

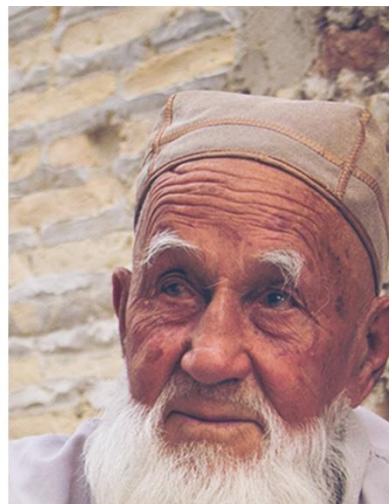


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CLIMATE CHANGE AND DISABILITY INCLUSION IN UZBEKISTAN



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Executive Summary

The impacts of climate change will be unevenly felt within and across countries partly due to social and economic inequalities. Persons with disabilities represent 16 percent of the global population and face widespread forms of social and economic marginalization yet have received little attention in prior studies of climate change and social inequality. The mortality rate of persons with disabilities in natural disasters is “up to four times higher than people without disabilities” (Stein and Stein 2021). How do the fast-moving shocks—flooding, drought, heatwaves—and slower-moving social and economic effects of climate change impact persons with disabilities? How can climate change adaptation efforts be disability inclusive?

This study examines these questions through original fieldwork and qualitative interviews conducted in Uzbekistan. In November 2022, the authors interviewed persons with disabilities in three regions of the country. Following this fieldwork, a team of four expert interviewers—themselves Uzbekistan-based persons with disabilities—interviewed 40 staff members of 15 disability rights organizations across the country. The resulting qualitative data afford key insights into how climate change and disability status interact to generate distinct vulnerabilities. Within the nascent field of climate change and disability studies, this report represents one of the first fieldwork-based accounts of how climate change presents heightened risks to persons with disabilities in a developing country context.

The report outlines several important findings organized along seven themes.

- i. *Social and Political Exclusion.* Persons with disabilities in Uzbekistan are strikingly excluded from local social and political life, placing them at greater risk to climate change events due to their lack of voice in decision making and policy discussions and smaller social networks.
- ii. *Accessing Essential Health Services.* Respondents highlight challenges in accessing essential health services and equipment, such as medical assessments, assistive devices, and health facilities. These challenges are likely to be even greater in the aftermath of climate-induced disasters when there can be an increase in the demand for—and more logistical challenges associated with—accessing social and medical assistance. Barriers to accessing public services and healthcare deepen risks among persons with disabilities.
- iii. *Pensions and the Enumeration of Persons with Disabilities.* Respondents pointed to hurdles in accessing pensions and stated that they were insufficient to cover basic costs. Further, the lack of reliable estimates of the number of persons with various disabilities impedes the government’s ability to craft disability-inclusive social assistance policies.
- iv. *Discrimination in the Labor Market.* Respondents described pervasive forms of discrimination against persons with disabilities in the labor market, further intensifying economic precarity in the face of climate change.
- v. *Disaster Management.* Field observations and interviews highlight several areas of disaster management that require greater inclusivity for persons with disabilities,

including the need for emergency communications systems to be accessible to persons who are deaf, hard of hearing, or blind and emergency services required by persons with disabilities, such as accessible evacuation points and temporary shelters.

- vi. *Awareness of Climate Change.* Fewer than half of the respondents to the 2021 Rural Infrastructure Development Project survey of over 4,000 households had heard of climate change. This study also found generally low levels of awareness of climate change. While low levels of awareness are not unique to persons with disabilities, it adds yet another source of vulnerability to a population that already faces heightened climate change risks. Without an understanding of climate change and the threats it poses to wellbeing, households and communities are less likely to take steps to adapt.
- vii. *Dignity.* The interviews and fieldwork highlight the importance of viewing disability inclusion—within climate change adaptation and more broadly—as a matter of dignity. Several respondents portrayed their experiences of navigating public spaces and institutions as humiliating. Not only were infrastructure and services inaccessible; they described bus drivers, employers, medical staff, and ordinary citizens as treating them with disregard and disrespect. Others asserted that they do not want to be passive recipients of charity or pity; they desire a form of disability inclusion that allows them to carry out everyday activities on an equal basis with persons without disabilities, with full agency and dignity.

The report concludes by discussing the policy implications of the findings for climate change adaptation efforts in Uzbekistan and elsewhere. The Government of Uzbekistan’s (GoU) ratification of the Convention on the Rights of Persons with Disabilities (CRPD) in 2021 was a turning point for the country’s disability inclusion efforts. The recommendations highlighted in Table 1 will help the GoU progressively realize its obligations under the CRPD, including Article 11, which obliges governments to ensure that persons with disabilities are included in all social protections and safety mechanisms.

Table 1: Overview of Policy Recommendations

| |
|---|
| <p>Policy Area 1: Promote the social and political inclusion of persons with disabilities</p> <ul style="list-style-type: none"> • Increase <i>mahalla</i>¹ (local government) leaders’ awareness of the importance of disability inclusion. • Promote mahalla leaders’ outreach to persons with disabilities to bolster the latter’s participation in local governance and community activities. • Increase efforts and funding to ensure that local government meetings are held in accessible spaces and formats. • Introduce a disability-inclusion position within mahalla citizen assemblies, held by a person with disabilities from within the community. • Implement mahalla-level, disability-inclusive climate action plans. |
| <p>Policy Area 2: Increase persons with disabilities’ access to essential health services</p> <ul style="list-style-type: none"> • Ensure persons with disabilities, especially those in rural areas, can more easily obtain medical assessments, assistive devices, and disability pensions. • Expand outreach services to rural villages, facilitate travel to district and regional centers, and streamline eligibility paperwork and processes. • Train mahalla leaders, medical staff, and relevant civil servants on how to help persons with disabilities access these services. |
| <p>Policy Area 3: Increase social protection and enumeration for persons with disabilities</p> <ul style="list-style-type: none"> • Increase the amount of social assistance channeled to persons with disabilities, taking into account their various needs (e.g., adaptive social protection). • Increase the types of social support available to persons with disabilities (i.e., unemployment benefits and social assistance in the aftermath of climate disasters). • Support the inclusion and use of the Washington Group Short Set on Functioning in upcoming population censuses and surveys. • Increase the availability and use of disability-disaggregated administrative data, including by the Ministry of Emergency Situations. |
| <p>Policy Area 4: Improve access to the labor market</p> <ul style="list-style-type: none"> • Raise the awareness of persons with disabilities regarding their labor rights by publishing accessible guidelines, in partnership with organizations of persons with disabilities. • Strengthen the accessibility of the Ministry of Employment’s grievance redress mechanism for receiving and responding to complaints of discrimination in the workplace, including within the informal sector. • Raise employers’ awareness of state incentives (tax benefits, micro-credit, subsidies for adapting workplaces) to improve disability inclusiveness. • Raise awareness of the illegality of discrimination based on disability when recruiting or employing persons with disabilities. • Introduce administrative liability in the national legislation on disability discrimination in employment and develop sanctions for non-compliant employers. |
| <p>Policy Area 5: Establish disability-inclusive disaster management systems</p> |

¹ Mahallas are the lowest tier of territorial organization.

- Establish disability-inclusive guidelines for preparing and responding to disasters, which include emergency hotlines, evacuation points, and temporary accommodation as well as medical equipment and medicine.
- Train the Ministry of Emergency Situations staff on the CRPD’s disability rights-based approach and disability-inclusive preparedness and response.
- Train and support community-level focal points to support persons with disabilities with reaching safety and accessing emergency services.

Policy Area 6: Raise awareness of climate change

- Organize disability-inclusive public awareness campaigns on the sources and consequences of climate change and ways to adapt. These campaigns should underscore the heightened risks of climate change to persons with disabilities.
- Train mahalla specialists on climate change to (a) improve their effectiveness in raising awareness of climate change and adaptation strategies; (b) inform local government planning and investments; and (c) target resources to vulnerable groups, including persons with disabilities.

Policy Area 7: Foster dignity

- Train all frontline service providers and mahalla leaders in the CRPD’s disability rights-based approach.
- Implement Article 11 of the CRPD, which obliges governments to ensure that persons with disabilities are included in all protection and safety mechanisms.
- Use rights-based, disability-inclusive language when addressing persons with disabilities and their needs.

Introduction

In April 2022, devastating mudslides leveled houses, damaged infrastructure, and killed several people in a cluster of villages in Jizzakh Province, Uzbekistan. These disasters occurred against the backdrop of alarming climate change projections for the country, including rising temperatures and intensifying drought, flooding, and wildfires (World Bank 2021a). Shahzod, a resident of Jizzakh, described the damage and explained the challenges he would face if he needed to evacuate his home during a future mudslide, given his physical disability. He relies on a makeshift plastic cane, and can only move about the village’s rugged, unpaved streets with assistance and caution. He explained:

After the recent mudslide, I was hospitalized for about a week...I am anxious about what will happen in the future...I cannot escape without special equipment.²

Nosir, 200 kilometers away in Tashkent city, highlighted a different experience and concern related to climate change. Nosir is deaf. He explained that the deaf community faces significant discrimination in the city’s labor market. One informal job that Nosir and other men who are deaf have taken in Tashkent is parking attendant—guiding cars into parking spots and watching them while their passengers are shopping, eating, or conducting other business in the area. In addition to facing routine forms of disdain and disrespect, Nosir explained the health risks of having to stand outside all day during the summer months, which increasingly feature blistering heatwaves.

