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**Disability and Citizenship in Post-Soviet Uzbekistan: the
role of disabled people's organisations, mahalla and Islam**

Dilmurod Yusupov

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Declaration

I hereby declare that this thesis has not been and will not be submitted in whole or in part to another university for the award of any other degree.

Signature:.....

Abstract

The very existence of disabled people in the Union of Soviet Socialist Republics (USSR) challenged the utopian ideals of the Soviet citizen which emphasised the ability to work and contribute to building a socialist society. In the context of the authoritarian state and constrained space for independent civil society, it was mainly deaf and blind people who could engage in the Soviet citizenship project. They did so by utilising their working capacities through public associations and specialised production enterprises strictly controlled by the Soviet government. Such a productivist approach to achieving Soviet citizenship excluded disabled people who were deemed to be ‘not fit for work’, particularly those with physical, intellectual, and/or mental impairments.

The collapse of the USSR in 1991 proved that the utopian experiment of constructing the ‘new Soviet men and women’ failed. This thesis explores how disabled people are enacting their citizenship in the context of post-socialist political, economic, social, and cultural transformations in Uzbekistan. Applying an emancipatory disability research approach that involves qualitative and elite interviews, participatory video, and critical ethnography with different groups of disabled and non-disabled people in Tashkent city, this critical study explores the complex nexus between disability and citizenship in post-Soviet Uzbekistan.

Building on the existing conceptualisations of disability and citizenship in other post-socialist contexts, I show that disabled people in Uzbekistan are struggling to assert their citizenship due to the Soviet legacies of i) authoritarian control, and ii) the focus on labour contribution as a fundamental criterion for being recognised as citizens. I further demonstrate how the Soviet disability policies of segregation resulted in new ways of

enacting citizenship by disabled people at the community (*mahalla*) level. Lastly, I examine how pious disabled Muslims in Tashkent are reconceptualising disability through Islamic cultural norms and practices. They are constructing so-called ‘spiritual citizenship’ which conflicts with the Soviet institutional and conceptual legacies.

The main contribution and the focus of the thesis is the way it explores the working and politics of an emerging disability movement in Uzbekistan around a number of vocal disabled activists and grassroots disabled people’s organisations. This study provides a deeper understanding of ‘disability’ and ‘citizenship’ in complex post-socialist contexts such as Uzbekistan. It develops a conceptual framework to critically analyse various visible and invisible barriers that disabled people are facing in their endeavours to achieve citizenship.

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I am also grateful to the Grace Eyre Foundation for hiring me as a part-time support worker during my PhD studies in Brighton, which helped me to cover the costs of living with my family. Importantly, I gained work experience with adults with learning disabilities, learned about the UK system of support for disabled people from within and made a lot of friends among service users and staff members. Living now in Tashkent, I miss those days of laughter and joy when I spent most of my weekends with Debs, Pauline, Sue and the late Gordon.

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I dedicate this dissertation to my late grandfathers Rikhsibay Yusupov, Honored Worker of Industry of Uzbekistan and Veteran of Labour; and Tursunbay Rashidov, Academician

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List of terms and abbreviations

ASL	American Sign Language
BCV	Basic calculation value in Uzbekistan
CPSU	Communist Party of the Soviet Union
CPU	Communist Party of Uzbekistan
CRA	Committee for Religious Affairs under the Cabinet of Minister of the Republic of Uzbekistan
DET	Disability Equality Training
DPO	Disabled people's organisation
FoRB	Freedom of Religion or Belief
GoU	Government of Uzbekistan
GONGO	Government organised non-government organisation
ICF	International Classification of Functioning, Disability and Health
Khokimiyat	Regional, district or city government administration
JICA	Japan International Cooperation Agency
L2CU	Listening to the Citizens of Uzbekistan
Mahalla committee	A self-governing body of citizens with an elected chairperson (<i>oqsoqol</i>)
Mahalla	A neighbourhood community
MBU	Muslim Board of Uzbekistan
MELR	Ministry of Employment and Labour Relations of the Republic of Uzbekistan
NGO	Non-governmental non-profit organisation
NIMFOGO	The Independent Institute for Monitoring the Formation of Civil Society
OGUz	The Society of the Deaf of Uzbekistan (<i>Obshchestvo glukhikh Uzbekistana</i>)
O'zKOJ	The Society of the Blind of Uzbekistan (<i>Obshchestvo slepykh Uzbekistana</i>)
PDP	People's Democratic Party of Uzbekistan
PCGN	The Permanent Committee on Geographical Names for British Official Use
PMPK	Medical-psychological-pedagogical commission
PFL	People First Language
PV	Participatory video
RSL	Russian Sign Language
SADUM	The Spiritual Administration of the Muslims of Central Asia and Kazakhstan
SanPin	Sanitary rules and regulations for the design of public infrastructure (<i>Sanitarnyye pravila i normy proyektirovaniya</i>)
Sovnarkom	The Council of People's Commissars of the Uzbek SSR
SDGs	Sustainable Development Goals
SNiP	Construction Norms and Rules (<i>Stroitel'nyye normy i pravila</i>)
UN	United Nations

USL	Uzbek Sign Language
USSR	The Union of Soviet Socialist Republics
UPIAS	Union of the Physically Impaired Against Segregation
UPP	Training and Production Enterprises – specialised production units under the Society of the Deaf of Uzbekistan (NGO)
UzOI	Uzbek Society of Disabled People (<i>Obshchestvo invalidov Uzbekistana</i>)
UzSSR	Uzbek Soviet Socialist Republic
VKK	Medical Consultative Commission (<i>Vrachebno-konsul'tativnaya ekspertnaya komissiya</i>)
VOI	The All-Russian Society of the Disabled (<i>Vserossiyskoe obshchestvo invalidov</i>)
VTEK	Medical Labour Expert Commission (<i>Vrachebno-trudovaya ekspertnaya komissiya</i>)
WHO	World Health Organization

Introduction

Figure 1. The old Soviet poster installed at the training and production enterprise UPP “CHYOTKA”¹



Source: author's photo

During my second field trip to Tashkent in the summer of 2019, a group of Muslim men with visual impairments invited me to visit their ‘mahalla² of blind people’ (*ko‘zi ojizlar mahallasi*). It existed as a separate blind community living on the outskirts of Tashkent.

In this area was a large, derelict, four-storey building. It once hosted a specialised training

¹ In Russian the word ‘chytka’ means ‘brush’.

² A traditional neighbourhood community in Uzbekistan and Central Asia. See Section 2.2. for a brief discussion of the role of mahallas in Uzbek society.

and production enterprise of the Society of the Blind of Uzbekistan, segregated for blind workers, which specialised in the manufacturing of industrial brushes for the Uzbek cotton industry. When we entered the sheltered workshop, I felt like I had travelled back in time to the Union of Soviet Socialist Republics (USSR). Not much had changed: every detail of the interior was untouched and held the aura of the Soviet past. As we walked through the dark hallways with the Soviet-style glass blocks on the walls, an old colourful poster caught my eyes (see Figure 1 above). This old Soviet poster depicted a man and woman, both able-bodied and brown-skinned with broad shoulders. Interestingly, it had been installed in the sheltered workshop specifically built for blind workers and represented the Soviet ideology that promoted physical fitness and a ‘healthy body’. This vision had constituted a core element of the socialist ideology that attempted to construct the “New Soviet man” (Hoffmann 2000). It seemed someone had provocatively poked the eyes out of the Soviet heroes of old times. It was unclear whether an act of anonymous resistance against the ableist Soviet propaganda was behind the defaced poster. Or was it a form of a tacit protest to acknowledge the existence of blind and visually impaired people in Uzbek society? This mysterious tension hints that the very existence of disabled people in the Soviet Union challenged the visions and promises of the utopian socialist project (Kolárová and Winkler 2021).

The specialised enterprise for blind people represented the legacy of the Soviet disability policy which had put people’s labour contribution at the heart of the communist ideology. Such a functional approach to disability emphasised capacity to work as a key criterion for achieving Soviet citizenship (Phillips 2009; Završek 2014). As I observed the ageing machinery on which people with visual impairments had once toiled, I wondered: what happened to those people who used to work here after the collapse of the Soviet Union?

How have disabled people in post-Soviet Uzbekistan enacted their citizenship, if not through their labour at this sheltered workshop in crisis? This thesis seeks to explore this legacy to find out how disabled people are asserting their citizenship in contemporary Uzbekistan. Citizenship is a rather nebulous concept which has been used by disability studies scholars in different ways and contexts (Sépulchre 2017, 2021; Watermeyer, McKenzie and Swartz 2019a). In this study, the term ‘citizenship’ emerged in the process of data analysis. It encompasses the different ways in which disabled people in Uzbekistan are trying to become recognised as citizens. Notably, this term in Uzbek can have two different meanings and be translated into two separate words: *fuqarolik* and *fuqaroviylilik*. The first term, *fuqarolik*, implies a static status where being a citizen of a country is proved by an individual’s passport. The second term, *fuqaroviylilik*, is more dynamic and can broadly be defined as a concept which enables a person or a group of people to enact citizenship through political, economic, social, and cultural perspectives. In this study, when I use the word ‘citizenship’ I interpret it through the lens of the second (dynamic) meaning.

Based on the critical evidence collected in Tashkent, through this emancipatory disability research approach, I argue that disabled people’s struggles for citizenship in post-Soviet Uzbekistan are fragmented, based on people having different types of impairments. Such a lack of cross-disability collaboration is explained by the legacy of the Soviet disability policies of segregation and exclusion, particularly when these policies affected individuals with physical and learning disabilities. As a result of the fragmentation of disabled people’s groups, the common feature of all their endeavours is that they remain barely visible. Their activity is mostly at grassroots level within disabled people’s organisations (DPOs), specialised training and production enterprises (UPPs), local

neighbourhood communities (*mahallas*) and Islamic religious institutions. The central argument of this thesis is that ‘disability’ in Uzbekistan is being politically, socially, and culturally constructed in very specific ways. This is due to the Soviet legacies of disability organising as well as the emerging role of traditional community structures and Islam in the daily lives of disabled people. Thus, disabled people are finding different ways to assert their citizenship through these various institutions. However, institutional barriers at each level of Uzbek society are disabling the formation of a genuine and united Uzbek disability rights movement and its citizenship goals.

Following the international slogan of the global disability rights movement “Nothing About Us Without Us” (Charlton 1998), I argue that the main disability NGOs, community self-governing bodies (*mahalla* committees) and Islamic charity institutions in Uzbekistan have turned into organisations *about* disabled people without their equal participation and inclusion in decision-making processes. I contend that major Uzbek disability NGOs like the Society of the Deaf, the Society of the Blind and the Society of the Disabled, which ought to facilitate their members’ struggles for citizenship, are in fact constraining disabled people’s bottom-up advocacy efforts. The research findings show that tacit relationships between dominant disability NGOs, *mahalla* committees and Islamic institutions and the Uzbek state reveal internal tensions and power inequalities between independent disability rights activists and disabled/non-disabled bureaucrats. These ongoing challenges and barriers reflect the wider tendencies of top-down state interventions aimed at controlling civil society institutions, *mahalla* institutions and the religious domain in Uzbekistan.

Disability and citizenship in the post-Soviet space

Prior research on conceptualising the relationship between disability and citizenship in the context of post-socialist transition has been conducted primarily in Eastern European nations. But Central Asian states, particularly Uzbekistan, have been largely overlooked. For instance, Phillips (2013, 2010, 2005) explored the struggle of people with physical impairments and their organisations to achieve “mobile citizenship” in Ukraine. Rasell (2011) also researched people with physical impairments in Kazan, Russia to study the connection between disability, citizenship, and welfare provision through theorisation of the concept of “social citizenship”. Hartblay (2015) carried out ethnographic fieldwork with adults with mobility impairments in Petrozavodsk, exploring the concept of accessibility and how disabled citizenship is enacted in Russia. Shaw (2017) made a rich historical analysis of how deaf people in the USSR negotiated their deaf identity and sense of belonging to the communist experiment to achieve Soviet citizenship. All the previous studies on disability and citizenship in post-Soviet contexts focused solely on single impairment groups, and predominantly persons with physical impairments. However, disabled people are not homogeneous, and this study shows that even within impairment-specific groups there are considerable power dynamics and complexities. This thesis builds upon prior research on disability and citizenship and goes beyond a singular focus on specific impairment groups. Applying a pan-disability lens, the thesis aims at understanding how people with various impairments assert citizenship in Uzbekistan.

This study contributes to comparative conceptual debates about disability and citizenship within and beyond the former Soviet states based on the lived experiences of various groups of disabled people in Uzbekistan. To focus on lived experiences, I conducted

fieldwork in Tashkent city in 2018-2019 with individuals with physical and visual impairments, as well as other underrepresented and marginalised impairment groups. These groups include deaf and hard-of-hearing people, deafblind people, people with learning disabilities, and their families. Unlike previous studies which were more quantitative and medical in nature, thus lacking a transformative and social approach to disability research,³ I applied an emancipatory approach to research with disabled people in Tashkent. Together with disabled co-researchers from NGO 'SHAROIT PLUS' which I co-founded with a group of disabled women in Tashkent, we applied a multi-method approach with persons with physical, visual, hearing and learning disabilities and their family members living in Tashkent city. We used a variety of research methods with different groups of disabled people including qualitative interviews, participatory video-making with adults with physical impairments, participant observation with blind and deaf communities, as well as elite interviews with non-disabled community and religious leaders, government officials, policymakers and experts. The critical evidence presented in the following chapters provides one of the first investigations of disability and citizenship in the post-Soviet context with direct involvement of disabled people as co-researchers, and their self-help groups and registered organisations as equal research partners.

The study shows that disabled people in Uzbekistan are not a homogenous group and are prone to power imbalances and inequalities between and within their impairment groups. The analysis of such tensions within civil society organisations, specialised enterprises and other social institutions sheds light on the larger picture of the challenges disabled

³ See Chapter 3 for a detailed explanation of the emancipatory disability research approach used in this research.

people are facing in their grassroots struggles for citizenship. Previous studies on citizenship focused on the conflict between civil society or “rights holders” and the state as “a duty bearer” (Marshall 1950, 1992). However, I argue that such relationships are not linear but complex, and embedded within the Soviet institutional legacy of control and suppression of bottom-up civil action. Although there are certain commonalities between Eastern European and Central Asian countries in terms of the Soviet institutional and functional approach to disability (Phillips 2009, 2010; Shaw 2017) there are also some distinctive contextual aspects. In contrast to the Eastern European contexts, Central Asia is characterised by the role that social networks based on kinship and community play in the daily lives of people (Geiss 2001; Kandiyoti 1998). For instance, mahallas or neighbourhood communities are traditional social institutions in Uzbekistan, Tajikistan and some parts of Kyrgyzstan that have historically emerged around family relationships and observance of Islamic ceremonies (Dadabaev 2013; Massicard and Trevisani 2003; Pétric 2004; Urinboyev 2011). The Soviet Union imposed harsh restrictions on religious practice and only it was in recent years that some degree of freedom was granted to local populations to practise Islam, thus turning it into an important cultural factor. The majority of people in Uzbekistan currently practise Sunni Islam and the state approach to regulating the religious lives of Uzbek people has been complex during both the Soviet and post-independence period (Khalid 2014; Rasanayagam 2011). Therefore, this research also looks at the role these social and religious institutions play in reconceptualising disability and citizenship in post-Soviet Uzbekistan.

[Why do disability research in Uzbekistan?](#)

In the process of researching this study, people in Uzbekistan and elsewhere frequently asked how and why I ended up doing research and carrying out activism with disabled

people. They generally assumed I must have some form of impairment and personal connection to disability, or at least a disabled family member; that only being disabled or having a disabled child or relative could be a motivation for active involvement in disability research and advocacy. However, I do not consider myself to be a disabled person, nor did any of my relatives have impairments before I started this research project. Besides, I did not even think about disability as a subject of academic inquiry and development practice before September 2013 when I first met disabled people in Tashkent. This happened after I completed a master's degree in development economics at Waseda University in Tokyo. I was attending a job interview for the position of a Project Assistant on "Improvement of Social Protection and Rehabilitation of Disabled People in Uzbekistan" at the Japan International Cooperation Agency's (JICA) Uzbekistan Office. Surprisingly, the first interview was held not at the JICA office at the International Business Centre but at a local community centre at Bobodehqon mahalla.⁴ I was welcomed by four disabled Uzbek women. A Japanese woman, a project expert, was sitting at the back of the room and observing the interview process. It was a strange feeling as I asked myself:

How is it that disabled women in a local Uzbek mahalla come to interview a recent graduate with a master of economics degree from a prestigious Japanese university?!

The first interview question was: "Do you have any disabled friends?" I did not know how to reply, as neither at school, university or at any stage of my life had I directly met any disabled person. So, I said that my late grandfather was disabled, although in fact despite his visual and hearing loss due to ageing he did not recognise himself as disabled. The question made me think deeply about the reasons for such an absence of disabled

⁴ A local self-governing body of citizens headed by a respected elder. I will talk about mahallas in detail in the contextual chapter (Chapter 4) and in the study in Chapter 6.

people in my daily life and our unwillingness to be associated with disability. Luckily, I was accepted for the position, and since then through professional and volunteer experience with disabled people at grassroots level in Uzbekistan I have discovered that ‘disability’ is not an individual problem of disabled people but rather a complex social phenomenon and a development issue which requires a multidisciplinary approach to analysis. I came to understand that disabled people’s struggle for equal citizenship and justice is not solely their fight but should be a collective action to promote human diversity and inclusive development.

JICA’s project served as an initial experiential learning space, where I went through a co-learning journey with a self-help group comprising mainly women with physical impairments based in Tashkent. We tried to enact social change by conducting Disability Equality Trainings (DET) as a tool for educating disabled and non-disabled people across the country, providing peer-counselling support, and promoting independent living among disabled people. A group of men and women with physical and visual impairments⁵ were trained by JICA as DET facilitators based on the approach developed by Carr, Darke and Kuno (2008, 2012). DET caused a paradigm shift in my perception of disability from an individual or medical problem located in an individual human body to a political problem of unequal social organisation which restricts participation and denies disabled people citizenship on an equal basis with others. After completion of the project together with the self-help group, we managed to register a Public Association of

⁵ This group later formed DET Forum Uzbekistan: <http://detforum.com/det-forum-uzbekistan/> as part of a registered NGO DET Forum in Japan which currently unites more than 270 DET facilitators in over 30 countries and territories in Asia, the Pacific region, Africa and Latin America: <http://detforum.com/>.

Disabled People NGO called ‘SHAROIT PLUS’⁶ on 29 December 2016. After about two years of struggles against bureaucratic obstacles, we were eventually able to register our organisation (after eight unsuccessful attempts) at the Tashkent city Department of Justice. This bitter experience of establishing a grassroots NGO also shed light on the barriers to the formation of independent civil society in Uzbekistan. Our efforts in applying the social model of disability⁷ through a trial-and-error process indicated that this approach might not work in Uzbekistan as it had proved to in ‘developed’ Western countries like the UK where it originated (Oliver 1990, 1996; UPIAS 1976). Importantly, advocating for equal rights and citizenship of disabled people turned out to be challenging in the complex and unique social, cultural, political, and economic environment in Uzbekistan. Various factors such as the legacies of Soviet disability policies, nascent civil society under an authoritarian regime and the emerging role of Islam can either hinder or support the formation of a collective disability identity. This research project is a logical extension of my previous hands-on experience with disabled people and their organisations, with a motivation to more deeply understand the joint struggle for equal rights through conceptualisation of unique understandings of disability and citizenship in post-Soviet Uzbekistan.

Doing disability research in post-Soviet Uzbekistan

In Uzbekistan, medical and rehabilitation professionals have long dominated the field of disability. This has resulted in conflation of ‘disability’ with health conditions and limited the scope of the problem to individuals and their bodies, rather than society at large.

⁶ ‘SHAROIT PLUS’ translated from the Uzbek language means improvement and creation of the necessary conditions or opportunities in society for people with various impairments. You can learn more about the organisation on its official website: <https://sharoitplus.uz/en/homepage/>.

⁷ I will talk in detail about the social model of disability in Section 1.1. of Chapter 1.

Although the distinction between ‘impairment’ and ‘disability’ can be drawn in English, it does not exist in either Uzbek or even Russian. Moreover, the issues pertaining to disability and civil society were under the strict control of the authoritarian Uzbek government until some opening up happened in late 2016. The government agencies have medicalised both legal and institutional perspectives towards disability and restricted the inputs from independent disabled people’s organisations (DPOs). As a result, the various perspectives of disabled people and their lived experiences; as well as social, cultural, and political aspects of experiencing disability; were largely excluded from both policy and academic discourses. Only a handful of studies have investigated disability in Uzbekistan from a social perspective. Zagirtdinova (2005) was one of the first Uzbek scholars to research disability from a social perspective by examining the dire situation of disabled people in the 2000s. In another mixed method study, Zagirtdinova (2009) explored the barriers that disabled women in Uzbekistan face with regard to realising their reproductive rights and achieving sexual citizenship. Katsui (2005) applied a qualitative approach to a political analysis of disability activism in four Central Asian states including Uzbekistan. The right to inclusive education for disabled children and young people has also been researched by Nam (2021, 2019). The United Nations (UN) recently conducted a situation analysis of disabled children and adults (UN Uzbekistan 2019), but the roles of civil society, mahallas and Islam were not examined. To date, however, studies have not dealt with the relationship between disability and citizenship in Uzbekistan which could shed light on the ongoing struggles and barriers disabled people are facing in their attempts to enact citizenship. Furthermore, the existing disability research has been descriptive in nature, lacking both an emancipatory approach and critical lens. Lack of knowledge or evidence gained through bottom-up participatory research and advocacy with disabled people themselves has been an impediment to the

better understanding of their needs and aspirations to become recognised as equal citizens.

