try not to request anything from them unless it is really necessary.³⁵

³¹ Researcher interview with Narges, mother of a deaf girl (Mahsa), November 29, 2016.

³² Researcher interview with Sohrab, deaf man living in Tehran, April 17, 2017.

³³ Researcher interview with Akbar, father of a man with psychosocial disability living in Tehran suburban, May 5, 2017.

³⁴ Researcher interviews with Bahram, blind man living in Karaj, May 11, 2017 and Zohreh, blind woman living in Tehran, May 13, 2017.

³⁵ Researcher interview with Banafsheh, blind woman living in Tehran, May 6, 2017.

Lack of Information

Many people we interviewed stated that social workers did not provide them with sufficient information in a timely manner about services and equipment to which they are entitled and the procedures for obtaining them. Many believed that social workers were only assigned to carry out only administrative work regarding their cases or to verify their residency at a particular address.³⁶

Ziba, a woman with physical disabilities said that when she first became disabled, after a car accident, she felt lost and confused and missed opportunities for treatment due to the lack of information. She explained:

No one explained what I should do and where I should go to get services for my disability. ... My name had been on the list of a small number of people eligible to receive periodic medical visits at home for two years before I learned that I could even get this service,” she said.³⁷

Akbar, father of a man with psychosocial disabilities said, “Once there was a [time] limited opportunity to get my other son exempted from compulsory military service because of his brother’s disability. But we missed it because the social worker didn’t tell us about it.”³⁸

Due to the lack of information from social workers, many people with disabilities we interviewed said they mostly rely on personal networks to hear about these opportunities or must frequently call the SWO office to check if any services are available.³⁹

State Welfare Organization Complaint Mechanism

The office of Evaluation, Inspection, and Addressing Complaints in the SWO is responsible for conducting regular inspections to evaluate the performance of SWO staff as well as

³⁶ Researcher interviews with Narges, mother of a deaf girl, Tehran, November 29, 2016; and Akbar, father of a man with psychosocial disability, Tehran suburb, May 5, 2017.

³⁷ Researcher interview with Ziba, woman with physical disability, Tehran, May 19, 2017.

³⁸ Researcher interview with Akbar, father of a man with psychosocial disability, Tehran suburb, May 5, 2017.

³⁹ Researcher interviews with Zeinab, woman with physical disabilities, city in southern Iran, November 21, 2016; Fatemeh, woman with physical disabilities, Tehran, December 5, 2016; Akbar, father of a man with psychosocial disability, Tehran suburb, May 5, 2017; and Yashar, man with physical disability, town near Tehran, May 15, 2017.

agencies and organizations providing services on behalf of the SWO. But persons with disabilities interviewed were either unaware of the existence of this office or said that they do not trust its impartiality and efficiency. Ziba, the woman with physical disability mentioned above, said that she never considered appealing to the SWO complaint office. She explained, “Staff working for SWO are all connected.... It would be as if I’m complaining about someone to themselves or to their family members.” Arezoo, a SWO staff member, confirmed that in her local office the complaint mechanism is not effective, saying, “In this office they try to make people withdraw their complaints either by discouraging them about any real results or by threatening them that if complain, they will lose the minimal services they have.”⁴⁰

Lack of Personal Assistants to Facilitate Independent Living

While family members play important roles in the lives of many people with disabilities in Iran, under the CRPD, people with disabilities should have access to a range of in-home, residential, and other community support. This support includes personal assistance necessary to support living and inclusion in the community and to prevent isolation or segregation from the community.⁴¹

None of the persons with disabilities interviewed for this report benefited from professional personal assistance (PA). A personal assistant is an individual supporting a person with a disability in different aspects of daily life – such as personal care, household tasks, assistance at school, university or the workplace, driving, interpretation, and other tasks customized to the individual. For the most part persons with disabilities we interviewed who needed assistance in fulfilling their most basic needs—including eating, getting dressed, or daily hygiene—relied solely on the help of family members or close friends.⁴²

⁴⁰ Researcher interview with Arezoo, Social Welfare Organization staff member, Tehran, March 29, 2017.

⁴¹ CRPD, art. 19.

⁴² Researcher interviews with Hamed, man with physical disability living in a small town northern Iran, November 11, 2016; Zeinab, woman with physical disability, a city south Iran, November 21, 2016; Hamid, man with physical disability, a city south Iran, November 22, 2016; Hassan, man with physical disability, Karaj, May 12, 2017; and Yashar, man with physical disability, a town south Tehran, May 15, 2017.

The SWO does not provide personal assistance or sufficient financial support for people with disabilities to hire personal assistants. It provides a “nursing allowance” only to people who have spinal cord injuries (roughly 19,000 persons) and not to people with other types of disabilities.⁴³ According to some advocates with disabilities this distinction is based on the incorrect assumption that persons with spinal cord injuries face more support needs than others due to lack of control over urinating and defecating.⁴⁴ As one advocate with a physical disability stated, “Instead of adopting a needs-based approach to allocating resources, the SWO relies exclusively on a medical diagnosis.”⁴⁵

Najmeh, mother of Shabnam (a 9-year-old girl with physical disabilities), explained that she did not receive a nursing allowance or other financial support because her daughter did not have a spinal cord injury:

I really can't understand the difference. I am with my daughter everywhere: at school, in the streets, in the bathroom, in her bedroom... I hardly find time for my other child or for myself. But we are not eligible for a nursing allowance just because Shabnam's condition is not caused by a spinal cord injury. If this is not daily care, then what is this?⁴⁶

Fatemeh, a woman with a physical disability, explained,

Different groups have different needs. For example, I have muscular dystrophy, which causes respiration issues for me. I really need someone in my home to help in case of an emergency. But I live alone. This is a life or death issue.⁴⁷

⁴³ UN CRPD Committee, Replies of Islamic Republic of Iran to the List of Issues, January 13, 2017, CRPD/C/IRN/Q/1/Add.1, para. 156, http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fIRN%2fQ%2f1%2fAdd.1&Lang=en (accessed February 15, 2017).

⁴⁴ Researcher interview with Fatemeh, woman with physical disabilities, Tehran, December 5, 2016.

⁴⁵ Researcher interview with Javad, disability rights advocate with physical disability, Tehran, December 5, 2016.

⁴⁶ Researcher interview with Najmeh, mother of a 9-year-old girl with physical disabilities living in Tehran suburbs, March 30, 2017.

⁴⁷ Researcher interview with Fatemeh, woman with physical disabilities living in Tehran, December 5, 2016.

Even for those who receive the benefit, the amount is far from being sufficient to hire a personal assistant for the hours needed. The monthly amount paid in 2017, for example, varied between 1.5 million Irl (\$39.89) and 2 million Irl (\$53.19) based on the “diagnosed severity of the spinal injury.”⁴⁸ The official rate for six hours of nursing services is 170,000 Irl (\$4.52). At this rate, 12 hours of support per day would cost 2.38 million Irl (\$63.30) per week.⁴⁹ According to some people with disabilities interviewed, the rate for personal assistants hired in the actual market was between 10 and 20 million Irl (\$265.95 to \$531.91) per month, depending on the place of residence and level of support needed, or more than 10 times the government nursing allowance and well above the official government rate.⁵⁰

Those who received the official nursing allowance still also rely on family care. Yashar, a man with a physical disability said: “I have no income or job. The amount of the nursing allowance is not sufficient to hire a personal assistant. So, for example, my brother comes to help me with bathing once a week. If he cannot make it, the only solution is to pay 500,000 Iri (\$13.30) to a neighbor to help me bathe.”⁵¹

Relying on family members as the sole source for personal care can impose limitations on the independence of many persons with disabilities. Tahereh, a woman with multiple physical disabilities whose attempts to hire a reliable personal assistant have failed, relies on occasional assistance by her son and some relatives or friends:

I need help to prepare my food and eat and drink. Unfortunately, my son is not always happy to help me. Sometimes I need to wait until 3:00 p.m. to get some breakfast. I have developed a chronic stomach problem because of eating irregularly.

⁴⁸ Farhad Mirzaie, Deputy Director of SWO in Zanjan province, official website of the SWO, 24/4/1396 (Jul 15, 2017) <http://www.behzisti.ir/Portal/home/?news/235053/264207/265796/> (accessed March 7, 2018). All conversions are based on the exchange rate on May 15, 2017 when most of interviews were already conducted. On this day 1 USD was equal to 37,600 Irl: The information is extracted from this website: http://www.teju.org/chart/price_dollar_ri/2

⁴⁹ Regulation No. 39706, adopted by Cabinet of Ministers, 28/3/1396 (June 18, 2017), <http://cabinetoffice.ir/fa/news/2088/> (accessed June 15, 2018).

⁵⁰ Researcher interviews with Hamed, man with physical disability, a city north Iran, Nov. 11, 2016; Yashar, man with physical disability, a town south Tehran, May 15, 2017; Tahereh, woman with physical disability, a central city of Iran, May 28, 2017.

⁵¹ Researcher interview with Yashar, man with physical disability, town near Tehran, May 15, 2017.

Tahereh is also not able to change her urinal catheter once a week as prescribed. “Sometimes I can do this every other week and even later,” she said. “I just have to wait until my son is willing to help or someone comes to visit. I have had urinary infections because of these delays.”⁵²

Nader, a man with physical disabilities also explained how he developed a new disability due to the lack of access to a professional personal assistant. He explained, “I need to use a urinal catheter, but for a lot [of the time] that there is no one around to help me [change it]. Once I tried to do it on my own, but I injured myself seriously because my hands are also weak. After that injury, I cannot use catheters anymore and have to go through a much more difficult and painful process for relieving myself.”⁵³

In many cases, parents supporting people with disabilities may be older, have health issues, or may not be physically capable of fully supporting another adult. For example, Hassan is a 27-year-old man with muscular dystrophy. He said that since he can barely use his hands, he needs personal assistance all the time. He said,

I fully rely on my mom to help with all my basic issues. I need to be moved from one side to the other during the night, but I don’t want to wake my mom up. So, I keep suffering but don’t call her.⁵⁴

Alireza, a 22-year-old man with cerebral palsy, relies on his 65-year-old mother for basic care. He said, “I’m very heavy (almost 90 kilograms). So, it’s very difficult for my mom to help me use the toilet, wash, and get dressed.” After years of helping him, Alireza’s mother has developed serious back pain. Although Alireza likes to go out, meet friends, and exercise, his ability to do so depends on how his mother feels each day and whether she can help him get ready.⁵⁵

⁵² Researcher interview with Tahereh, woman with physical disability, city in central Iran, May 28, 2017.

⁵³ Researcher interview with Nader, man with physical disability, town near Tehran, May 18, 2017.

⁵⁴ Researcher interview with Hassan, man with physical disability, Karaj, May 12, 2017.

⁵⁵ Researcher interview with Alireza, man with physical disabilities, city in southern Iran, November 23, 2016

Lack of Access to Other Disability-Related Services

Interviews also revealed how many persons with disabilities face barriers in accessing essential services such as physiotherapy, speech therapy, occupational therapy, and psychotherapy.⁵⁶ Neither private nor public insurance schemes in Iran cover these services.⁵⁷ Although the National Health Transformation Plan, established in 2013, has expanded the number of people having access to the national health insurance scheme and reduced health care expenses, the plan does not specifically reference persons with disabilities or disability-related healthcare services.⁵⁸ As Alihemmat Mahmoodnejad, head of the Association for Defending Rights of Disabled Persons, noted, “Unfortunately, disabled persons have no place in the National Health Transformation Plan and even have to purchase wheelchairs at a very high price. They face many problems in accessing rehabilitation equipment, but the government has not supported these needs so far.”⁵⁹

Mohammad Ali Mohseni Bandpay, supreme consultant of the SWO, said the government would pay particular attention to rehabilitation services for persons with disabilities in further development of the National Plan.⁶⁰ However, in 2017, the vice president of the parliamentary health and treatment commission stated that although 350 additional medical services have been included in the national health insurance plan as part of the National Health Transformation Plan, rehabilitation services and other disability-related health services are still not covered.⁶¹

⁵⁶ Researcher interviews with Alireza, man with physical disabilities city in southern Iran, November 23, 2016; and Hamed, man with physical disability, small town in northern Iran, November 11, 2016.

⁵⁷ Hossein Nahvinezhad, rehabilitation director of SWO, interview with Mizan News Agency, December 10, 2016, <http://www.mizanonline.ir/fa/news/253819/> (accessed August 13, 2017).

⁵⁸ National Plan to Improve Health Care System 1393 (طرح تحول نظام سلامت) <http://nihr.tums.ac.ir/دیده-بانی-دید> (accessed May 3, 2017); and “Rouhanicare: Iranian President’s Unsong Domestic Success,” *The Guardian*, September 4, 2017 <https://www.theguardian.com/world/2017/sep/04/rouhanicare-iran-president-unsung-domestic-success-healthcare-hassan-rouhani> (accessed April 16, 2018).

⁵⁹ “Employment the main challenge before disabled persons in Iran/ non-inclusion of rehabilitation services in the National Plan to Improve Health Care System” (اشتغال اصلی‌ترین چالش معلولان ایران/ جای خالی خدمات توانبخشی در طرح تحول نظام سلامت), Mizan News Agency, 1395 (2016) <http://www.mizanonline.ir/fa/news/158901/> (accessed May 3, 2017).

⁶⁰ “Bitter story of disabled persons ends by realization of the promise of the Minister of Health in the second phase of National Plan to Improve Health Care System” (در اجرای مرحله دوم طرح تحول سلامت صورت می‌گیرد: پایان قصه تلخ معلولان با تحقق وعده وزیر بهداشت) Fars News Agency, interview with Mohammad Ali Mohseni Bandpay, supreme consultant of the State Welfare Organization, 1395 (2016) <http://www.farsnews.com/13950125001253> (accessed May 3, 2017).