During heatwaves we work in the parking lot until lunch time due to unbearable heat. We cannot work after lunch as it gets very hot; our hands burn, and it affects our skin. We can go in if there is shade, but there are few trees in Tashkent now. During such heatwaves, we usually don’t stand outside; no one works at the parking lot. Our income is usually lower during this season, and we must eat only bread products; we survive only thanks to our limited disability pension.³

Are climate change adaptation efforts inclusive of persons with disabilities? Although 16 percent of the world’s population has some form of disability (WHO 2023), an emerging literature demonstrates that climate change adaptation efforts do not adequately address the needs of persons with disabilities (Gaskin et al. 2017; Jodoin et al. 2020). Yet this population faces heightened threats from climate change (World Bank 2018). Reflecting these heightened threats, the mortality rate of persons with disabilities in natural disasters is “up to four times higher than people without disabilities” (Stein and Stein 2021). Disability-inclusive planning is thus a critical aspect of climate change adaptation.

This report presents findings from an original qualitative study of climate change vulnerabilities among persons with disabilities in Uzbekistan. In November 2022, a research team conducted fieldwork in the regions of Jizzakh, Sirdaryo, and Tashkent. This fieldwork included interviews with nearly two dozen persons with disabilities across six villages and

² Interview with Shahzod, November 2022.

³ Interview with Nosir, November 2022.

several urban neighborhoods. A team of four expert interviewers involved in Uzbekistan's disability rights space then interviewed 40 staff members from 15 disability rights organizations across the country. These organizations cover a variety of disabilities, providing key insights into the state of disability inclusion in Uzbekistan and the climate-change-related threats to persons with disabilities.

The report proceeds as follows. It first situates the study within the literatures on disability rights and the social impacts of climate change and motivates the need to examine the intersection of these two research areas. It then describes the qualitative research design and outlines the findings of the fieldwork and interviews. The report concludes by discussing the policy implications of the findings for climate change adaptation in Uzbekistan and elsewhere.

Disability Inclusion and Climate Change Adaptation

The impacts of climate change are, and will continue to be, unevenly felt within and across countries due in part to social and economic inequalities (Harlan et al. 2015; Islam and Winkel 2017). Prior research has demonstrated how women's economic and political marginalization often makes them more vulnerable to the adverse impacts of climate change than men (Denton 2002; Abebe 2014; Perez et al. 2015). Other studies have revealed how structural racism places disproportionate burdens from climate change on disadvantaged ethnic and racial groups. In the United States, social and race-based discrimination has powerfully shaped events such as the water crisis in Flint, Michigan (Meehan et al. 2020). Persons of color in US cities are also exposed to urban "heat islands" more than other social groups (Hsu et al. 2021). Economic inequalities further shape exposure to the risks of climate change. Sedova et al. (2020), for instance, document how poor farmers in India face greater struggles in recovering from weather shocks than their higher-income neighbors. Likewise, low-income migrants in India's cities, who often face dismissive bureaucracies and rely on informal housing and employment, are more vulnerable to climate change than propertied, long-time residents (Chu and Michael 2019).

Over 1 billion people, or about 16 percent of the global population, have some form of disability. This number has increased due to ageing populations and a surge in chronic illnesses such as diabetes, heart diseases, cancer, and mental health disorders (WHO and World Bank 2011). The vast majority (80 percent) of persons with disabilities live in low- and middle-income countries (WHO and World Bank 2011). The 2030 Agenda for Sustainable Development highlights the needs of persons with disabilities (UN 2015b). Persons with disabilities all over the world face widespread discrimination and lack sufficient access to their physical environment.

A nascent literature explores the heightened threats of climate change to persons with disabilities. In a review of studies on the topic, Gaskin et al. (2017) find that persons with disabilities face increased vulnerabilities due to their exclusion from adaptation planning and implementation. Jodoin et al. (2020) outline a "disability rights approach" to climate change adaptation and advocate mainstreaming the recommendations of the Convention on the Rights of Persons with Disabilities (CRPD) within global climate governance. Gartrell et al. (2022) examine how women with disabilities in Cambodia face intersectional vulnerabilities during disasters. This emerging literature concentrates mostly on policy discussions and critical engagements with international law. Empirical studies predominantly examine the interaction of disability and climate change in the United States, especially in the context of Hurricane Katrina in 2005 (Gaskin et al. 2017). This report advances the literature on disability inclusion and climate change through a fieldwork-based study in a Global South context.

Uzbekistan is an appropriate context in which to examine disability inclusion and climate change (World Bank 2021a). Climate change is expected to create significant vulnerabilities in the country. Under the highest projected emissions pathway (RCP8.5), by the 2090s average temperatures in Uzbekistan will increase by 4.8°C, and severe droughts will occur 9 out of every 10 years, with alarming implications for water access, nutrition, and agricultural productivity. Flash flooding, wildfires, and mudslides are expected to increase in frequency and severity, generating local and regional disasters with substantial human and economic costs. The desertification of the Aral Sea is expected to hasten, leading to more frequent dust storms and the spread of ground contaminants from earlier pesticide use in the region. Inclusive adaptation and disaster risk management is therefore of critical importance in Uzbekistan.

Research Design

Data collection took place in two stages. In the first stage, 24 semi-structured, face-to-face interviews were conducted with persons with disabilities in Jizzakh, Sirdaryo, and Tashkent regions in November 2022. These interviews generated insights into the climate-change-related challenges faced by persons with disabilities. Given differences in labor markets, local administrative capacity, the physical built space, and the reach of non-governmental organizations (NGOs), the experiences of persons with disabilities likely vary across the rural–urban divide. Interviews were administered in both urban and rural areas—in the capital (Tashkent) and in villages in Jizzakh and Sirdaryo, respectively. In the second stage, between November and December 2022, phone interviews were conducted with 40 representatives from 15 national and regional disability rights organizations.

The face-to-face interviews asked broad questions that allowed ample room for narration and unanticipated directions. This approach was important given the understudied nature of disability inclusion in climate change adaptation. The respondents experienced several types of disabilities, including visual, hearing, mobility/physical, and developmental/intellectual. The sample included men and women, providing insights into intersectional forms of marginalization. Jizzakh and Sirdaryo were selected because they present varied topographies, including snow-capped mountains and rolling grasslands, affording a degree of variation in local climate change vulnerabilities.

The findings cannot be assumed to apply uniformly across Uzbekistan’s socially and geographically diverse regions. For example, Jizzakh and Sirdaryo, located in the eastern part of the country, experience different climate change vulnerabilities than the arid western province of Karakalpakstan. Yet the findings from the 40 interviews with staff members of disability rights organizations resonate with those conducted in Jizzakh and Sirdaryo, which increases overall confidence in the study’s conclusions.

Following the interviews in Jizzakh, Sirdaryo, and Tashkent, a team of four issue experts involved in the country’s disability rights movement—themselves persons with disabilities—was convened to advise on questionnaire design and sampling and then interview staff members from 15 national and regional disability rights organizations. These organizations provide services to persons with a wide range of disabilities (visual, hearing, physical, developmental/ intellectual, and persons with HIV/AIDS). This variation in geography and substantive focus affords rich insights into the state of disability inclusion and exposure to climate change threats among persons with disabilities. Interviews were audio recorded, transcribed, and translated into English.

Climate Change Threats to Persons with Disabilities

The interviews and fieldwork generated a rich set of qualitative data. The findings are organized into seven broad themes illustrated using quotes from the interviews: social and political exclusion, navigating the state for essential services, pensions and salaries, discrimination in the labor market, disaster management, awareness of climate change, and dignity. These themes include indirect areas of vulnerability—forms of everyday social and political marginalization that intersect with climate change to deepen the risks facing persons with disabilities—as well as those that are more direct, including forms of exclusion within disaster response systems.

Social and Political Exclusion

The persons with disabilities interviewed for this study were strikingly excluded from social life. Most respondents, especially in Jizzakh and Sirdaryo, were housebound due to a combination of social discrimination, a lack of assistive devices, and inaccessible public infrastructure. As such, they had limited social engagement with people outside of their household. For example, one man in a remote village in Sirdaryo had been paralyzed in a car accident. He expressed an eagerness to visit other areas of the village to socialize, but the unpaved roads had already damaged several wheelchairs. Movement in public was just too cumbersome and risky. While he aspired to work from home as a cell phone repair person, it was difficult to start the business without being able to visit potential customers. Another respondent in a mountainous village of Jizzakh injured her legs and spine in a fall. For months she had been unable to leave a mattress on the floor, save a few visits to a doctor, who has been unable to provide treatment. Worries about her physical health were compounded by mounting distress about social isolation.