Until late 2016, Uzbekistan remained one of the most authoritarian countries in the world. Since early 2000s the Uzbek government has restricted the ability of international scholars and civil society organisations to do fieldwork research (Markowitz 2016). Therefore, the international disability rights movement and disability studies, which emerged out of the “last civil rights movement” (Driedger 1989) could not spread to this remote double-landlocked post-Soviet state in Central Asia. Zagirtdinova (2005) argued that the product of this global movement – the *social model of disability*⁸ – remained largely unknown to local scholars, policymakers and even disability rights activists. She questioned when the social model of disability would eventually arrive in Uzbekistan, without asking whether such an approach would bring about much needed social change. This frames disabled people in Uzbekistan as detached from global disability rights discourses and social activism. However, a portrayal of disabled people as victims of Soviet disability policies of segregation, neglect, and abandonment (Rasell and Iarskaia-Smirnova 2014) contributes to an image of disabled people as passive and disenfranchised citizens who lack individual and collective agency to claim equal rights with others

My fieldwork research with disabled people in Tashkent revealed their struggles for citizenship were already ongoing on different fronts within the complex political, social, and cultural landscape of Uzbekistan. Most of the disabled people and activists I spoke with were not familiar with the *social model of disability*, as a new and alternative way of conceptualising difference. Nevertheless, they understood that the cause of their

⁸ See Section 1.1. in Chapter 1 for a detailed discussion of the social model of disability.

disenfranchisement and marginalisation lay not in their physical impairments, but in the unequal organisation of social institutions and society at large. Based on the critical ethnographic accounts of the role these social institutions play in the everyday lives of disabled people, the problem is not in disabled people themselves or their impairments but in visible and invisible barriers at each societal level that are inhibiting their bottom-up advocacy for citizenship. Moreover, as my fieldwork coincided with a period of considerable political changes in Uzbekistan, this study generates fresh insights into broader contemporary problems concerning the development of civil society, self-governing bodies and religious freedoms. A longstanding authoritarian leader of Uzbekistan, Islam Karimov, who ruled the country from its independence in 1991 suddenly died on 2 September 2016. The next president, Shavkat Mirziyoyev, initiated large-scale reforms to develop civil society and protect the rights of disabled people. Therefore, in this research I also applied ‘disability’ as an analytical lens to shed light on recent political, social, and cultural dynamics in “new Uzbekistan” (Starr and Cornell 2018).

Aim and objectives

The aim of this thesis is to explore the working and the critical politics of disabled activists who animate and participate in the emerging Uzbek disability movement. It does so by understanding how these disabled activists as well as their grassroots organisations including DPO ‘SHAROIT PLUS’ based in Tashkent are constructing various ways of achieving citizenship. I conduct this critical study through co-production of knowledge and practice with disabled people at the margins and co-operative inquiry about a diverse range of lived experiences of ‘disability’. The research attempts to apply emancipatory disability research approaches, during which as a non-disabled researcher I inevitably

became an ally of the emerging Uzbek disability rights movement for achieving full citizenship. The objectives of this thesis are to:

- provide important insights based on the lived experiences of disabled people into how they can or do achieve full citizenship in political, social, and cultural domains;
- make theoretical, methodological, empirical, and practical contributions to the conceptualisation of disability and citizenship in post-socialist Uzbekistan; and
- together with disabled people, and their representative independent organisations and self-help groups, advocate for their rights for full citizenship in Uzbekistan.

After recent ratification of the UN Convention on the Rights of Persons with Disabilities (CRPD) by Uzbekistan on 7 June 2021 ([GoU 2021](#)), the critical evidence generated with disabled participants, co-researchers and their organisations is intended to be beneficial for the implementation of the national plan of action to fulfil the rights of disabled people. This critical evidence is expected to influence the development of disability-inclusive policies, raising societal awareness of the negative attitudes and barriers disabled people are facing to achieving citizenship on equal basis with others.

Research questions

I initially formulated open-ended and broad research questions; this is consistent with the emancipatory disability research paradigm. I realised that disability research should be grounded in lived experiences and aspirations of disabled people, and should not constrain or narrow down their various perspectives. Thus, the preliminary research questions were not fixed, and evolved during my fieldwork and data analysis. Furthermore, as I have worked closely with (mainly) women with physical impairments, I could not help observing the intersections of gender and disability, and the barriers that

disabled women face concerning participation in the social life in mahallas. Therefore, I was equally interested in how factors like age, gender, impairment (acquired/congenital), relative wealth, location (urban/rural) and so on promote or hinder participation of disabled people in their local communities. In other words, Uzbekistan presented a complex and unique context in which to assess whether internationally produced models and frameworks of disability and citizenship could be adapted to suit the local realities and actual needs of disabled people.

In the process of conducting my fieldwork in 2018-2019, my research questions shifted from exploring personal understandings of disability and formation of a disability identity at the mahalla level, to the exploration of all possible forms of collective agency and disability organising in post-Soviet Uzbekistan. Moreover, through examining disabled people's conceptions of injustice and how these affected their lives at the community level, my focus switched to exploring the grassroots advocacy efforts of blind and visually impaired residents.⁹ The ethnographic fieldwork with blind and deaf people also shed light on the internal power dynamics within existing DPOs. Although my initially chosen thematic focus on the Soviet legacies, the role of mahallas and Islam had not changed, I felt that my research questions transformed from micro-understandings of disability to macro-perspectives and the role of social institutions. Based on preliminary data and action with disabled participants on the ground, I started exploring how different impairment-specific groups are conceptualising or reconceptualising disability and/or impairment in contemporary Uzbekistan, and getting themselves organised to advocate for their rights and citizenship. As a result, upon completing my initial fieldwork in

⁹ See empirical Chapter 6 for detailed discussions on the role of mahalla in claiming citizenship by blind and residents with visual impairments.

Tashkent, analysing the collected data and the ongoing disability advocacy with disabled people, I reformulated the main research question and four sub-questions that this thesis seeks to provide answers to:¹⁰

Main research question:

How do disabled people's lived experiences and societal perceptions of disability shape their practices and forms of citizenship in Uzbekistan?

Sub-research questions:

1. What is the role of local disabled people's organisations (DPOs) and the state in enabling or constraining disabled people's citizenship?
2. What is the role of labour and specialised training and production enterprises (UPP) in achieving citizenship by disabled people?
3. How do disabled people use existing community (mahalla) institutions to claim citizenship at the grassroots level?
4. How are Islamic cultural and religious institutions shaping local understandings of disability and generating distinctive practices and forms of citizenship?

Outline of the thesis

This thesis has been organised in the following way. The first three chapters lay out the groundwork for this study by presenting conceptual (Chapter 1), contextual (Chapter 2) and methodological (Chapter 3) background and concepts, which are then followed by

¹⁰ I should also mention that after I completed my fieldwork in early September 2019 and arrived in the UK, the ongoing COVID-19 pandemic had also hit Uzbekistan. The first case of COVID-19 was officially confirmed on 15 March 2020. The infection and strict lockdown measures introduced by the Uzbek government have severely affected the wellbeing and livelihoods of disabled people. However, exploring the impact of the COVID-19 pandemic and associated state measures on disabled people in Uzbekistan is out of the scope of this thesis and could be a subject for further research on disability and development in Central Asia.

four empirical chapters. In Chapter 1, I revisit existing conceptualisations of disability and citizenship in the world and specifically in the post-socialist region. This chapter examines previous disability studies and area studies literature to develop a conceptual framework for exploring how dominant DPOs, mahalla and Islam impact the advocacy efforts of disabled people for citizenship in Uzbekistan.

Chapter 2 provides an overview of the Uzbek state and society by examining political, social, and cultural ideologies and practices. It situates disabled people within this unique post-socialist context by analysing existing disability policies and legislation, official disability statistics, and disability terminology and categorisation. In the final section, I discuss political, physical, and economic barriers that are hindering equal citizenship for disabled people in Uzbekistan.

The third chapter discusses the design of this research and why I chose an emancipatory lens. I reflect on the way I organised the research process applying a multi-method approach to collecting and analysing data. Then I move on to discussing the various methodological challenges I faced while doing fieldwork with disabled people in Tashkent city. Finally, this chapter provides critical reflections on ethical concerns and dilemmas encountered during the fieldwork as well as my positionality as a non-disabled and privileged researcher.

The subsequent chapters present the empirical findings, with a focus on three distinct 3, as influenced by the Soviet legacy, mahallas, and Islam. Chapters 4 and 5 analyse the role of major post-Soviet DPOs and the state in constructing citizenship by disabled people and how this impacts current advocacy efforts of disabled people for achieving equal

citizenship. Chapter 5 examines how people with visual and hearing impairments have understood disability in the framework of the Soviet functional approach to disability and how this perception is continuing to influence the current practices of ‘Soviet citizenship’.

Chapter 6 explores the explicit and implicit barriers disabled people are facing within their communities when enacting ‘mahalla citizenship’ at the grassroots level. Using the case of the mahalla chairperson elections in a unique ‘mahalla of blind people’ located in Tashkent city, I argue that the quasi-state mahalla committee has become a barrier to the realisation of disabled people’s political rights. Moreover, by analysing the findings from participatory video-making with people with physical impairments, I show how the mahalla committee has become an obstacle to implementing a social right to independent living and accessible housing for a woman with physical impairments.

Chapter 7 provides new insights into how emerging Islamic culture and religious institutions in Uzbekistan are shaping local understandings of disability and generating distinctive forms of citizenship. I refer to these understandings as forms of ‘spiritual citizenship’ which are being constructed by disabled people through the prism of spiritual values and moral norms. Despite this new notion of citizenship, I argue that the Uzbek state is still trying to constrain the emerging bottom-up advocacy efforts of these pious disabled communities through heavily controlled religious institutions similar to government-organised disability organisations and mahalla committees.

Finally, Chapter 8 draws together the research findings and the analysis in the empirical chapters and provides a synthesis of distinctive forms and practices of citizenship of disabled people and their implications for bringing about social change in Uzbekistan.

The thesis concludes with suggestions and recommendations for improving theory and practice in the field of disability-inclusive development in Uzbekistan. This study calls for sensitivity and promotes the importance of disabled people's lived experiences, perspectives, and existing practices and forms of citizenship in the context of a complex civil society landscape, mahallas and Islam in post-Soviet Uzbekistan.

Chapter 1. Conceptualising disability and citizenship in post-Soviet space

Introduction

The Uzbek Soviet and post-Soviet disability community had little contact with critical disability theorists and activists abroad (Zagirdinova 2005). This was due to the isolation of the Soviet Union from the rest of the world until its collapse in 1991 and further closure of independent Uzbekistan to international actors. Due to the Soviet legacy, ‘disability’ has been mainly conceptualised and institutionalised through a functional model of disability which emphasised labour contribution (Phillips 2009, 2010; Zaviršek 2014). The Soviet state applied productivism as a mechanism that reduced “humans to resources utilizable for the enhancement of productive output” (Mladenov 2017: 1110) thus diminishing the worth of those disabled people who were considered to be ‘unemployable’. Besides this productivist approach to disability, the authoritarian communist state had suppressed any independent civil society activism up until the mid-1980s (White 1999). Considering this, in this chapter I move beyond the liberal conceptualisations of citizenship by disability studies scholars. I argue that the relationships between civil society institutions, NGOs and the government challenges liberal understandings of disabled people’s citizenship in post-socialist contexts. Therefore, this chapter examines alternative conceptualisations of disability and citizenship in the post-Soviet space. It problematises the role of government-organised Soviet disability organisations as state-subordinate institutions constraining citizenship of disabled people at the grassroots level.

Global academic scholars and activists in the field of disability studies produced different perspectives on the conceptualisation of ‘disability’ as a social and political problem.

Since the 1960s, the global disability rights movement has spurred productive theoretical debates critical of traditional approaches to understanding disability as an individual tragedy or a medical problem (Barnes 1992a; Oliver 1996; Thomas 2007). These discussions resulted in the development of critical conceptualisations of disability from a social perspective in the form of the social model of disability in the UK (Barnes and Mercer 2010; Thomas 2007; UPIAS 1976), the minority (Hahn 1988, 1995) and cultural models (Garland-Thomson 2002; Snyder and Mitchell 2006) in North America, and the relational model in the Nordic countries (Gustavsson 2004; Tøssebro 2004). Furthermore, the key debates about citizenship of disabled people occurred in the same locations (Beckett 2004, 2005, 2006) and were framed based on liberal notions of citizenship where oppressed and minority groups of disabled people and their organisations claim their civil, political and social rights from the state (Marshall 1992). However, beyond these main geographical locations there has been a lack of conceptualisation of disability and citizenship in the post-Soviet contexts, particularly in Uzbekistan.

In this research, I define ‘disability’ as a political, social, and cultural construct based on the evidence of lived experiences of disabled people in Tashkent. Drawing on the scholarly works of key social model theorists and activists like Barnes (1992a), Barnes and Mercer (2010), Oliver (1990, 1996), I show the significance of materialist approaches to conceptualising disability which separate “the oppressive social experience of disability from the unique functional limitations (and capacities)” (Gleeson 1997: 194). The ethnographic evidence collected with blind and deaf people, which I will discuss in detail in Chapters 4, 5 and 6, suggests that sensory impairments are not hindering their struggle for citizenship. Rather, social oppression and exclusion within social institutions are having a ‘disabling’ impact on their bottom-up efforts to assert citizenship. At the

same time, I argue that the ontological and political separation of ‘disability’ and ‘impairment’ by the social model of disability does not translate well in Uzbekistan, either linguistically or contextually. Participants in this study were not aware of the social model of disability and in Uzbek or Russian languages it is difficult to separate ‘disability’ from ‘impairment’. Furthermore, I challenge the critical stance of social model theorists towards cultural and moral perspectives on disability as a sin/karma or God’s punishment by referring to the theorists of Islam and disability (Al-Aoufi, Al-Zyoud and Shahminan 2012; Bazna and Hatab 2005; Ghaly 2010).

1.1 Models of disability: from individual to social

Personal tragedy and charity models of disability

Although understanding of disability varies across cultures (Ingstad and Whyte 1995, 2007) there has been one dominant framing of disability (based on religious values and beliefs) as God’s punishment. In this moral perspective, disabled people have been traditionally viewed as objects of pity and victims of their bodily conditions, unable to lead an independent life and therefore in constant need of charity. The personal tragedy model implies that disability is “some terrible chance event which occurs at random to unfortunate individuals” (Oliver 1996: 32). From this point of view, disabled people can be considered as “second class citizens because of the tragedy of their impairments” (Oliver 1996: 163). This understanding of disability also refers to a charity model of disability that perpetuates rather than challenges the established status quo (Coleridge 1993). Understanding disability as a personal tragedy emphasises the dependency of disabled people and depicts them as passive recipients of state welfare or charity. Such a paternalistic attitude towards disabled people is the basis of charitable activities and usually takes a form of a unidirectional relationship from a giver to a receiver.

Portraying disabled people as those who are ‘suffering’ also denies their citizenship. Bezmez and Yardımcı (2010) argued that framing disability through the feelings of ‘understanding’ and ‘compassion’ may conflict with the rights-based approach to disability and hinder the efforts of disabled people for equal citizenship. Such top-down attitudes may result in a “protectionist and charity-based relationship” (Bezmez and Yardımcı 2010: 608), putting disability NGOs under state patronage and limiting their involvement in rights-based discourses. According to Bezmez and Yardımcı (2010), the government may instead adhere to a strong centralisation of power and the establishment of charity-based organisations (*vakif* in Turkish) to address a variety of social issues relating to health, education, and the poverty of disabled people. On the one hand, disabled people in Islamic contexts might be viewed as passive recipients and objects of charity which denies their citizenship rights. On the other hand, Islamic conceptualisations of disability may not necessarily be associated with personal tragedy or some moral deficiency as a punishment for previous sins.

In the *Qur’an*¹¹ disabled people are referred to as a group with a ‘disadvantage’ in physical, social, and economic aspects, which society is believed to have created and imposed (Bazna and Hatab 2005). Although the *Qur’an* (Abdel Haleem 2008) does not explicitly mention the term ‘disability’, it is believed that society is to blame for inequality, and thus the disadvantaged should be cared for. Several concepts of charity, including *zakat*, *sawab*, and *ushr*,¹² are enshrined in both the *Qur’an* and the Hadiths (Ghaly 2010). Every Muslim must donate 2.5% of their yearly income to charity in the

¹¹ A holy script for Muslims.

¹² Different concepts of charity in Islam.

form of zakat or almsgiving and Muslims should help disabled people not solely out of pity but as a “gesture of seeking goodwill from God” (Al-Aoufi *et al.* 2012: 209). Thus, Islamic scholars and researchers have pointed to the fact that Islam as a system of belief and practices has shaped the way disability is conceptualised (Al-Aoufi *et al.* 2012; Bazna and Hatab 2005; Ghaly 2010). They argue that, through Islamic perspectives, disability is framed not as a punishment for previous sins in a negative sense but more positively as a *test* or a *challenge*.

For instance, Turkish scholars argued that disability was defined as “a form of being put to test in front of God” (Bezmez and Yardımcı 2010: 607-608) which requires a person to be grateful for whatever happens in their life. Such a definition of disability requires a ‘rise to the challenge’ approach from both disabled people and their families and calls for a divine gratitude. Therefore, ‘disability’ in Islamic contexts is not always defined as a ‘personal tragedy’ with all its negative connotations. On the contrary, disability can be viewed a sign of being chosen or being possessed by God and a disabled person may have their social status enhanced in the community. Muslim disabled people reconceptualised and legitimised their world through Islam, and this provided them with a cultural and religious narrative that would explain the disability through a divine relationship with God. Importantly, cultural and religious perceptions of disability should be recognised and well understood to explore distinct conceptualisations of disability and citizenship. In Chapter 7, I will discuss how disabled people in Uzbekistan are generating new approaches to understanding these two concepts through the prism of Islamic norms and values.

Individual and medical models of disability

Besides the traditional ways of conceptualising disability as a moral condition, another dominant perspective arose with the development of medical science and the role of healthcare professionals in the 19th century. Oliver (1996) defined it as the *individual* or *medical model* of disability that viewed disability as a problem inherent to the individual and as a result of functional limitations or psychological losses. Locating the ‘problem’ in the individual body implies that the main solution to it is medical intervention; for example, surgery or medical rehabilitation to make a person ‘normal’. Finkelstein (1993) criticised this individualised and medicalised view of disability as it focuses only on impairments of the body rather than wider societal issues of discrimination against, and oppression of, disabled people.

This model proposes an idealised concept of ‘normality’ (as an opposite to ‘abnormality’) as a sole criterion for social integration (Linton 1998). This model conflates ‘disability’ with impairments that should be overcome through medical treatment and procedures. In other words, the ‘problem’ is located within the physical body, and it is impairment that ‘disables’ people. Like the personal tragedy and charity models of disability, individual and medical models promote the view that disabled people are mere patients and passive recipients of medical care and rehabilitation services. As a result, medical professionals are given the right and privilege to define the needs of disabled people within the boundaries of medical and rehabilitation institutions and even beyond, in domains like education and employment. The end goal of such top-down medical interventions has been to expect adjustment by disabled people to the society of able-bodied ‘normal’ people as much as possible, rather than adapting the society to the various needs of disabled people. Therefore, as Abberley (1987) argued, this model fails to address

discrimination and exclusion of disabled people who are undervalued in contrast to non-disabled people.

Likewise, in many Muslim societies ‘disabilities’, particularly learning or mental impairments, are attributed to contact with spirits called *jinn* that require divine intervention to expel them from the human body (Rasanayagam 2006). *Jinns* are well described in the *Qur’an*, specifically in the *Surah Al-Jinn* and in the dozens of Hadiths, as beings created by *Allah* (Hasnain, Shaikh and Shanawani 2008). In their interpretation, *jinns* are closely related to evil-minded creatures and usually ascribed to impurities or pollution (Rasanayagam 2011). Certain mental and physical impairments are believed to be caused by them. For instance, in his studies of South Asian cultures and particularly in Pakistan, Miles (1992, 1995, 2000) argues that many Muslims tend to associate mental disorders or other kinds of unusual behaviour with intervention or possession by a *jinn*. Similar to the dominant view that promotes medical professionals as disability experts, traditional societies believe that the impairments can be treated only with the help of traditional or spiritual healers who know how to control and work with evil spirits (Rasanayagam 2006). This religious perspective on disability is interlinked with the personal tragedy and medical models of disability and promulgates negative understandings.