⁶¹ Mohammad Hossein Ghorbani, vice-president of the Parliamentarian Commission of Health and Treatment, interview with Islamic Consultative Assembly News Agency, August 9, 2017, <http://www.icana.ir/Fa/News/343953/> (accessed March 26, 2018).

People we interviewed said that the lack of access to rehabilitation and other services harmed their development, health, and well-being or that of their family members. For example, Bahar, a 7-year-old girl with physical disabilities, was forced to stop occupational therapy sessions for six months because her parents could not afford the approximately 1.5 million IRI (\$39.89) monthly fee. Her mother, Farideh, explained that this interruption in occupational therapy has caused a serious deterioration in Bahar's condition:

Her feet have become more rigid. She loses her balance while seated and can't even lie down easily. Lack of sufficient exercise had even weakened her writing and drawing because she can't hold the pencil tight in her hands.⁶²

Najmeh, mother of a girl with physical disabilities said, "I had to cut back on food for my family to continue taking Shabnam to hydrotherapy. This is very important for her. She also had physiotherapy before but had to stop because we couldn't afford it anymore."⁶³ Arash, a 24-year-old man with muscular dystrophy said, "Hydrotherapy and exercise in the swimming pool is crucial to slow my condition's progression. But I can't go to public pools because they are not accessible. I wish the SWO had at least dedicated one exercise and pool facility for us in the whole city."⁶⁴

Fariba, a teacher working at a special school for children with disabilities in Tehran, spoke about a boy with autism in the school, who is the only child in a family with a good income. Fariba explained,

His mother says that they still can't afford all the services he needs and must compromise on many household expenses for their son's sake. So, you can imagine the situation for other children with autism who are not that fortunate.⁶⁵

⁶² Researcher interview with Farideh, mother of a 7-year-old girl with physical disabilities, Tehran, May 24, 2017.

⁶³ Researcher interview with Najmeh, mother of a 9-year-old girl with physical disabilities, Tehran suburbs, March 30, 2017.

⁶⁴ Researcher interview with Arash, man with physical disability, city in eastern Iran, May 16, 2017.

⁶⁵ Researcher interview with Fariba, teacher working in special school for boys, a town north Iran, November 16, 2016.

Limited free or subsidized rehabilitation services are provided in some centers subcontracted by the SWO in major cities of Iran. But persons with disabilities who used them said that the services are often of poor quality and that sufficient time is not allocated for each person, so they stopped using them.⁶⁶ Some said they could not use such services due to long distances from their homes and lack of accessible transportation.⁶⁷

For example, Fatemeh, a woman with physical disabilities, said,

Our local SWO office once arranged with a rehabilitation center to offer occupational therapy sessions to us for 20 percent of the market price. But there were too many clients and very few specialists. Most of the therapists were university students who were still training. So I realized that it was not worth the transportation costs and difficulties, so I withdrew.⁶⁸

Psychotherapy and psychological consultation is not covered by any public or private insurance, nor through any SWO support programs.⁶⁹ As a result, persons with psychosocial disabilities are limited to medical treatment and hospitalization as their only available options. In the Persian year 1396 (March 2017 to March 2018), the official fee for one session of psychological consultation varied between 430,000 to 1.5 million Iri (\$39.89) depending on the location and level of expertise

Five persons with psychosocial disabilities we interviewed said that they would like to have regular psychological consultations but cannot afford it.⁷⁰ One man with a psychosocial disability said,

⁶⁶ Researcher interviews with Mahnaz, woman with physical disability using crutches, city in southern Iran, November 22, 2016; and Fatemeh, woman with physical disabilities, Tehran, December 5, 2016.

⁶⁷ For example, researcher interview with Farideh, mother of a 7-year-old girl with physical disabilities, Tehran, May 24, 2017.

⁶⁸ Researcher interview with Fatemeh, woman with physical disabilities, Tehran, December 5, 2016.

⁶⁹ Seyed Vahid Shariat, a member of the National Mental Health Committee and head of "Iran Psychiatric Hospital," Website of the Ministry of Health, Jan. 13, 2017 <http://behdasht.gov.ir/?siteid=1&pageid=1508&newsview=156279> (last accessed May 3, 2017).

⁷⁰ Researcher interviews with Sara, woman with psychosocial disabilities, Mahdi, Jafar and Asghar, men with psychosocial disabilities, Tehran, January 16, 2017; and Farah, woman with psychosocial disability, Tehran, May 17, 2017.

I wish I could see ... someone who wouldn't make fun of me, but just listened to me. I went to such a doctor three years ago and felt very good. But it was very expensive, and the insurance agency said they don't pay that cost back, so my brother who is my guardian said that I should not go anymore because we are not that rich.⁷¹

The new Law to Protect the Rights of Disabled Persons, which came into force in May 2018, mandates the Ministry of Health to ensure that health insurance provided to persons with disabilities registered with SWO covers the physical and mental rehabilitation services they need.⁷²

Inadequate Provision of Assistive Devices

The SWO is responsible for providing assistive devices such as wheelchairs, crutches, and hearing aids. However, many persons Human Rights Watch and the Center for Human Rights in Iran interviewed said that they encountered excessive waiting times to obtain free or subsidized supportive equipment from the SWO.⁷³ People who did receive equipment were not satisfied with its quality and found the procedure for obtaining assistive devices overly complex. An article by a prominent social welfare scholar similarly noted the problem of inadequate, deficient, and unaffordable assistive devices for many persons with disabilities in Iran.⁷⁴ In an interview in February 2017, Hossein Nahvinezhad, rehabilitation director of SWO, told the Iran News Agency that one million service requests from persons with disabilities are currently awaiting the SWO's response with some people waiting on multiple requests.⁷⁵

⁷¹ Researcher interview with Asghar, man with psychosocial disabilities, Tehran, January 16, 2017.

⁷² Law to Protect Rights of Disabled Persons (قانون حمایت از حقوق معلولان) adopted by Islamic Consultative Assembly on March 10, 2018, published in Official Gazette No. 21303, May 3, 2018, <http://www.hvm.ir/lawdetailnews.aspx?id=53257> (accessed May 28, 2018).

⁷³ Researcher interview with Ehsan, man with physical disabilities, town in western Iran, November 18, 2016; Homa, woman with physical disability, Tehran, November 20, 2016; Shahla, deaf woman, Tehran, November 29, 2016; Narges, mother of a deaf girl, Tehran, November 29, 2016; and Hassan, man with physical disability, Karaj, May 12, 2017.

⁷⁴ Kamali, M., "An Overview of the Situation of the Disabled in Iran," in *Advancing the Rights of Persons With Disabilities: A US-Iran Dialogue on Law, Policy and Advocacy* (Allen Moore & Sarah Kornblet eds. 2011), p. 18.

⁷⁵ "SWO deputy: we need seventy thousand billion IRI to provide quality rehabilitation services" (معاون بهزیستی: برای ارائه خدمات 70 هزار میلیارد ریال نیاز است), Iran News Agency (IRNA), February 9, 2017 <http://www.irna.ir/golestan/fa/News/82423473/> (accessed June 30, 2017).

For example, SWO offices provided only low-quality manual wheelchairs to some persons with physical disabilities, and often only after long delays. Persons with physical disabilities told Human Rights Watch and the Center for Human Rights in Iran that the government-provided wheelchairs often broke after as few as four months to one year of use,⁷⁶ and that they could only expect a new wheelchair four to five years after receiving the previous wheelchair.⁷⁷ Many people also said they preferred to sell the government-issued wheelchair and buy a more sturdy one.⁷⁸ Others kept the government-provided wheelchair for use for short distances or at home, and purchased another higher quality one for longer distances.⁷⁹ Some of those who purchased wheelchairs said they did so relying on loans from friends or relatives.

Fatemeh, a wheelchair user in Tehran, said,

The government does not consider specific features for different disabilities in providing wheelchairs. They just provide one type of wheelchair known as a ‘hospital wheelchair.’ These wheelchairs are actually meant to transfer patients within hospitals, not for daily navigation for persons with disabilities. So, if we get them, we directly take them to sell.⁸⁰

People with disabilities who cannot independently use manual wheelchairs said that they had to purchase electronic wheelchairs at their own expense because the SWO does not provide them. Electronic wheelchairs cost between 50 million to 120 million Irl (\$1,329.78 to \$3,191.49) in Iran.⁸¹ Those who could not afford to purchase electronic wheelchairs said

⁷⁶ Researcher interviews with Homa, woman with physical disability, Tehran, November 20, 2016; Yashar, man with physical disability, town near Tehran, May 15, 2017; and Farideh, mother of a 7-year-old girl with physical disabilities, Tehran, May 24, 2017.

⁷⁷ Researcher interviews with Zeinab, woman with physical disability, city in southern Iran, November 21, 2016; Hamid, man with physical disability, city in southern Iran, November 22, 2016; Homa, woman with physical disability, Tehran, November 20, 2016; Yashar, man with physical disability, town in southern Tehran, May 15, 2017; and Farideh, mother of a 7-year-old girl with physical disabilities, Tehran, May 24, 2017.

⁷⁸ Researcher interviews with Fatemeh, woman with physical disabilities, Tehran, December 5, 2016; and Yashar, man with physical disability, town near Tehran, May 15, 2017.

⁷⁹ Researcher interview with Zeinab, woman with physical disability, city in southern Iran, November 21, 2016.

⁸⁰ Researcher interview with Fatemeh, woman with physical disabilities, Tehran, December 5, 2016.

⁸¹ Researcher interviews with Hamed, man with physical disability, small town in northern Iran, November 11, 2016; Hassan, man with physical disabilities, Karaj, May 12, 2017; and Yashar, man with physical disabilities, town near Tehran, May 15, 2017.

that they could be stuck at home for weeks or months. To leave home, they depend on someone to push the manual wheelchair.⁸²

For example, Arash told his social worker that the manual wheelchairs SWO provides do not work for him due to limitations he has in his hands. The social worker replied that electronic wheelchairs are “luxurious items” and he should not expect the government to provide such things. “I felt very disappointed and humiliated. I think these people have no understanding of disability and what it really means,” he said.⁸³

People interviewed also described the SWO’s often complicated and at times intrusive process to determine eligibility for a wheelchair. The SWO does not consistently communicate the criteria for eligibility. Some said that SWO social workers conducted a detailed investigation of their family’s financial situation before confirming their eligibility to be placed on waiting lists. This would often lead to people withdrawing their requests.⁸⁴ For example, one person said that he had been asked to bring and show the broken wheelchair to get a new one.⁸⁵

Hassan, a 27-year-old man with physical disabilities living in Karaj, a city bordering the outskirts of Tehran, said,

When I see all the detailed questions that so many people ask me and the number of detailed documents I must provide only to be put on a waiting list and have no idea if and when this wheelchair would be provided, then I prefer to give up. It’s true that I need support because of my disability, but I still have my dignity and deserve to be treated with respect.⁸⁶

⁸² Researcher interviews with Arash, man with physical disability, city in eastern Iran, May 16, 2017; and Nader, man with physical disability, town near Tehran, May 18, 2016.

⁸³ Researcher interview with Arash, man with physical disability, city in eastern Iran, May 16, 2017.

⁸⁴ Researcher interviews with Hamed, man with physical disability, small town in northern Iran, November 11, 2016; and Hassan, man with physical disabilities, Karaj, May 12, 2017;

⁸⁵ Researcher interview with Nader, man with physical disability, town near Tehran, May 18, 2017.

⁸⁶ Researcher interview with Hassan, man with physical disability, Karaj, May 12, 2017

Discriminatory and Inadequate Disability Pension System

Under the CRPD, the government of Iran is committed to “take appropriate steps to safeguard and promote” the realization of the right to an adequate standard of living and to the continuous improvement of living conditions for persons with disabilities and their families without discrimination on the basis of disability. Social protection programs and poverty reduction programs should be equally available to people with disabilities and should include assistance from the government with disability-related expenses.⁸⁷

The Committee on the Rights of Persons with Disabilities has expressed concern about limiting access for persons with disabilities to social protection benefits and subsidies based on poverty criteria or a financial assets test.⁸⁸ While poverty reduction programs should include additional disability-related expenditures, disability-specific social protection programs should not be limited in scope to those living below the poverty line, but should also consider the extra costs, higher rates of unemployment, obstacles to education, and other factors that result in higher rates of poverty among people with disabilities.⁸⁹

Human Rights Watch and the Center for Human Rights in Iran found several concerns regarding the current disability pension program. In the most recent Persian year 1396 (March 2017 to March 2018), after five years with no increase, the disability pension paid by the SWO increased to 1.48 million Iri (\$39.36) per month.⁹⁰

The amount of the SWO disability pension is substantially less than other pensions paid under other social protection programs. For example, the pension paid to veterans with disabilities by FMVA is equal to or more than the minimum wage of 9.3 million Iri (\$247.34) per month.⁹¹ This practice of paying significantly smaller pensions to people with

⁸⁷ CRPD Convention, art. 28.

⁸⁸ Un CRPD Committee, Concluding Observations on the Initial Report of Costa Rica, adopted by the Committee at its 11th session, 31 March–11 April 2014, CRPD/C/CRI/CO/1, para. 57; and Un CRPD Committee, Concluding Observations on the Initial Report of Croatia, adopted by the Committee at its 13th session, 25 March–17 April 2018, CRPD/C/HRV/CO/1, para. 44.