The interviews with staff members, most of whom experience some form of disability, echoed feelings of isolation:

Interviewer: Do people with disabilities participate in the life of the neighborhood?

Respondent: No, no, no, no.

Interviewer: There are those who are involved in neighborhood life, right?

Respondent: There are some but not many.⁴

As noted above, social exclusion is partially the result of inaccessible public transportation, public buildings, and spaces where people gather to socialize and seek entertainment. This theme frequently emerged across the interviews:

There are very few buses with ramps; I wouldn't be wrong if I said 5 percent or 1 percent.⁵

I can say that this is a sad and painful point in Namangan region...almost all the small Isuzu buses running on the road routes of Namangan region do not have any comfort or opportunity for disabled people to move freely...⁶

⁴ Interview with Respondent 1.

⁵ Interview with Respondent 1.

In many places...there are ramps in public buildings, but they do not meet the standard. After that, you will go inside, inside the barrier will open for you, but it is difficult to get to the 3rd floor.⁷

Bus stops are not only inaccessible for persons with disabilities, but also inaccessible to ordinary people. Sometimes you must go down from the sidewalk and walk along the roadway. This is a complete disgrace.⁸

The unsuitability of transport, especially the metro, the poor attitude of drivers toward passengers with disabilities, all of this is a barrier...because the transport system is not adapted [for persons with disabilities], they are deprived of the opportunity to study and work.⁹

The social exclusion of persons with disabilities generates increased risks in the context of climate change. Studies point to the key role of social capital in pre-disaster preparedness and post-disaster recovery (Woolcock 2010). Drawing on case studies of Hurricane Katrina, the 2004 Indian Ocean tsunami, and the 1995 Kobe earthquake in Japan, Aldrich (2012) shows how communities with dense social networks are better able to rebuild following disasters. Dense social ties help people handle shocks, especially among households facing economic precarity (Krishna 2010), because they facilitate mutual aid and consumption smoothing (Rosenzweig and Stark 1989; Fafchamps and Lund 2003; Ambrus et al. 2014). Social ties outside the household further underpin the ability of individuals and groups to mobilize to secure public goods and services (Krishna 2002; Kruks-Wisner 2018; Auerbach 2020).

The role of social capital in development has gender dimensions as well. Multiple studies highlight the pivotal role of social ties among women in increasing intrahousehold bargaining power and political participation (Sanyal 2009; Prillaman 2023; Anukriti et al. 2022). Research in post-disaster settings also indicates that women may access services in different ways than men (for instance, by relying more heavily on formal state actors and institutions), which may require collective action (Kruks-Wisner 2011). The seclusion of many of the female respondents undermines their ability to draw on social ties to boost decision-making agency at home or to participate in the public sphere, generating intersectional sources of vulnerability in the face of climate change.

Constrained social networks also slow or stop the spread of information. The provision of new information can encourage behavioral change and the adoption of new technologies (Conley and Udry 2010; Allcott 2011; Zilberman et al. 2012; Banerjee et al. 2013). The social isolation described by many respondents can inhibit their access to information about climate change and adaptive measures, deepening their vulnerability.

⁶ Interview with Respondent 2.

⁷ Interview with Respondent 3.

⁸ Interview with Respondent 4.

⁹ Interview with Respondent 6.

Our blind people, who mostly stay at home, are separated from society, and do not participate in the events organized by society; [they] usually remain unaware of such information [about climate change].¹⁰

Persons with disabilities are also excluded from public participation. Most respondents in Jizzakh and Sirdaryo did not attend local government meetings. One respondent's relative told us, "He [a man with a physical disability] can't participate in the *mahalla*¹¹ meetings because he can't wait, can't sit." This lack of participation partly stems from the built space: the rural mahalla buildings the team visited had steep staircases with no railings or ramps and were thus inaccessible to persons with physical disabilities. Many study respondents would require substantial assistance to enter their local mahalla center. And for persons with disabilities who can travel to and enter the building, there might not be necessary services—such as sign language interpreters—to allow them to engage in discussions with officials and residents. The Rural Infrastructural Development Survey (RIDP)—administered in 2021 to 4,000 households in 100 villages across five regions of Uzbekistan—revealed that persons with disabilities have relatively low levels of participation and perceptions of influence in local decision making.

Respondents commented on the marginalization of persons with disabilities in local governance, and several suggested the need for institutionalized measures like hiring civil servants and frontline service providers with disabilities to support their full inclusion:

It is difficult to get information from the *mahalla*; it is basically closed, and even if I offer my services as a disabled person, they say, 'We'll think about it,' and that's it. They try not to let me into the *mahalla*'s affairs...I think in our *mahalla* there should be at least one employee with disabilities, because when this person has experience, he knows how to solve the problems of people with disabilities.¹²

People with disabilities cannot be included in neighborhoods. State programs have been issued for the inclusion [of persons with disabilities], and the convention on disabled people has been adopted. They [government officials] don't even have 1 percent understanding in this field. For that, they need to be trained and retrained...¹³

No one is calling them; the deaf-mutes [*sic*] are being ignored for now. They do not [participate] in the mahallas.¹⁴

The staff members interviewed for the study observed that persons with disabilities and disability rights organizations remain sidelined from policy discussions at multiple levels of government. These conversations highlighted a demand for greater representation in government institutions and policy discussions:

¹⁰ Interview with Respondent 7.

¹¹ *Mahallas* are the lowest tier of territorial organization. See Urinboyev and Eraliev (2022) on formal *mahalla* institutions as well as the informal histories of these community organizations.

¹² Interview with Respondent 8.

¹³ Interview with Respondent 9.

¹⁴ Interview with Respondent 10.

The Councils of People’s Deputies are held in regions and districts, but our organizations are not invited to the meetings. Persons with disabilities are also not invited to the sessions...In 2022, a program was formed to further support persons with disabilities...no organizations that work with disabled people were invited.¹⁵

I don’t know a person with a disability who has been a member of the local authority; not only deputies, but of the *mahalla* authority. So, I don’t think they [persons with disabilities] have any involvement [in local governance].¹⁶

Let...people with disabilities into their ranks [the government], so that they also can participate...so that they could show how vulnerable they are, from the point of view of a person with a disability...¹⁷

Public participation is an important aspect of climate change adaptation (Ayers 2011; Arnold et al. 2014; Sarzynski 2015). A large literature demonstrates the pivotal role that citizen participation can have in improving local development projects (see Mansuri and Rao 2013). In the context of climate change, such participation allows officials to identify local vulnerabilities and harness community knowledge, preferences, and participation to adapt to climate change and mitigate potential disasters. In some instances, communities may already have informal organizations to manage common pool resources, such as water use associations, and to reduce intracommunity conflicts (Ostrom 1990; Adger et al. 2005). These informal institutions and local civil society, in partnership with the state, can help “co-produce” important public goods (Ostrom 1996). The disability studies field also highlights the need to involve persons with disabilities in governance activities, captured in the motto “nothing about us without us” (Charlton 1998). The marginalized status of persons with disabilities precludes their active participation, muting their voices in decision making related to climate change adaptation.

Accessing Essential Health Services

Respondents discussed the challenges of navigating state institutions to secure medical assessments, assistive devices, and disability pensions. Such barriers are especially high in rural areas, where villages can be far from district centers and public transportation is limited and often inaccessible for persons with disabilities.¹⁸ A woman with a spinal cord injury told us, “We went to the local government several times, but people did not do one-third of what our president declared. The mayor did not help at all, and neither did the regional prosecutor.” Many interviewees expressed such feelings of frustration and despondency:

¹⁵ Interview with Respondent 11.

¹⁶ Interview Respondent 12.

¹⁷ Interview with Respondent 13.

¹⁸ Interview with Respondent 14.

Imagine a blind person going to a clinic...I did not see anyone at the clinic trained to deal with the blind...there is no Braille about admission days. Or there is no equipment to provide voice information. Such things don't exist...¹⁹

I recently had health problems; they took me to the hospital in an ambulance...I'm lying on the hospital bed, and they brought me to the surgery room and the doctor was not there...There were 6 nurses gathered and playing songs on their phones, but there was no word from the doctor...After being in there, they asked, 'Have you paid the fee?' 'No, I'm a disabled person of the first group, we don't pay, I have a group card that we haven't paid yet.' He kicked me out, saying that I will not look after you if you don't have money. They took me from one end of the corridor to the other end, and finally they threw me out into the corridor.²⁰

Our women, deaf women, are ashamed to go to the hospital because they cannot explain their thoughts. Even if she goes with a translator...She [the translator] doesn't tell everything until the end. She doesn't say the whole thing...Translators are a complicated and urgent issue for us. We have few translators in Uzbekistan.²¹

Hospitals do not create a barrier-free environment for people with disabilities. First, they do not create comfort. A simple example is the rehabilitation center in Nukus district, where it is difficult for a person in a wheelchair to enter the toilet.²²

To get to an ophthalmologist, a person with a disability must first find a companion...If there is no companion, then the person with a disability will not be able to go to the doctor in time. This is the first thing. The second is free orders...if you want to get an order, not just for treatment, but for an exam, then you must go to the clinic first, get a referral. Get some certificates, then go to the district health department, submit all the documents, and only then can you be given an order for an exam, for a free exam at any hospital...It would be better for a person with a disability to go directly to the institution, register as a person with a disability, and receive free services.²³

To call a doctor to your house, you must swear on the phone. Even your local doctor won't come if he knows you can't take care of yourself...Here, we suffer at all levels: you won't get to transport; you won't get into the transport, if you get to the clinic, then you won't be able to climb to the second floor in the clinic.²⁴

¹⁹ Interview with Respondent 15.