Social and political perspectives on disability

Since the 1960s, disability rights movements were triggered by disabled people and their organisations around the world to claim equal rights and citizenship. This was the result of a radical change in understanding of the concept of ‘disability’ in both academia and social activism. For a long time, disability was perceived as a personal tragedy, an

individual and medical problem that needed to be overcome solely by disabled people. To counter such individualising and medicalising discourses towards disabled people, disability rights activists and scholars reconceptualised ‘disability’ as a social and political issue (Barnes 1992a; Oliver 1996; Thomas 2007). Disabled people have redirected the gaze from people’s bodies to attitudinal and environmental barriers that are actually ‘disabling’ people. In this study, based on my advocacy work with disabled people in Uzbekistan, I consider ‘disability’ as a socially and politically constructed phenomenon. However, I also discuss possible limitations of these models to explain the complex situation in Uzbekistan and what existing disability studies literature fails to grasp.

Disability rights movements led by disabled people worldwide were critical retaliations to the two dominant perspectives on disability discussed above. UK disability scholars and activists who formed the Union of the Physically Impaired Against Segregation (UPIAS) located disability not in the individual but in society. According to (UPIAS 1976: 14):

... it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society. (UPIAS 1976: 14)

Oliver (1990, 1996) argues that disability is a form of social oppression that is imposed on disabled people on top of their impairments. Oliver (1996: 1) provided a materialist understanding of disability as the product of social organisation in a capitalist society rather than as the personal limitations of an individual. Disability studies scholars like (Oliver 1990, 1996) reflected upon their own context in northern Europe and did not consider the application of these ideas to non-capitalist economies elsewhere. However,

I argue that the same arguments can be applied with adaptation to other political economies. Social models relocated the problem not in the individual, but in a society, which restricts participation of disabled people through attitudinal and environmental barriers. Such barriers may be a negative consequence of a current political system, and/or processes of economic development, as well as historical and cultural background. This model had the power to transform consciousness from understanding disability as a personal tragedy or individual/medical problem to that of a social problem created by the social organisation. It has been largely influenced by the ideas of the UK disabled activists, who defined disability as:

the disadvantage or restriction of activity caused by a contemporary social organization which takes no or little account of people who have [...] impairments and thus excludes them from the mainstream of social activities (Oliver 1990: 11)

In other words, instead of the personal tragedy model which focuses on ‘individual suffering’, all the attention was switched to ‘social suffering’ (Shakespeare 2008). The social model of disability distinguishes between ‘disability’ and ‘impairment’. Impairments relate to the body’s structure and function (how the body works or doesn’t work); they are biological and related to a health condition, while disability is a culturally produced and socially constructed phenomenon. The problem is not in the body but mainly in the society which excludes disabled people. Thus, ‘disablement’ as coined by Oliver (1990, 2009) occurs due to unequal political and social organisation, rather than impairments. Thomas (2007) introduced another term, ‘disablism’, which is defined as:

A form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well-being.
(Thomas 2007: 73)

As an outcome and a tool of the grassroots activism by disabled people in the context of the UK, the social model became a catalyst for the disability movement in the UK and

worldwide. ‘Disablism’ was put on a par with racism, sexism and other forms of negative discrimination and marked a new critical identity. Disability rights activists struggled to redirect the focus from the impaired body to unequal and inaccessible societies. In the 1960s and 1970s, similar related ideas emerged in the US and in Scandinavian countries. For instance, in the US, inspired by the civil rights movement in the 1960s and 1970s, disability rights activists came up with the *minority group model* (Hahn 1996). This model framed people with disabilities¹³ as contesting an issue of minority politics like Black people, LGBTI+ (lesbian, gay, bisexual, trans, intersex, other) people, and other minority groups whose rights and citizenship were denied. In Scandinavian countries, disability researchers developed a *relational model of disability* (Goodley 2016: 16–17; Gustavsson 2004; Tøssebro 2004) which analysed disability in a relationship between body and/or mind and the environment. Similar to previous disability studies scholars, I view ‘disability’ as a socially constructed phenomenon in this study; however, I maintain an open mind regarding the local conceptions of disability employed by my disabled co-researchers and participants. I turn now to the disability terminology I use in English, which is also influenced by how I look at ‘disability’ from a social perspective.

A note on disability terminology

The language that we use shapes the way we think or express our feelings and attitudes towards a certain phenomenon. Following the social model of disability (Oliver 1990, 1996) discussed in the previous section, I deliberately use the terms *disabled people* and not *people with disabilities*. This is because I approach ‘disability’ as a social and cultural

¹³ I use the term “people with disabilities” from People First Language (PFL) – following the tradition in the US – in this phrase, because this paragraph is reflecting on the US context. See the following section where I reflect on the English disability terminology used in this study.

construction that is not an inherent aspect of a human body but is the outcome of negative attitudes and inaccessible physical environments. The term ‘disabled people’ implies that persons are mainly disabled not by their impairments (such as deafness, blindness, cerebral palsy, autism, depression, and other conditions) but due to society’s attitudinal and environmental barriers (CRPD 2006). In other words, a wheelchair user with cerebral palsy would not be disabled if a building that they would like to enter had an accessible ramp, a blind person would not be disabled if there was tactile paving in the metro, a deaf person would not be disabled if sign language interpretation or captions were provided on the national TV channel, and so forth. In contrast to ‘disability’, the term ‘impairment’ describes a bodily/mental condition that without any doubt can also influence a person’s functioning. I use the terms ‘disabled people’ and ‘people with physical, visual, hearing, learning (intellectual) or mental impairments’ sometimes to refer to the same groups, but recognising the distinct meanings of the terms.

The term *people with disabilities* is common in the US and many other countries globally and is used in CRPD (2006). This ‘People-first’ language (PFL) is based on the principle of prioritising people rather than their impairment. However, I avoid using ‘people with disabilities’ unless this term is used in official documents or names of institutions. Although PFL intends to show respect towards disabled people by putting them first and their impairments after, it locates ‘disability’ in disabled people by using the preposition ‘with’. Moreover, the PFL approach fails to distinguish between ‘disability’ as a social construct and ‘impairment’ as a physical condition and does not critically acknowledge the oppression caused by society. In contrast, the term ‘disabled people’ indicates that people are ‘disabled’ by society. Thus, I use ‘non-disabled’ people rather than ‘healthy’, ‘able-bodied’ or ‘abled’. I also do not use ‘persons with ...’ as it is a legal term used in

the CRPD (2006) and use ‘people with ...’ instead. Furthermore, I also avoid using terms with the article ‘the’, such as ‘the deaf’, ‘the blind’, ‘the disabled’, as such expressions are depersonalising (Oliver 1990: 3) and put emphasis only on the impairments when the official names of the organisations include such terms. However, I keep the original official names of organisations like ‘the Society of the Disabled’, ‘the Society of the Blind’, ‘the Society of the Deaf’.

The term ‘deaf-mute’ or ‘deaf and mute’ has been considered derogatory by some people in the deaf community and/or an expression of oralism as deaf people can communicate in their sign language. Therefore, I abstain from using such disabling language including terms like ‘deaf and dumb’ or ‘deaf and mute’. However, in some cases throughout the thesis, I keep the original use of this term translated from Uzbek and/or Russian official names of deaf organisations or in direct quotations of research participants. Moreover, I avoid using such expressions like ‘bedridden’ or ‘wheelchair bound’, ‘handicapped’, ‘crippled’, ‘a victim of...’, ‘suffering from...’; as such language denies disabled people’s agency and abilities by portraying them as those who suffer because of their impairments when the real problem is in society rather than their bodies. Instead, I use ‘wheelchair user’ and there is no problem if a person uses a wheelchair in daily life as it assists them and provides freedom of movement. The problem occurs when a wheelchair user comes across stairs where there is no ramp or a lift. Having discussed various models of disability and how they impact the terminology used in this study, I now move on to consider the relationship between disability and citizenship.

1.2 Disability and citizenship

The concept of citizenship

A common feature of the social and political perspectives on disability is that such critical conceptualisations enabled DPOs in northern Europe and the United States to be involved in contentious relationships with governments to demand civil, political, and social rights and claim equal citizenship. In addition to the reflections on what ‘disability’ means, it is important to ask how disabled people achieve ‘citizenship’ in various contexts. Despite a recent upsurge in the number of studies on disability and citizenship in various contexts (Sépulchre 2017), researchers have not considered the nexus of these two concepts in much detail while the majority of the studies were conducted in Western countries through liberal rights-based approaches. Citizenship remains a highly controversial concept in both theory and practice, and has been understood in different ways depending on the historical period as well as cultural and political contexts. The seminal work of Marshall (1950) offered a definition of citizenship influenced by social class concerns as “a status bestowed on those who are full members of a community” (Marshall 1950: 18).

Marshall argued that citizenship is:

...rooted in a conception of what it is to be a full member of a community and the social rights that are necessary to protect and reinforce that membership. (Marshall 1992: 11)

He understood citizenship as a process or the ability to act as a citizen, and divided it into three distinct elements: civil, political, and social rights. Each of these elements of citizenship – as Marshall (1950) argued – evolved over the course of history, starting with the civil element that included the rights to individual freedoms like human liberty, free speech, thought and faith, to own property, make contracts, and the right to justice. The political element comprised the right to elect and be elected to positions of trust and be involved in decision-making processes. The last social element entailed the right to a

secure economic situation, to receive education, social services, and healthcare (Marshall 1950). Thus, citizenship implied the extension by the state of civil, political, and social rights to the whole population while all these rights entail both responsibilities and obligations. Such a liberal understanding of citizenship is conceptualised as a contentious relationship between an individual or a group of individuals as ‘rights holders’ and the state which is a ‘duty bearer’. As a result, citizenship is not merely a status but a practice of everyday strategies to claim rights from state institutions. However, as a UK-based scholar, Marshall largely wrote about citizenship in the context of the UK, while the global aspects of citizenship have been less explored.

The liberal or rights-based conceptualisation of citizenship (Marshall 1950) failed to address issues of social inequality and excluded the dimensions of identity and culture which produce alternative “pluralist accounts of citizenship” (Beckett 2005: 413–417). Comparing case studies from Nigeria, South Africa, India, Bangladesh, Brazil and other non-European contexts, Kabeer (2005) articulated the concept of “inclusive citizenship” defined at the grassroots level by those who were excluded from their societies. The evidence and action on the ground showed the limitations of liberal understandings of citizenship promulgated by high-income countries (as reflected by United Nations human rights treaties) and pointed out the differences in the contexts of low- and middle-income countries. Listening to the voices of excluded and marginalised communities, Kabeer (2005: 5) found that they shared common values of inclusive citizenship including such elements as justice, recognition, self-determination and solidarity. Similarly, previous theoretical debates and citizenship practice showed that “inclusive citizenship is as much about recognition as about access to formal rights” (Lister 2007: 51). Therefore, apart from liberal notions of citizenship which define it in a relationship to the state and

entitlement to political, social and civil rights, there can be alternative conceptualisations of citizenship. Lister (2003) argued that citizenship reflects not only political but also moral and ethical issues related to the “individual’s relationship to the state and the wider society” (Lister 2003: 14).

Thus, excluded groups may also utilise culture to construct an alternative notion of belonging when the state fails to recognise individuals due to their differences. For instance, individuals can understand themselves via culture in a way that is informed by their being denied membership of the state, and which enables them to construct a form of ‘cultural citizenship’ (Ong *et al.* 1996). The notion of cultural citizenship enables people to focus on the ways in which they construct their sense of belonging and membership, which is defined by marginalised and alienated communities outside state-based belonging (Kymlicka 1996; Ong *et al.* 1996; Rosaldo 1994). According to Lister (2007), our understanding of ‘citizenship’ is driven by theoretical debates rather than empirical approaches to unpacking this complex concept. My main aim in this study is to unpack the “lived citizenship” (Lister 2007) as perceived and practised by disabled people in post-Soviet Uzbekistan by exploring:

how people understand and negotiate rights and responsibilities,
belonging and participation (Lister 2007: 55).

Having defined ‘citizenship’ through liberal and alternative approaches, I will now move on to discuss what ‘disability’ brings as a lens to understanding this contested concept for disabled people.

Disability as a lens for understanding citizenship

The concept of citizenship was initially applied by disability scholars and activists in non-European contexts (Meekosha and Dowse 1997) to measure the extent to which disabled

people were or were not integrated or included¹⁴ in society (Oliver 1996: 45). The achievement of rights was seen as a means of integration in developed societies, and including disabled people in full citizenship equally with others. The concept of citizenship provided a useful approach for analysing the relationship between disabled people and the state or society at large, particularly when such a relationship was in crisis (Oliver 1996; S epulchre 2021). To gain equal citizenship status, disabled people had to claim civil rights including property rights, the right to make contracts as well as rights to the freedoms of thought and speech, religious practice and of assembly and association (Oliver 1996: 48). For instance, disabled people living in institutions and segregated settings may have been deprived of the freedom of assembly and association. Morris (2005: 6) provided three concepts of citizenship defined by disabled people in the context of the UK: self-determination (capacity for free choice and exercise of autonomy), participation (political/community), and contribution to economic and social life. These three concepts of citizenship are also in line with Marshall’s civil, political and social rights mentioned earlier (Marshall 1950, 1992). Barton (1993: 240) argued that certain forms of citizenship of disabled people are formed through interactions between the ‘individual’ and their ‘community’. Morris (2005) provided two distinct approaches to theorising and practising the concept of citizenship in relation to disability – an individualistic and a structuralist approach. The supporters of the former approach focus on the individual’s ability to choose as a means to shape the essence of citizenship, while the latter approach pays attention to structural socio-economic factors that influence the individual’s abilities (Morris 2005: 3). Structuralists pay more attention to the social norms and values that define citizenship of disabled people. Likewise, Oliver (1996: 23)

¹⁴ In this thesis I prefer using “inclusion”, as “integration” means adapting disabled people to society rather than changing society. “Inclusion” refers to embracing diversity and adapting society to the needs of disabled people.

pointed out “the need to make a full analysis of the organisation of society” which produces various degrees of exclusion and disablement of people with various impairments in different contexts. Moreover, the analysis of interaction between the individual and the collective is important for all political and social movements (Oliver 1996: 163).

For this purpose Goodley *et al.* (2016: 28) suggest several levels of analysis: individual, relational, social and cultural. ‘Disability’ as a social construct needs to be studied taking into consideration the complexity of institutional, cultural, socio-political, and economic contexts. It is impossible to study disability focusing only on impairments, at the individual level, as experiences of disabled people take place in the process of their interaction with existing societal structures and attitudes. The concept of ‘citizenship’ encompasses all the above-mentioned complexities and provides an analytical tool for exploring the relationships of disabled people with the state and how they construct their notions of belonging and recognition. However, much of the focus on the disability and citizenship nexus has explored the tension between disabled people, their organisations, and the state, while the tensions and power relationships between disabled individuals, their groups within disability organisations and the rest of the community were neglected. The next section considers the role of disabled people’s organisations in claiming citizenship.

Disability organisations in a liberal approach to citizenship

As a response to the troubled relationship with a majority ‘able-bodied’ non-disabled society and the state, disabled people responded in three different ways: creating their own post-human ‘*crip communities*’, establishing the self-advocacy communities striving

to be part of the society, or trying to do both at the same time and taking a ‘DisHuman positionality’ (Goodley, Lawthom, Liddiard and Runswick-Cole 2016: 148). DPOs played a significant role in claiming rights to citizenship on equal terms with other non-disabled people in the context of European countries where liberal or rights-based approaches to citizenship have been prevalent. For a long time, disabled people were considered as ‘patients’, recipients of charity or welfare and service users, and were ascribed a status as passive members of the society. To change this, disabled activists drew a distinction between organisations *for* disabled people and organisations *of* disabled people, in order to move from the patronage- and charity-based approaches promoted by non-disabled people (Oliver 1990; Oliver and Zarb 1989). Oliver (1996: 21) asked for understanding of the difference between representative, accountable and democratic organisations of disabled people and those which are tokenistic, unaccountable, and undemocratic. Describing the struggles of disabled activists against organisations *for* disabled people, Oliver (1996: 166) pointed out that the “tension between individuals and the collectivity” as well as tensions between “the organisation becoming bureaucratic and oligarchical and remaining democratic and rooted in the personal experiences of its membership” were of crucial importance. Apart from the internal tensions within disability organisations, Shakespeare (1993) refers to tensions manifested through the use of ‘direct action’ towards the state by disabled people and their organisations in the UK and the US in the 1960s and the 1970s, which formed a disability rights movement with a shared political identity (Shakespeare 1993: 252).

However, disability organisations often excluded disabled people in their decision-making processes, arguing that there were no capable people with the relevant expertise to run such organisations among the disabled community (Morris 1991: 177). Moreover,

Oliver (1990) argued that existing political parties in the UK context could not represent the interests of disabled people. Consequently, for some time, involvement of disabled people in the organisations *for* disabled people remained tokenistic and patronising. Therefore, Oliver (1990: 117) divided disability organisations into five main categories by constructing a typology:¹⁵ partnership/patronage, economic/parliamentarian, consumerist/self-help, populist/activist and umbrella/co-ordinating organisations. While the first two types of disability organisations were considered by Oliver (1990) to be organisations *for* disabled people, the remaining three were organisations *of* disabled people representing single or cross-impairment groups. Moreover, only those organisations who were established and led by a majority of disabled people, and independent from state institutions, were considered to have the potential to advocate for themselves. For instance, more than half of the members of the decision-making bodies within such organisations needed to be disabled people themselves (Driedger 1989: 11) in order for them to have control over the organisation. In the US, the protest of deaf students against a hearing president at Gallaudet University, Washington D.C. (a ‘deaf university’) in March 1988, which later became known as the ‘Deaf President Now’ movement, was a defining moment in the disability rights movement (Shapiro 1994: 74–104). Oliver (1996) stated that:

Only organisations controlled by disabled people could properly represent the wishes of disabled people. (Oliver 1996: 12)

He stressed that democratic procedures should be in place within such organisations. Thus, organisations *of* disabled people constituted the core of the disability rights movement; they represented the interests of their disabled members and could speak on

¹⁵ Based on their historical development the types of disability organisations are listed in a chronological order based on the period of their establishment.

their behalf according to the principle ‘Nothing about us without us’ (Charlton 1998). Disabled activists and scholars have argued that unless organisations *of* disabled people are strong in advocating for fully-fledged citizenship rights, they will not be able to achieve them (Morris 2005: 10). Only disabled people’s own organisations could become the “essential messengers of disability as a rights issue” (Hurst 1999). However, in reality, the organisations *of* disabled people have usually lacked finances for running their activities, while the organisations *for* disabled people were affluent. Driedger (1989: 10) quotes a blind activist: “The organisations *for* the blind possess the resources and the emerging organizations *of* the blind the ideals”. The situation relating to availability of resources has been worse in low-income countries. The following section shows that the liberal rights-based approach is not always applicable in different contexts where disabled people’s organisations need to navigate various complexities related to the condition of the state, economy, and society.

1.3 Disability and citizenship: alternative approaches

Disability organisations through alternative approaches to citizenship

Meekosha (2011: 670) criticised rights-based discourses produced mainly in European contexts, and stressed that the key debates around disability and impairment, independent living, care, and human rights are often irrelevant to disabled people in the contexts where poverty is pervasive, and the major goal of disabled people is survival. In contrast, she proposed the development of a “southern theory of disability” which would comprise the interests and aspirations of disabled people in non-Western contexts. Apart from the differences in economic development which define the needs of disabled people in various parts of the world, cultural differences play an important role in conceptualising disability and citizenship (see Watermeyer, McKenzie and Swartz 2019). For instance,

Meyers (2020) urged us to rethink citizenship of disabled people in non-European contexts and noted that liberal-individualistic models are deemed to be inappropriate in local contexts where community and mutual self-help form an important aspect of citizenship of disabled people, particularly in a weak state. Even in the context of economically developed and strong states, DPOs may use multiple tactics and be involved in various approaches to claiming citizenship. Nakamura (2006) described how the Japanese Federation of the Deaf carefully sustained the balance between cooperation and co-optation by the Japanese government, by limiting its headquarters' activities to advocacy and lobbying efforts through liberal rights-based discourses. Thus, while it retained its political and economic independence from the state in the capital city, its local prefectural associations fulfilled the role of service provision organisations funded by the state budget.