⁸⁹ World Health Organization and World Bank, “World Report on Disability,” 2011, https://www.unicef.org/protection/World_report_on_disability_eng.pdf (accessed June 11, 2018).

⁹⁰ The pension is paid partly by SWO and partly under the national “Targeted Subsidy Plan.” Fariba Barimani, head of the Information Technology Center of the SWO, interview with Young Journalists Club, November 10, 2017, <https://www.yjc.ir/fa/news/6315754/> (accessed March 15, 2018); and Anooshiravan Mohseni Bandpei, head of SWO, Iranian Students News Agency (ISNA) March 17, 2018 <https://www.isna.ir/news/96122614336/> (accessed March 19, 2018).

⁹¹ UN CRPD Committee, Replies of Islamic Republic of Iran to the List of Issues, January 13, 2017, CRPD/C/IRN/Q/1/Add.1, para. 158. The pension received by national Social Security Organization pensioners was also equal to the minimum wage in

disabilities registered with SWO is discriminatory, because it treats people with disabilities differently based on the cause of their disability and cannot be justified. The government should take immediate steps to ensure disability pensions paid by the SWO are equal to other types of social pensions.⁹²

According to the government, in 2016, 25 percent of persons with disabilities registered with the SWO, or about 321,000 people, received disability pensions.⁹³ However, we found evidence indicating that many persons with disabilities are left out of this plan despite serious financial needs. According to the SWO, unemployment among persons with disabilities is 60 percent, much higher than the national average of 12.4 percent for the period of March 2016 to March 2017.⁹⁴ In 2017, the head of the SWO acknowledged that 150,000 persons with disabilities were confirmed eligible to receive pensions but were still waiting to receive them.⁹⁵ Some people we interviewed said that SWO staff inform people with disabilities that they will remain on waiting lists until another recipient becomes ineligible (finds a job, for example) or passes away.⁹⁶

The eligibility criteria for the disability pension are overly strict and exclude many who need support. Rather than considering the level of support each applicant needs to live an independent and dignified life, only those with disabilities “diagnosed to be severe or very severe” are eligible.⁹⁷ The applicant also should not receive any other form of government

the Persian year 1396. Taghi Noorbakhsh, head of national Social Security Organization, Iran Labour News Agency (ILNA), April 3, 2017, <https://www.ilnanews.com/بخش-کارگری-9-مستمری-سال-به-میزان-و-نیم-درصد-افزایش-یافت> (accessed May 8, 2018).

⁹² UN CRPD Committee, Concluding Observations on Iran, para. 52.

⁹³ UN CRPD Committee, Replies of Iran to the List of Issues, para. 156.

⁹⁴ Anooshiravan Mohseni Bandpei, head of the SWO, interview with Iranian Students News Agency (ISNA), March 17, 2018, <https://www.isna.ir/news/96122614336/> (accessed March 19, 2018). For national unemployment rate, see Omid Ali Parsa, deputy of the National Statistics Center, Islamic Republic of Iran News Channel, May 2, 2017 <http://www.irinn.ir/fa/news/496586/> (accessed April 16, 2018).

⁹⁵ Anooshiravan Mohseni Bandpei, head of the SWO, addressing the Coordination Council of the Ministry of Labor and Social Welfare of Sistan and Baloochestan province, April 21, 2017, official website of SWO, <http://www.behzisti.ir/Portal/home/?news/235053/235982/238041/> (accessed March 19, 2018).

⁹⁶ Researcher interviews with Arezoo, staff member of the State Welfare Organization, Tehran, March 29, 2017; Daryoush, blind man, city northern Iran, May 17, 2017; and Zohreh, blind woman, Tehran, May 13, 2017.

⁹⁷ Researcher interviews with Mahnaz, woman with physical disability, city in southern Iran, November 22, 2016; and Afsaneh, mother of Golnaz, a young girl with intellectual disability, Tehran, November 30, 2016. See also Hossein Nahvinezhad, rehabilitation director of SWO, interview with Tasnim News Agency, January 5, 2018, <https://www.tasnimnews.com/fa/news/1396/10/15/1619936> (accessed March 19, 2018).

support or have any income, no matter how small, and irrespective of whether the support they receive from other sources is adequate to meet their basic needs.

The current disability pension also fails to serve as meaningful financial support, being six times smaller than the official minimum wage.⁹⁸ The minimum wage itself has been criticized as being too low by the head of the parliamentary commission and the UN Committee on Economic, Social, and Cultural Rights.⁹⁹ Yet, the government has yet to increase it to meet household needs. For the Persian year 1396, the minimum cost of household living expenses was nearly 24.9 million Irl (\$662.23) per month, based on data provided by the National Central Bank and the Institute of Nutrition and Food Industry Research.¹⁰⁰

Persons with disabilities interviewed described the amount of disability pension as “trivial,” “ridiculously inadequate,” and “insulting.” Hassan, a 27-year-old man with a physical disability, said, “With this money, I even can’t afford living in the streets as a homeless person. I am fully dependent on my family. I feel I am no one.”¹⁰¹ People who received disability pensions also said the payment is irregular and may be delayed for weeks or months.¹⁰²

In a positive step, the 2018 Law to Protect Rights of Disabled Persons requires the government to “increase disability pensions paid to persons with severe or very severe disabilities who lack job and income up to the minimum wage level.”¹⁰³

⁹⁸ Ministry of Cooperatives, Labor and Social Welfare, March 15, 2017, <https://www.mcls.gov.ir/fa/news/76602/> (accessed March 19, 2018).

⁹⁹ Salman Khodadadi, the head of Parliamentary Social Commission, “With 9.3 million IRI as minimum wage, workers will still live under the poverty line,” March 15, 2017, Islamic Consultative News Agency (ICANA) <http://www.icana.ir/Fa/News/327982/> (accessed April 16, 2018); and UN Committee on Economic, Social and Cultural Rights, Concluding Observations on the Second Periodic Report of the Islamic Republic of Iran, fiftieth session, E/C.12/IRN/CO/2 June 10, 2013, para. 14, http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=E%2fC.12%2fIRN%2fCO%2f2&Lang=en

¹⁰⁰ “Details of the minimum living expense of the household” (جزئیات حداقل هزینه معیشت خانوار) Mehr News Agency, March 3, 2017 <https://www.mehrnews.com/news/3921770/> (accessed March 19, 2018).

¹⁰¹ Researcher interview with Hasan, man with physical disability, Karaj, May 12, 2017.

¹⁰² Ibid.

¹⁰³ Law to Protect Rights of Disabled Persons (قانون حمایت از حقوق معلولان) Article 27.

III. Discriminatory Laws and Policies

The Iranian government's approach to disability continues to rely heavily on the medical model of disability, which contributes to discrimination and stigmatization. Until recently, disability was widely understood through the lens of a person's defect, difference, or illness. Persons with disabilities were seen as vulnerable, in need of care, or in need of curing. Disability today is viewed as an interaction between individuals and their environment, and the emphasis is on identifying and removing barriers in the environment and discriminatory attitudes. This paradigm shift from the "medical model" of viewing disability to a social, or rights-based, model is codified in the CRPD.

Iranian legislation, including the Civil Code, Islamic Penal Code, and Law on Criminal Procedure, use derogatory and outdated language such as "insane," "mentally ill," "retarded," "eyeless," and "crippled."¹⁰⁴ Some of this language can also be found in Iran's communications with the CRPD Committee.¹⁰⁵ The government has sought to revise some language in recent years, including use of the terms "physical disability" and "mental disability." Yet, it has also introduced terms such as "chronic mental disease," which still reflects an outdated medical approach to psychosocial disabilities.

The 2016 Charter on Citizenry Rights includes a relatively new expression to describe persons with disabilities as "ability-seekers," implying that people with disabilities see themselves as needing to be fixed or to acquire certain abilities in order to be members of society on an equal basis with others.¹⁰⁶

Unnecessarily Restrictive Disability Definition

There is no internationally accepted definition of disability. The CRPD describes people with disabilities as including those "who have long-term physical, mental, intellectual, or

¹⁰⁴ UN CRPD Committee, Concluding Observations on Initial Report of Islamic Republic of Iran, adopted by the Committee on its 17th session, CRPD/C/IRN/CO/1, May 10, 2017, para. 8.

¹⁰⁵ See Government of Iran, Report Submitted by State Party Under Article 35 of the Convention to the United Nations Committee on the Rights of Persons with Disabilities, CRPD/C/IRN/1, July 8, 2015, paras. 36(a), 134, 135, 136; UN CRPD Committee, Replies of Iran to the List of Issues, paras. 3, 44, 75, 77.

¹⁰⁶ Charter on Citizenry Rights (منشور حقوق شهروندی) launched and signed by president Rohani, Congress on the Constitution and Nation's Rights, December 19, 2016, Ministry of Foreign Affairs Website, http://kazan.mfa.ir/uploads/متن_کامل_منشور_حقوق_شهروندی.pdf (accessed March 22, 2017).

sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others.”¹⁰⁷ Iran’s 2004 disability law defines a person with a disability as:

[A]ny person who, based on diagnosis of the SWO Medical Commissions, has physical, intellectual, mental, or multiple impairments amounting to continuous and considerable deficiency in their health and general functioning to the level that the person’s social and economic independence is reduced.¹⁰⁸

This definition reflects a medical model by focusing on an individual’s health and functioning as determiners of disability. It also suggests that the government excludes conditions as disabilities in some way determined to be “less severe” or non-continuous. SWO Director Anooshiravan Mohseni Bandpei confirmed in a 2016 news interview that “only those having severe or very severe disabilities are covered by the SWO.”¹⁰⁹ SWO Rehabilitation Director Hosein Nahvinejad described the government’s approach as:

In our definition, only a person who has an impairment hindering their life course and requires rehabilitative interventions is accepted as a disabled person. Based on field studies ... we found that 2 percent of the population have higher than moderate level of disabilities requiring rehabilitation.¹¹⁰

For persons with psychosocial disabilities, only those who are identified as having “chronic mental disease” are registered as persons with disabilities with the SWO. A person with a “chronic mental disease” is defined by having a psychological disease that

¹⁰⁷ CRPD, art. 1.

¹⁰⁸ Comprehensive Law to Protect Rights of Disabled Persons, Islamic Consultative Assembly, *Official Gazette*, no. 17264, 1383 (2004). The disability legislation which came into force shortly before publication of this report essentially repeats the same definition in Article 1(a).

¹⁰⁹ “Persons with severe disabilities are covered by SWO,” (افراد با معلولیت شدید تحت پوشش بهزیستی قرار می‌گیرند) interview with Tasnim News Agency, December 18, 2016, <https://www.tasnimnews.com/fa/news/1395/09/28/1270112/> (accessed September 21, 2017).

¹¹⁰ Hosein Nahvinejad, rehabilitation director of SWO, news debate on International Day of Persons with Disabilities on the 2nd channel of Iran’s governmental television, December 3, 2016, http://www.monazereh.ir/images/Bank/Movie/Ejtemaie/95-09/11_vijeh_khabari_2230/01_vijeh_khabari_2230.mp4, (accessed September 22, 2017).

has been continuous for at least the past two years and who has been hospitalized for their mental condition more than once in the last two years. The individual must also currently face social or professional dysfunction.¹¹¹

As a result of this overly restrictive definition, a large number of persons with psychosocial disabilities are not able to register with the SWO and receive SWO services. According to a 2011 Ministry of Health study, 23.6 percent of 15 to 64-year-olds in Iran (12.5 million persons) had some mental health condition.¹¹² However, only a very small number of persons with mental health conditions, approximately 103,000 persons who have been assessed as having “chronic mental diseases” are currently registered with the SWO and thus eligible for support services.¹¹³

Farah, a woman with psychosocial disabilities, said she has not been able to register with the SWO because she refused to be hospitalized. She said, “My mom worked in a mental hospital for many years and knew that they used electronic shock [Electroconvulsive Therapy] there. She didn’t want me to go through it, so I was never hospitalized and then never got the chance to register with SWO.”¹¹⁴

Prevention of Disability

Human Rights Watch and the Center for Human Rights in Iran found that preventing disability is one of the main priorities of Iran’s disability policy. In a 2015 speech SWO Director Anooshiravan Mohseni Bandpei said, “We should use medical science evidence to remove disabilities and decrease the number of disabled persons to the least possible.”¹¹⁵

¹¹¹ Regulations on Establishment of the Rehabilitation and Treatment Centers for Persons with Chronic Mental Disorders (دستور العمل شرایط و ضوابط اختصاصی مراکز توان بخشی و درمانی بیماران روانی مزمن) Article 1(1) adopted by SWO Council of Directors, Summer 2007, Website of the SWO Tehran provincial office, <http://tehran.behzisti.ir/portal/file/?286877/دستورالعمل-روزانه-روان-مزمن.pdf>, (accessed July 17, 2017).

¹¹² Ali Akbar Sayari, deputy of Health affairs of the Ministry of Health, Treatment and Medical Education: “23/6 percent of the 15 to 64-year-old population suffer from mental disorders (ایرنا: 23.6 درصد جمعیت 15 تا 64 سال کشور از اختلال روانی رنج می‌برند) October 21, 2015, <http://www.irna.ir/fa/News/81808077/> (accessed May 3, 2017).

¹¹³ “Estimating existence of 200,000 chronic mental patients in the country,” (پیشبینی وجود 200000 بیمار روانی مزمن در کشور) interview with Iranian Students News Agency (ISNA) reported by Public Relations and International Affairs Deputy of SWO, July 1, 2017, <http://www.behzisti.ir/Portal/home/?news/235053/235987/263976/> (accessed July 22, 2017).