²⁰ Interview with Respondent 1.

²¹ Interview with Respondent 16.

²² Interview with Respondent 3.

²³ Interview with Respondent 12.

²⁴ Interview with Respondent 17.

The villages in Jizzakh and Sirdaryo had no local NGOs working to support persons with disabilities; most such organizations seem to operate primarily in urban areas. Thus, it is challenging for persons with disabilities to access state as well as NGO services. A staff member of one disability rights organization pointed to the difficulties of accessing many rural areas due to their remote locations and often underdeveloped public roads.

We used to go to the remote areas; the roads are rough...it was a problem for a person with a disability to go to the store or other necessary places for his needs.²⁵

Policymakers stress the importance of having robust social safety nets in place to address disasters and climate change vulnerabilities (Davies et al. 2008; United Nations 2015a; World Bank 2022). As illustrated in the quotes above, the persons with disabilities interviewed for the study described daunting hurdles to accessing state and non-state services. These challenges are likely to be even greater in the aftermath of climate-induced disasters, when there is likely to be an increase in the demand for—and more logistical challenges associated with accessing—social and medical assistance and employment opportunities. These challenges increase the climate change risks to persons with disabilities—individuals who already frequently face economic precarity and health risks due to social discrimination and inaccessible public infrastructure. Several staff members reflected on the economic vulnerabilities facing persons with disabilities:

These are families that have little income...People with children with disabilities spend most of their salaries, opportunities, and finances on treatment, and to recover from some kind of natural disaster, they are more vulnerable...²⁶

Our people live below the poverty line, on one pension. I knew one family with eight children. Their father died and the mother cannot go to work because her child has tuberculosis. He lies down and she takes care of him. They can't even get a pension for it. We helped them and they began to receive a pension. The whole family—nine people—lived on this pension.²⁷

Social Protection and the Enumeration of Persons with Disabilities

Several interviewees mentioned challenges linked to Uzbekistan's pension system. There are disability-specific benefits for children and adults with disabilities, but the amount and coverage of such benefits is insufficient. As of April 1, 2022, the minimum amount of disability benefits paid to citizens with disabilities, as well as disability pensions for those who do not have work experience, was 622,000 soums (about US\$55). According to UNICEF Uzbekistan (2020), this scheme covers only 52 percent of children with severe disabilities. Based on administrative data, out of 484,000 people, 66 percent receive the Disability Pension, 30 percent receive the Disability Allowance (for those recognized as having a disability since childhood), and only 4

²⁵ Interview with Respondent 11.

²⁶ Interview with Respondent 13.

²⁷ Interview with Respondent 17.

percent have access to the Disability Social Pension, which is provided to those who acquired a disability in adulthood but do not contribute to the pension fund (UNICEF Uzbekistan 2020: 38). Mothers aged 60 and above with no work experience and whose children have disabilities since childhood are eligible for an old-age benefit. During the COVID-19 pandemic, the Government of Uzbekistan (GoU) introduced ‘iron notebooks’ (*temir daftar*) to identify socially vulnerable groups in need of social support;²⁸ notebooks have since been created for women and youth.

Respondents pointed to hurdles in accessing pensions as well as their inability to meet basic needs:

Today, our government has a minimum pension amount. But we are not satisfied with it.²⁹

Disabled people receive a pension of 700,000 soums...700,000 soums is nothing...They are spending that money on electricity and gas. They can't pay for their electricity and gas. The government turns it off for nonpayment...No one listens to us when we go to the power plant.³⁰

Unfortunately, blind people are left out of these youth and women's registers. It is not transparent.³¹

When we received the list of the youth register, many of our young people [with disabilities] were not included. Young people are not able to fully use the notebooks. Not all women are included in the women's register. It turned out that many women who studied at our center were not included in the women's register...³²

The authorities dismiss disabled people in many ways. ‘Deaf mutes’ are being left out...It is very difficult for me to get a subsidy for them. Sometimes they [officials] say that they reached the limit, sometimes they say that the person is registered in an iron notebook, sometimes they return from the register from another place.³³

I can tell you how disabled people are assessed in mahallas when they need some kind of material assistance or a pension. So, they refuse financial assistance to those disabled people who have a TV and a refrigerator at home. Can you imagine? How can having a TV and a refrigerator cause a denial of financial assistance?³⁴

²⁸ The “iron notebooks” contain lists of low-income households that are eligible for social welfare programs.

²⁹ Interview with Respondent 18.

³⁰ Interview with Respondent 10.

³¹ Interview with Respondent 19.

³² Interview with Respondent 20.

³³ Interview with Respondent 10.

³⁴ Interview with Respondent 6.

Respondents also frequently mentioned that they must choose between pension systems, for example between a retirement pension and a disability pension. Where other pensions are more generous, respondents did not pursue a disability pension—which may contribute to undercounting the number of persons with disabilities. While the GoU estimates that 2.1 percent of the population has some form of disability (World Bank 2021b), a World Bank study found that the percentage is substantially higher, at around 13.5 percent (UNICEF Uzbekistan 2019, p. 11). Without reliable estimates of the number of persons with various disabilities, governments have less information with which to craft disability-inclusive policies.

The most important thing is to keep an accurate record of people with disabilities, including whether they are single or not and how many people with disabilities are in the family, so that during an emergency they can be the first to [get] help.³⁵

There are very big problems with the evacuation of disabled people, people with limited abilities. In our country, the state and many agencies and ministries, they are not informed in which flat, in which house, or in which area a person with disabilities lives...When these disasters come, they will not come to help and the person with disabilities is left without protection and must rely on themselves.³⁶

Discrimination in the Labor Market

Persons with disabilities experience widespread discrimination in the job market. One organization staff member, who is blind, noted that persons with disabilities face barriers to finding jobs because they are “considered the weak points in society.”³⁷ A staff member in a related organization concurred: “Today, more and more of our youth with limited opportunities are studying, graduating from university, and [some] find their way, to a certain extent, after graduation. But most stay home.”³⁸ Another respondent reported, “business managers are afraid to hire them [persons with disabilities].”³⁹ Feelings of being treated dismissively by employers resonate across many of the other interviews:

Workplaces are not adapted for people with disabilities; people with disabilities often don’t work because employers don’t trust them.⁴⁰

Here, you go to work and have a 3-month trial period. Despite this, they don’t even pay attention to your resume, but if you are physically disabled? That’s it! You will be unable to work for them. You can’t do the work for them, that is all, they don’t even check whether you can do it even if you know your job.⁴¹

³⁵ Interview with Respondent 12.

³⁶ Interview with Respondent 8.

³⁷ Interview with Respondent 15.

³⁸ Interview with Respondent 18.

³⁹ Interview with Respondent 20.

⁴⁰ Interview with Respondent 3.

⁴¹ Interview with Respondent 21.

Unfortunately, even if people with disabilities have higher education or secondary specialized education, organizations rarely hire people like them.⁴²

Wherever they go they are denied, be it government agencies or other enterprises. We advise them to go through employment centers or [we go] with them to get a job. I have done this several times, to help people with disabilities find jobs.⁴³

Since independence in 1991, the GoU has established an employment quota for persons with disabilities. Article 43 of the 2021 law, On the Rights of Persons with Disabilities in the Republic of Uzbekistan, requires state institutions and private enterprises with at least 20 employees to set aside at least 3 percent of jobs for disabled people. However, persons with disabilities are about four times less likely to find a job than persons without disabilities, and only 7.1 percent of the former who are of working age were employed in 2019 (UN Uzbekistan 2019). Women with disabilities are even more marginalized in the labor market than men with disabilities: 4.4 percent of women versus 8.9 percent of men were employed in 2019 (UN Uzbekistan 2019).

According to the Disability Act, 3 percent of jobs must be reserved for persons with disabilities, with all accommodations made for them, or that 3 percent must be permanently vacant. But even in this regard, the implementation of the decision is not visible; it cannot be said to be satisfactory.⁴⁴

One common pathway of responding to the fast-moving shocks and slow-moving social and economic consequences of climate change is migration. Moving away from areas with mounting climate change risks, and shifting away from sectors of the economy threatened by climate change, is more difficult for persons with disabilities, partly due to discrimination in the labor market. One respondent commented on this in the context of Karakalpakstan, where the collapse of the Aral Sea has created ecological crises:

A healthy person can become a migrant and work elsewhere. Or he can move from one place and come from the outskirts of Karakalpakstan to work as a craftsman in Tashkent...A blind person cannot do this.⁴⁵

The increased hurdles to migration among persons with disabilities produce yet another climate change vulnerability. State and civil society efforts to mainstream disability inclusion in the labor market are therefore crucial in the context of climate change.