In Turkey, Bezmez and Yardımcı (2010: 606) emphasise the republican vision of citizenship and a “strong-state tradition” with its focus on duties rather than rights. In their view, this framed within the Islamic ethos, and this results in protectionist and charity-based top-down approaches to disabled people and their organisations, which as I argue later is more nuanced in Uzbekistan. Bezmez and Yardımcı (2010: 606) show how the Turkish government promoted a nationalised type of citizen who piously observes Sunni Islam and speaks Turkish. Nevertheless, in some cases, disability NGOs engage in a *clientelist relationship* with the state and become dependent on government structures and actors in terms of resources, which sustains protectionist and charity-based approaches to disability (Bezmez and Yardımcı 2010). As a result, it becomes impossible for a disability NGO to promote a rights-based approach and claim equal citizenship through the liberal approach, due to co-optation by the state. Bezmez and Yardımcı (2010:

609) found that cooperation between disability NGOs and political parties may inhibit united cross-disability actions and can lead to clientelism. If in Turkey the “strong-state tradition” was the historical legacy of the formation of the Turkish state (Bezmez and Yardımcı 2010), in Uzbekistan this tradition was founded by the Soviet legacy of authoritarianism. Such a variety of strategies for claiming citizenship by disabled people confirm that it remains a complex and multidimensional concept which should include considerations of various organisational structures, as well as cultural, economic and political factors. Having defined the role of disabled people’s organisations in claiming citizenship in various contexts, I will now discuss the role of dominant organisations of disabled people in the USSR in constructing a distinctive form of ‘Soviet citizenship’.

The role of Soviet disability organisations

In the Soviet Union, only two societies for those with hearing or sight impairments, the All-Russian Society of the Blind (Society of the Blind) and the All-Russian Society of the Deaf¹⁶ (Society of the Deaf), were allowed to exist after the mid-1920s. They were integrated into the organisational structure of the ministries of social security in each of the 15 Soviet republics (Madison 1989: 167). Although both organisations were founded and run by blind and deaf people themselves, they operated within the strict hierarchy of the government structure and were part of the bigger socialistic revolutionary project of transformation into the *‘New Soviet Men and Women’* or so-called *‘Homo Sovieticus’*. These two societies were public organisations subordinate to the Ministry of Welfare of the USSR. They both promoted employment of people with sensory impairments in all branches of Soviet production accessible to them, “uniting them in artels, comradeships,

¹⁶ *Vserossiiskoe obshchestvo slepykh* – All-Russian Society of the Blind and *Vserossiiskoe obshchestvo glukhikh* – All-Russian Society of the Deaf.

communes and collectives based on independent activities,^[17] mutual assistance and individual initiative” (Mirkhodjaev 1979: 16). Deaf and blind people united in artels and, by the 1970s, in the specialised training and production enterprises (UPP) which were subject to all the benefits, privileges and advantages established by the Soviet state for organisations of disabled people. UPPs not only employed persons with sensory impairments but provided initial vocational training for graduates of specialised boarding schools for children with hearing and visual impairments. Mirkhodjaev (1979) stated that the introduction of deaf and hard-of-hearing people to “socially useful work” in the Uzbek USSR began in the 1930s with the creation of a material base for training and production, and the first workshops for the deaf were established in 1933 in Tashkent. At these sheltered workshops deaf people were involved mainly in the production of saddleries, bed linen, traditional skullcaps, and so on.

Collective labour strengthened the feelings of friendship, comradeship, and mutual assistance. The spirit of competition was born. (Mirkhodjaev 1979: 18)

Importantly, people with hearing impairments were not only employed at UPPs but were actively integrated into the general Soviet industries and gigantic construction projects of the five-year industrial plans. Thousands of “shock workers of Communist labour”¹⁸ were employed at UPPs as well as general Soviet industries and construction sites. The acute lack of labour from 1930 onwards made the Soviet government use the labour of women and disabled people (Shaw 2017: 60). Moreover, a hearing impairment was considered to be an advantage in noisy industrial production. At the same time, persons with visual impairments required accommodation of the workplace to their needs. Therefore, the

¹⁷ In Russian ‘samodeyatel’nost’.

¹⁸ In Russian *udarnik kommunisticheskogo truda*, which was a formal title of honour awarded to workers who showed impeccable achievements in labour production.

Society of the Blind was not that successful in integrating blind and visually impaired workers into mainstream Soviet industries, as they required considerable workplace adaptation. For instance, for persons with visual impairments to be able to work safely and effectively, the Society of the Blind provided specialised tiftotechnics (in Uzbek *maxsus tiflotexnika*) at its UPPs.

Industrial equipment used at the sheltered workshops was adapted to the needs of blind workers. By the 1980s a list of jobs that blind and visually impaired adults could do in 52 areas of production, and more than 200 labour processes, was reflected in the resolutions adopted by the Society of the Blind (Primkulov 1983). Established in 1932, the Society had a special relationship with the Uzbek socialist government up until the collapse of the Soviet Union in 1991. Starting from 1947, the Soviet government exempted UPPs for blind people from paying turnover tax which remained at the disposal of the Society of the Blind. The Society had state-guaranteed orders and enjoyed a monopoly status for mostly manual production of certain types of goods (such as industrial brushes for the Uzbek cotton industry, knitting and weaving products, can lids, buttons, corks for wine bottles, cardboard items for packaging purposes, and so on). Therefore, the Society and its specialised enterprises were financially stable and able to provide jobs for blind and visually impaired members. Although blind workers were mainly employed at segregated sheltered workshops, the Society of the Blind asserted its strong affiliation to the Soviet state and society:

The workers of Society [of the Blind] stand in a single line with the entire Soviet people to implement the historic decisions of the congresses of the Communist Party of the Soviet Union (CPSU) (Primkulov 1983: unpaginated).

One of the main goals of the Society of the Blind and the Society of the Deaf was to unite blind and deaf people across the country through actively involving them in labour. For instance, one of the main objectives of the first Charter of the Society of the Blind, adopted on 15 June 1932, was to involve its members in decent employment opportunities as well as to support social and economic activities through specialised training and production enterprises¹⁹ (UPPs) and subsidiary companies affiliated with the societies. For this purpose, the societies could establish new UPPs, business societies, limited liability companies, printing and publishing houses, cultural and educational institutions, rehabilitation centres, resorts and recreation facilities and other entities and business structures which were not prohibited by law. The control of properties belonging to the Society of the Blind and the entrepreneurial activities indicated in the Charter was conducted according to its requirements by the central board of the organisation located in Tashkent. In other words, disability organisations in the Soviet Union served as proxies for control of workers with sensory impairments through a centralised top-down approach. Let us now consider what happened to these dominant government-controlled organisations after the collapse of the Soviet Union.

The role of disability organisations in the post-Soviet context

The Soviet Union presented a rather complicated socio-political environment, which does not fall within the contexts mentioned above in terms of conceptualising citizenship of disabled people. The political system of the Soviet Union was dominated by the Communist Party, the only political party which was allowed to exist per the constitution. Therefore, the Soviet political system could not be called democratic due to a lack of

¹⁹ In Uzbek *o'quv ishlab chiqarish korxonasi* and in Russian *uchebno proizvodstvennoe predpriyatie* or for short, UPP.

plurality of ideologies and a lack of independent civil society. The Soviet government did not tolerate any independent grassroots activism by disabled people and put severe restrictions on the establishment of independent organisations of disabled people. For instance, in the late 1970s and early 1980s activists with physical impairments who founded the Action Group to Defend the Rights of the Disabled in the USSR were persecuted, forcibly put into institutions to silence them, or had to flee the country to seek political asylum abroad (Fefelov 1986; Glick 1981; Phillips 2009; Raymond 1989; White 1999: 58–60). They wanted to establish a national society of people with physical impairments like the Society of the Blind and the Society of the Deaf. An organisation uniting people with physical impairments called the All-Russian Society of the Disabled (VOI)²⁰ was established only in 1988 after the emergence of first voluntary organisations under Gorbachev’s democratisation policy of *glasnost* in 1985-1991 (White 1999). Although the VOI was a bottom-up initiative of people with physical impairments, the Cabinet of Ministers of the Russian SSR directly intervened in the formation of the organisation’s governing bodies which included the *nomenklatura*²¹ approved by the Communist Party (Phillips 2010: 75; White 1999: 13).

One of the Soviet legacies of such systems of control was that even after the collapse of the Soviet Union in 1991, disability NGOs in Russia remained intertwined with the state (Fröhlich 2012). As recipients of state grants and support, Russian disability NGOs continued to be deprived of their independence, thus becoming “de facto extensions of the state” (Holland 2008: 552). Mladenov (2018: 100) argued that in the context of post-

²⁰ *Vserossiiskoe obshchestvo invalidov (VOI)* – All-Russian Society of the Disabled.

²¹ In the Soviet Union and other Eastern Bloc countries, *nomenklatura* referred to people who occupied major positions in the administrative bodies covering various spheres based on the system of appointments controlled by the Communist Party in each of the Soviet republics and satellite states.

socialist neoliberalisation in Central and Eastern Europe, disabled people's organisations were depoliticised, and their role was limited to service provision through their "incorporation in structures of tokenistic participation" based on tripartism. In contrast to the rights-based and activist approach promoted by the organisations of disabled people in Western countries, disability organisations in post-communist states preferred a consensus-based approach which stressed the provision of services rather than activism and advocacy for disability rights and equal citizenship (Holland 2008: 550).

However, Hann (2004: 41) criticised the imposition of the Anglo-Saxon liberal and individualist models of civil society, arguing that their narrow focus on NGOs did not take into account local patterns of sociality based on kinship, and religious and ethnic loyalties. Hann warned that such a "civil society export" might be counterproductive in the post-Soviet context. Kulmala (2011: 78) set out the view that the Soviet legacy is not wholly negative but could also serve as a resource for Russian civil society organisations and have a positive impact on their capacities to promote change. She also questioned the adequacy of the liberal model of civil society as independent and antagonistic to the state by showing that the boundaries between them can be blurred. This can happen because disability NGOs may receive financial support from government institutions, which may constrain advocacy and activism. Moreover, Kulmala (2011) argued that the sharp distinction between policy/advocacy and service provision organisations is reductionist, as in the post-Soviet authoritarian contexts, disability NGOs may perform both functions and employ a variety of confrontational and collaborative tactics (Toepler and Fröhlich 2020: 1485). This argument is also applicable to Western contexts where disability organisations can apply both tactics to achieve their goal of disability inclusion. For instance, in the context of post-Soviet Ukraine, Phillips (2005, 2010) found that people

with physical impairments and their NGOs employed various formal and informal strategies to claim citizenship that she referred to as “mobile citizenship”. Consequently, the typology of disability organisations offered by Oliver (1990: 117) cannot be straightforwardly applied in the post-Soviet contexts where the relationship between state and civil society actors is complex and may take various forms. Moreover, the “direct action” mentioned by Shakespeare (1993) which creates contentious relationships with state institutions was impossible in the authoritarian Communist regime where public gatherings, demonstrations and other forms of independent civil action were banned. Thus, Western models of citizenship achieved by disabled people can be inadequate for analysing post-Soviet spaces. In contrast, the significant factor in disabled people achieving citizenship in the socialist and post-socialist contexts has been labour contribution which is analysed in the next section.

1.4 The role of labour in achieving Soviet citizenship

Achieving citizenship through communist labour

Historical records and previous studies on disability and citizenship in the Soviet Union acknowledged the role of labour contribution in the integration of disabled people within communist societies. An eminent chairperson of the Society of the Blind in the Uzbek Soviet Socialist Republic, Qudrat Primkulov (1983), who was at the origins of the organisation and led it for almost 40 years, made an interesting analogy with the way women’s emancipation was achieved during the Soviet period:

...the main way to liberate Uzbek women was to involve them in mass production, so that they would be economically equal to men and have ample opportunities to grow spiritually and politically (Primkulov 1983: unpaginated).

In similar fashion, liberation of disabled people was possible through their active involvement in communist labour. Studying deaf people in the USSR, Shaw (2017) found that labour served as a “criterion of normality” which showed “a practical path to liberation” (Shaw 2017: 17). In other words, increased labour contribution would compensate for hearing or vision loss and enable deaf and blind workers to prove that they were also fully-fledged and equal citizens of the communist state. Such a functional approach resembles the neoliberal discourse on citizenship which judges people and their status based on the productivity, and produces ableist notions (Waldschmidt and S epulchre 2019: 425).

“There are no invalids in the USSR!” was a famous response by a Soviet official to the question of whether the Soviet Union would host the Paralympic Games as well as the Moscow Olympics in 1980. Fefelov (1986) argued that although this at first appeared to be a joke, it did reflect the real situation of disabled people in the socialistic structure. Indeed, there was no place for disabled people in the ‘ideal’ socialist society of strong and able-bodied heroic workers, sports champions and soldiers. Impairments were considered to be ‘defects’ in a heavily standardised and communitarian system of mass production, urbanisation and state planning, and thus were not tolerated or accepted (Rasell and Iarskaia-Smirnova 2014). State propaganda promoted an image of an ideal and whole person – a role model that should be aspired to, while disabled people were considered as polluted, corrupt, and impure. The cornerstone of the Soviet disability policy was institutionalisation of disabled people in medical, educational and welfare spheres. Although specialised institutions isolated disabled people from mainstream society, they also had some “unintended side effects” of bringing disabled people together and shaping their collective identity (Phillips 2009).

Shaw (2017) argued that deaf people strived to make themselves as Soviet as possible through the Society of the Deaf and its UPPs. They managed to construct a distinct Soviet deaf identity and culture within the boundaries of communist ideology. Labour not only represented a tool of emancipation but was also a means of individual self-transformation into a ‘normal’ Soviet citizen, for whom disability could be overcome. In other words, labour served both as a criterion and a tool for achieving the state of ‘normality’.



Figure 2. A Soviet poster “The Way of the Deaf: From disenfranchised citizens to active builders of communism”

Made by M. A. Vaapov, an employee of the Samarkand training and production enterprise (UPP) for the deaf: The certificate held by this Soviet deaf woman reads: “Shock worker of Communist Labour”.

Source: Mirkhodjaev (1979).

Soviet propaganda widely promoted the belief that through the transformative power of labour, disabled people could become “conscious and active builders of a classless

socialist society” (cited in Shaw 2017: 60). In contrast to visual impairments, those with hearing impairments retained their full physical bodily capacity to work and, therefore, did not even consider themselves to be disabled. There is also a debate among deaf people in other contexts about whether they want to identify as disabled or more as a cultural group (Lane 2002). At the same time, the Soviet state applied similar rhetoric to blind and visually impaired people in the following manner:

... a blind person is not a disabled person, in need of charity; a blind person is just as capable of work as a healthy seeing person, only in need of special preparation. (cited in Shaw 2017: 36)

The Soviet ideal embodied physical fitness and contribution of labour based on Lenin’s slogan during the October Revolution which later became a major socialist principle: “He who does not work, shall not eat”.²² ‘War invalids’ contested the imagined Soviet body politic and were prosecuted as ‘anti-Soviet elements’ subject to forced detention at specialised labour camps (Dale 2013; Edele 2006, 2008; Fieseler 2006, 2014). Bodily impairments particularly, and physical impairments more than hearing or visual impairments, challenged the notion of the ideal Soviet citizen. Physical impairments were treated as ‘defects’ (Grigorenko 1998; McCagg 1989) in a heavily standardised and homogeneous socialist system of mass production, urbanisation and state planning where institutionalisation of disabled people dominated in healthcare, education and welfare (Rasell and Iarskaia-Smirnova 2014: 5-6). However, Shaw (2011, 2015, 2017) argued that despite these practices of undeniable exclusion and marginalisation, deaf people claimed their agency and independence by constructing a distinct deaf community

²² This socialist principle was enshrined in the first Constitution of RSFSR of 1918 and was further included in Article 12 of the 1936 Soviet Constitution: “In the U.S.S.R. work is a duty and a matter of honour for every able-bodied citizen, in accordance with the principle: ‘He who does not work, neither shall he eat’. The principle applied in the U.S.S.R. is that of socialism: ‘From each according to his ability, to each according to his work’.”

identity within the institutional framework of the All-Russian Society of the Deaf. People with hearing and visual impairments enjoyed a privileged status compared with those with physical, intellectual, or mental impairments. Importantly, the Soviet ideology based on Marxism and egalitarianism framed hearing impairment as “a social defect that could be overcome by social means” (Shaw 2017: 225), through collective labour as a tool for emancipation and self-transformation into fully-fledged Soviet citizens. Soviet citizenship was a tool for integration into social and cultural Soviet life. Thus, disabled people strived to achieve equal citizenship in a constant tension and negotiation between their disabled ‘defective’ bodies and the Soviet ideal type.

Apart from the official disability classification, according to disability group, these three categories existed: ‘invalids of war and army’, ‘invalids of labour’, and ‘invalids suffering from a systemic disease’. The latter category included ‘invalids from childhood’, ‘invalids from accidents’ and those people who became ‘invalids in custody’ (Fefelov 1986). The sequence of these categories is very important here, as the Soviet state prioritised ‘war invalids’ and those who became disabled at work over congenitally disabled people and those who acquired impairments due to private accidents not related to work. This is because early Soviet disability policy was developed in the context of two devastating wars and initially focused on providing welfare benefits for disabled veterans. However, rather than being egalitarian in its nature, the social security system in the periods following each war adhered to some form of inner hierarchy among ‘war invalids’ and many war veterans were subject to forced detention at special labour camps for disabled people (Fieseler 2014).

Functional model of disability

The social model of disability was the cornerstone of the disability rights movement in the UK and elsewhere. But it was little known in the Soviet Union due to the state's isolation, and the Soviet disability communities' lack of involvement in the international disability movement. Instead, the Soviet government applied a *functional model of disability* which evaluated a person's "usefulness for society" (Phillips 2009, 2010: 50). This notion can also be observed in the use of specific terminology: 'invalid' (or *invalidnost*) by the Soviet state and in the official disability classification system. Disability was defined as the degree of loss of working capacity and all measures were focused on assisting disabled people to regain their ability to work (Madison 1989). Medical Labour Expert Commissions (VTEK) determined the degree of loss of working capacity and allocated relevant social benefits. The functional model of disability located the problem in the work capabilities and work potential, thus constraining the problem to the individual. It resembled the individual and medical models of disability, as VTEK members were medical professionals who measured and determined the 'severity of disability'. Thus, people were categorised into groups based on their 'degree of disability' and were ascribed roles through medical and welfare bureaucracies.

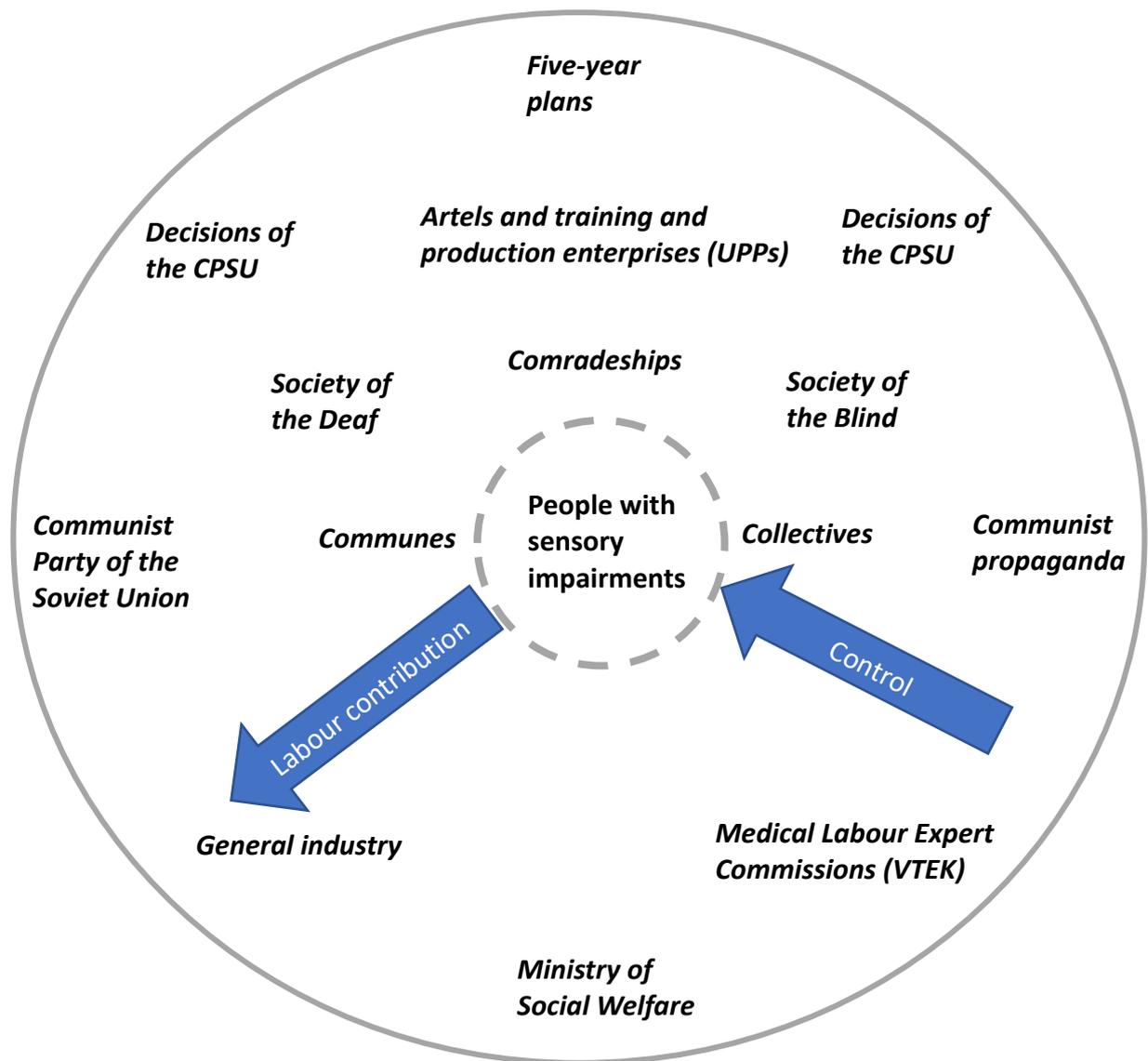
This model resembled aspects of the personal tragedy theory and medicalisation of disability, as all the power belonged to VTEK bureaucrats. Mladenov (2018) criticised this medical-productivist understanding of disability as it culturally and economically devalues disabled people and marginalises them, objectifying them as "deficient bodies and inefficient resources" (Mladenov 2011: 483). Based on this functional model, labour capacity served as the central criterion for Soviet citizenship and any deviance from being able to work therefore diminished citizenship (Phillips 2010: 59). This notion of disability

is aligned with a neoliberal approach that marginalises those who cannot pay taxes or contribute to the economy. Thus some groups like disabled children and persons with intellectual, mental and complex impairments were denied social rights. Phillips (2010: 54-55) argued that the Soviet government used a functional approach not only to involve disabled people in productive activity and maintain a strong workforce, but also to save resources and maintain control.