¹¹⁴ Researcher interview with Farah, woman with psychosocial disability, May 17, 2017.

¹¹⁵ Speech addressing a gathering to celebrate International Day of Persons with Disabilities, Azad News Agency (ANA), December 7, 2015, <http://www.ana.ir/news/70270> (accessed May 6, 2017).

Including disability prevention as a component of the government's policies and programs on disability reflects a medical approach to disability as something to be cured or fixed. While government actions to improve public health, access to health care services and information, and other policies may result in a reduction in the number of disabilities, prevention of disabilities is distinct from the protection of the rights of people with disabilities. Some aspects of the current disability prevention policies are incompatible with Iran's commitments under the CRPD.

For example, the SWO provides free or affordable cochlear implant surgeries for people who are deaf but does not allocate sufficient support for professional sign language interpreters, including in courts, hospitals, or other critical situations. While cochlear implantation may be an option for some very young deaf children, the government should ensure that the resources allocated to promote disability rights are not disproportionately allocated to treatment procedures.

Sohrab is a young deaf man and activist who explained,

State Welfare Organization officials encourage cochlear implantation a lot. They pay part of the surgery expenses. But if we ask them to train sign language interpreters, they say they don't have money. They tell us that they have limited resources and that we need to improve our remaining hearing instead of using sign language. Instead of supporting us, they want to eliminate us. They want all deaf persons to disappear. The day my heart really broke was the day I heard my favorite actress say, "We pray to God that one day, there are no more deaf people in Iran." The highest priority is to prevent our existence or cure our conditions to the extent possible rather than supporting us to fulfill our capabilities.¹¹⁶

In the agreement concluded between representatives of the deaf and hard of hearing community and the SWO in March 2016 (see annex 2), the SWO has committed to provide clearer and more accurate information about cochlear implantation surgery.

¹¹⁶ Researcher interview with Sohrab, deaf man living in Tehran, April 17, 2017.

Iran’s policy on prevention of disability has other problematic aspects, including compulsory pre-marriage genetic screening, which has been in effect nation-wide since early 2018. To register a marriage, couples must provide a certificate documenting a genetic consultation.¹¹⁷ While the law does not prohibit marriage based on the outcome of the consultation, it violates the right to the respect for private and family life. For people whose disabilities have a genetic component, this can have a potential disproportionate impact on their rights to marry and have a family. The CRPD Committee had recommended that the Iranian government withdraw this legislation, which was in draft form at the time of Committee’s consideration.¹¹⁸

¹¹⁷ “Sixth National Plan for Economic, Social and Cultural Development” (برنامه ششم توسعه اقتصادی، اجتماعی و فرهنگی کشور)، adopted by Islamic Consultative Assembly (Parliament) 14/12/1395 (March 5, 2017) Article 75, <https://shenasname.ir/1391-09-30-20-01-30/tosee/plan6/3579-ایران-اسلامی-جمهوری-توسعه-ششم-قانون-برنامه-ششم-توسعه-جمهوری-اسلامی-ایران>.html (accessed July 11, 2017); Anooshiravan Mohseni Bandpei, head of SWO, Iranian Students News Agency (ISNA), March 17, 2018 <https://www.isna.ir/news/96122614336/> (accessed March 19, 2018).

¹¹⁸ UN CRPD Committee, Concluding Observations on Iran, para. 9.

IV. Inaccessible infrastructure

The transportation system here is so weak and difficult to use even for those who do not have to use a wheelchair. The sidewalks are also a real catastrophe. So, I have no choice but to ask others to do my stuff for me while I spend most of my days trapped in my room.¹¹⁹

—Hassan, 27, wheelchair user with muscular dystrophy, May 12, 2017

As a result of the poor accessibility of Iran’s public infrastructure and transportation, people with disabilities in Iran we interviewed often remain trapped in their homes, unable to live independently and participate in society on an equal basis with others. While many interviewees reported that in recent years the Iranian government has made some progress in making public infrastructure and transportation more accessible, especially in Tehran and larger cities. However, the interviewees noted that it is still far from being fully accessible.¹²⁰ Iranians with disabilities who live in rural areas face particular difficulties as there is limited physical accessibility of public infrastructure and transportation in these areas.¹²¹ Authorities have also not consistently provided accessibility for all types of disabilities; for instance, new buses in some major cities are now equipped with ramps for wheelchairs to board. Yet, these buses lack audio systems to announce current and upcoming bus stops, which are essential for people who are blind or have low vision.¹²²

Public Transportation

Tehran is home to the country’s first underground rail system, which serves over eight million people a day. The capital city also has a four-line Bus Rapid Transit system (BRT) that serves 1.8 million people daily.¹²³ Underground rail systems now are present or under

¹¹⁹ Researcher interview with Hassan, May 12, 2017.

¹²⁰ Researcher interviews with Ehsan, man with physical disability, small town in western Iran, November 18, 2016; and Mahnaz, woman with physical disability, a city in southern Iran, November 22, 2016.

¹²¹ Researcher interviews with Davoud, blind man, Tehran, November 16, 2016; Ehsan, man with physical disability, town in western Iran, November 18, 2016; Mina, blind woman living, small city in central Iran, November 10, 2016; Homa, woman with physical disabilities, Tehran, November 20, 2016; and Hamed, man with a physical disability, small town in northern Iran, November 11, 2016.

¹²² Researcher interviews with Mahmood, blind man, city in southern Iran, November 9, 2016; and Bahram, blind man, Karaj, May 11, 2017.

¹²³ Shiva Shahmohammadi, “Tehran Traffic Woes & Urban Challenges,” August 9, 2015, <https://financialtribune.com/articles/people/22995/tehran-traffic-woes-urban-challenges> (accessed on August 10, 2017).

construction in other major cities, including Shiraz, Mashad, Isfahan, Tabriz, and Ahvaz.¹²⁴ Some important developments in accessibility in major cities include the installation of about 40 tactile directing lines in 104 of Tehran’s metro stations to facilitate accessibility and safety for blind people; adjustable doorsteps on some new buses in major cities, including Tehran’s BRT to allow wheelchairs to board; and braille signs at some bus stops.¹²⁵

However, for many persons with disabilities, public transportation is either wholly inaccessible or extremely challenging to navigate—either due to the complete absence of accessible infrastructure or because existing infrastructure does not always work. Consequently, many persons with disabilities interviewed never navigate public transportation without help.

People interviewed living in smaller cities and rural areas faced even more difficulties in accessing transportation, since there is typically minimal or no public transportation in these locations and, where it does exist, it is overwhelmingly inaccessible. Most people in these locations in Iran rely on different types of taxis. For people with certain disabilities, however, this is often not an option as they are not accessible, and drivers may charge more for people with disabilities, such as transporting a wheelchair.¹²⁶

Bus system

Many persons with physical disabilities who use wheelchairs said that they rarely use the bus system.¹²⁷ Those who do attempt to use buses often rely on the help of strangers, family members, or friends. Both BRT and regular buses generally are not accessible for

¹²⁴ The Business Year, “Moving Around: Iran 2011 Review of Transport,” <https://www.thebusinessyear.com/iran-2011/moving-around/review> (accessed on August 10, 2017).

¹²⁵ “Metro’s green track is dark for disabled persons,” (مسیر سبز مترو برای معلولان خاکستری است) Iran Newspaper, October 6, 2016, <http://www.iran-newspaper.com/newspaper/BlockPrint/153525> (accessed July 14, 2017).

¹²⁶ Researcher interviews with Vajiheh, woman with physical disabilities, small city in central Iran, November 21, 2016; Hamed, man with physical disability, small city in northern Iran, November 11, 2016; Fatemeh, woman with physical disability, Tehran, December 5, 2016; Hamid, man with physical disability, city in southern Iran, November 22, 2016; Alireza, man with physical disability, city in southern Iran, November 23, 2016; Hassan, man with physical disability, Karaj, May 12, 2017; and Yashar, man with physical disabilities, town near Tehran, May 15, 2017.

¹²⁷ Researcher interviews with Hamid, man with physical disabilities, city in southern Iran, November 22, 2016; and Yashar, man with physical disabilities, town near Tehran, May 15, 2017. The Disabled and War Veterans Transportation System provides some accessible transport services in Tehran, including 61 wheelchair-accessible vans available to 3,000 people with disabilities registered with the system. Saeed Zareh Zahrani, “Tehran Bus Company” (شرکت واحد اتوبوسرانی تهران) <http://bus.tehran.ir/Default.aspx?tabid=204> (accessed April 18, 2017).

many persons with disabilities. Few buses have adjustable doorsteps to allow people who use wheelchairs, crutches, or walkers to board.¹²⁸ The platforms for boarding BRT buses often have steps to reach them and do not have ramps.¹²⁹

Many said that even when a bus is equipped with adjustable doorsteps, drivers often do not know how to adjust the door and open the ramp.¹³⁰ For example, Hassan, a 27-year-old wheelchair user in Karaj said, “When I explain to them the existence of a ramp, or when my mother opens it, drivers and other passengers are often surprised. They tell us that they were not aware of such an option before.” Hassan described one incident when his mother was trying to open the ramp for him to board the bus, the bus driver closed the door and left Hassan on the platform with his mother on the bus.¹³¹

Fatemeh, a woman with a physical disability who uses a wheelchair, said, “When I notice that people do not have the time or knowledge to open the ramp, I ask someone to lift me on and off the bus in my wheelchair. It’s really difficult. Sometimes I have to let five or six buses pass, before I can get assistance to board the bus.”¹³²

Metro system

People we interviewed faced barriers in accessing the metro system in the cities where they live. Even where elevators do exist for the metro, they are often out of service. Hassan, who uses a wheelchair, said, “It happened a lot that upon arriving at the [metro] station, I realized that the elevator was broken. So, I had to change my route to find a working elevator.”¹³³

Despite these barriers, some persons with physical disabilities who use wheelchairs said that since the metro is fast and more affordable, they continue to use it. They plan their route

¹²⁸ Researcher interviews with Javad, man with physical disability and disability rights advocate, Tehran, December 5, 2016; Homa, woman with physical disabilities, Tehran, November 20, 2016; and Mahnaz, woman with physical disability, a city in southern Iran, November 22, 2017.

¹²⁹ Researcher interviews with Fatemeh, woman with physical disabilities, Tehran, December 5, 2016 and Hassan, man with physical disabilities, Karaj, May 12, 2017.

¹³⁰ Researcher interview with Fatemeh, woman with physical disability, Tehran, December 5, 2016.

¹³¹ Researcher interview with Hassan, man with physical disabilities, Karaj, May 12, 2017.

¹³² Researcher interview with Fatemeh, woman with physical disability, December 5, 2016.

¹³³ Researcher interview with Hassan, man with physical disabilities, Karaj, May 12, 2017.

to use stations that have elevators but may need to change trains more than once or travel some part of the way along sidewalks which could add significant time to their commute.¹³⁴

Some persons with disabilities shared that they even resort to using escalators despite the significant dangers. Hassan said:

I tried to avoid using escalators, but sometimes I had no other choice. With my heavy electronic wheelchair and my heavy body, getting on the escalator was indeed a suicide [mission]. Once, I almost fell down. Had I not been lucky, I could have sustained a deadly injury.¹³⁵

Fatemeh, who uses a wheelchair, said,

I know it's very dangerous. Each time I get on an escalator with my wheelchair, I prepare myself for death. But I have no other choice. I have nobody to help me.¹³⁶

Upon reaching the platform, persons who use wheelchairs may have to ask other passengers to help them pass the gap between the train car and the platform. The same is often true upon reaching the destination station to get off the train.¹³⁷

The Bavar Association, a prominent nongovernmental organization advocating for persons with disabilities in Iran, maintains a database of accessible transportation stations, health clinics, and government offices in the city of Tehran and some other cities. According to their map, as of October 30, 2016, out of some 82 metro stations in the province of Tehran, only 11 stations were fully accessible for people with physical disabilities and blind people and five more were partially accessible.¹³⁸

¹³⁴ Researcher interviews with Hassan, man with physical disabilities, Karaj, May 12, 2017; and Yashar, man with physical disability, town near Tehran, May 15, 2017.

¹³⁵ Researcher interview with Hassan, man with physical disabilities, Karaj, May 12, 2017.

¹³⁶ Researcher interview with Fatemeh, woman with physical disabilities, Tehran, December 5, 2016.

¹³⁷ Researcher interview with Yashar, man with a physical disability, town near Tehran, May 15, 2017.

¹³⁸ Accessible Metro Stations in Tehran, Accessibility database (ایستگاه‌های دسترس‌پذیر متروی تهران، بانک اطلاعات) <http://www.monasebsazi.com/metro/> (last updated 9/8/1395 (October 30, 2016) (accessed May 2, 2018)).

Obstacles for Blind People

Blind persons are hampered by the lack or low quality of tactile tiles or paving (raised bumps and ridges) on metro and bus station floors to help guide them while walking.¹³⁹ Most blind persons interviewed said that they avoid using buses because buses often stop before or after the designated area, and the bus stops are not verbally announced. Regular buses may stop between designated stops to let passengers get on and off, which hinders the ability of a blind person to count stops as a means of orienting in the absence of announcements.¹⁴⁰

The lack of tactile strips or tiles indicating the platform edge is dangerous for people who are blind, and the absence of this critical safety measure has led to serious accidents and at least one death in the Tehran metro. In October 2010, a blind teacher and mother of two was struck and killed by a train after falling off the platform and onto the rails in Tehran's Khazaneh station.¹⁴¹ In 2014, a blind man was injured after falling from the platform in Tehran's Hassanabad station. He told the *Iran Sepid* newspaper,

I went to the platform and thought that the train I could hear was the one I should get on... but it was for the other side. So I stepped forward and fell on the platform instead. If they hadn't taken me off [the tracks], I wouldn't be alive.¹⁴²

In 2016, Tehran Metro officials reported that all station staff, including the heads of stations, are now required to approach persons with disabilities and others who might need help in navigation and assist them in boarding trains.¹⁴³ Yet, this step is insufficient to ensure the safety of people who are blind or have low-vision in metro stations.