Disaster Management

Respondents expressed concerns about disaster management. Given the poor state of roads and the frequent inaccessibility of public transportation, respondents with physical, hearing, and

⁴² Interview with Respondent 22.

⁴³ Interview with Respondent 23.

⁴⁴ Interview with Respondent 7.

⁴⁵ Interview with Respondent 15.

visual disabilities discussed the challenges they would face if they needed to quickly evacuate their homes due to flooding or mudslides. Other respondents pointed to deficiencies in multi-story buildings—a lack of elevators and accessible exits—that would endanger persons with disabilities in the event of an emergency.

The government in Uzbekistan is not ready for disasters...The lack of equipment is a clear problem.⁴⁶

How does the Ministry of Emergency Situations work in general? They came to our school and showed us. How to be rescued during a fire? Doors must be in every hallway, there must be several doors on different sides. These measures are not designed to save people with disabilities...[They are] designed for the masses.⁴⁷

I talked with *mahalla* committees and with representatives of the Ministry of Emergency Situations...I said, ‘do you have some kind of action plan on how to provide assistance to people with disabilities in cases of disasters of some kind?’ ‘No, we should all gather here in the *mahalla*.’ I said: ‘I can’t come in a wheelchair. And if the people who are lying cannot come to you, does this mean that you let them lie and wait for the water to rise?’⁴⁸

Our building is not adapted for persons with disabilities. We are on the 3rd floor of our building...we have a fire system, but there is no elevator to bring persons with disabilities out of the building...⁴⁹

When I talked with the people affected by the tragedy in Sardoba...the disabled people living there struggled to get out, and there were family members who could not get out. Dozens of people with disabilities died; this situation was not reported to the mass media.⁵⁰

People with a [physical] disability who move in wheelchairs cannot go out on their own when the elevator is not working. Who will carry them at a time like this? What if they stay at home? What will people with visual impairments do? Even if they can somehow get around on their own, panic will make them not know what to do. In such situations, people with disabilities are the most vulnerable.⁵¹

⁴⁶ Interview with Respondent 19.

⁴⁷ Interview with Respondent 24.

⁴⁸ Interview with Respondent 17.

⁴⁹ Interview with Respondent 25.

⁵⁰ Interview with Respondent 22.

⁵¹ Interview with Respondent 23.

Respondents also pointed to the need for disability-inclusive goods and services during disasters and evacuations, such as accessible toilets and temporary shelters.⁵² Other respondents highlighted the need for mental health professionals to help persons with disabilities address the anxieties and stresses associated with disasters. Respondents with visual and hearing disabilities felt they could not rely on public emergency alerts. Instead, they would have to depend on trusted people to share this news—which might not be instantaneously available during an emergency. One respondent with a hearing disability explained, “There is little sign language interpretation on TV...No one warns us before an emergency happens; they cannot provide us information quickly.”⁵³ Another respondent discussed the need to train emergency personnel in basic sign language:

Because they can’t hear, they can get stuck. Rescuers do not know the gesture. Right? The problem arises who speaks and who does not speak here. Who is listening and who is not?⁵⁴

While some of these concerns can be addressed with disability-inclusive investments in physical infrastructure, others require reforms to communication systems or more systematic, disability-inclusive planning for emergency service provision. The literature on disability and climate change underscores the importance of taking these steps to mitigate the vulnerabilities of persons with disabilities to climate change (Gutnik and Roth 2018; Jodoin et al. 2022).

Reforming disaster management systems must also involve carefully considering the significant heterogeneity of disabilities within the population. The interviews highlighted that climate change affects persons with disabilities in ways that partly depend on the *type* of disability. For example, respondents with physical disabilities often expressed different challenges than those with hearing, visual, or intellectual disabilities. One respondent reflected on the paucity of understanding of the range of disabilities in the population, and the problems that creates for disaster management:

Well, in principle, yes, our government is ready, but they probably misunderstand such people [persons with disabilities]...They don’t understand what types of disabilities you might face; for the government, most [disabilities] are physical; they are wheelchair users, visually impaired, blind, and others...[Everyone] thinks that a disability is physical...but this is such a large group of people...Most in government do not see this, because there are no disabled people in government.⁵⁵

Awareness of Climate Change

Fewer than half of the respondents to the 2021 RIDP survey of over 4,000 households had heard of climate change. The current study also found generally low levels of awareness of climate change, especially among respondents in rural Jizzakh and Sirdaryo. The interviewees mentioned

⁵² Interview with Respondent 26.

⁵³ Other respondents noted the dearth of sign language interpreters in Uzbekistan, and the barriers that generates for the community of persons who are deaf (interview with Respondent 27).

⁵⁴ Interview with Respondent 16.

⁵⁵ Interview with Respondent 13.

dwindling snows in the winter, sweltering heat waves in the summer, and declining crop yields. In Bakhmal, a district in Jizzakh, these conversations frequently revolved around the production of apples—an important crop for small-scale farmers in the area. This mountainous corner of Uzbekistan has faced rising temperatures over the past decade, as well as irregular rainfalls and flooding. In one village, a farmer showed us a handful of small, half-rotten apples. He and his neighbors reported that their yield was much lower than in the past, and that many of the apples that did grow were smaller than usual. Yet they were unaware that these changes were part of systematic shifts in the climate due to greenhouse gas emissions.

While low levels of awareness are not unique to persons with disabilities, it adds yet another source of vulnerability to a population that already faces heightened climate change risks. Without an understanding of climate change and the threats it poses to wellbeing, households and communities are less likely to take steps to adapt. Building awareness of climate change and the need to adapt to it, especially among vulnerable populations who will be disproportionately impacted, is a key area for future interventions.

Dignity

A final theme that emerged from the interviews and fieldwork is the importance of viewing disability inclusion—within climate change adaptation and more broadly—as a matter of dignity. Several respondents portrayed their experiences of navigating public spaces and institutions as humiliating. Not only were infrastructure and services inaccessible; they described bus drivers, employers, medical staff, and ordinary citizens as treating them with disregard and disrespect. Others asserted that they do not want to be passive recipients of charity or pity; they desire a form of disability inclusion that allows them to carry out everyday activities on an equal basis with persons without disabilities, with full agency and dignity.

Well, there is no access to public buildings. I suffer a lot from this, I suffer because I move in a wheelchair...When I saw an available pharmacy in our area, I was so delighted and our clinic also built such a cool ramp, you can go wherever you want. [But] you move in, there is only registration on the first floor, all the doctors are on the second floor, and there is no elevator...I think that they don't want to see me here, they don't expect me here, this is so humiliating.⁵⁶

Social service is not about giving them something. The creation of opportunities can be considered a real social service...⁵⁷

One organization staff member reflected on changes in her own perceptions of the purpose of service in the disability rights space—moving away from notions of charity and symbolic gestures toward empowerment and equal opportunities:

On the 3rd of December we handed out pilaf, gave presents, and on the 4th of December we ticked off and forgot about it. Now the attitude is changing, and we

⁵⁶ Interview with Respondent 17.

⁵⁷ Interview with Respondent 28.

are talking about it, that we should not go in terms of pity for [persons with disabilities]. Let us help them so that they can be independent.⁵⁸

A budding literature examines the importance of respecting human dignity in international development (Wein et al. 2022). The concept of dignity also echoes across research in disability studies (Garland-Thomson 2005; World Bank 2018). Mainstreaming disability inclusion in climate change adaptation policies must therefore be approached in ways that respect the intrinsic dignity of persons with disabilities.⁵⁹

Policy Recommendations

This report’s findings suggest a set of policy recommendations to reduce climate change’s risks to persons with disabilities. The following discussion of policy recommendations is organized around the seven themes that structured the discussion of the findings above.

Promote Social and Political Inclusion

Ameliorating climate change’s risks to persons with disabilities involves removing barriers to their inclusion in *everyday* social and political life. These barriers—for example, social discrimination, inaccessible mahalla buildings, and a lack of sign language interpreters during mahalla assembly meetings—may at first appear unrelated to climate change. However, they underpin many of its heightened threats to persons with disabilities by limiting social networks—a key factor in climate change adaptation and resilience—and marginalizing persons with disabilities in local decision making related to community development and governance, which directly and indirectly shape climate change risks.

The participation of persons with disabilities in mahalla governance should be encouraged, facilitated, and institutionalized. Persons with disabilities are best positioned to voice their own concerns, narrate their experiences, and express their policy preferences. Yet this study’s findings reveal that persons with disabilities participate very little in mahalla governance. The civic participation of persons with disabilities can be fostered in several ways. Training programs targeted to mahalla leaders and local officials can deepen awareness of the importance of disability inclusion and the specific risks that climate change poses for persons with disabilities. These training programs can encourage local officials to conduct outreach efforts to persons with disabilities to boost the latter’s involvement in local governance and other community activities. The GoU should further consider introducing a disability inclusion position within mahalla citizen assemblies, held by a person with disabilities from the community. This role would serve as a point of contact for persons with disabilities in the community to mobilize them during mahalla meetings and help spread information about relevant government programs.