Soviet framework of citizenship for disabled people

The following diagram shows the conceptual framework of Soviet citizenship for disabled people which consisted of people with sensory impairments (hearing and visual) located in the centre. The Communist Party oversaw all the activities and organisations including the Society of the Deaf and the Society of the Blind. No autonomous self-help groups and organisations of disabled people were allowed to exist until 1985 when Gorbachev initiated his political reforms of *glasnost* and *perestroika* (White 1999). Therefore, in the Soviet framework, the organisations of deaf and blind people were not separate from the elements of the totalitarian one-party communist state but were embedded within it. The Society of the Deaf and Society of the Blind had to function under the Ministry of Social Welfare and, thus, were extensions of the Soviet government. In this framework, independent civil society institutions were not allowed to exist, and only people with sensory impairments (as opposed to other impairment types) had an opportunity to enact Soviet citizenship through their active labour contribution in mass production as well as in specialised enterprises. The system was embedded within both the “hegemonic normalcy” (Oliver 1990) of the ideal type of Soviet citizen (*homo Sovieticus*) and the imposed hegemony of the Soviet state through penetration of government institutions and ideology into people’s daily lives.

Figure 3. *Conceptual framework of Soviet citizenship for disabled people*



Source: author's illustration

The Soviet government operationalised a functional model of disability (Phillips 2009) in which the labour capacity of people with sensory impairments was the key criterion for achieving Soviet citizenship. In other words, disability was framed as an individual lack of work capacity that could be overcome through active labour participation, thus proving oneself a capable and equal Soviet citizen. However, this functional approach to citizenship resulted in exclusion of those disabled people who were found to be less capable, productive, and thus 'useless' in contributing to building the utopian communist

state. Such groups included adults with physical, learning, and mental impairments as well as disabled children and non-disabled elderly people who were considered to have lost their labour capacities. In the functional approach, disability was framed as an individual or medical problem of losing personal labour capacity. Blind and deaf people could not exist outside this model and had to build their Soviet disability identity within the boundaries of communist propaganda. Consequently, they shaped distinctive disability identities rooted in a sense of belonging to the socialist project through establishment of their societies (Shaw 2017). Due to the isolation of the USSR, there was a lack of communication between Soviet disability organisations and their international counterparts. An exception to this was a conference organised in the Soviet Union with the participation of the countries from the communist bloc, where the societies boasted about their success in integrating blind and deaf people through the UPP system (Mirkhodjaev 1979). Thus, the Soviet citizenship model was successfully isolated from the rest of the world and detached from the global disability movement that took off in the 1960s in the UK, US, and other Western contexts.

Conclusion

This chapter has defined the key concepts used in this study, with the aim of conceptualising the nexus between disability and citizenship in the post-Soviet context. In summary, there have been various conceptualisations of disability by academic scholars and activists in different geographical locations and historical periods. I recognise the importance of critical conceptualisations of disability as a social construct and adopt the social model of disability as a conceptual framework (Barnes 1992a; Barnes and Mercer 2010; Oliver 1990, 1996). Nevertheless, I point out the possible deficiencies of a purely materialist stance towards disability in contexts where moral, cultural, and

linguistic factors might play an important role. I criticise the position of social model theorists who portray religious understandings of disability as a form of personal tragedy model which conflates ‘disability’ with sin or God’s punishment. Moreover, as disabled people in the Soviet Union have been largely isolated from the global disability rights discourses, I argue that functional and productivist approaches to disability (Phillips 2009; Završek 2014) are still prevalent in post-Soviet countries.

This chapter has also shown that ‘citizenship’ remains a much contested concept (Lister 2003, 2007) which is increasingly being applied in the field of disability studies across the world (Sépulchre 2017, 2021; Watermeyer *et al.* 2019b). Reviewing how ‘citizenship’ was conceptualised in Western contexts through achievement of civil, political and social rights (Marshall 1950, 1992), I argue that this liberal rights-based approach to citizenship cannot be straightforwardly applied in the post-Soviet context. The political legacy of the totalitarian communist states has left limited space for independent civil society activism. Thus, confrontational activism by disabled people and their organisations to claim citizenship rights from the state might not work in post-socialist authoritarian regimes. Instead, I problematise such liberal approaches to citizenship by reviewing the role of dominant disabled people’s organisations established in the Soviet era. In contrast to the conflict approach, I argue that Soviet disability organisations had to work within the boundaries of the communist ideology and the state which strictly controlled the management and financial flows of these organisations. Achievement of ‘Soviet citizenship’ was enabled through labour contribution of people with sensory impairments at the two public organisations of deaf and blind people allowed to exist under top-down supervision of state institutions.

In conclusion, the concept of ‘citizenship’ is useful in exploring how disabled people are constructing their relationships with the state or finding alternative ways to nurture their feelings of belonging and participation. However, rather than relying on theoretical debates on the links between disability and citizenship, I argue in favour of empirical or practical conceptualisations of these two key concepts by people with various forms of impairments. Therefore, I do not restrict myself to a particular conceptual framework but have left myself open to various conceptualisations of disability and citizenship as suggested by my disabled co-researchers and participants. In this emancipatory study I focused on the “lived citizenship” (Lister 2007) of disabled people in Uzbekistan to explore how they construct various forms of citizenship and ways to achieve it through various institutions. The chapter that follows considers the political, social, and cultural context of contemporary Uzbekistan in view of how the Soviet legacy has defined disability and citizenship. It then moves on to discuss the role of the traditional community structures (*mahallas*) and Islam and locates disabled people within the context of post-Soviet Uzbekistan.

Chapter 2. Situating disabled people in post-Soviet Uzbekistan

The wider political and socio-economic context is relevant to analysis of how disabled people claim citizenship in contemporary Uzbekistan. This chapter builds on conceptualisations of disability and citizenship in the post-Soviet space and investigates the role of context-specific institutions. It critically examines the nature of the authoritarian Uzbek state and its role in controlling civil society institutions, community-level self-governing bodies (mahalla committees) and Islamic ideology and practices. It shows how political, social, and cultural factors specific to the context of Uzbekistan may become either barriers or facilitators to disabled people's citizenship on an equal basis with others. I provide a review of current disability policies and national legislation, official disability statistics, and the specifics of Uzbek language in formulating disability terminology and categorisation. The final section presents the various barriers that disabled people face on their path to achieving citizenship, including the challenges for implementing political rights, access to public infrastructure as well as their dire social and economic situation.

2.1 The nature of the Uzbek state: ideologies and practices

An authoritarian state in transition

Uzbekistan is a post-Soviet lower middle-income²³ country (World Bank n.d.) in the heart of Central Asia. It gained its independence in 1991 and officially declared its commitment to democracy and a market-based economy. Uzbekistan is the most populous nation in Central Asia and as of 2020 its total population reached 33.9m people. Almost half

²³ As of 2021, the World Bank includes Uzbekistan in lower middle-income group of countries. Lower-middle-income economies are those in which 2019 GNI per capita was between \$1,036 and \$4,045.

(49.4%) live in rural areas.²⁴ There are explicit differences in the standard of living between comparatively developed urban areas and rural areas where people live more in communities with a lack of basic infrastructure and utilities.

Figure 4. Map of Uzbekistan



Source: The World Factbook

Contemporary Uzbek society represents a complex mixture of different cultures, ethnicities and languages because of its rich history and location at the crossroads of several civilizations. On the one hand, the secular Soviet legacy is strongly present, particularly in state bureaucracy and its totalitarian control of almost every sphere of life; on the other, there is a new national ideological discourse with Islam playing an emergent role in the lives of Uzbek people.

²⁴ Based on the official data provided by the State Committee on Statistics of the Republic of Uzbekistan.

Islam Karimov, the authoritarian leader of the newly independent Uzbek state, served as the first president from 1991 until his death in September 2016. Karimov was a Soviet apparatchik and the last Secretary of the Communist Party of Uzbekistan who led the Uzbek Soviet Socialist Republic from 1989 to 1991. Under his authoritarian rule the Uzbek government gradually transitioned from the planned and centralised socialist economy. Karimov (1992) promoted Uzbekistan's own approach to renewal and progress which referred to East Asia's experience in transitioning from a middle- to high-income economy (Cavanaugh 1992). Unlike the neoclassical approach, which regards a minimal state as essential for economic growth, Uzbekistan took the path of a developmental state where "powerful technocratic bureaucracies, shielded from political pressure, devise and implement well-honed interventions" in the market to promote economic development (World Bank 1993: 13). The chosen approach to development became known as the "Uzbek model" of gradual transformation which included implementation of a strong social policy and social protection of vulnerable populations as its fourth fundamental principle (Karimov 1995).

After the collapse of the Soviet Union, Karimov tried to fill the 'ideological vacuum' by replacing the Marxist-Leninist foundations of state and society with his secular ideology of '*ma'naviyat va ma'rifat*' ('spirituality and enlightenment') (Sattarov 2017). He used this new 'national ideology' to legitimate his hard authoritarian rule although it was "national in content but Leninist in form" (March 2003: 318). In her linguistic analysis of official Uzbek discourses on *manaviyat* (spirituality), Maerz (2018) also found striking similarities between Karimov's application of this concept and Soviet strategies for promoting communist ideology. Sattarov (2017) argued that the new national ideology was effectively used by Karimov to exercise control over the lives of Uzbek citizens. The

government was given the role of “the main reformer” (Karimov 1992) and advanced principles of state paternalism and Uzbek ‘traditional values’ over political pluralism, human rights and democracy. Ilkhamov (2007) characterised Karimov’s rule as a neopatrimonial regime which combined absolutist presidential power with selective adoption of market mechanisms and a legal-administrative system which allowed enrichment of powerful elites.

March (2003) distinguished three interconnected elements of Karimov’s state ideology as: i) providing “ideological immunity” for Uzbek people by protecting them from negative Western influences (Teles Fazendeiro 2018), globalisation, extreme forms of Islam and the Soviet legacy; ii) the “reflection thesis” which shows the true character and culture of the Uzbek people based solely on the inner and organic nature of the Uzbek nation; and iii) the “unification thesis” – the idea of national independence uniting all citizens under a single national flag to pursue common state goals. The primary goal was the achievement of economic development which had “priority above politics” (Karimov 1992) and required national unity over a period of gradual transformation. In this authoritarian ideological paradigm, any political opposition or independent civil society activism (for instance, supposedly inspired by Western values) was framed as adversarial to the state. Thus, anything out of the patrimonial government’s control was deemed to be alien, threatening the regime’s stability and its pursuit of much promised ‘development’. Consequently, independent Uzbekistan has become repressive, with restricted freedoms for its citizens, and it has been closed to international organisations and researchers until recently.

Thus, the ‘strong state’ was considered to be a prerequisite for development of a distinctive Uzbek civil society particularly with the widespread top-down imposition of Karimov’s national ideology, which replaced Marxism-Leninism. Thus, the “unification thesis” ([March 2003](#)) under the auspices of Karimov’s ideology of ‘spirituality and enlightenment’, and Uzbekistan’s own model of development, did not leave space for any opposition, whether political or civil. Consequently, as with Soviet absolutism, there was no place for private-public tension and competing values and interests, as there was a common national goal and ideology already formulated by the ‘father of the nation’. Such post-Soviet absolutism was exacerbated after the so-called ‘colour revolutions’ which changed governments in Georgia, Ukraine, Kyrgyzstan and other post-Soviet states in the 2000s, posing risks to Karimov’s regime. In addition, the Andijan unrest in 2005 triggered increasingly controlling state behaviour towards local civil society organisations and the ousting of international NGOs and media. [Ismailov \(2013\)](#) argued that the space for local NGOs to engage in advocacy and activism was constrained, except for a few organisations. Independent grassroots NGOs were forced to shut down or operate under strict state guidelines and a hostile legal environment which sought to control all their activities and sources of funding. It also became difficult for independently-formed groups of citizens to register grassroots NGOs due to red tape and bureaucratic hurdles.

Post-Karimov era: ‘New Uzbekistan’

After 25 years of consecutive presidential rule, Karimov died suddenly in September 2016 and was succeeded by his apprentice Shavkat Mirziyoyev who had served as a prime minister of Uzbekistan since 2003. Unlike his predecessor, Mirziyoyev has remade himself as a ‘reformist’ by opening up the country to the international community and introducing Uzbekistan’s “new face” ([Starr and Cornell 2018](#)). However, experts argue

that following his predecessor, Mirziyoyev came to power in undemocratic elections in 2016 (Lewis 2021). During his presidency no opposition parties have so far been allowed to register or participate in either presidential or parliamentary elections. Despite some freedoms granted to local media, release of political prisoners convicted on religious extremism charges and partial liberalisation of the economy, [Lemon \(2019\)](#) argues that Mirziyoyev's regime still represents a version of "soft authoritarianism". My fieldwork conducted in Tashkent from 2018 to 2019 coincided with the early years of Mirziyoyev's presidency when his government pledged a series of economic and social reforms. In 2017, his government adopted a national development strategy for 2017-2021 which among other goals prioritised improvement of social protection, social services, and healthcare for disabled people ([GoU 2017](#)). Moreover, Mirziyoyev's government adopted measures for significant improvement of the state support system for disabled people at the end of 2017 ([GoU 2017](#)). If this research had been undertaken under Karimov's rule, I believe it would have been more challenging to access the field and establish relationships of trust with research participants. The sudden change in political leadership has inevitably impacted the direction this project took. The empirical analysis in later chapters captures the ongoing transformations that happened during Mirziyoyev's administration through the prism of disabled people's struggle for citizenship. By nature a political issue, 'disability' is a powerful lens for critically examining the role of civil society, mahalla and Islam in achieving citizenship by disabled people.

2.2 The nature of the Uzbek society: ideologies and practices

Civil society landscape

To understand the current situation of Uzbek civil society one needs to look at the Soviet legacy. In contrast to liberal democracies, which arguably cultivate and nurture

relationships between private interest and public good, [Pottenger \(2004\)](#) argued that the Soviet Union subscribed to Marxist-Leninist absolutism which erased the boundaries between private and public and identified them as one and the same. In other words, in the Soviet state, where a single communist ideology penetrated all spheres of life, there was no perceived place for such a tension nor any ‘need’ for independent civil society organisations (Pottenger 2004). Karimov’s notion of civil society was different from a conventional liberal interpretation (where independent NGOs are involved in advocating for various interests, values, and ideas). [Ismailov \(2013\)](#) argued that although in his political discourses Karimov propagated the idea of a step-by-step transformation, “from strong state to a strong civil society” (Karimov 1995), he tried to distance himself from Western definitions of civil society, referring to Eastern ‘orientalist’ notions and differences in the historical background, culture, and mentality of Uzbek people. The Soviet government gradually changed its attitude towards voluntary associations during Gorbachev’s era, with new policies and the emergence of the voluntary sector (White 1999).

Despite Mirziyoyev’s announced measures to “radically improve the role of civil society institutions in the process of democratic renewal of the country” ([GoU 2018](#)), NGOs are still facing challenges in Uzbekistan (Yusupov 2020). The 2016 government made cosmetic changes by reducing NGO registration fees, shortening the application review period, and easing some requirements and procedures for NGO activities. However, NGO registration processes remained complicated (Yusupov and Isakov 2020a) and Mirziyoyev’s government still prefers excessive control and regulation of NGOs rather than equal social partnerships with them (Yusupov and Isakov 2020b). The legacy of Karimov’s crackdown on independent civil society remains prevalent due to a repressive

legal framework designed to impose strict controls on independent NGOs and their activities.

In 2020, the authorities boasted that there were more than 10,000 NGOs in the country (Ministry of Justice of the Republic of Uzbekistan n.d.-b) but this number is misleading due to a number of reasons. Firstly, it does not reflect the quality and composition of these NGOs (it is important to distinguish between two main types of NGOs in Uzbekistan). There are so-called ‘system-forming NGOs’ which are established on a top-down basis by state decrees, and self-initiated NGOs registered on a bottom-up basis by groups of citizens. According to the Independent Institute for Monitoring the Formation of Civil Society (NIMFOGO)²⁵ about 65% (more than 6,000) of total registered NGOs in Uzbekistan are system-forming or government-organised NGOs (GONGOs) and only 35% or 3,000 NGOs can be considered to be self-initiated (NIMFOGO 2018). This shows that the current civil society landscape in Uzbekistan is dominated by government-controlled NGOs. I argue that the existence of such GONGOs contradicts Article 4 of the Law of Uzbekistan on NGOs which bans the interference of government bodies in the activities of NGOs and vice versa (GoU 1999). System-forming NGOs usually possess a wide-ranging network of branches across the country and are supported by the government budget (covering staff salaries, renting offices, and so on).

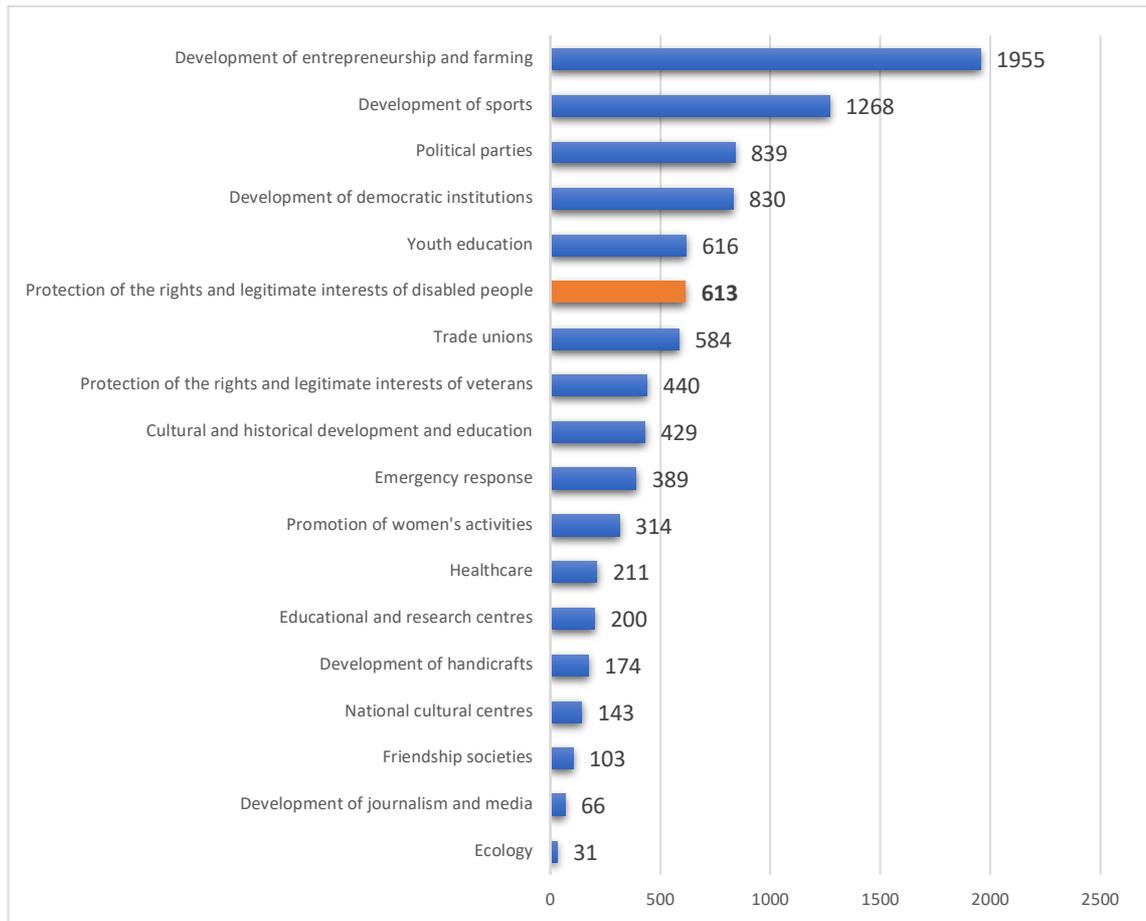
Secondly, as a local feminist activist Matvienko (2021) argued, the Ministry of Justice counts regional branches of system-forming NGOs as separate legal entities which leads to a so-called ‘multiplier effect’ used by the Uzbek authorities to boast about the

²⁵ On 30 October 2019, President Mirziyoyev transformed the Independent Institute for Monitoring the Formation of Civil Society into the Center for the Development of Civil Society.

increasing quantity of NGOs in the country (Yusupov and Isakov 2020a). A good example is a system-forming NGO Youth Union of Uzbekistan (*O'zbekiston Yoshlar Ittifoqi*), formerly known as *Kamolot* (Youth Social Movement),²⁶ which is a successor of the Soviet youth organisation *Komsomol* (McGlinchey 2009). A search in the open register of NGOs and their branches (Ministry of Justice of the Republic of Uzbekistan n.d.-a) with the key words *yoshlar ittifoqi* (youth union) returned 168 branches of the organisation across the country which are all counted as separate NGOs. Sattarov (2017) argued that the Uzbek authorities established *Kamolot* in 1996 in order to impose single state youth politics and control young people through Karimov's national ideology. Maerz (2018) compared Uzbek state discourses on *Kamolot* to those of the Soviet *Komsomol* and found striking similarities in their approaches to shaping the 'perfect generation' (*barkamol avlod*). In other words, having a legal NGO status, *Kamolot* imposed a single state ideology over youth politics and tried to establish political patronage over all young people in Uzbekistan (McGlinchey 2009). In this top-down system underpinned by an absolutist national ideology, there is no space for either alternative views on Uzbek youth politics, or self-initiated youth organisations.