¹³⁹ Researcher interviews with Davoud, blind man, Tehran, November 16, 2016; Bahram, blind man, Karaj, May 11, 2017; and Laleh, blind woman, Tehran, May 24, 2017.

¹⁴⁰ Researcher interviews with Keivan, blind man, Tehran, May 12, 2017; Bahram, blind man, Karaj, May 11, 2017; and Laleh, blind woman, Tehran, May 24, 2017. BRT buses do not make undesignated stops.

¹⁴¹ "Heartbreaking death of the female blind teacher in metro station" (مرگ دلخراش خانم معلم نابینا در ایستگاه مترو), *Iran newspaper* No. 4627, October 17, 2010, <http://www.magiran.com/npview.asp?ID=2170523> (accessed February 27, 2017).

¹⁴² "Falling of a blind person on the metro rail" (سقوط یک نابینا در چاله مترو) *Iran Sepid Newspaper*, January 28, 2014, <http://www.iransepid.ir/News/2228.html> (accessed July 14, 2017).

¹⁴³ "Metro's green track is dark for disabled persons" (مسیر سبز مترو برای معلولان خاکستری است) *Iran Newspaper*, October 6, 2016, <http://www.iran-newspaper.com/newspaper/BlockPrint/153525> (accessed July 14, 2017).

Blind persons also described various barriers on sidewalks that made them difficult and even dangerous to navigate.¹⁴⁴ For example, Laleh, a 29-year-old blind woman, told us about the barriers she encounters in Tehran: motorbikes parked on the sidewalks, potted plants, holes in the sidewalk, stairs, and uneven ground. She said:

I can't count how often I have hurt my arm by bumping into motorbike handles, or hit my head or chin on something, or fallen into an uncovered ditch. I call some of these sidewalks "death stations."¹⁴⁵

Laleh said that she sometimes chooses to walk on the street to avoid these obstacles. "I find streets safer because there is only [the] risk of [a] car accident and I can walk faster," she said.¹⁴⁶ Bahram, a 36-year-old blind man living in Karaj (Iran's fourth largest city), said that in 2016, his foot became stuck in a hole in the sidewalk, and he fell. "I had surgery, but I still can't fully bend my leg," he said.¹⁴⁷

Tactile paving that can help guide people with visual disabilities on sidewalks and across intersections are installed in some streets. But blind persons reported that the lack of quality, improper installation, and non-observance of accessibility standards often mean that these lines are useless.¹⁴⁸ For example, Mahmood, a blind man living in a southern Iranian city, explained that officials used yellow material on sidewalks, apparently to guide people with low-vision, but the material is not sufficiently raised to be recognized by his white cane.¹⁴⁹ Many blind persons said that because of improper installation, tactile lines often guide them into poles, trees, or telephone booths. Not knowing what tactile lines are for, street vendors may place their carts on them.¹⁵⁰

¹⁴⁴ Researcher interview with Keivan, blind man, Tehran, May 12, 2017.

¹⁴⁵ Researcher interview with Laleh, blind woman, Tehran, May 24, 2017.

¹⁴⁶ Researcher interviews with Laleh, blind woman, Tehran, May 24, 2017, and Keivan, blind man, Tehran, May 12, 2017.

¹⁴⁷ Researcher interview with Bahram, blind man, Karaj, May 11, 2017.

¹⁴⁸ Researcher interviews with Davoud, blind man, Tehran, November 16, 2016; Mahmood, blind man, city in southern Iran, November 9, 2016; Keivan, blind man, Tehran, May 12, 2017; and Laleh, blind woman, Tehran, May 24, 2017.

¹⁴⁹ Researcher interviews with Mahmood, blind man, city in southern Iran, November 9, 2016 and Bahram, blind man, Karaj, May 11, 2017.

¹⁵⁰ Researcher interviews with Mahmood, blind man, city in southern Iran, November 9, 2016; Bahram, blind man, Karaj, May 11, 2017; and Daryoush, blind man, city in northern Iran, May 17, 2017.

In a 2016 media interview, the head of the Secretariat of the National Headquarters to Follow-up on Accessibility blamed subcontractors hired by municipalities for improper installation of tactile lines: “This is due to the lack of training for those subcontractors and has caused many injuries and issues for blind persons.”¹⁵¹

Obstacles for People Who Are Deaf or Hard of Hearing

Deaf and hard of hearing persons reported that they face different barriers accessing metros and buses. Although public transportation is typically slower or sometimes not available at all, many said they use public transportation rather than taxis because of difficulties communicating with drivers.¹⁵² Shahla, a deaf woman who lives in Tehran, said, “Sometimes the signs in the metro or bus stations are not visible, or I can’t read them quickly due to the crowd. So I miss the right station or vehicle. When I ask people for help, they make fun of me because I use sign language.”¹⁵³

Deaf and hard of hearing persons also face challenges driving. There are no standard signs to inform others that a deaf or hard of hearing person is driving a car. The SWO gives specialized car plates with the sign of a wheelchair to persons with disabilities. Sohrab, a 30-year-old deaf man, explained why this is not sufficient for people who are deaf: “What we need is a specific sign so that people can know that beeping for us does not work. Instead, they should flash their lights or use other visual ways to communicate with us.”¹⁵⁴

In March 2016, a group of deaf and hard of hearing people demonstrated in front of the SWO’s main office in Tehran. Following these protests, SWO rehabilitation director Hossein Nahvinezhad signed an agreement with representatives of organizations for people who are deaf pledging to ensure the provision of car plates indicating a driver who is deaf (see the annex included in the online version of this report).

¹⁵¹ Ebrahim Kazemi Momensarayi, Head of Secretariat of the National Accessibility Headquarters, interview with Mizan News Agency, December 11, 2016 <http://www.mizanonline.ir/fa/news/253941/> (accessed June 16, 2017).

¹⁵² Researcher interviews with Sohrab, deaf man, April 17, 2017; Shahla, deaf woman, Tehran, November 29, 2016; and Forough, hard of hearing woman, city in southern Iran, December 9, 2016.

¹⁵³ Researcher interview with Shahla, deaf woman, Tehran, November 29, 2016.

¹⁵⁴ Researcher interview with Sohrab, deaf man in Tehran, April 17, 2017.

Barriers in Accessing Public Buildings and Services

I have missed many opportunities in my life due to inaccessible buildings. I couldn't take care of my education and student affairs [issues] at the university because offices were located upstairs and there was no accessible elevator. I couldn't go to the English language and music courses I dreamed of. Once my brother had to carry my wheelchair up to the third floor to have my eyes examined for my driver's license. The worst part was that only once we reached the third floor we learned that the ophthalmologist was not even working that day!"

—Homa, 23-year-old woman with physical disabilities, Tehran, November 20, 2016

Persons with physical disabilities told Human Rights Watch and the Center for Human Rights in Iran that finding an accessible public building is an exception.¹⁵⁵ Persons with disabilities interviewed said that they find the entrances of most public buildings inaccessible, especially those who use wheelchairs due to stairs with no alternative ramps or elevators. Even when an elevator is available, interviewees said that many elevators were too small to fit most wheelchairs, or there were stairs before reaching the elevator.¹⁵⁶

Ehsan, a man with a physical disability who lives in a small town in western Iran, said that while local hospitals and clinics have elevators, no other public building in his town is accessible. He said, "Even the municipality office which supports making public spaces accessible has more than 30 stairs."¹⁵⁷ Hamed, a 27-year-old man who uses a wheelchair, said that when he had to go to court in the town where he lives, two people had to carry him in his wheelchair up 40 stairs.¹⁵⁸

¹⁵⁵ Researcher interviews with Ehsan, man with physical disability, small town in western Iran, November 18, 2016; and Hassan, man with physical disability, Karaj, May 12, 2017.

¹⁵⁶ Researcher interviews with Vajiheh, woman with physical disabilities, small city in central Iran, November 21, 2016; Hamed, man with physical disability, small city in northern Iran, November 11, 2016; Ehsan, man with physical disability, small town in western Iran, November 18, 2016; Fatemeh, a woman with physical disability, Tehran, December 5, 2016; Hamid, man with physical disability, city in southern Iran, November 22, 2016; Alireza, man with physical disability, a city in southern Iran, November 23, 2016; and Javad, disability advocate with a physical disability, December 5, 2016.

¹⁵⁷ Researcher interview with Ehsan, man with physical disability, small town in western Iran, November 18, 2016

¹⁵⁸ Researcher interview with Hamed, man with physical disability, small town in northern Iran, November 11, 2016.

Even SWO offices are typically inaccessible, despite the fact that people with disabilities must visit them in order to receive various services. Mansour, an accessibility consultant and evaluator, said that the SWO office in the city where he worked is less accessible than many other government offices he visited. “The elevator was small and couldn’t fit a wheelchair. The safety handle was also very high and unreachable. The elevator’s door shut so fast that it could hurt you if you didn’t get in quickly,” he said.¹⁵⁹

Persons with physical disabilities who were interviewed expressed specific concerns about accessing banks and ATM machines. Inaccessibility to these financial resources hinders persons with disabilities from conducting their financial matters in a private and secure way. Most of them must ask a family member or friend to do their banking for them, which can undermine their privacy and independence.¹⁶⁰ When a trusted person is not available, persons with disabilities may feel their only choice is to ask strangers for assistance despite the risk of theft.¹⁶¹

Yashar, a 39-year-old man with physical disabilities, said that he has identified a few banks without stairs, but has not managed to find a single ATM machine that he can use from his wheelchair. He often resorts to asking strangers to withdraw money from his account for him.¹⁶²

Fatemeh, a woman with a physical disability, explained the difficulties she experiences accessing the bank. She said:

When I need to use an ATM machine, I stand in a corner and look at people’s faces to guess who could be a trustworthy and supportive person to help me. Then, I give them my card and tell them my pin and ask them to

¹⁵⁹ Researcher interview with Mansour, accessibility consultant and evaluator, June 13, 2017.

¹⁶⁰ Researcher interview with Hamed, man with physical disabilities, town in northern Iran, November 11, 2016; Nader, man with physical disability, town near Tehran, May 18, 2017.

¹⁶¹ Researcher interview with Fatemeh, woman with physical disabilities, Tehran, December 5, 2016; and Yashar, man with physical disabilities, town near Tehran, May 15, 2017.

¹⁶² Researcher interview with Yashar, man with physical disability, town in southern Tehran, May 15, 2017.

withdraw money for me or do any other banking I need. It is a stressful and uncomfortable situation.¹⁶³

Blind persons or persons with low vision reported inaccessible elevators in many public buildings. In some cases, elevator call and floor buttons are not accessible because they do not have braille or voice controls.¹⁶⁴ One blind person said that in a few public buildings he visited, Braille signs have been installed improperly, such that the button indicated in braille that it is for the first floor, when actually the button is for the second floor.¹⁶⁵ Blind persons and people with low vision also said that in many public buildings, elevators do not announce the floor number, so they must ask others to tell them which floor is coming up. If there is no one else in the elevator, they rely on trial and error to find the right floor.¹⁶⁶

Banafsheh, a blind woman who works for a public company in Tehran, described how one morning when she tried to use the elevator to go to her office on the sixth floor, she found that an inaccessible electronic touch key pad had been installed for the elevator. She said, “I was really disappointed that they had changed it without considering my needs. From that day onward, I needed to wait for a colleague to help me select the right floor. Quite often, I preferred to walk all the way up to the sixth floor instead.”¹⁶⁷

Government Response on Accessibility

In recent years, the government has taken some concrete measures to improve accessibility, including by adopting mandatory accessibility standards for urban architecture.¹⁶⁸ However, the standards relate only to accessibility for people with “movement restrictions,” ignoring accessibility requirements for people with other types of disabilities. In addition, the standards are not available in an accessible and readable format for people who are not

¹⁶³ Researcher interview with Fatemeh, woman with physical disability, Tehran, December 5, 2016.

¹⁶⁴ Researcher interviews with Davoud, blind man, Tehran, November 16, 2016; Mahmood, blind man, city in southern Iran, November 9, 2016; and Mina, blind woman, small city in central Iran, November 10, 2016.

¹⁶⁵ Researcher interview with Mahmood, blind man, city in southern Iran, November 9, 2016.

¹⁶⁶ Researcher interviews with Zinat, woman with low vision, Tehran, March 29, 2017; Marzieh, woman with low vision, Tehran, November 16, 2016; Davoud, blind man, Tehran, November 16, 2016; Mahmood, blind man, city in southern Iran, November 9, 2016; and Banafsheh, blind woman, Tehran, May 6, 2017.

¹⁶⁷ Researcher interview with Banafsheh, blind woman, Tehran, May 6, 2017.