Other barriers to civic participation stem from inaccessible buildings and an absence of disability-inclusive communication services. With support from higher levels of government,

⁵⁸ Interview with Respondent 24.

⁵⁹ See Soss (2000) on how citizen–state interactions and the personal treatment of welfare beneficiaries shape political participation.

efforts should be made to improve the physical accessibility of mahalla buildings—equipping them with proper ramps, railings, seating, tactile flooring guides, and other features that permit inclusive participation.⁶⁰ Efforts should also be made to provide services that allow persons with hearing or visual disabilities to fully engage in public deliberation and decision making.

More broadly, while communities experience the brunt of climate impacts, they are often excluded from policy discussions that impact their climate resilience. To address this gap, the GoU can empower mahallas to advance local climate action, for example by identifying socially inclusive plans tailored to local needs and priorities, including those of persons with disabilities, and resourcing those plans with devolved financing (World Bank 2023b). A recent example of local and inclusive climate action planning is Kenya’s Financing Locally Led Climate Action (FLLoCA) Program, which includes guidelines that highlight the need to facilitate the participation of persons with disabilities in risk assessments and planning (World Bank 2023c). Such programs reinforce systems and capacities for climate action by engaging with different levels of government; empowering communities to share local knowledge, assess their climate risks, and prioritize actions for resilience under a range of climate scenarios; and increasing the transparency and accountability to local stakeholders of processes for program financing, design, and delivery. This recommendation to give mahallas a role in local climate action is consistent with recent reforms that have enabled mahallas to raise revenues and execute local development projects.

Ease Access to Essential Health Services

Persons with disabilities in Uzbekistan encounter a variety of hurdles when seeking public health services—testing, treatment, and obtaining medication and assistive devices. Such hurdles exacerbate health vulnerabilities and economic precarity and thus intensify the threats from climate change. The GoU should therefore make sustained efforts to improve access to public health services for persons with disabilities.

Public health buildings in Uzbekistan are often physically inaccessible to persons with disabilities. These buildings also often lack the necessary services to communicate with medical personnel, such as braille and sign language interpreters. The GoU should support—with resources and training—improvements in the accessibility of public health buildings as well as the provision of communication services for persons with disabilities. Moreover, interview respondents described instances of social discrimination by officials and medical staff as an additional barrier to public health services. Training of medical staff and relevant civil servants should emphasize the importance of treating persons with disabilities with full dignity and respect.

Accessing public healthcare is even more daunting in rural areas, where traveling to district or regional centers involves traversing long distances and incurring considerable travel costs. Public health institutions should expand outreach services to persons with disabilities in remote communities, facilitate travel to district and regional centers, and reduce the need for eligibility travel and paperwork as much as possible.

⁶⁰ Relatedly, there is a need to improve the capacity of licensed design institutes to provide disability-inclusive designs and to increase government supervision to ensure that contractors implement them.

Strengthen the Social Protection and Enumeration of Persons with Disabilities

Access to robust social protections helps individuals and households withstand and respond to sudden climate disasters as well as the slower-moving impacts of climate change on labor markets and agricultural production. It also helps prevent individuals and households from resorting to negative coping mechanisms. Interview respondents described current disability pensions as inadequate to support themselves and their families. The World Bank (2023a) elaborates on the limitations of Uzbekistan's social protection system for persons with disabilities. Article 39 of Uzbekistan's constitution requires that pensions, benefits, and other types of social assistance must not be lower than the officially established minimum subsistence levels (World Bank 2023a). The GoU uses a minimum consumer spending basket to establish the minimum subsistence level, which is significantly less than the minimum wage and average salary.⁶¹ In addition, the consumer spending basket does not account for extra disability-related costs, such as rehabilitation equipment, wheelchairs, and specialized medical services such as speech therapy. Further, disability benefits are not tailored to different types and levels of disability. Persons receiving disability benefits are also excluded from unemployment benefits. Thus, the GoU should take steps to increase the amount as well as the types of social assistance channeled to persons with disabilities, including emergency assistance following disasters.

Building adequate social safety nets and planning for climate change disasters requires having reliable information on the number of persons with disabilities, as well as the type and distribution of those disabilities. There is a large gap between government estimates of the percentage of persons with disabilities and the actual percentage due to how individuals are brought into the pension system, as well as other social, political, and state capacity barriers to enumeration (World Bank 2023a). The GoU should accurately count the number of persons with disabilities in ways that ensure privacy and dignity. This can be partly achieved by supporting the inclusion and use of the Washington Group Short Set on Functioning in upcoming population censuses and surveys. The resulting data should be made publicly available and be used to inform policies related to climate change adaptation and emergency disaster response.

Improve Access to the Labor Market

Uzbekistan's labor market systematically discriminates against persons with disabilities, which deepens their economic precarity and intensifies their vulnerability to climate change. Respondents described feeling alienated and disrespected in the labor market. The GoU has enacted an employment quota for persons with disabilities, but more must be done to ensure that it is enforced and monitored. In addition to GoU incentives to the private sector in the form of subsidies for employment and workplace adaptation for persons with disabilities, specific anti-discrimination legislation would give persons with disabilities more opportunities to participate in the labor market.⁶² In accordance with Article 27 of the CRPD, the GoU should enforce anti-

⁶¹ In January 2022, the consumer spending basket was UZS 498,000 per month compared to a minimum wage of UZS 920,000 per month, while the average salary was UZS 2.78 million per month.

⁶² This legislation could include introducing administrative liability in the national legislation on disability for employers who discriminate in employment and introducing sanctions for non-compliant employers in the Code on Administrative Liabilities (World Bank 2023a).

discrimination in the labor market and encourage businesses to adopt inclusive employment practices.

Promoting the inclusion of persons with disabilities in the labor market may also entail raising the awareness of persons with disabilities of their labor rights and strengthening the Ministry of Employment and Poverty Reduction's (MEPR) national feedback mechanism for labor-related complaints. Like its labor rights campaigns during the cotton harvest, the GoU could implement accessible information campaigns targeted at persons with disabilities, disability rights organizations, and employers to raise awareness of persons with disabilities' labor rights. Moreover, the MEPR could strengthen its national feedback mechanism to receive and respond to complaints related to discrimination based on disability status, including those working in the informal sector.

Improve Disability-Inclusive Disaster Management

Given Uzbekistan's vulnerability to climate-induced disasters, the GoU should establish disability-inclusive guidelines in collaboration with Organizations of Persons with Disabilities for preparing and responding to climate change disasters, which include accessible emergency hotlines, emergency responders who can communicate in sign language, location-specific evacuation points, inclusive temporary accommodations (including housing and toilets), and a stockpile of sufficient medical equipment, assistive devices, and medicines. Interview respondents also highlighted the need to have mental health professionals on hand during disasters. The Ministry of Emergency Situations staff and other front-line service providers during emergencies should be trained on the importance of disability-inclusive preparedness and response. Further, local mahalla governments should appoint focal points within the community to help persons with disabilities reach safety and access services in the aftermath of disasters. One of these focal points can be the proposed disability inclusion position-holder within the mahalla citizen assembly, described above.

Build Awareness of Climate Change

Knowledge of climate change is needed to motivate citizen adaptation and resilience. Interviews conducted for this study, as well as broader survey data collected as part of the RIDP, show that awareness of climate change is generally low in Uzbekistan, including among persons with disabilities. The GoU should organize disability-inclusive public awareness campaigns on the sources and consequences of climate change and ways to mitigate and adapt to it. These campaigns should underscore the heightened vulnerabilities to climate change of persons with disabilities. Training programs should additionally target mahalla leaders and local officials to (a) strengthen their ability to raise awareness within communities; (b) advance local adaptive planning and investments; and (c) more efficiently target resources to vulnerable community members, including persons with disabilities.

Foster Dignity

Persons with disabilities in Uzbekistan are often treated as either recipients of charity or medical cases; both approaches disregard “disability as functional limitations as well as social-contextual factors based on the human-rights approach to disability assessment,” as established in the CRPD

(World Bank 2023a). Both charity and medical approaches fail to treat persons with disabilities as rights-bearing citizens with full dignity, as several of our respondents emphasized during interviews. Training programs for service providers, mahalla leaders, and government officials should underscore the disability rights approach embedded in the CRPD. The GoU should relatedly implement Article 11 of the CRPD, which obliges governments to ensure that persons with disabilities are included in all social protections and safety mechanisms. More broadly, in addressing persons with disabilities and their needs, government officials should use rights-based, disability-inclusive language that respects their dignity.