²⁶ On 30 June 2017, Mirziyoyev criticised the activities of "Kamolot" Youth Social Movement and proposed its transformation into the Youth Union of Uzbekistan.

Figure 5. Distribution of NGOs in Uzbekistan by sector in 2018 (in units)



Source: [NIMFOGO \(2018\)](#), translated into English by the author.

Figure 5 shows that in 2018 there were 613 registered NGOs working on protection of rights and legitimate interests of disabled people, out of 9,205 registered NGOs in Uzbekistan (NIMFOGO 2018: 11). As was mentioned earlier, the total number of disability NGOs includes all their territorial branches as separate organisations. For instance, the Uzbek Society of Disabled People, a system-forming NGO, has more than 150 regional branches across the country. Each branch has its own organisational charter and is registered at a local justice department. Based on unconfirmed sources, there are in total about 76 NGOs working on disability issues in Uzbekistan, not counting their territorial branches. In Chapter 4, I provide a critical examination of the dominant Uzbek disability organisations and explore the role of the Soviet legacy in forming a specific

civil society landscape in post-Soviet Uzbekistan. One specific element of this legacy was the mahalla, which as Karimov argued, reverted to Eastern ‘orientalist’ notions of civil society (see the following section on the role of mahalla), and which served as a foundation of Uzbek civil society (Masaru 2006).

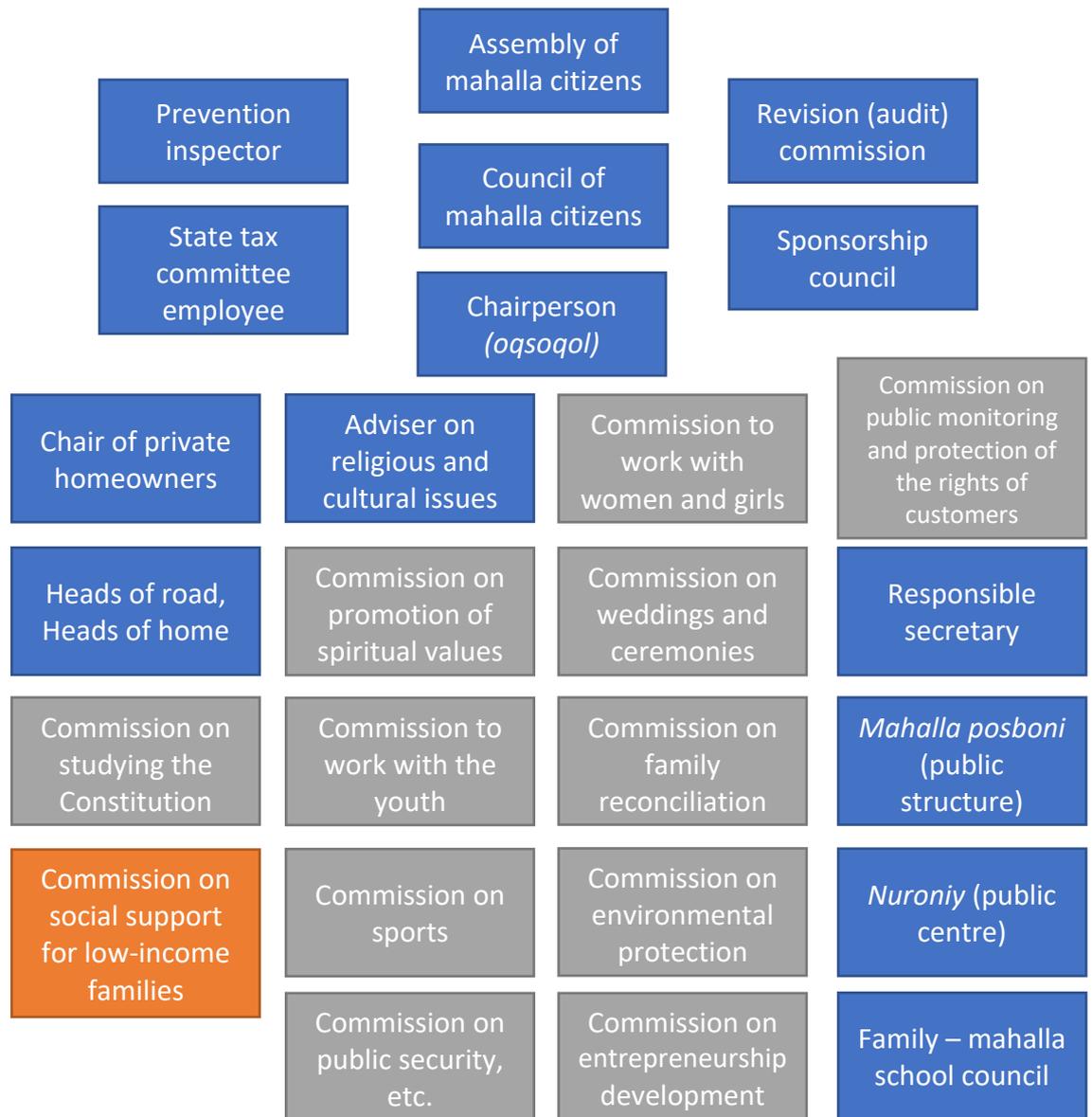
The role of the mahalla in Uzbek society

In Central Asia, and particularly in Uzbekistan, local neighbourhood communities are referred to as *mahallas*. A mahalla is “a territorially defined residential subdistrict that has been formalised as an organ of self-government” which is involved in religious practice (Rasanayagam 2011: 26). Long before the Russian Revolution of 1917 these community-based institutions had represented religious communities in Central Asia which were based on the observance of Islamic law, *sharia* (Geiss 2001). The leader of a mahalla was known as the *oqsoqol*²⁷ who was elected with the assistance of the local religious leader, or *imam*. The *oqsoqol* enjoyed influence and authority, and was respected by other community members for his personal integrity and wealth (ibid.). The *oqsoqol* represented the mahalla externally, settled local disputes, collected taxes and allocated income on mahalla affairs including financial support for those in need. Geiss (2001) argues that in the 19th century, community networks were very strong as participation in communal celebrations and religious life was compulsory. Each mahalla had its own mosque, cemetery and communal buildings which were regarded as communal properties even if they were owned by a person or a religious authority.

²⁷ In Uzbek, the ‘whitebeard’ (*oqsoqol*) is usually an elderly male representative of a local community. In some rare cases the chairperson of the mahalla can be female as well.

In 1930s, the Soviet authorities legalised to a certain extent some of these local community institutions by establishing a ‘mahalla committee’ which was used as a channel to spread communist ideology (Rasanayagam 2011). After 1991, the government of Uzbekistan went further by formalising mahalla committees as local self-governing bodies and delegating to them functions including local administration of state benefits for children and the poor (Article 12, GoU 1993). The administrative structure of the mahalla committees was explicitly defined by law (GoU 1993) and includes the *oqsoqol* who is elected by the general assembly of households (*kengash*), a deputy chairperson (*muovin*), and a secretary (*kotib*); as well as specific mahalla commissions who are responsible for improving living conditions, organising ceremonies, maintaining public order, housing stock and finances, and overseeing issues concerning women, children, and veterans of war (Bektemirov and Rahimov 2003). Depending on the relevance and importance of the issues and problems existing in each mahalla, other commissions may also be established by the citizens’ assembly. These commissions are usually led by a chairperson (*oqsoqol*) and his advisers. The commissions carry out their activities based on a *nizom* (charter) approved by the citizens’ assembly and confirmed by the Cabinet of Ministers of Uzbekistan. The work of the elected commission members is not remunerated: they all work on a voluntary basis. Below is an example of a mahalla committee’s management model.

Figure 6. Example of a mahalla committee's management structure



Source: Based on Bobodehqon mahalla poster board in Tashkent, author's illustration

Rasanayagam (2011) found that mahalla committees were viewed by local residents as government bodies implementing state directives while their leadership was considered to be corrupt and engaged in rent-seeking behaviour. Massicard and Trevisani (2003), and Bogner (2003) criticised mahalla structures as integrated in the vertical hierarchy of the Uzbek government as a tool of control and surveillance over the population. The election of the mahalla leadership is not a bottom-up process implemented by residents

but heavily influenced by the decisions of local governors to appoint and dismiss the mahalla chairmen (ibid.). Noori (2006) concludes that decentralisation in the form of proliferation of the mahalla institutions was ineffective in alleviating poverty and improving local infrastructure. The mahalla institution proved to be an ineffective instrument of state control and monitoring, and actually reduced democratic legitimacy and access of the residents to government services.

Importantly, Rasanayagam (2011: 51) argues that a distinction between “the state-formalised institution and the informal mahalla, which is a local social institution but has no legal status” should be made clear. This ‘informal mahalla’ is referred to as *masjid qaum* (mosque community) and is in a hierarchical relationship with the official mahalla committee as “*an extension of the daily flow of sociality*” (ibid: 55). Freizer (2004: 116) described it as a “communal civil society based on kinship [which] was strengthened by links based on proximity”. After mahallas were awarded legal status as institutions of local self-governance in 1999 by the Law on Self-governing Bodies of Citizens, the authoritarian Uzbek government transformed these communal forms of civil society into “obedient clients of the state” (ibid.). Despite this change in status, mahallas heavily depend on direct financial support from local governments and do not usually have independent income to run activities. For instance, the salaries of the mahalla chairperson (*oqsoqol*) and other core staff members of the mahalla committee are financed by the state budget. As a result, the formal mahalla remains a control tool for local governments at the grassroots level (Bektemirov and Rahimov 2003; Dadabaev 2013; HRW 2003; Pétric 2004; Urinboyev 2011). In other words, mahalla committees are part of a large bureaucratic apparatus with a strict vertical management structure where the mahalla chairperson is effectively a cog in the state machine, rather than a representative of a

genuine community-based civil society organisation. In 2018, Mirziyoyev's government introduced several changes to national legislation regulating mahalla committees, NGOs and other civil society organisations in Uzbekistan. For instance, formal procedures for electing chairpersons of mahalla committees changed in 2018 ([GoU 2018](#)), and several government decrees ([GoU 2018](#)) were adopted to increase the role of NGOs and civil society institutions in the country's democratic development. However, it is not clear whether such legislative and policy changes led to positive developments for mahalla institutions. Importantly, there is no single academic study related to mahallas in Uzbekistan that has specifically examined their role in the lives of disabled people. Therefore, in this thesis I aim to explore how disabled people are using existing mahalla institutions to claim citizenship at grassroots level.

Islam in post-Soviet Uzbekistan

Across the world, unique local concepts and beliefs shape and influence perceptions of disability and may have a direct impact on the lives of disabled people (Holzer, Vreede, Weight and Weigt 2001; Ingstad and Whyte 1995, 2007). In low- and middle-income countries people may have very different cultural and religious interpretations of disability, which should be taken seriously rather than denied in favour of social theories, constructs and representations imported mainly from high-income countries. Islam in contemporary Uzbekistan presents unique local understandings and religious practices due to Soviet legacies and post-independence authoritarianism. Although some aspects of Islam can be universal, there is no single version of it practised around the world. Islam does not exist as a dogma to be strictly followed by its adherents but is constantly reproduced in specific social and historical contexts, enmeshed with everyday life (Marsden and Retsikas 2013: 4). Currently, the Uzbek population practises mostly Sunni

Islam (about 88%), Eastern Orthodox (9%) and other religions (3%) (CIA.gov n.d.). According to other estimates about 93-94% of Uzbekistan's population belong to the Hanafi School, and only about 1% are Shia belonging to the Jafari School and living mainly in Bukhara and Samarkand (Bureau of Democracy, Human Rights, and Labor 2021: 3). As of 2017 the official data shows that Uzbeks comprise an ethnic majority of 83.8% while there are also Tajiks (4.8%), Kazakhs (2.5%), Russians (2.3%), Karakalpak (2.2%), Tatars (1.5%) and other ethnicities (2.9%) (CIA.gov n.d.). However, reliable data on the religious and ethnic composition of Uzbekistan's population is non-existent as the last population census was conducted in 1989.

During the Soviet era, the repressive Communist regime propagated atheism and strictly controlled any religious activity in Central Asia. This was achieved through Soviet institutionalisation of Islam (Tasar 2018) which resulted in a constrained public space for 'being Muslim' in Uzbekistan (Rasanayagam 2014). The Soviet government established a quasi-state institution, the Spiritual Administration of the Muslims of Central Asia and Kazakhstan (SADUM). After Uzbekistan gained its independence in 1991, SADUM was transformed into the Muslim Board of Uzbekistan (MBU). MBU retains control over religious activity and can be regarded as a Soviet legacy (Hilgers 2009: 34). In fact, the question of whether MBU actually represents the Muslim community remains open (Rasanayagam 2007). In the late 1990s and early 2000s, Karimov's dictatorial rule began stifling democratisation and suppressed independent religious practices. In the context of the global war on terror after 9/11, Karimov used anti-terrorist rhetoric and state security forces to legitimise his crackdown on any political opposition by framing it as Islamic extremism (Khalid 2014). Aggressive positioning by the state intensified particularly

after violent state reprisals in 2005 following the Andijan uprising, which was triggered by the arrest of several religious businessmen (Megoran 2008).

According to its constitution, Uzbekistan (GoU 1992) recognises itself as a secular country which provides freedom of religion or belief (FoRB) to every citizen. However, in practice, the state reserves power to define the contours of ‘official Islam’; thus any other Islamic manifestations beyond the allowed boundaries are automatically framed as ‘extremist’ and destructive to the secular regime (Khalid 2003). Since Mirziyoyev came to power in late 2016, he has initiated reforms to loosen Karimov’s grip on Islamic practice and ameliorate the country’s international image as an abuser of religious rights (Sheralieva 2020). One of the main changes in religious policy happened in 2018, when President Mirziyoyev adopted a decree for the improvement of religious and educational activities (GoU 2018). The decree included the establishment of *Vaqf* Public Charitable Foundation which, among its activities, provided material and moral support to socially vulnerable groups and disabled people.²⁸ However, there have been no studies looking into the role of spirituality and religious institutions in the lives of disabled people and how they conceptualise ‘disability’ and ‘citizenship’ in the context of post-Soviet Uzbekistan. In Chapter 7, I attempt to bridge this gap by exploring how changing Islamic culture and religious institutions under Mirziyoyev’s rule are shaping local understandings of ‘disability’ and generating distinctive practices and forms of citizenship.

Some scholars questioned the very existence of spirituality at either the individual and collective level during the Soviet era. Hilgers (2009: 75) referred to this period as a

²⁸ See paragraph 8 of the presidential decree (GoU 2018).

“spiritual vacuum” which might have led to an identity crisis in post-Soviet Uzbekistan. Thus, the question of what it means to be ‘a good Uzbek’ remains open due to the complex intersections of Uzbek ethnic identity and Muslim religious identity. After the collapse of the Soviet Union, an identity crisis happened due to the ‘spiritual vacuum’ which was replaced by Karimov’s nationalistic ideology of ‘*ma’naviyat va ma’rifat*’ (‘spirituality and enlightenment’) as discussed earlier. Soviet citizenship was replaced by new concepts of ‘Uzbekness’ (*o’zbekchilik*) and ‘Muslimness’ (*musulmonchilik*) (Hilgers 2009: 10) while the tools of Soviet ideological propaganda to promote a certain type of citizen are still widely used in Uzbekistan (Maerz 2018).

In Uzbekistan, Islam has emerged in new contexts of religiosity and has become deeply entwined with the regeneration of Uzbek national culture and identity. The independent Uzbek government has called for a return to Uzbek origins and ‘Golden Heritage’ with a strong sense of Muslim identity derived not from individual religious learning, but rather through collective apprehension of Islam (Khalid 2003; Rasanayagam 2011). Therefore, Islam in the everyday lives of Uzbeks remains diverse and multifaceted, bearing the imprint of regional cultures, traditions, histories, and dynamics (Louw 2007; Peshkova 2015; Rasanayagam 2011). For instance, Muslim religious sentiment was found to be not so strong in the north-western region of Khorezm (Kehl-Bodrogi 2008) while the Fergana Valley, particularly the Namangan Region is believed to be inhabited by “better Muslims” (Rasanayagam 2011: 386).

Taking into consideration such a diversity of “living Islam” (Marsden 2005) in Uzbekistan, I aim to explore disabled people’s lived experiences and perceptions. I did not look deeply into the meanings and concepts of disability outlined in the *Qur’an* and

by Islamic doctrine. I instead analysed various perceptions of disability in the specific cultural context of contemporary Uzbek society. The focus will be on assessing how far Islam plays a critical role in shaping perceptions and understandings of disability and citizenship in Uzbekistan, and how far these perceptions and understandings are similar to or different from other Muslim majority contexts. Thus far, this section has argued that civil society, community, and religious institutions play an important role in the lives of people in Uzbekistan but that there has been a considerable gap in the literature where their role in the lives of disabled people is concerned. The next section locates disabled people within the context of post-Soviet Uzbekistan.

2.3 Disabled people in post-Soviet Uzbekistan

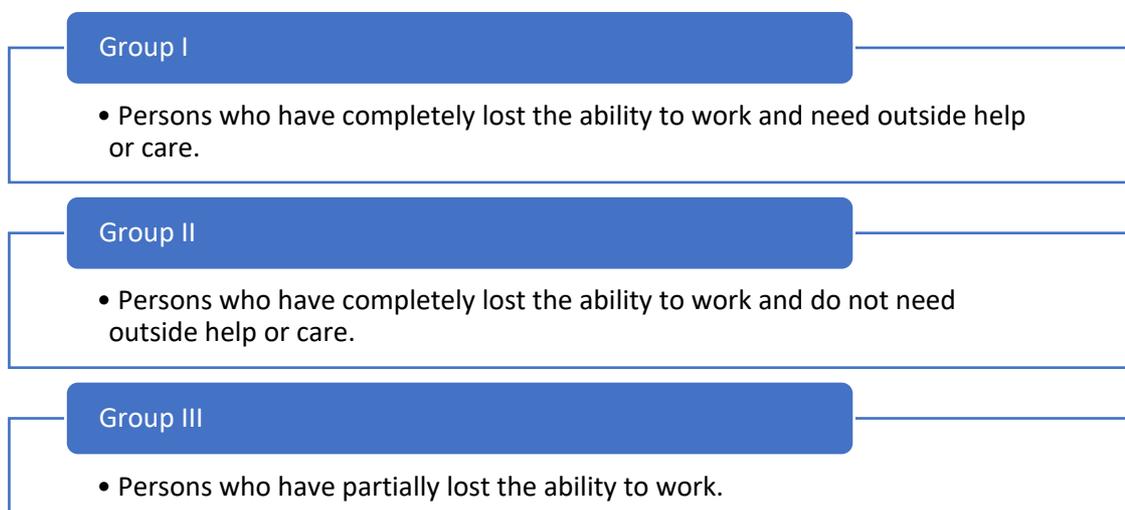
Soviet legacy in disability policy

In Uzbekistan, contemporary understandings and practices related to disability at a policy level have been heavily influenced by programmes for disabled people that were developed in the USSR (McCagg and Siegelbaum 1989). In the Soviet Union, disability was determined based on the degree of loss of working capacity and all state measures were aimed at assisting disabled people to regain their ability to work (Madison 1989: 170). The Soviet government applied a “functional model of disability” (Phillips 2009) based on person’s “usefulness for society”, as Soviet citizens were valued for their labour contribution and productivity (see Section 1.4 for a detailed discussion of the Soviet legacy of disability policies). This is also reflected by the specific use of the term *invalid* by the Soviet state and later by the government of independent Uzbekistan. Soviet disability policies still have strong implications for contemporary definitions of disability and have influenced current policies and practices in Uzbekistan. This is evident from the survival of the Medical Labour Expert Commissions (in Russian ‘Vrachebno-trudovaya

ekspertnaya komissiya’ or shortly ‘VTEK’) which have the power to determine an official disability status and assign relevant state benefits.