¹⁶⁸ “Book on Architecture and Urban Regulation for Physically Disabled People,” <http://www.nezammohandesi.ir/uploads/zavabet-malolin.pdf> (accessed May 3, 2018).

architects or engineers. Our research could not determine if and how the principles of Universal Design have been considered in creating these standards.¹⁶⁹

Since 2015, the national and provincial Headquarters to Coordinate and Follow-up on Accessibility have carried out policy-making, planning, monitoring, and creation of a national database on accessibility at the national and provincial levels.¹⁷⁰ In 2016, the Headquarters on Accessibility collected information on accessibility in public agencies by investigating roughly 1,200 public agencies in 31 provinces for compliance with 13 criteria on building accessibility.¹⁷¹

The results found that public agencies in Yazd province were the most accessible, meeting 59 percent of the accessibility criteria, while Tehran province's public buildings were the least accessible at 24 percent. The National Gas Corporation and the Foundation of Martyrs and Veterans Affairs were the most accessible agencies, while the Iran Medical Council and Iran Broadcasting Organization were the least accessible.¹⁷²

In recent years, municipalities around the country have appointed advisors on citizens with disabilities or urban accessibility, some of whom are persons with disabilities. For example, in Isfahan, persons with disabilities and their organizations have participated in

¹⁶⁹ UN CRPD Committee recommends that the Iranian government includes the principles of Universal Design in its legislation and promote its application by relevant stakeholders. UN CRPD Committee, Concluding Observations on Initial Report of Islamic Republic of Iran, adopted by the Committee on its 17th session, CRPD/C/IRN/CO/1, May 10, 2017, para. 21. According to Article 2 of the CRPD, "Universal design means the design of products, environments, programs and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design. "Universal design" shall not exclude assistive devices for particular groups of persons with disabilities where this is needed."

¹⁷⁰ The Ministry of Interior serves as its head and the head of the SWO serves the head of the secretariat. See Article 8, Executive Regulation on the Implementation of Article Two of the Comprehensive Law on Protecting Disabled Persons, Ratification No. 31960, adopted by Cabinet of Ministers, May 30, 2005 <http://rc.majlis.ir/fa/law/show/123284> and amended by Ratification No. 45457ت/45515 adopted by Cabinet of Ministers, May 28, 2012 <http://rc.majlis.ir/fa/law/show/811408>. See also Article 1, Comprehensive Plan to Protect Disability Rights, Act No. 77303, adopted by Cabinet of Ministers, September 6, 2015, <http://rc.majlis.ir/fa/law/show/936758>.

¹⁷¹ Ebrahim Kazemi Momensarayi, Head of Secretariat of the National accessibility Headquarters, interview with Mizan News Agency, December 11, 2016 <http://www.mizanonline.ir/fa/news/253941/> (accessed June 16, 2017).

¹⁷² Official website of SWO, Fourth meeting of the National Headquarters to Follow-up on Accessibility, June 21, 2017 <http://www.behzisti.ir/Portal/home/?news/235053/235982/263070/> (accessed July 14, 2017).

accessibility evaluations of 80 government bodies.¹⁷³ In Shiraz, each of the ten municipal districts have appointed one person with a disability as accessibility consultants.¹⁷⁴

Pooya, a blind man who advocates for disability rights, said that based on his observations, the appointment of persons with disabilities as advisors in many cities may be largely symbolic. “I do value this even as a symbolic action. But, [...] the level of real impact depends on the will and interest of officials to seek and listen to the opinions of people with disabilities.”¹⁷⁵ The UN CRPD Committee has also expressed concerns regarding the lack of information about how “representative organizations of persons with disabilities are consulted in the development of measures to accomplish accessibility.”¹⁷⁶

However, our research indicates that persons with disabilities are not always meaningfully included in the accessibility planning, implementation, or monitoring processes. Javad, a disability rights advocate with a physical disability said, “If they included us in what they intend to do for our benefit, then we could see a much better outcome in making sidewalks, roads, and other public facilities accessible. I was really disappointed when I realized that such meagre resources available for making cities accessible was wasted simply because they don’t ask the eventual users to participate.”¹⁷⁷ Ziba, a woman with a physical disability, said that she found a park advertised as a “disabled persons park” mostly inaccessible. “I only could use one of the entrances with my wheelchair. The benches were not designed to be accessible and the ramps were often [too] steep. I was so disappointed to find that this was mostly for show.”¹⁷⁸

The National Headquarters on Accessibility recently introduced a text message system, known as “Mabar,” through which people can report accessibility problems with public roads and public buildings. According to the authorities, upon verifying the complaint, the

¹⁷³ “Director of SWO Isfahan office: accessibility investigation of 80 government buildings commenced” (مدیرکل بهزیستی استان اصفهان: بررسی شاخص مناسبسازی ساختمان 80 دستگاه اداری استان اصفهان آغاز شد) <http://www.behzisty-esfahan.ir/index.php/8313/اخيار-سازمان/26-صفحه-اصلي> (accessed June 15, 2017).

¹⁷⁴ Mohammad Bagher Safvat, Shiraz Mayor interview with Mehr News Agency: “Collaboration of disabled consultants in renovation of urban environment in Shiraz” (همکاری مشاوران معلول در بهسازی شهری شیراز)، February 18, 2013 <http://www.mehrnews.com/news/1817461/> (accessed June 15, 2017); Fars province SWO website, <http://www.behzisti-fars.ir/Portal/Show.aspx?Page=17187&NewsId=12835> (accessed June 15, 2017).

¹⁷⁵ Researcher interview with Pooya, blind man a city west Iran, May 11, 2017.

¹⁷⁶ UN CRPD Committee, Concluding Observations on Iran, para. 20(D).

¹⁷⁷ Researcher interview with Javad, disability rights advocate with physical disability, December 5, 2016.

¹⁷⁸ Researcher interview with Ziba, woman with physical disability, Tehran, May 19, 2017.

Headquarters' secretariat will follow-up with relevant bodies to resolve the issue.¹⁷⁹ In our research we could not find publicly-available information on the mechanism, including the number of complaints and any outcomes.

Our research did not identify any legal case resulting in sanctions for non-compliance with accessibility standards.¹⁸⁰ The law envisages denial of construction permits or completion certificates to public roads and buildings which fail to fulfill accessibility standards. However, the government of Iran has not made public any information about implementation of this regulation.

¹⁷⁹ Anooshiravan Mohseni Bandpei, Head of SWO: “Mabar text message system started working” (سامانه پیامکی معبر راه- “Tasnim News Agency, January 3, 2017 <https://www.tasnimnews.com/fa/news/1395/10/14/1286646/> (accessed June 14, 2017).

¹⁸⁰ UN CRPD Committee, Concluding Observations on Iran, para. 20.

V. Lack of Accessibility and Discrimination in Healthcare

For many people with disabilities we interviewed in Iran, lack of inaccessible facilities, discriminatory attitudes, and a lack of awareness about disability among doctors and medical staff, impede access to medical care. Barriers to accessibility described in detail above include: in accessing personal care and assistive devices; lack of insurance coverage under the national insurance scheme; a lack of financial means including inadequate government support; inaccessible transportation and physical infrastructure, such as in health care facilities impeding access to medical services for people with disabilities on an equal basis with other people in Iran.¹⁸¹

We also documented cases in which doctors and other healthcare professionals did not seek or obtain the informed consent of their patients with disabilities and did not provide them with comprehensive information about treatment or potential side-effects in an understandable format, if at all.

The CRPD requires that persons with disabilities enjoy the highest attainable standard of health with the same range, quality, and standard of free or affordable health care and programs as provided to other persons.¹⁸²

Lack of Availability, Accessibility, and Reasonable Accommodations

Quality and specialized health care services are not provided in some provinces, particularly in remote and rural areas.¹⁸³ People living in these locations often must travel to major cities to access more advanced health care services or visit a specialist. Vajiheh, a 41-year-old woman with a physical disability who lives with her son, explained, “If I have to go, my son needs to take time off from his job, rent a private taxi, carry me and my wheelchair, and take me to the clinic or hospital. It’s all a huge burden, which I try my best

¹⁸¹ Researcher interview with Vajiheh, woman with physical disabilities, small city in central Iran, November 21, 2016; Hamed, man with physical disability, small city in northern Iran, November 11, 2016; Ehsan, man with physical disability, small town in western Iran, November 18, 2016.

¹⁸² CRPD, art. 25.

¹⁸³ UN Committee on the Rights of the Child, Concluding observations on the combined third and fourth periodic reports of the Islamic Republic of Iran, CRC/C/IRN/CO/3-4 para. 70, http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRC/C/IRN/CO/3-4&Lang=En

not to impose on him.”¹⁸⁴ Ehsan, 37, who has a spinal cord injury, said that in order to visit a specialist he needs to travel to another province, which would take at least four hours.¹⁸⁵ Reihaneh, whose daughter Yasamin has intellectual disabilities, also said that she had to travel three hours to Tehran once a week for several years for her daughter to access quality occupational therapy and physiotherapy.¹⁸⁶

Upon reaching a hospital or clinic, persons with disabilities often cannot access them. Saeed, a 28-year-old man who uses crutches, described one experience that kept him from receiving treatment for his eyes:

It happens a lot that I need to go up somewhere without an elevator. I sit on the stairs and pull my body upstairs by the railings. This is not something new. But one day I had to reach the doctor’s office on [the] third floor, and the stairs were uneven and narrow, and the stair railings broken and unsafe. I feared I would fall and get injured. So, I decided just to live with my eye condition and not go up such stairs.”¹⁸⁷

Vajiheh, 41, has been using a wheelchair for the past 10 years. She said that many essential medical services in her town do not have ramps or elevators. “It’s not just the clinics, I also can’t purchase anything from the drug store because all of them are upstairs,” she said. “The same is true about other health care facilities such as labs or radiology facilities.”¹⁸⁸ Ziba, a woman who uses a wheelchair, said that she has been hospitalized in two public hospitals where bathrooms in them were inaccessible. She could not enter the bathroom with her wheelchair and there was no grab bar to facilitate her using the bathroom independently.¹⁸⁹

Blind people and those with low vision said that they do not go to health care facilities alone because the buildings are not accessible and staff there do not provide them with

¹⁸⁴ Researcher interview with Vajiheh, woman with physical disabilities, small city in central Iran, November 21, 2016

¹⁸⁵ Researcher interview with Ehsan, man with physical disability, small town in western Iran, November 18, 2016.

¹⁸⁶ Researcher interview with Reihaneh, mother of a 14-year-old girl with intellectual disability, city in central Iran, November 17, 2016.

¹⁸⁷ Researcher interview with Saeid, man with physical disability, a city in eastern Iran, August 17, 2017.

¹⁸⁸ Researcher interview with Vajiheh, woman with physical disabilities, November 21, 2016.

¹⁸⁹ Researcher interview with Ziba, woman with physical disability, Tehran, May 19, 2017.

accommodations. People interviewed described how they faced barriers in finding their way, filling out different forms, or purchasing medicines or other medical products.¹⁹⁰ Some people who are blind or have low vision also said that neither the prescribing physician nor drug store personnel would assist them in understanding how they should identify different medications and how to use them.¹⁹¹

Deaf and hard of hearing persons interviewed said that they cannot use health care services independently due to the lack of sign language interpreters. Shahla, a deaf woman living in Tehran said, “There is no sign language interpreter provided in the hospitals or clinics. I have to ask my mother to accompany me if I become sick. If she is not available, then I don’t go. Because if I go alone, they won’t understand what my medical need is and could give me the wrong medication.”¹⁹² Sohrab, who is deaf and has been an advocate for deaf persons’ rights for several years, said that deaf persons “do their best to avoid going to hospitals or other medical facilities because people hardly understand them, which is really annoying.”¹⁹³

Discriminatory Attitudes among Health Care Professionals

Many people with disabilities Human Rights Watch and the Center for Human Rights in Iran interviewed said that they faced discrimination by health care personnel, including denial of care. There is no publicly available information about the training doctors and other medical personnel receive regarding the rights of persons with disabilities.

Vajiheh, a woman with physical disabilities, said, “Some of those working in hospitals or clinics behave in ways that make me think this is the first time they’ve ever seen someone using a wheelchair in their lives.”¹⁹⁴ Davood, a blind man living in Tehran, described a difficult experience at a hospital. He said, “The environment is so inaccessible, and they require you to go to so many different offices. But there is no one officially responsible to

¹⁹⁰ Researcher interviews with Leila, woman with low vision, town in western Iran, November 22, 2016; Marzieh, woman with low vision, small city in northern Iran, November 16, 2016; and Mina, blind woman, a small city in central Iran, November 10, 2016.

¹⁹¹ Researcher interviews with Leila, woman with disability living in a small town west Iran, November 22, 2016; Mina, blind woman, small city in central Iran, November 10, 2016; and Davood, blind man, Tehran, November 16, 2016.

¹⁹² Researcher interview with Shahla, deaf woman, November 29, 2017.

¹⁹³ Researcher interview with Sohrab, deaf man, April 17, 2017.

¹⁹⁴ Researcher interview with Vajiheh, woman with physical disabilities, small city in central Iran, November 21, 2016.

provide assistance, and when they found that I needed help, they finally asked one of the staff to help me. I could hear their pitiful words.... I really felt humiliated.¹⁹⁵

Persons with intellectual and psychosocial disabilities and their parents told our researcher that they occasionally faced inappropriate comments or negligence from health care personnel. Azam, the mother of a 12-year-old girl with Down Syndrome, said that once a physician refused to examine her daughter. “When he saw my daughter had Down Syndrome, he blamed me for giving birth at an old age and causing her disability. He then said that if my daughter has a cold, I could give her medicine at home and shouldn’t bring her to the clinic.”¹⁹⁶

Jafar, a 52-year-old man with a psychosocial disability said, “When I tell the physicians or drugstore staff that I have a mental disorder, their behavior changes and becomes cold and negative. They are scared of us because they are not aware. Even the psychiatrist’s assistants or office secretaries don’t know how to interact with mental health patients.”¹⁹⁷

We also documented barriers in accessing dental medical care for some persons with disabilities. For example, Arash, a 24-year-old man with muscular dystrophy said, “Muscular dystrophy causes extreme limitations in the muscles. But the dentists I visited did not know about this condition and tried to open my mouth by force. It seems they have not been educated on how to provide dental care to people with different types of disabilities.”¹⁹⁸

Some parents of children with intellectual or psychosocial disabilities also said they face difficulties finding dental professionals who have the skills for and are patient enough to provide services to their children.¹⁹⁹

¹⁹⁵ Researcher interview with Davood, blind man, Tehran, November 16, 2016.