References

- Abebe, Medhanit. 2014. "Climate Change, Gender Inequality and Migration." *Washington Journal of Environmental Law and Policy* 4 (1): 104–40.
- Adger, W. Neil, Terry Hughes, Carl Folke, Stephen Carpenter, and Johan Rockstrom. 2005. "Social-Ecological Resilience to Coastal Disasters." *Science* 309 (5737): 1036–39.
- Aldrich, Daniel. 2012. *Building Resilience*. Chicago: University of Chicago Press.
- Allcott, Hunt. 2011. "Social Norms and Energy Conservation." *Journal of Public Economics* 95 (9–10): 108295.
- Ambrus, Attila, Markus Mobius, and Adam Szeidl. 2014. "Consumption Risk-Sharing in Social Networks." *American Economic Review* 104 (1): 149–82.
- Anukriti, S., Catalina Herrera-Almanza, and Mahesh Karra. 2022. "Bring a Friend: Strengthening Women's Social Networks and Reproductive Autonomy in India." Working Paper, World Bank, Washington, DC.
- Arnold, Margaret, Robin Mearns, Kaori Oshima, and Vivek Prasad. 2014. *Climate and Disaster Resilience: The Role for Community-Driven Development*. Washington, DC: World Bank.
- Auerbach, Adam. 2020. *Demanding Development: The Politics of Public Goods Provision in India's Urban Slums*. New York: Cambridge University Press.
- Ayers, Jessica. 2011. "Resolving the Adaptation Paradox: Exploring the Potential for Deliberative Adaptation Policy-Making in Bangladesh." *Global Environmental Politics* 11 (1): 62–88.
- Banerjee, Abhijit, Arun Chandrashekar, Esther Duflo, and Matthew Jackson. 2013. "The Diffusion of Microfinance." *Science* 341 (6144).
- Charlton, James. 1998. *Nothing About Us Without Us: Disability Oppression and Empowerment*. Berkeley: University of California Press.
- Chu, Eric, and Kavya Michael. 2019. "Recognition in Urban Climate Justice: Marginality and Exclusion of Migrants in Indian Cities." *Environment and Urbanization* 31 (1): 139–56.
- Conley, Timothy, and Christopher Udry. 2010. "Learning about a New Technology: Pineapple in Ghana." *American Economic Review* 100 (1): 35–69.
- Davies, Mark, Katy Oswald, Tom Mitchell, and Thomas Tanner. 2008. "Climate Change Adaptation, Disaster Risk Reduction, and Social Protection." Briefing Note, Institute of Development Studies, Brighton, UK.

- Denton, Fatma. 2002. "Climate Change Vulnerability, Impacts, and Adaptation: Why Does Gender Matter?" *Gender and Development* 10 (2): 10–20.
- Fafchamps, Marcel, and Susan Lund. 2003. "Risk-Sharing Networks in Rural Philippines." *Journal of Development Economics* 71 (2): 261–87.
- Garland-Thomson, Rosemarie. 2005. "Feminist Disability Studies." *Signs* 30 (2): 1557–87.
- Gartrell, Alexandra, Emma Calgaro, George Goddard, and Ngin Saorath. 2022. "Disaster Experiences of Women with Disabilities." *Global Environmental Change* 64: 1–11.
- Gaskin, Cadeyrn, Davina Taylor, Susan Kinnear, Julie Mann, Wendy Hillman, and Monica Moran. 2017. "Factors Associated with the Climate Change Vulnerability and the Adaptive Capacity of People with Disability." *Weather, Climate, and Society* 9 (4): 801–14.
- Gutnik, Alyssa, and Marcie Roth. 2018. *Disability and Climate Change: How Climate-Related Hazards Increase Vulnerabilities Among the Most At-Risk Populations and the Necessary Convergence of Inclusive Disaster Risk Reduction and Climate Change Adaptation*. Humanity and Inclusion.
- Government of Uzbekistan. 2021a. 'Nogironligi bo'lgan shaxslarning huquqlari to'g'risidagi O'zbekiston respublikasining qonuni' (Law of the Republic of Uzbekistan on the Rights of Persons with Disabilities), Pub. L. No. O'RQ-641. <https://lex.uz/ru/docs/-5049511>.
- . 2021b. 'Nogironlar huquqlari to'g'risidagi konvensiyani (Nyu-york, 2006-yil 13-dekabr) ratifikatsiya qilish haqida' (Ratification of the Convention on the Rights of Persons with Disabilities (New York, December 13, 2006)), Pub. L. No. 695. <https://lex.uz/docs/-5447413>.
- Harlan, Sharon, David Pellow, Timmons Roberts, Shannon Bell, William Holt, and Joane Nagel. 2015. "Climate Justice and Inequality." In *Climate Change and Society*, edited by Riley Dunlap and Robert Brulle, 127–63. New York: Oxford University Press.
- Hsu, Angel, Glenn Sheriff, Tirthankar Chakraborty, and Diego Manyá. 2021. "Disproportionate Exposure to Urban Heat Island Intensity Across Major US Cities." *Nature Communications* 12: 2721.
- Islam, Nazrul, and John Winkel. 2017. "Climate Change and Social Inequality." New York: United Nations DESA Working Paper 152.
- Jodoin, Sebastien, Nilani Ananthamoorthy, and Katherine Lofts. 2020. "A Disability Rights Approach to Climate Governance." *Ecology Law Quarterly* 47 (73): 73–116.
- Jodoin, Sebastien, Katherine Lofts, and Amanda Bowie-Edwards. 2022. *Disability Rights in National Climate Policies: Status Report*. Centre for Human Rights and Legal Pluralism and International Disability Alliance.

- Krishna, Anirudh. 2002. *Active Social Capital*. New York: Columbia University Press.
- . 2010. *One Illness Away*. New York: Oxford University Press.
- Kruks-Wisner, Gabrielle. 2011. “Seeking the Local State: Gender, Caste, and the Pursuit of Public Services in Post-Tsunami India.” *World Development* 39 (7): 1143–54.
- . 2018. *Claiming the State: Active Citizenship and Social Welfare in Rural India*. New York: Cambridge University Press.
- Mansuri, Ghazala, and Vijayendra Rao. 2013. *Localizing Development*. Washington, DC: World Bank.
- Meehan, Katie, Jason Jurjevich, Nicholas Chun, and Justin Sherrill. 2020. “Geographies of Insecure Water Access and Housing.” *Proceedings of the National Academy of Science* 117(46): 28700-28707.
- Ostrom, Elinor. 1990. *Governing the Commons*. New York: Cambridge University Press.
- . 1996. “Crossing the Great Divide: Coproduction, Synergy, and Development.” *World Development* 24 (6): 1073–87.
- Perez, C. E.M. Jones, P. Kristjanson, L. Cramer, P.K. Thornton, W. Forch, and C. Barahona. 2015. “How Resilient are Farming Households and Communities to a Changing Climate in Africa?” *Global Environmental Change* 34: 95–107.
- Prillaman, Soledad. 2023. “Strength in Numbers: How Women’s Groups Close India’s Political Gender Gap.” *American Journal of Political Science* 67 (2): 390–410.
- Rosenzweig, Mark, and Oded Stark. 1989. “Consumption Smoothing, Migration, and Marriage: Evidence from Rural India.” *Journal of Political Economy* 97 (4): 905–26.
- Sanyal, Paromita. 2009. “From Credit to Collective Action: The Role of Microfinance in Promoting Women’s Social Capital and Normative Influence.” *American Sociological Review* 74 (4): 529–50.
- Sarzynski, Andrea. 2015. “Public Participation, Civic Capacity, and Climate Change Adaptation in Cities.” *Urban Climate* 14 (1): 52–67.
- Sedova, Barbora, Matthias Kalkuhl, and Robert Mendelsohn. 2020. “Distributional Impacts of Weather and Climate in Rural India.” *Economics of Disasters and Climate Change* 4: 5–44.
- Soss, Joe. 2000. *Unwanted Claims: The Politics of Participation in the U.S. Welfare System*. Ann Arbor: University of Michigan Press.

- Stein, Penelope, and Michael Stein. 2021. "Climate Change and the Right to Health of People with Disabilities." *The Lancet* 10 (1): E24–E25.
- UNICEF Uzbekistan. 2019. *Building a National Social Protection System Fit for Uzbekistan's Children and Youth*. Tashkent.
- . 2020. *Building a National Social Protection System Fit for Uzbekistan's Children and Young People*. <https://www.unicef.org/uzbekistan/en/reports/building-national-social-protection-system-fit-uzbekistans-children-and-youth>.
- United Nations. 2015a. *Sendai Framework for Disaster Risk Reduction, 2015–2030*.
- . 2015b. *Transforming Our World: The 2030 Agenda for Sustainable Development*.
- UN Uzbekistan. 2019. *Situation Analysis on Children and Adults with Disabilities in Uzbekistan*. Tashkent: United Nations Uzbekistan.
- Urinboyev, Rustamjon, and Sherzod Eraliev. 2022. "Informal Civil Society Initiatives in Non-Western Societies: Mahallas in Uzbekistan." *Central Asian Survey* 41 (3): 477–97.
- Wein, Tom, Mary Blair, and Nakubyana Mungomba. 2022. *Dignity Report 2022*. IDinsight.
- Woolcock, Michael. 2010. "The Rise and Routinization of Social Capital, 1988–2008." *Annual Review of Political Science* 13: 469–87.
- World Bank. 2018. *Disability Inclusion and Accountability Framework*. Washington, DC: World Bank.
- . 2021a. *Climate Risk Country Profile: Uzbekistan*. Washington, DC: World Bank.
- . 2021b. *Uzbekistan: Country Profile on Disability Inclusion*. Washington, DC: World Bank.
- . 2022. *Charting a Course Towards Universal Social Protection*. Washington, DC: World Bank.
- . 2023a. *Technical Note on the Implementation of the Convention on the Rights of Persons with Disabilities in Uzbekistan*. Washington, DC: World Bank.
- . 2023b. *Uzbekistan Climate Change Development Report*. Washington, DC: World Bank.
- . 2023c. *Participatory County Climate Risk Assessment and Action Planning Guidance for Kenya's Financing Locally Led Climate Action Program (FLLoCA)*. Washington, DC: World Bank.