VTEK, which functions under the Ministry of Healthcare, is responsible for determining both types and severities of impairments and the extent of loss of working capacity, identifying causes of such losses, assigning a disability group (three levels), making recommendations on suitable types of work and working conditions, assisting in regaining the ability to work, and other measures of medical, social, and professional rehabilitation for adults over 18. Based on an examination by VTEK, disabled people are divided into three groups depending on the severity of their impairments, associated degree of loss of labour capacity, and need for nursing care.

Figure 7. Disability groups in Uzbekistan



Source: Registration of documents for obtaining disability, single portal of interactive government services, <https://my.gov.uz/ru/life-situations/10> (assessed on 17 January 2021). Author’s own illustration.

VTEK determines the degree of impairments and loss of labour capacity for those aged over 16 (referred to as adults), while Medical Consultative Commissions (VKK) assess disabled children under 16. Disability assessment and determination procedures are

burdensome and corrupt as they require additional costs and time even for those with visible forms of congenital or acquired impairments who need to go through re-examination at VTEK on a regular basis. According to the current regulations on the procedure for examining citizens in VTEK commissions (GoU 2011), people with long-term diseases (except for tuberculosis patients) are admitted for initial disability assessment if their temporary inability to work lasts for more than four consecutive months. For a preliminary disability assessment, a disabled person must provide a referral from a medical institution with an extract from their medical history, certified by the attending physician, head of department, chief physician and carrying the round stamp of the institution and an outpatient card. The period of compulsory inpatient treatment varies from four to twelve months depending on the nature of the disease. VTEK then carries out a disability assessment to determine the eligibility of an adult for state-guaranteed social benefits and medical rehabilitation services. In a 2019 survey, 42% of disabled adults and parents/guardians of disabled children evaluated the procedure of obtaining disability status as “difficult” or “very difficult” (UN Uzbekistan 2019: 56). As of January 2019, 709,814 people were officially registered as disabled including 101,316 disabled children under 16. Disability group I, with the most severe impairments, accounted for about 9.2% or 65,406 disabled adults, group II about 66.4% and group III about 10.1%. Uzbekistan invests 1.2% of its GDP in adult disability benefits which is higher relative to other low- and middle-income countries but well below average for high-income countries that spend 2.1% of their GDP (UNICEF Uzbekistan 2020: 32).

The Ministry of Labour and Social Protection of Population of Uzbekistan was the main state body responsible for providing medical and social assistance to disabled people, including disabled children, war veterans, lonely elderly people, and other vulnerable

groups, as well as for the organisation of vocational training for disabled people and the development of inclusive vocational education. However, since 22 February 2016 the Ministry was transformed, and functions of social protection and rehabilitation of disabled people have been given to the Ministry of Healthcare of Uzbekistan ([GoU 2016](#)). In December 2018, the Agency for Medical and Social Services was established under the Ministry of Healthcare, and implements a unified policy aimed at supporting disabled people and other socially vulnerable groups. Such institutional transformation has further medicalised the definition of ‘disability’, and social protection of disabled people was left to healthcare experts and medical professionals. Soviet disability policies and institutions still play a significant role in contemporary Uzbekistan, and in the next section I argue that the definition of disability in Uzbekistan is still based on the medical model of disability (see Section 1.1 for further discussion of this model).

Definition of disability in Uzbekistan

One in seven people (about 15%) of the global population have some form of impairment and about 80% of them are in low- and middle-income countries (WHO and World Bank 2011). The number of disabled people is expected to increase as the world population continues to grow. Although Uzbekistan is a developing nation with lower-middle income, as of 2020, 718,300 people disabled people reportedly received disability pensions and social benefits ([Gender Statistics 2021](#)). Interestingly, this official number accounted for only about 2% of the country’s population of almost 34 million people (Stat.uz 2021b). However, the UN and World Bank estimated that in 2020 there were 4.5 million disabled people in Uzbekistan, including 1.15 million people with severe impairments (UN Uzbekistan 2020). Such a big discrepancy may be explained by the lack of reliable and comparable data on disability prevalence in the country. Uzbekistan has

not conducted any population censuses since 1989 when it was still part of the Soviet Union, and both quantitative and qualitative evidence on disability has been scarce. I argue that there is a considerable underestimation of disabled people in Uzbekistan, not only due to the lack of survey data, but also because of a weak system of disability assessment and determination. This suggests a significant exclusion of disabled people from the national social protection system and denies them their right to formal representation in official statistics. Consequently, many disabled children and adults are believed to be hidden and thus are excluded from Uzbek society as equal citizens. Despite this shortcoming, Uzbekistan was one of the first of the Commonwealth of Independent States to adopt the Law On Social Protection of Disabled People on 18 November 1991, the main legislative tool for regulating disability issues in the country. According to this law, a disabled person is defined as

...a person who due to the physical dysfunction as a consequence of physical, intellectual, mental and sensory impairments was recognised as a disabled person in accordance with the procedure established by law and is in need of social assistance and protection (GoU 2008).²⁹

Internationally, there has been a move away from such purely medical definitions of disability towards the multifaceted International Classification of Functioning, Disability and Health (ICF) (WHO 2001). However, on 16 January 2021, a new Law on the Rights of Persons with Disabilities came into force, which defines a person with a disability³⁰ as:

...a person with persistent physical, intellectual, sensory or mental impairments in need of social assistance and protection, creating conditions for full and effective participation on an equal basis with

²⁹ Translated into English by the author from Article 3 of the Law No. 422-XII “On Social Protection of Disabled People in the Republic of Uzbekistan” from 18 November 1991 (GoU 2008).

³⁰ One of the novelties of this new law was a switch to a new terminology: “persons with disabilities”. See section 1.1 on “A note on disability terminology” in Chapter 1 for a detailed discussion of disability terminology.

others in the political, economic, social life of society and the state.
(Government of Uzbekistan 2021b: online)

However, both the old and new national definitions of disability are based on a purely medical approach to disability and conflate it with physical dysfunction or impairment (see Section 1.1 for a critical review of various models of disability). This is not compatible with the provisions of the UN Convention on the Rights of Persons with Disabilities (CRPD 2006), which in paragraph 5 of its Preamble recognises that:

disability results from the interaction between persons with impairments and **attitudinal** and **environmental barriers** that hinders their full and effective participation in society on an equal basis with others^[31] (CRPD 2006: online)

This internationally recognised CRPD definition focuses not only on impairments, but also on societal barriers that disable people. Until 7 June 2021 (GoU 2021), when it ratified the CRPD, Uzbekistan remained one of the few countries in the world which had not done so (United Nations Treaty Collections 2021). Uzbekistan is currently aligning its national legislation with the principles and provisions of the Convention. The legal definition of disability in Uzbekistan is still not in line with the CRPD, or the ICF which defines impairments as:

problems in body function and structure such as significant deviation or loss' e.g. deafness or paralysis while disability is regarded as an umbrella concept which arises through interaction among impairments, activity limitations and participation restrictions. (WHO 2001: 212-213).

The primary focus of this study is not to examine how impairments may restrict participation of disabled people, but to explore the attitudinal and environmental barriers inherent in civil society, community, and religious institutions. To conclude, legal documents in Uzbekistan provide a medical definition of disability which contradicts the

³¹ Emphasis added by the author.

principles and provisions of the CRPD (2006). In the next section, I will discuss linguistic aspects of defining and categorising disabled people in Uzbekistan.

2.4 Barriers to disabled people’s citizenship

Inaccessible public infrastructure

Most of the public infrastructure in Uzbekistan was designed and built during the Soviet era, when the needs of disabled people, particularly those with physical impairments and reduced mobility, were not considered. As a result, many buildings and public transport systems remain largely inaccessible for disabled people; this severely hinders their participation in public life. In 1991, the independent Uzbek state adopted the Law On Social Protection of Disabled People (GoU, 2008)³² which required both state bodies and the private sector to create necessary conditions for unhindered access of disabled people to social infrastructure. Article 12 provided economic accountability in the form of fines and penalties for failure to fulfil these obligations. Moreover, Article 9 of the same law required the construction sector to develop norms and rules for taking into account opinions of relevant public associations of disabled people, in agreement with the Ministry of Employment and Labour Relations of the Republic of Uzbekistan.³³ Article 6 of the Town Planning Code of Uzbekistan also requires “creation of conditions for unimpeded access for disabled people to social infrastructure facilities (residential, public, industrial buildings and structures, recreation areas, cultural and entertainment institutions and other facilities)” (GoU 2002: online). The Law On the Rights of Persons with Disabilities which came into force on 16 January 2021 also stipulates that “design,

³² The Law was amended in 2008 and lost its force on 16 January 2021 when the new Law on the Rights of Persons with Disabilities (GoU 2021) came into force.

³³ Since 22 February 2016 this ministry has been known as the Ministry of Employment and Labour Relations of the Republic of Uzbekistan.

construction and reconstruction of public buildings and objects, regardless of the organisational and legal form, should be carried out taking into account the needs of persons with disabilities” (GoU 2021: [online](#)) Apart from these laws, there are specific construction norms and regulations (SNiP) (GoU 2008), sanitary regulations and norms (SanPin) (GoU 2009), and a legal framework which guarantees accessibility for disabled people. The SanPin specifically mentions that “projects about facilities visited by disabled people must be coordinated with the Uzbek Society of Disabled People”.³⁴ Hence in theory, the development of public infrastructure has to include the adaptation of housing and means of transportation, communication and information for access and use by disabled people. Despite the fact that almost 30 years have passed since Uzbekistan gained its independence, social infrastructure remains largely inaccessible for disabled people and those with reduced mobilities.

Recent analysis conducted as part of the project “City for All” implemented by the Public Council under the *khokimiyat* (city administration) of Tashkent city revealed that 85% of buildings and social infrastructure facilities are not adapted for use by disabled people (Gorod.uz n.d.). In total about 70,000 disabled people and 300,000 elderly people live in the capital city. The monitoring of public transport in Tashkent showed that transport accessibility cannot be evaluated as “satisfactory” which has serious socio-economic consequences for disabled people’s livelihoods (Bakaeva and Muratova 2015). Lack of accessible physical infrastructure and reasonable accommodation violates the rights of disabled people and discourages them from participating in public life, education, labour and other activities, thus affecting the quality of their lives. For instance, inaccessibility of public buses in Tashkent makes disabled people dependent on taxi services which are

³⁴ Paragraph 1.2. of SanPin (GoU 2009).

the most expensive means of transport in Uzbekistan (UN Uzbekistan 2019: 86). Consequently, disabled people, particularly those with physical impairments, find themselves in forced social isolation, becoming highly dependent on others and deprived of urban citizenship.

The main reasons for the inaccessibility of public infrastructure are: dysfunctional decision-making mechanisms that do not consider the needs of disabled people and those with limited mobility, a lack of enforcement and ineffective state control, and a lack of public control over the implementation of legal accessibility requirements. Although Uzbekistan ratified the CRPD in 2021 ([GoU_2021](#)), national legislation still does not include the concept of “universal design” enshrined in the Convention. Although the existing legal base contains relevant rules and norms on providing accessibility, it does not comply with the CRPD principles. For instance, the Construction Rules and Regulations (SNiP) promote segregation of disabled children and adults by specifying separate regulations for specialised boarding schools and residential institutions, while the Uzbek Society of Disabled People is the only public organisation of disabled people invited for consultation on those construction projects which will be visited by disabled people. However, in practice, all kinds of public infrastructure should be accessible for persons with various forms of impairments.

Isolated and segregated low-quality education

Although Article 41 of the Constitution of Uzbekistan ([GoU_1992](#)) guarantees every citizen equal right to free general education, disabled children are disproportionately disadvantaged compared with non-disabled children. Starting from early childhood, registered disabled children have lower rates of attending pre-school education (about

20% lower than non-disabled peers), general secondary education (22% lower attendance rates) and high school and secondary specialised vocational education (46% lower attendance rates) compared with non-disabled children (UN Uzbekistan 2019: 133–134). Access of disabled people to higher education has improved since 2018 when the government introduced additional 2% admission quotas for people registered as belonging to disability groups I and II to enter national universities (GoU_2017). Nevertheless, physical and attitudinal barriers within universities, and a lack of sign language interpreters, textbooks in Braille and other assistive services and devices are making quality higher education inaccessible for disabled students (Yusupov 2019a). Children and adults with intellectual and mental impairments are particularly disadvantaged in their access to vocational and higher education, being framed as ‘mentally retarded’ or having ‘delays in intellectual development’ (Yusupov 2019d). For other impairment groups, choices for vocational training and future professions are limited to the repair of household appliances, shoemaking, sewing, accounting and basic computer skills.

According to a survey conducted by the UN agencies, 82.4% of participants indicated “health conditions and disability” as the main obstacles restricting access to education (UN Uzbekistan 2019: 136). However, I argue that inaccessibility of public educational institutions and lack of reasonable accommodation inhibit the opportunities to study on an equal basis with others. Moreover, the above-mentioned dry figures do not reflect the quality of education received by disabled children and adults. As of 2020, about 21,200 children in total studied at 86 specialised, sanatorium-type and boarding schools for disabled children (GoU_2020). These schools are all segregated institutions where children with sensory, physical, intellectual, and mental impairments are taught

separately depending on their types of impairments. In addition, about 13,300 children considered by the government to be ineligible to study in segregated educational settings due to ‘long-term medical treatment’ are sent to their homes where they receive low quality education on individual basis, socially isolated from their peers and society in general. Mainly, these are children with severely reduced mobility such as wheelchair users who cannot commute to school due to lack of accessible infrastructure. Thus, in addition to inequalities in accessing education between disabled and non-disabled children, there is an observable divergence in the level of education among different impairment groups. For instance, blind and visually impaired children have had better opportunities to receive quality education compared with children with significantly reduced mobility and/or learning disabilities who have had to homeschool.

Despite multiple government efforts to develop inclusive education in Uzbekistan since early 2000s, it is still embryonic. Nam (2021) identified numerous challenges that are constraining these efforts including: a lack of qualified personnel and adverse working conditions at mainstream schools (such as availability of professionally trained tutors or the restrictions on parents working as teaching assistants); inaccessible infrastructure of educational institutions; and deficiencies in the legal framework that should enable inclusive education (Nam 2019); and persistent negative attitudes both within schools (from teachers, parents and other actors) and in Uzbek society generally. The government boasts that in 2020 inclusive education was introduced in 18.4% of general secondary schools and that there are plans to increase this number to 51% by 2025 (GoU 2020). Based on official data, as of 2020 16.5% of all registered disabled children were enrolled in inclusive education at mainstream schools while 26.8% studied at segregated schools and 16.8% studied at home (ibid.). However, the reported data is unreliable as it includes

only those children who were registered by VKK commissions. Many children and adults may be illiterate but excluded by official statistics. The recent state data is also doubtful, as only in 2020 did the new law ‘On Education’ include for the first time the legal definition of inclusive education in Article 20:

Inclusive education aims to provide equal opportunities for all learners to study in educational institutions, taking into account the individual educational needs and the diversity of individual opportunities.³⁵ ([GoU_2020: online](#))

Yet, despite this legal recognition, Article 15 of the law lists inclusive education as only one form of education rather than a universal concept of “inclusion, equality, and non-discrimination on the basis of disability” (World Bank 2021: 8). Importantly, the choice of this form of education is still restricted by the medical-psychological-pedagogical commissions (PMPKs), which retain all the power to select education for each disabled child.

Inadequate standards of living and social protection

Zagirtdinova (2005) argued that during the transition from a planned to a market economy the Uzbek government has covertly applied retrogressive austerity measures to limit the number of those eligible for state-guaranteed social protection and rehabilitation. As discussed in the previous section, many disabled children and adults have been excluded from official statistics without any access to disability services or benefits guaranteed by the state. In the Soviet Union disabled people were assigned to two main types of state benefits – disability and survivor pensions, as well various grants for children with congenital impairments (Madison 1989). These benefits were financed by local budgets in each Soviet Republic. Eligibility to receive them and the amount of payments were

³⁵ Author’s translation.

determined by the cause of impairment (work-related or non-work-related), length of work experience and other related factors. If in the Soviet Union the social benefits system tended to be universal, the coverage of social protection schemes has considerably decreased after the government of independent Uzbekistan introduced poverty-targeting measures (Coudouel and Marnie 1999). For instance, UNICEF Uzbekistan (2020: 41), based on the Listening to the Citizens of Uzbekistan (L2CU) survey results, estimates that child disability benefit currently reaches only 52% of children with severe impairments aged 3-17, despite state guarantees to provide it for all disabled children on a universal basis.

As of 2020, child disability benefit amounted to 513,350 soums (less than US\$50) per month (GoU 2020) which is inadequate for basic needs even before considering the extra costs faced by households with disabled children. Starting from 1 March 2019, mothers of children registered with congenital impairments were eligible for a limited social benefit of 243,300 soums (less than US\$25) per month (GoU 2019) upon reaching pension age³⁶ if without an employment record. This is unreasonable as caregivers need financial and other kinds of support during the early stages of child development. Based on Article 39 of Uzbekistan's constitution, "pensions, allowances and other kinds of welfare may not be lower than the officially fixed minimum subsistence wage" (GoU 1992: online). However, in practice the minimum living wage is not legally fixed, while the average monthly nominal wage in Uzbekistan in 2020 was 2,660,000 soums (Stat.uz 2021a) (about US\$250). Moreover, the commodity bundle required for a working-age person amounted to 2,157,000 soums (about US\$200) per month in December 2020 (Istemol.uz 2020) which does not reflect the extra costs of disability. In general, due to

³⁶ As of 2020 the pension age in Uzbekistan for women was 55 and for men 60.

the lack of information about existing social protection schemes, barriers to disability determination including red tape and corruption, additional costs for transportation and inpatient treatment required for preliminary VTEK assessment, only 46% of children and adults of working age with severe impairments are able to access state-guaranteed disability benefits. No statistically significant difference was observed between men and women³⁷ (UNICEF Uzbekistan 2020: 37).

Adult disability benefits for persons over 16 are limited to those who are assessed by VTEK as unable to work. VTEK still applies the ability to work as a proxy for disability assessment and, therefore, only 162,200 registered disabled adults were recognised as “capable of performing certain types of work” in 2020 (MELR 2020). VTEK determines the degree of loss of working capacity and issues a disability certificate which labels about 75% of all registered disabled adults as “unfit for work”, “unemployable” or “fit for work in specially created conditions” (UN Uzbekistan 2019: 148). For instance, only 7,200 disabled people in group I (with severe impairments) were recognised by VTEK as “employable” compared with 107,900 people in group II and 49,400 people in group III. The purely medical approach to disability assessment used by VTEK focuses on impairments but the problem is not in functional limitations of the body, but in attitudinal and infrastructural barriers including widespread discrimination on the basis of disability in the labour market and inaccessibility of workplaces. As access to disability benefits is limited to those who are assessed by VTEK as not “capable to work” it leads to exclusion from the open labour market. Based on this logic, the Uzbek government cancelled benefits for disabled people in group III in 2011 as they were viewed as fit for work. Thus, if formally employed, disabled people in groups I or II fear being transferred to

³⁷ Based on the results of the L2CU household survey in 2018.

group III and hence losing access to benefits during a VTEK re-examination. The situation analysis carried out by UN Uzbekistan (2019) showed that 40% of registered disabled people are employed in the informal sector where they earn less than half the income of non-disabled people. Thus, VTEK examination is one of the biggest barriers and disincentives to decent employment of disabled people in the formal sector. The VTEK record of discrimination in awarding disability certificates contradicts Article 27 of (CRPD 2006) which recognises the right of disabled people to work on equal basis with others. Due to institutional barriers and widespread disability discrimination in employment, disabled people are about four times less likely to find a job and only 7.1% of those of working age were officially employed in 2019 (UN Uzbekistan 2019: 147). Importantly, only 5.8% of disabled people were employed in rural areas while disabled women are more vulnerable than men: 4.4% of women versus 8.9% of men were employed (ibid.). According to the data provided by the Ministry of Employment and Labour Relations of Uzbekistan, only 21,100 out of 162,200 “employable” disabled people were officially employed, which is only about 6% of all registered disabled people of working age (MELR 2020).