¹⁹⁶ Researcher interview with Azam, mother of a girl with Down Syndrome (Shima), small town west Iran, November 30, 2016.

¹⁹⁷ Researcher interview with Jafar, man with psychosocial disability, January 16, 2017.

¹⁹⁸ Researcher interview with Arash, man with physical disability, city east Iran, May 16, 2017.

¹⁹⁹ Researcher interview with Azam, mother of a girl with Down Syndrome (Shima), small town west Iran, November 30, 2016; Nahid, mother of Shayan, boy with autism, Tehran, November 30, 2016.

Barriers to Accessing Sexual and Reproductive Healthcare and Information

Access to sexual and reproductive health care and information is difficult for most of the population in Iran. Traditional and religious beliefs about sexuality, lack of any sexual health education in official school curricula, and the absence of public information programs have contributed to low levels of awareness.

Due to additional barriers, persons with disabilities experience greater difficulties accessing these services and information. Women with physical disabilities told us that they rarely visit gynecologists or undergo sexual health preventative care due to financial and mobility restrictions, a lack of professional assistance to facilitate doctors' visits, and a lack of information about the importance of this care.

For example, Vajiheh, a woman with a physical disability who uses a wheelchair said, "Going out is so difficult and expensive for me that I do my best to limit it to the most urgent cases. Because I have a spinal cord injury, I don't feel anything in my body below my chest. So, I have not noticed any problems in my sexual organs. I don't give priority to this issue. I really don't remember when I last visited a gynecologist."²⁰⁰

Reliance on family members, due to the lack of availability of personal assistants or sign language interpretation, interferes with women's comfort in seeking gynecological care. Fatemeh, a 32-year-old woman with a physical disability using a wheelchair, said that it had been two years since she was able to visit a gynecologist despite her feeling that she needed to do so. She said, "The only close person I have is my brother. But I really feel embarrassed to ask him to prepare me for a gynecology checkup and lift me on the gynecology exam table."²⁰¹ Shahla, a 24-year-old deaf woman said that she is not able to have a gynecological examination, unless her mother accompanies and interprets for her. "But this is very embarrassing to share everything when my mom is there. So it's better not to go," she said.²⁰²

²⁰⁰ Researcher interview with Vajiheh, woman with physical disabilities, small city in central Iran, November 21, 2016.

²⁰¹ Researcher interview with Fatemeh, woman with physical disability, Tehran, December 5, 2016.

²⁰² Researcher interview with Shahla, deaf woman, Tehran, Nov. 29, 2016.

Inaccessible buildings and facilities may also prevent women who use wheelchairs from accessing diagnostic services. For example, mammography machines are overwhelmingly inaccessible, with only one accessible machine in Tehran with a months-long waiting list.²⁰³

Two mothers of girls with intellectual or psychosocial disabilities said that when they spoke with health care professionals about how to teach their daughters to manage their menstruation, the medical workers advised them to artificially delay their girls' puberty through medication.²⁰⁴ Reihaneh, mother of Yasamin, a 14-year-old girl with intellectual disabilities, said, "When Yasamin was about to start menstruating, our family doctor suggested that we could delay it by injecting some drugs in her. But when I consulted with one of my friends who was a gynecologist, she said it would have lots of side effects. So we decided not to do it."²⁰⁵

Lack of Informed Consent and Adequate Information about Medical Treatment

My son has undergone electroshock therapy for 14 years now. Each time they tell me that he needs it and that, "You should sign this paper to allow it," and I just sign the paper. But I still don't know what shock therapy is and how it works. I think my consent for my son would be genuine only if I knew what exactly I'm permitting to happen.

—Akbar, father of Hesam, a 34-year-old man with a psychosocial disability

We documented many cases in which doctors and other healthcare professionals did not seek or obtain the informed consent of their patients with disabilities and did not provide them with comprehensive information about the treatment or potential side-effects in a fully understandable format, or often at all. In many cases, parents or other family members consented for their adult children or relatives to be treated, and such consent is

²⁰³ Researcher interview with Roya, gynecologist, Tehran, March 25, 2017.

²⁰⁴ Researcher interviews with Reihaneh, mother of a 14-year-old girl with intellectual disability, a city in central Iran, November 17, 2016; and Afsaneh, mother of Golnaz, a 13-year-old girl with Down syndrome, Tehran, November 30, 2016;

²⁰⁵ Researcher interview with Reihaneh, mother of a 14-year-old girl with intellectual disability, a city in central Iran, November 17, 2016.

typically obtained as part of the paperwork required for the treatment to start, also often without full information about the treatment.

For adults with disabilities, medicine and medical treatment should be delivered with the consent of the individual being treated. The CRPD requires health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent.²⁰⁶ The CRPD Committee has held that treatment by health professionals without consent is a violation of the right to equal recognition before the law and an infringement of the right to personal integrity; freedom from torture and inhuman and degrading treatment; and freedom from violent exploitation and abuse.²⁰⁷ The UN special rapporteur on the right to health has also stated that informed consent “is a core element of the right to health both as a freedom and an integral safeguard to its enjoyment.”²⁰⁸ The special rapporteur also noted that where grounds of “medical necessity” and “dangerousness” of the person are used as justification for non-consensual treatment; their application is open to broad interpretation and, consequently, raises questions of arbitrariness.²⁰⁹

Inappropriate Use of Electroconvulsive Therapy [ECT]

According to mental health professionals in Iran whom we interviewed, Electroconvulsive Therapy [ECT] is often carried out unnecessarily, or for conditions in which ECT is not likely to be helpful, and without the informed consent of the person receiving the treatment.²¹⁰ ECT consists of passing electricity through the brain to induce a seizure and is used in mental hospitals in many countries to treat bipolar disorder and severe depression.²¹¹ ECT

²⁰⁶ CRPD, art. 25.

²⁰⁷ CRPD, arts. 17, 15 and 16.

²⁰⁸ Human Rights Council, “Report of the special rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health,” A/HRC/35/21, March 28, 2017, <https://documents-ddsny.un.org/doc/UNDOC/GEN/G17/076/04/PDF/G1707604.pdf?OpenElement> (accessed February 12, 2018), para. 63.

²⁰⁹ *Ibid.*, para. 64.

²¹⁰ Researcher interviews with Farhad, psychotherapist, Tehran, March 26, 2017; and Reza, psychiatrist practicing in Tehran and one other city in central Iran, November 28, 2016.

²¹¹ Electroconvulsive therapy, also known as electroshock or ECT, is a controversial type of psychiatric shock therapy involving the induction of an artificial seizure in a patient by passing electricity through the brain. ECT is used to treat bipolar disorder and severe depression in cases where antidepressant medication, psychotherapy, or both have proven ineffective. See Human Rights Watch, *Like a Death Sentence: Abuses against Persons with Mental Disabilities in Ghana*, October 2012, <http://www.hrw.org/reports/2012/10/02/death-sentence-o>.

is used as a last resort in cases where people are unresponsive to medication or in cases where an immediate or swift recovery is sought.

Hoda, a social worker specializing in therapy with persons with psychosocial disabilities, said, “All mental patients and their families know that hospitalization in a psychiatric hospital very likely, if not always, equals shock-therapy. At the first noise or signs of disobedience, they send the patient to be shocked.”²¹² Reza, a psychiatrist, who has worked for more than 20 years in Tehran and another city in central Iran, stated, “If the person has the ability to judge and understand, we tell them what we are going to do. Otherwise, we speak with the family. But in urgent cases where the mental patient is a threat to themselves or to the society, then we practice it without getting the consent form and ask for the consent when the emergency is over,” he said.²¹³

Similarly, Farhad, a psychotherapist who has been practicing in Tehran for nearly 30 years said, “But even if the psychiatrists explain the process and effects, this does not mean that they ask permission from the patients and if the patient refuses, they are not going to practice it. They tell the patient’s family that ECT is the only solution and they must accept it if they want their patient to feel better. So families eventually agree.”²¹⁴

All persons with psychosocial disabilities interviewed said that each time they have been hospitalized, they received between 6 to 12 ECT sessions.²¹⁵ Persons with psychosocial disabilities interviewed said that they learned about ECT by experiencing it several times. “The first time I had electroshock, a heart physician visited me the day before. Then they took me for the shock and it was only then that I learned how it was. I forgot many things after that. They did it every other day. Now, I know how it is and what happens afterward,” said Jafar, a man with psychosocial disabilities.²¹⁶ Another man with a psychosocial disability said, “The night before they take me to receive shocks, they gave me light food and told me that I was going to be shocked the next day. That’s how I knew it was going to happen.”²¹⁷

²¹² Researcher interview with Hoda, social worker, Tehran, January 16, 2017.

²¹³ Researcher interview with Reza, psychiatrist practicing in Tehran and one other city in central Iran, November 28, 2016.

²¹⁴ Researcher interview with Farhad, psychotherapist, March 26, 2017.

²¹⁵ Researcher interviews with Sara, woman with psychosocial disabilities, and Mahdi, Jafar and Asghar, men with psychosocial disabilities, Tehran, January 16, 2017; and Farah, woman with psychosocial disabilities, Tehran, May 17, 2017.

²¹⁶ Researcher interview with Jafar, man with psychosocial disability, January 16, 2017.

²¹⁷ Researcher interview with Mahdi, man with psychosocial disabilities, January 16, 2017.

Lack of Adequate Information about Psychosocial Disabilities

People whom we interviewed said mental health professionals did not always provide adequate information to patients with psychosocial disabilities and their family members about their conditions or treatment options. Soheila, who has worked with persons with psychosocial disabilities for many years in different healthcare positions said,

For example, some psychiatrists do not explain to family members that when a person with schizophrenia says that they see images or hear voices, they really do, and that the family should not try to argue with them. Failure to provide such simple explanations makes the situation very difficult ... for the patient and the family. We had a case in which the family was [only] informed after 40 years of living with someone with schizophrenia about the condition and its nature.²¹⁸

Mahdi, a man with a psychosocial disability, said, “Once, I got a job as a secretary and stopped taking my medication because I didn’t want to look languid and sleepy. But after a couple of months I felt terrible and had to go to the hospital. I didn’t know that I should not stop taking my drugs whenever I wanted. My doctor never told me.”²¹⁹

Persons with psychosocial disabilities interviewed also stated that they were not aware of their right to know about the treatment they are receiving and available alternatives. “I regret to say that persons with mental health conditions are so unaware of their rights and have so deeply absorbed the message that they are a burden to society that they rarely raise any complaint about not being included in their treatment process. So, we hardly feel any problem about the lack of free consent,” said Soheila.²²⁰

Jafar, a 52-year-old man with a psychosocial disability said, “When I go to the [psychiatric] hospital, I let them restrain me to my bed to prove that I want to cooperate and to ensure that I’m not injuring anyone.”²²¹

²¹⁸ Researcher interview with Soheila, advocate and expert on psychosocial disabilities, Tehran, January 16, 2017.

²¹⁹ Researcher interview with Mahdi, man with psychosocial disabilities, January 16, 2017.

²²⁰ Researcher interview with Soheila, advocate and expert on psychosocial disabilities, Tehran, Jan. 16, 2017.

²²¹ Researcher interview with Jafar, man with psychosocial disability, January 16, 2017.

National and International Legal Framework

National Law

The constitution of Iran does not include any explicit reference to persons with disabilities, although it states that “All citizens of the country, both men and women, equally enjoy the protection of the law and enjoy all human, political, economic, social, and cultural rights, in conformity with Islamic criteria.”²²² The constitution also guarantees social pensions to every person. This covers retirement, unemployment, old age, loss of working capability, accidents, and events giving rise to the need for health services and medical care and treatment, through insurance or other means. The government should provide these services and support for every individual in the country.

In May 2004, the adoption of the Comprehensive Law to Protect Disabled Persons was a turning point for the disability movement in Iran. This legislation guarantees fundamental rights and privileges for persons with disabilities in areas such as accessibility, education, rehabilitation, and employment. However, the legislation contains no disability-based discrimination clause, and does not refer to basic rights such as legal capacity or freedom from violence and abuse. The law requires “all ministries, government organizations, and public and revolutionary institutions to design, produce and construct public buildings and facilities, roads and service equipment in a way that disabled persons can use them as other people do.”²²³ Regulations developed after the law require all government bodies to ensure that thirty percent of their buildings and facilities are made accessible annually.²²⁴ Municipalities must also ensure that all new buildings, roads and facilities fulfill accessibility requirements.²²⁵

The 2016 Charter on Citizenry Rights, which largely reiterates rights and protections that exist in Iran’s constitution and domestic laws, includes references to persons with

²²² Constitution of Islamic Republic of Iran 24 (قانون اساسی جمهوری اسلامی ایران) October 1979, (official translation) available at: <http://www.refworld.org/docid/3ae6b56710.html> (accessed 8 July 2017).

²²³ “Comprehensive Law on Protecting Rights of Disabled Persons” (قانون جامع حمایت از حقوق معلولان) 2004.

²²⁴ Executive Regulation on the Implementation of Article Two of the Comprehensive Law on Protecting Disabled Persons, Ratification No. 31960, adopted by Cabinet of Ministers, May 30, 2005 <http://rc.majlis.ir/fa/law/show/123284> and amended by Ratification No. 45457-45515 adopted by Cabinet of Ministers, May 28, 2012 <http://rc.majlis.ir/fa/law/show/811408>, art. 23.