World Health Organization. 2023. “Disability Key Facts.” <https://www.who.int/news-room/fact-sheets/detail/disability-and-health>.

World Health Organization and World Bank. 2011. *World Report on Disability*. Geneva: World Health Organization.

Zilberman, David, Jinhua Zhao, and Amir Heiman. 2012. “Adoption versus Adaptation, with Emphasis on Climate Change.” *Annual Review of Resource Economics* 4: 27–53.

Persons with Disabilities Questionnaire

Personal Information

1. Were you born in this community?
 - a. If no, where were you born?
2. What is your age?
3. Are you able to read and write in any language?
4. To what level of schooling were you educated?
5. Do you currently work?
 - a. If yes, what do you do for work?
 - b. Is this a permanent job or is it temporary?
 - c. How much money do you personally earn in a month?
6. How many people reside within your household?
7. Collectively, about how much do all members of your household earn each month?
8. What is the primary language used in your household?

Disability Status

1. What disability do you have?
2. How long have you had this disability?
3. What government services, if any, do you receive to assist you with this disability?
4. What NGO services, if any, do you receive to assist you with this disability?
5. What challenges, if any, exist for you with respect to participating in local social life?
6. What challenges, if any, exist for you with respect to participating in community decision-making and local governance?
7. What challenges, if any, do you have in physically moving around in public?
8. In your experience, is local public transportation, like buses and trains, accessible to you?

9. What challenges, if any, have you faced in securing and performing a job?
10. What challenges, if any, do you experience in accessing healthcare services?
11. In your personal experience, what challenges, if any, have you faced in attending school and learning in school?
12. Do you feel like your disability makes people treat you with less dignity and respect?
 - a. If yes, can you tell me more about this feeling?

Climate Change

1. Have you heard of climate change?
 - b. If yes, can you please describe your understanding of climate change?
 - c. What, in your understanding, are the causes of climate change?
 - d. What, in your understanding, will the impacts of climate change be for your community?

Climate Change and Disability Inclusion

1. I would like to provide you some information about climate change projections in Uzbekistan. This information comes from a World Bank report from 2021. After I'm finished, I will ask you some questions about how climate change is likely to impact you and others in this community that have similar disabilities.
 - Under the highest projected emissions pathway, average temperatures in Uzbekistan will increase by 4.8C by 2090.
 - Heatwaves will increase in frequency and severity.
 - Droughts will increase in frequency and severity.
 - Flooding will increase in frequency and severity.
 - Crop yield losses are projected to reach 25–63 percent by the 2050s even under a moderate emissions pathway.
2. Given what we just discussed, can you please describe what concerns, if any, you have about how climate change will impact you and persons with your same type of disability?

3. Some climate change events are “sudden-onset” disasters, such as flooding, drought, and mudslides. Has your community experienced any of these disasters in your lifetime?
 - a. When was the last time such a disaster happened?
4. What challenges, if any, did you face during these disasters?
5. In the future, when such disasters might happen, what concerns do you have for your safety and wellbeing, if any, stemming from your disability?
6. I’d like to follow up on that question with more specific ones:
 - a. In your opinion, how prepared is the GoU to communicate with persons with disability about an upcoming potential disaster and plans to keep people safe?
 - b. In your opinion, how prepared is the GoU to evacuate persons with your type of disabilities in this community, from areas that have been impacted by flooding, drought, or mudslides?
 - c. How prepared is the GoU to provide necessary services—assistive devices, medication, counseling, disability-inclusive transportation, and shelter—to persons with disabilities who have been evacuated from a disaster-stricken area?
 - d. What advice do you have for the GoU disaster preparation policies, to make them more inclusive for persons with your type of disability?
7. Other impacts of climate change will be “slow-moving” problems like rising temperatures, increasing heat waves, worsening air quality, increasing food insecurity, and reduced agricultural yields.
 - a. In your opinion, how are increasing temperatures and more frequent heat waves likely to impact you and persons with the types of disabilities that you experience?
 - b. How is worsening air quality likely to impact you and other people with the types of disabilities that you experience?
 - c. How might increasing food insecurity you and other persons with the types of disabilities that you experience?
 - d. How might challenges to the agricultural sector impact you and other people with the types of disabilities that you experience?

Final Question

1. What advice do you have for the GoU as it seeks to address the rising challenges of climate change, to make policies and programs disability inclusive?

Interview Questionnaire for Organization Staff Members

General Questions

1. Can you please describe your organization—its mission and activities?
2. What geographic areas of Uzbekistan does your organization work in?
3. Can you please describe your position in the organization?
4. How long you have worked in the organization?
5. What are your specific responsibilities within the organization?
6. How long have you worked within the field of disability rights and inclusion?
7. How many people work in your organization?
8. What specific services, if any, does your organization provide to persons with disabilities?
9. Does your organization do disability rights and inclusion advocacy work with the GoU?
If so, what kinds of advocacy work?
10. Do you yourself have a disability? If yes, what kind of disability?

Disability Inclusion Questions

1. What are the specific types of disability that your organization focuses on?
2. Drawing on your experience working in the field of disability rights and inclusion, can you please describe the current barriers that persons with disabilities—the specific types of disabilities your organization focuses on—face within Uzbekistan in the following issue areas?
 - a. Accessing public transportation, including buses, trains, and taxis
 - b. Accessing public buildings and public infrastructure like sidewalks and transit stations
 - c. Accessing public education—both in terms of the physical aspects of schools as well as the nature of teaching
 - d. Accessing social protection programs and services
 - e. Accessing employment

- f. Accessing healthcare services
- g. Participating in local governance and community decision making
- h. How, if at all, does gender intersect with disability to create specific challenges and barriers for women with disabilities?
- i. Are there any other issue areas that you would like to discuss, which generate barriers for persons with the type of disability that your organization focuses on?

Climate Change Questions

1. Have you heard of climate change?
2. In your understanding, what are the major causes of or reasons for climate change?
3. In your understanding, what, if any, are the different types of threats and vulnerabilities that climate change poses to Uzbekistan?

Climate Change and Disability Inclusion

1. I would like to provide you some information about climate change projections in Uzbekistan. This information comes from a World Bank report from 2021. After I'm finished, I will ask you some questions about how climate change is likely to impact persons with the disabilities that your organization focuses on.
 - Under the highest projected emissions pathway, average temperatures in Uzbekistan will increase by 4.8C by 2090.
 - Heatwaves will increase in frequency and severity.
 - Droughts will increase in frequency and severity.
 - Flooding will increase in frequency and severity.
 - Crop yield losses are projected to reach 25–63 percent by the 2050s even under a moderate emissions pathway.
2. Can you please describe, in detail, what concerns, if any, you have about how climate change will impact persons with disabilities in Uzbekistan? Please speak to these concerns in relation to the types of disabilities that your organization focuses on.
3. In your experience, among the persons with disabilities that your organization works with, how much awareness is there about climate change and the risks and vulnerabilities associated with it?

- a. If no or mixed awareness: why do you think awareness is generally low or mixed among persons with disabilities?
4. Some climate change events are “sudden-onset” disasters, such as flooding, drought, and mudslides. In your opinion, what problems do persons with disabilities (with the types of disabilities the organization focuses on) in Uzbekistan face in such sudden disasters?
5. I’d like to follow up on that question with more specific ones:
 - a. What challenges, if any, would you anticipate in evacuating persons with disabilities from a local disaster area?
 - b. What challenges, if any, would you anticipate in making sure that persons with disabilities are provided necessary services and care after being evacuated from a local disaster area?
 - c. In your opinion, how prepared is the GoU to evacuate persons with the types of disabilities that your organization focuses on, from areas that have been impacted by disasters like flooding, drought, or mudslides?
 - d. In your opinion, how prepared is the GoU to provide necessary services—assistive devices, medication, counseling, disability-inclusive transportation, and shelter—to persons with the types of disabilities that your organization focuses on, who have been evacuated from a disaster-stricken area?
6. Other impacts of climate change will be more “slow-moving” problems like rising temperatures, increasing heat waves, worsening air quality, increasing food insecurity, and reduced agricultural yields.
 - a. In your opinion, how are increasing temperatures and more frequent heat waves likely to impact persons with the types of disabilities that your organization focuses on?
 - b. How is worsening air quality likely to impact persons with the types of disabilities that your organization focuses on?
 - c. How might increasing food insecurity impact persons with the types of disabilities that your organization focuses on?
 - d. How might challenges to the agricultural sector, in terms of employment, impact persons with the types of disabilities that your organization focuses on?
7. What advice do you have for the GoU as it seeks to address the rising challenges of climate change, to make policies and programs inclusive of persons with disabilities?