²²⁵ Ibid.

disabilities, including that citizens with disabilities have the right to enjoy treatment and rehabilitative facilities to achieve independent living and participation in different aspects of life. It also recognizes the rights of war veterans and their families to enjoy special measures. The charter also states: “Any inappropriate discrimination against citizens in accessing public services such as health care services, employment and education opportunities is prohibited. The state must refrain from conducting any decision or measure that would lead to social class distancing and inappropriate discrimination and deprivation from citizenry rights.”²²⁶

In March 2017, the National Administrative Council, which includes the president, several government ministers, and other senior officials involved in overseeing Iran’s national budget, adopted the “Ratification on the Implementation of Citizenry Rights Charter in the Administrative System,” which states that “any differentiated support on the basis of disability, age, or any other justifiable basis would not be considered discrimination.”²²⁷ This regulation also requires all government bodies to swiftly facilitate access of persons with disabilities to service provision and obligates all government bodies to “install in their respective buildings signs and figures easily readable and understandable for persons with disabilities.” Public bodies should also adequately train their staff on respect for people with disabilities and must improve their information and communication sources and technologies to allow independent use by persons with disabilities.”²²⁸

The Law on Criminal Procedure provides that NGOs, including those whose mandate is to protect the rights of “patients and mentally or physically disabled,” can file complaints on behalf of them regarding the crimes committed in their jurisdiction and participate in all stages of the hearing to provide evidence.²²⁹

²²⁶ Charter on Citizenry Rights (منشور حقوق شهروندی).

²²⁷ “Ratification on the implementation of Citizenry Rights Charter in Administrative System” (مصوبه در خصوص منشور حقوق شهروندی در نظام اداری) adopted by National Administrative Council, 1395 (2017) ratification No. 1127128, <http://www.rrk.ir/Laws/ShowLaw.aspx?Code=13140> (accessed March 22, 2017).

²²⁸ “Ratification on the implementation of Citizenry Rights Charter in Administrative System.”

²²⁹ Law amending the “Law on Criminal Procedure”, (قانون اصلاح قانون آیین دادرسی کیفری) Islamic Consultative Assembly, 1394 (2015), art. 5 amending Art. 66, <http://rc.majlis.ir/fa/law/show/934354>

International Obligations

Iran is a party to several major international human rights conventions, including the International Covenant on Civil and Political Rights (ICCPR),²³⁰ the International Covenant on Economic, Social, and Cultural Rights (ICESCR),²³¹ and the Convention on the Rights of the Child (CRC).²³² In 2009, Iran acceded to the Convention on the Rights of Persons with Disabilities (CRPD), but it has not signed the treaty's Optional Protocol.²³³ Under these treaties, Iran has obligations to ensure the rights of all persons with disabilities, including children. According to the Civil Code, treaties ratified in accordance with the constitution are considered to be domestic law.²³⁴ However, Iranian judges rarely invoke international treaties in their judgments.²³⁵

Nondiscrimination

The CRPD defines discrimination on the basis of disability as “any distinction, exclusion, or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment, or exercise on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field.” Discrimination includes “denial of reasonable accommodation” for the needs of persons with disabilities and involves any distinction or exclusion, including, for example, a transport operator failing to stop to let a person using a wheelchair onto a bus.²³⁶ The CRPD also specifically requires state parties to take appropriate measures to eliminate discrimination against people with disabilities with in regard to marriage, parenthood, and family. This includes protecting the right of persons with disabilities to found a family.²³⁷

²³⁰ International Covenant on Civil and Political Rights (ICCPR), adopted December 16, 1966, G.A. Res. 2200A (XXI), 21 U.N. GAOR Supp. (No. 16) at 52, U.N. Doc. A/6316 (1966), 999 U.N.T.S. 171, entered into force March 23, 1976, ratified by Iran, June 24, 1975.

²³¹ International Covenant on Economic, Social and Cultural Rights, G.A. res. 2200A (XXI), U.N. Doc. A/6316 (1966), entered into force January 3, 1976, ratified by Iran, June 24, 1975.

²³² Convention on the Rights of the Child, G.A. res. 44/25, annex, 44 U.N. GAOR Supp. (No. 49) at 167, U.N. Doc. A/44/49 (1989), entered into force September 2, 1990, ratified by Iran, July 13, 1994.

²³³ Optional Protocol to the Convention on the Rights of Persons with Disabilities, G.A. Res. 61/106, Annex II, U.N. GAOR, 61st Sess., Supp. No. 49, at 80, U.N. Doc. A/61/49 (2006), entered into force May 3, 2008. The Optional Protocol creates a “Committee on the Rights of Persons with Disabilities ... to receive and consider communications from or on behalf of individuals or groups of individuals subject to its jurisdiction who claim to be victims of a violation by that State Party of the provisions of the Convention.” *Ibid.*, art. 1.

²³⁴ Civil Code of the Islamic Republic of Iran (available in Farsi and English) *Official Gazette*, . 1928) 1307

²³⁵ UN CRPD Committee, Replies of Iran to the List of Issues, para. 1.

²³⁶ CRPD, art. 2, para 3

²³⁷ CRPD, art. 23.

Accessibility

The CRPD requires that states take measures to ensure persons with disabilities have access, on an equal basis with others, to the physical environment, to transportation, to information and communication, including information and communication technologies and systems, and to other facilities and services open or provided to the public both in urban and in rural areas. The physical environment includes buildings, roads, schools, housing, medical facilities, workplaces, and “other indoor and outdoor facilities.”²³⁸

Living Independently and Being Included in the Community

The CRPD requires states to enable persons with disabilities to live independently and to participate and be included fully in their communities, including by guaranteeing their right to choose their places of residence and access services and facilities available to the general population on an equal basis with others.²³⁹ The right to live independently and be included in the community should not depend on the level of support a person with a disability needs.²⁴⁰ In order to realize this right, States should ensure: “...[a] range of in-home, residential, and other community support services, including personal assistance...”²⁴¹

According to the UN Committee on the Rights of People with Disabilities, support services must be considered a right rather than a form of medical, social, or charity care. Persons with disabilities have the right to choose services and service providers according to their individual requirements and personal preferences, and individualized support should be flexible enough to adapt to the requirements of the users. Support services must be available within a safe physical and geographical reach to all persons with disabilities living in urban or rural areas. They have to be affordable, taking into account persons living on low incomes. They also need to be acceptable, which means that they must respect standard levels of quality and be gender, age, and culturally sensitive. While implementing legislation, policies, and programs, states parties must closely consult and actively involve a diverse range of persons with disabilities.²⁴²

²³⁸ CRPD, art. 9, para 1.

²³⁹ CRPD, art. 19.

²⁴⁰ CRPD, preamble (j).

²⁴¹ CRPD, art. 19 (b).

²⁴² Committee on the Rights of Persons with Disabilities, General Comment no. 5 on Article 19: Living independently and Being Included in the Community, CRPD/C/18/1, paras. 28, 35, 56.

The Rights to Health and Rehabilitation

The CRPD makes certain guarantees to people with disabilities as part of their right to the highest attainable standard of health, including the right to a range of healthcare services of adequate quality as close as possible to their communities and the right to means of rehabilitation with the purpose of enabling them to participate fully in their communities. People with disabilities are entitled to health services needed specifically because of their disabilities, including early identification and intervention as appropriate.²⁴³

The CRPD also guarantees people with disabilities access to rehabilitation services based on a “multidisciplinary assessment” of peoples’ needs and geared toward their participation in their communities. The government is obligated to promote not only the availability of assistive devices but also “knowledge and use of assistive devices and technologies, designed for persons with disabilities” and to “promote the development of initial and continuing training for professionals and staff working in habilitation and rehabilitation services.”²⁴⁴

Awareness-Raising

The CRPD requires states parties to adopt immediate and effective measures to “raise awareness throughout society ... to foster respect for the rights and dignity of persons with disabilities; to combat stereotypes, prejudices and harmful practices relating to persons with disabilities ... in all areas of life; and to promote awareness of the capabilities and contributions of persons with disabilities.” Measures to this end include but are not limited to: initiating public awareness campaigns that “promote positive perceptions and greater social awareness towards persons with disabilities” and promoting “recognition of the skills, merits, and abilities of persons with disabilities.”²⁴⁵

²⁴³ CRPD, art. 25b.

²⁴⁴ CRPD, art. 26, para 2.

²⁴⁵ CRPD, art. 8, part a.

Recommendations

While some of these recommendations should be implemented by individual authorities or government agencies, overwhelmingly these recommendations can only be implemented through meaningful inter-agency coordination at the national level, as well as by provincial offices and municipalities. The government of Iran should establish an inter-agency working group to address the short-term and long-term policy actions and other changes necessary to ensure the rights of people with disabilities in Iran.

To the government of Iran:

- Implement a comprehensive review of legislation and policies including a legal definition of disability, to ensure that they are in line with the requirements of the Convention on the Rights of Persons with Disabilities;
- Remove all derogatory language from legislation and policies;
- Adopt a legal provision based on CRPD requirements defining and prohibiting disability-based discrimination including denial of reasonable accommodation;
- Implement public awareness campaigns about people with disabilities, emphasizing their equality, inherent dignity, and human rights.
- Ensure that public officials refrain from any language that is discriminatory or derogatory towards people with disabilities as an essential part of combatting discrimination and stigma;
- Ensure that all persons with disabilities have the opportunity and accessible information to register as a person with a disability with relevant state agencies;
- Ensure that SWO staff, particularly social workers who are in daily contact with people with disabilities, receive adequate and regular training on rights and needs of people with different disabilities, based on the principles underlying the CRPD;
- Establish effective and independent monitoring systems to ensure that SWO staff respect the rights, dignity, and diversity of people with disabilities;
- Establish accessible and confidential complaint mechanisms to ensure that any alleged abusive or negligent treatment by SWO staff is properly investigated and appropriate remedies are provided in the event of a violation. Information about how to use these mechanisms should be distributed in accessible formats,

- including sign language, Braille, audio, or large fonts, and easy-to-read formats to people with disabilities and their support persons upon registration with SWO;
- Ensure that all individuals or companies offering home-care services to people with disabilities are licensed and that home-care providers fulfill background checks and professional training. Ensure that people with disabilities who use home care services have access to effective complaint mechanisms in case of any abusive or negligent treatment;
 - Ensure that any financial support including “nursing allowance” or “disability pension” is allocated based on a transparent, confidential and needs-based assessment.
 - The SWO should prepare an individual support plan for each person with a disability that includes the types of assistive equipment and other services according the individual’s needs; to maximum extent feasible using available resources, support people in obtaining assistive devices and services determined in their individual support plans;
 - Ensure that the procurement of assistive equipment aligns with the actual needs determined by the individual support plans;
 - Ensure that disability prevention programs are funded and implemented separately from policies designed to ensure the rights of persons with disabilities. The State Welfare Organization, as the main implementing agency of the CRPD should not have responsibility for disability prevention. Any disability prevention policies should be designed and implemented with full respect for the autonomy and right to private and family life of persons with disabilities;
 - Withdraw any legislation or policy leading to any obligation for people to undergo genetic testing or consultation, including as a requirement for registration of a marriage;
 - Develop and publish a time-bound detailed plan to ensure, using maximum available resources, that public transportation would become equally accessible for persons with disabilities. At the mid-term/short-term level, dedicate specific services to facilitate access to transportation for all persons with disabilities in order to ensure their social inclusion and exercise of other basic rights;
 - Provide adequate training to public transportation staff, including bus and social taxi drivers, to support persons with disabilities in their use of public transportation while respecting their dignity and autonomy;

- Develop a time-bound detailed, plan, using maximum available resources, to ensure that people with disabilities in rural and remote areas can access transportation on an equal basis with others including by provision of reasonable accommodation;
- Develop and publish uniform standards on accessibility in line with Universal Design Principles, and ensure that these standards are accessible to all persons with disabilities and other stakeholders; coordinate and consult with people with disabilities and disabled persons' organizations on distribution of the standards;
- Conduct regular comprehensive studies on accessibility of all public buildings and publish the findings, including in the media;
- Introduce and enforce meaningful penalties for non-observance of accessibility requirements and denial of reasonable accommodation to persons with disabilities;
- Make accessibility standards mandatory for any procurement of goods, services and technologies which will be used to serve the public;
- Ensure that medical care for persons with disabilities is of the same quality and equally accessible for persons with disabilities on an equal basis with others. Medicines and treatment should only be given on the basis of free and informed consent.
- Ensure that the National Health Transformation Plan extends coverage under the national health insurance scheme coverage to disability-related healthcare and rehabilitation services.
- Ensure that health care professionals are adequately trained on how to inform persons with disabilities about available medical choices, any proposed treatment, including potential side-effects, and support them in making decisions if so desired by the person;
- Ensure that all persons with disabilities, particularly women and girls with disabilities, have access to sexual and reproductive services, information, and choice;
- In consultation with deaf and hard of hearing persons and organizations representing them, develop and publish a detailed time-bound plan to realize, using maximum available resources, access to professional sign language interpretation for deaf and hard of hearing persons who seek to use public services including SWO and other organizations serving people with disabilities, health care facilities, and the justice system.

To Iran's international partners, including the EU and its member states:

- Include human rights, including the rights of people with disabilities, in all bilateral and multilateral discussions with Iran.
- Ensure that funding for civil society and economic and social development include benchmarks and reporting regarding progress in ensuring the rights of people with disabilities.

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