Although national legislation on the rights of disabled people requires state institutions and private enterprises with over 20 members of staff to reserve at least 3% of jobs for disabled people, the employment quota is barely enforced in practice despite fines and penalties for those who do not comply. The Uzbek government adopted several legal acts related to improving the state support system for disabled people (GoU 2017), focused on assisting disabled people’s organisations and their specialised business enterprises which employ disabled people. Nevertheless, disabled people, particularly girls and women and those living in rural areas, eke out a living in Uzbekistan. Economic

participation of disabled people is constrained by negative perceptions and attitudes regarding their abilities, and discrimination in the Uzbek labour market which is already challenged by high unemployment and a lack of decent job opportunities even for non-disabled people.

Conclusion

Chapter 2 has examined the unique political, economic, social, and cultural contexts of post-Soviet Uzbekistan and located disabled people within those. Despite Uzbekistan gaining its independence in 1991, authoritarian ideologies and practices (which are different in content from those of the communist regime but similar in form) still control political, civil, and religious domains in the country. Likewise, the Soviet legacy is largely felt in national disability policies and programmes which use work capacities as a proxy for determining the ‘level of disability’. National legislation still defines disability as a medical condition to be overcome through rehabilitation, and portrays disabled people as mere recipients of social welfare and medical care. Moreover, disability terminology and categorisation in Uzbek does not distinguish between disability and impairment, which is possible in British English within the social model of disability. Although Uzbekistan ratified CRPD (2006) in 2021, the legal framework is still not aligned with the principles and provisions of the Convention. As a result, purely medical and productivist definitions of disability as well as bureaucratic obstacles in obtaining an official disability status exclude many children and adults from both national data and policies. Disabled people remain invisible and face numerous attitudinal and infrastructural barriers to achieving their political, economic, and social rights and equal citizenship alongside non-disabled people. In the next chapter, I develop a conceptual framework tailored to the Uzbek

context that will enable systemic analysis of all the barriers disabled people encounter on their path to achieving citizenship.

Chapter 3. Methodology: emancipatory research with disabled people in Uzbekistan

Introduction

Building on the seminal works of disability studies scholars (Barnes 1992b, 1996, 2003; Oliver 1992; Stone and Priestley 1996a; Zarb 1992) I applied an emancipatory disability research paradigm in this thesis. This meta-methodology involved a local DPO, ‘SHAROIT PLUS’, and grassroots disabled activists in co-producing knowledge and practice to uncover their perspectives on disability and citizenship. In contrast to conventional research methods, where a researcher (usually non-disabled) seeks to make an inquiry *on* or *about* disabled people, I argue that doing emancipatory research with disabled people and their organisations can bring more insights into the barriers that disabled people seeking to assert citizenship in Uzbekistan are facing. Importantly, an emancipatory position aims to explore not only the nature of social change, but also how and in what circumstances it might happen. Therefore, in this study I attempted to do emancipatory research *with* disabled co-researchers and participants in Tashkent city.

In the first exploratory phase of inquiry, I conducted semi-structured qualitative interviews with disabled people together with disabled co-researchers from DPO ‘SHAROIT PLUS’. During the second phase, I set up a co-operative inquiry with a group of adults with mainly physical impairments, with whom we organised a series of participatory workshops. These workshops involved participatory video as an umbrella method encompassing other participatory methods. Moreover, I did participant observation with adults with visual and hearing impairments in various locations of the city including the religious sites and segregated residential areas for blind and deaf communities. Doing this fieldwork research in several phases and locations allowed me

to learn from each phase and place of inquiry and the associated methodology. In this chapter, I critically reflect on a variety of methodologies that I used to understand the diverse lived experiences of people with various impairments in Tashkent city and its suburbs. Researching such experiences was challenging due to the Soviet legacies of segregation of disabled people by type of impairment. Therefore, I chose specific research methods due to the pragmatics of accessing different contexts with different people. Moreover, being a non-disabled and privileged researcher raised additional challenges in terms of my positionality. My role in this research changed considerably over the course of the fieldwork, from an outsider qualitative researcher to an insider advocate for the rights of disabled people in Uzbekistan. Thus, I describe various challenges of being at once a researcher, co-worker, friend, journalist, and a disability rights advocate.

3.1 Research design

Why emancipatory disability research?

For a long time, disabled people in Uzbekistan have been excluded both from research about their lives and as researchers themselves. Research on disability has been dominated by non-disabled experts in the field of medical rehabilitation, social protection, and other related fields. This was largely due to a purely medical definition of disability in the national legislation which conflated disability with illness, framing disabled people merely as patients and/or recipients of social welfare. However, Oliver (1992) condemned positivist medical research approaches to disability as making a limited contribution to policy and the wellbeing of disabled people. As a logical extension of this critical argument, he advocated changing disability research relations through the development of a new paradigm of *emancipatory disability research*. This paradigm views ‘disability’ not as an individual or medical problem but as a form of social oppression and facilitates

political and social action to challenge this oppression. Critical disability scholars like Oliver (1992), Stone and Priestley (1996) drew inspiration from Chambers (1983, 1997) who advocated a reversal of unequal power relations in research and learning predominantly done by outside ‘experts’ by “putting the last first”. In this emancipatory paradigm, the experience and knowledge of disabled people would count for more than those of rehabilitation experts, social protection specialists or non-disabled researchers.

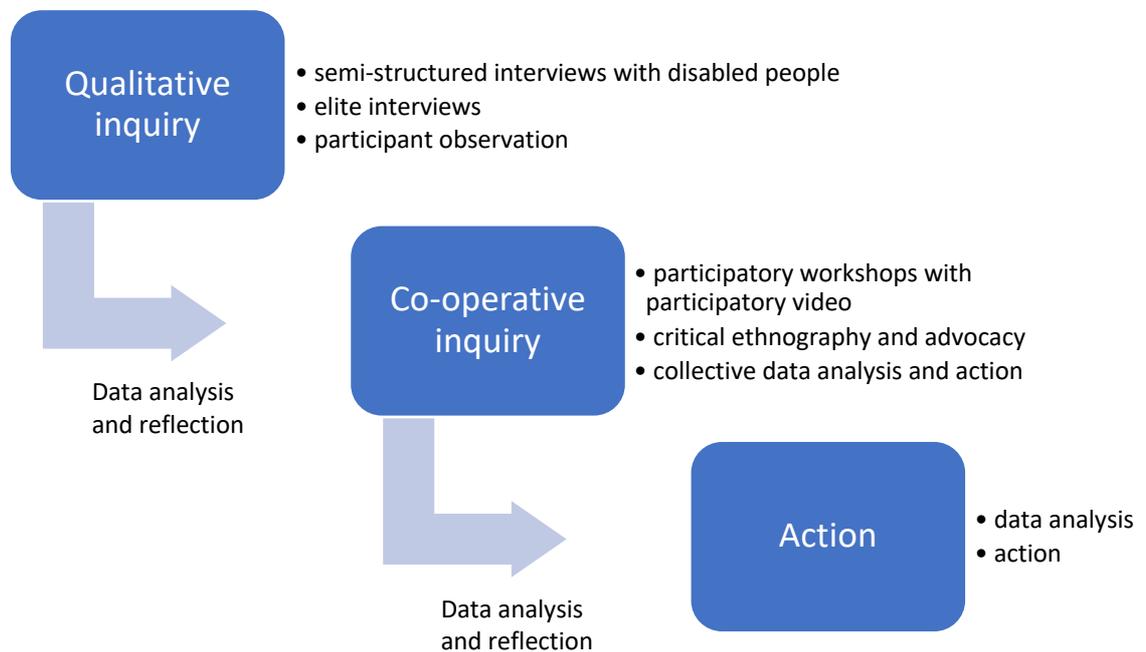
Shakespeare (1993: 249) stressed the need for engagement of disability researchers in praxis – “the unity of theory and practice within struggle” – against the oppression of disabled people. In other words, the research process and outcomes should have a cathartic and catalytic impact on existing social inequalities (Goodley 2016: 28). Thus, emancipatory disability research should tackle social oppression and discrimination against disabled people through building equal partnerships and alliances between non-disabled researchers and disabled people to promote inclusion and social change. Therefore, I adopted *critical ethnography* as an underlying approach. The emancipatory disability research approach shares a lot with critical ethnography, as both are reflective processes that do not simply produce knowledge but use it for social change. Unlike the conventional ethnographer who asks: “What is?” questions and studies culture by describing it and producing a “thick description” (Geertz 1973), a critical ethnographer asks: ‘What could be?’ and examines culture in order to change it by advocating the emancipation of marginalised groups (Madison 2011; Thomas 1993). Thomas (1993) warned that critical ethnography should not be associated with mere criticism but should be accepted as a “conventional ethnography with a political purpose” (ibid.: 4). In critical ethnography, ‘disability’ like ‘race’ or ‘gender’ is understood as a culturally and socially constructed concept, originating in cultural norms and ideology. Rather than taking this

cultural reality for granted, as a critical ethnographer I dug deeper into analysis, and through self-reflection tried to uncover local meanings, relationships and understandings which may marginalise disabled people and deprive them of equal citizenship. Having defined what I mean by emancipatory disability research and why I adopt this critical approach, I will now move on to discuss the research process.

Research process and methods

The fieldwork was conducted in three phases of exploratory qualitative inquiry, co-operative inquiry, and action; it included phases in between of self-reflection and analysis from 1 June 2018 to 20 September 2019 (see Figure 8).

Figure 8. Research phases and associated methods



Source: Author's illustration

Semi-structured interviews with disabled people

I started fieldwork in Tashkent city in June 2018 by conducting interviews with disabled adults aged over 18 (with physical, visual, and hearing impairments; learning disabilities; and multiple forms of impairments) as well as parents and relatives of disabled children and adults. The interviews with disabled participants were semi-structured and conducted in pairs with my co-researchers with the aim of collecting life story narratives and identifying participants for co-operative enquiry. Four female co-researchers with physical impairments from NGO 'SHAROIT PLUS'³⁸ participated in conducting semi-structured interviews. I worked with them to interview most participants with physical impairments and learning disabilities as well as the representatives of the mahalla committees. Other interviews with participants with visual and hearing impairments were conducted solely by me due to the communication and infrastructural barriers that my co-researchers with physical impairments encountered during the fieldwork.

In total, we managed to interview 52 disabled people and seven parents and/or relatives of people with mainly learning disabilities. Among interviewees with multiple forms of impairments were deafblind people, and those with combinations, such as hearing and physical and/or learning disabilities. 14 elite interviews were also conducted with chairpersons and staff of mahalla committees, government officials and religious figures (male and female imams), as well as international experts working in the field of disability and development. In total, 73 interviews with disabled and non-disabled people were conducted.

³⁸ See the 'Why do disability research in Uzbekistan?' section in the Introduction to learn more about DPO 'SHAROIT PLUS' and my involvement in that organisation.

Table 1. Number of disabled and non-disabled interviewees

		Type of impairment/interviewee							
		Physical	Visual	Hearing	Learning	Deafblind	Relatives	Elites	Total
Gender	Male	6	10	5	4	0	0	6	31
	Female	14	5	4	2	2	7	8	42
	Total	20	15	9	6	2	7	14	73

Source: author

Initially the aim of my study was to explore how age, gender, type of impairment and socio-economic background promote or hinder participation of disabled people in their local communities. Therefore, together with co-researchers from ‘SHAROIT PLUS’ we applied purposive sampling using their existing networks. Although we tried to have a balanced sample with diverse participants based on various factors, we ended up with physical impaired interviewees as the largest group (n = 20). The ‘SHAROIT PLUS’ network was limited mainly to girls and women with physical impairments like my four co-researchers who were women with physical impairments.³⁹

As a result, female interviewees with physical impairments were the biggest group in the sample. Snowballing through ‘SHAROIT PLUS’ with disabled co-researchers led me to participants solely with physical impairments. I had to search for participants with other impairments through other channels and via other gatekeepers. Similarly, a male blind gatekeeper at the Society of the Blind pointed me to potential interviewees with visual impairments. Besides types of impairment, the gender of a gatekeeper played another crucial role which is reflected in the overrepresentation of women among participants with physical impairments, and men among participants with visual impairments, even

³⁹ Three of the co-researchers used wheelchairs and one co-researcher used walking frames.

though I did explicitly ask male gatekeepers to indicate potential female interviewees with visual impairments. Such a distribution clearly reflects the fragmentation of the Uzbek disability community by impairment type and gender. The sample of disabled interviewees also reflects underrepresentation of people with hearing, learning and multiple impairments (deafblind) who are less visible in contrast to those with physical and visual impairments. I will discuss this further in Chapter 4 in terms of internal power inequalities and hierarchies within and between existing disability NGOs headed by disabled or non-disabled elites. Therefore, I avoided selecting disabled people in leadership positions in disability NGOs. Although it would be interesting to interview these disabled and non-disabled elites, their voices were being heard by state institutions and international organisations. My purpose was to include the most marginalised disabled people who were not or could not be active within dominant disability organisations and whose voices were suppressed by those in positions of power.

Semi-structured interviews with disabled people explored their personal understandings and lived experiences of disability, societal attitudes towards their disability, the role of family, self-help groups, mahallas, religious institutions, and disability NGOs.⁴⁰ These interviews lasted on average for about an hour and were conducted mainly at participants' homes. The majority of disabled interviewees did not have any experience of being interviewed and recorded so they felt nervous during the interview and considered it to be a form of examination. Moreover, the formality of the interview process made some participants cautious as their tone changed considerably after the recording was stopped.

⁴⁰ See the interview guide we developed together with co-researchers to interview disabled participants in Appendix 2.

Where necessary I did not record the interview and instead made brief notes during the informal conversations.

Another challenge was the fact that we conducted most of the interviews in the households of disabled participants and could not avoid the presence of family members. In many cases, parents or other close relatives intervened in the interview process and participants could not openly discuss the issues which troubled them within their families. More often it happened with participants with learning disabilities when mothers took over the role of the interviewee and talked on behalf of their children even though they were already grown up. Consequently, I ended up interviewing mothers (n=7) of participants with learning disabilities which is also important data. Through initial interviews we also selected participants for further co-operative inquiry where we tried to establish a communicative space to avoid parental intervention. These interviews provided initial data for understanding the context within families (out of scope of this thesis as my primary focus was to explore the role of various institutions in achieving citizenship).

Elite interviews

Prioritising the lived experiences of disabled people may exclude powerful groups whose perspectives may also be important (Beazley and Ennew 2006). Therefore, I tried to conduct elite interviews with non-disabled groups such as local mahalla leaders, religious figures, service providers, businesspeople, government officials, representatives of international organisations and NGOs.⁴¹ These non-disabled elites were asked about their understanding of ‘disability’ and how they describe it in their own words, their

⁴¹ See Appendix 5 for the detailed list of elite interview participants.

professional experience in supporting disabled people, the problems disabled people are facing in their daily lives, the role and attitudes of Uzbek society in solving these problems and other related questions.⁴² Elite interviews were quite different from semi-structured interviews with disabled participants in terms of securing access to powerful groups, using collaborative approaches to the research and complying with ethical codes (Smith 2006). Initially, I thought that it would be difficult to approach disabled people for the purposes of interviewing. But on the contrary, interviewing non-disabled elites turned out to be more challenging in terms of securing access and establishing trustful relationships. Although I established connections with several relevant government officials during my work at JICA, it was quite challenging to gain access to them as an independent researcher. Even in situations when such access was secured, the elite groups were inclined to give sanitised, politically correct or vague answers and avoided sincere discussion. They were reluctant to give their own opinion and spoke defensively, protecting the government policies of support for disabled people.

It was particularly difficult to gain access to the chairpersons of mahalla committees and the Republican Council for the Coordination of Activities of Citizens' Self-Government Bodies (referred to as the Mahalla Fund). Even though I was a local researcher who spoke Uzbek, and an intern at the Department of Ethnology and Anthropology under the Institute of History of the Academy of Sciences of Uzbekistan during my fieldwork in Tashkent, I could not interview anyone from the Mahalla Fund and did not get any response to my letter of interview request, sent on behalf of the Academy of Sciences. I encountered similar difficulties when trying to interview mahalla committee chairpersons. Even those who agreed felt extremely nervous, particularly when I provided

⁴² See elite interview guide in the Appendix 3.

them with the information sheet and consent form, and this raised more suspicions when they saw the name of a foreign university (see Section 3.3 for further discussions on ethical considerations). Some mahalla chairpersons even rejected my interview invitation arguing that it was too sensitive for them to be tape recorded, even though I said it was not required.

In the process of the fieldwork, it turned out that many mahalla chairpersons were retired law enforcement officials for whom public security is of utmost importance. Thus, they perceive any strangers as a threat to the security of the mahalla, particularly with reference to interviewing for data collection purposes. As one of my disabled co-researchers argued, despite their independent legal status as a self-governing body, mahalla committees are heavily dependent on the local government:

Although mahalla committees are NGOs, chairpersons cannot overstep the boundaries defined for them from above. They also lack competence to respond to your questions. They usually work with a population of about 2,000-3,000 people living in the mahalla and should be aware of everything. But when something is out of their control, they will refuse to be involved in that issue.

Moreover, as mahalla committees are subordinate to a local government (*khokimiyat*), chairpersons are usually afraid of saying something inappropriate and facing repercussions from the higher authority. This observation confirms my findings in Chapter 6 where I argue that, in practice, mahalla committees are not bottom-up self-governing community institutions but strictly controlled by *khokimiyats*.

Co-operative inquiry with people with physical impairments

Reflection on the gaps and limitations of learning from qualitative interviews in the first phase led me and my co-researchers to the second phase of inquiry. Semi-structured

interviews with disabled people were a good start in understanding their lived experiences but in a single conversation it was challenging to gain trust (particularly of those with physical impairments), even in the presence of a disabled co-researcher. Therefore, in the second phase of the research, I set up a *co-operative inquiry* which is “a form of second-person action research in which all participants work together in an inquiry group as co-researchers and co-subjects” (Heron and Reason 2008: 366). Co-operative inquiry requires active involvement of two or more persons to research an issue through their own experience of it with the purpose of

understanding their world to make sense of their life and develop new and creative ways of looking at things; learn how to act to change things they might want to change and find out how to do things better. (Heron and Reason 2001: 179).

I chose participatory video as an umbrella methodology as it includes all the above-mentioned cycles and provides a communicative space for disabled people, enabling them to reflect critically on their social situation. Participatory video is “a process of media production to empower people with the confidence, skills and information they need to tackle their own issues” (Shaw and Robertson 1997b: 26). Close to the end of the first exploratory phase in Tashkent on 20 July 2018, I organised a participatory video (PV) (Shaw and Robertson 1997b) workshop session with my co-researchers from ‘SHAROIT PLUS’. I decided to use participatory video due to its community-building potential (Mistry and Shaw 2021; Shaw 2015b) for people with physical impairments. Unlike blind or deaf communities who used to be segregated in their ‘mahallas of blind people’ and ‘towns of deaf people’ (see Chapter 6), people with physical impairments have been scattered around the city, lacking strong community identity and agency.

In the co-operative inquiry phase my co-researchers engaged in a step-by-step exercise of familiarising themselves with the video equipment and building communication confidence, establishing inclusive dynamics (Shaw and Robertson 1997b). I wanted my disabled co-researchers to clearly understand the method and assist me in the actual participatory video workshops with disabled participants in the next co-operative phase (summer 2019). We then selected the participants for our participatory video workshops. Initially, we had two separate participatory video groups of adults, with physical and learning disabilities respectively. The first group met twice (on 31 July and 14 August 2018) while the second group met only once. PV activities were implemented mainly with participants with physical impairments over progressive phases starting from group building, mediating participants' exploration of their situation, surfacing their agendas with the use of video and finally influencing action (Shaw 2018).

Table 2. Disabled participants in participatory video workshops

Gender	Impairment	Equipment	Type	Disability group	Year of birth	Mahalla
male	physical	wheelchair	acquired	1	1993	Yangi Zamon
female	physical	n/a	acquired	1	1983	Shukrona
female	physical	wheelchair	acquired	1	1976	Jurabek
female	physical	n/a	congenital	2	1997	UzBum
male	physical	crutches	acquired	1	1984	Yashnobod
male	physical	wheelchair	congenital	1	1990	Jurabek
female	physical	wheelchair	congenital		1984	Katta Olmazor
male	visual	white cane	congenital	1	1990	Yangi Zamon
female ⁴³	physical	wheelchair	congenital	1	1972	Bobodehqon

⁴³ My co-researcher from NGO 'SHAROIT PLUS' who assisted me in organising the participatory video workshops.

Source: author

In total, we organised more than 20 participatory workshops of 2-3 hours each. Participatory video was applied as an umbrella methodology and included other participatory methods such as river of life, role plays and community drama, drawing, mahalla/community mapping, transect walks to check the accessibility of public infrastructure (social housing, parks, theatres, museums, universities, libraries, public transport, and so on), and various power analysis methods (see Table 3). Through a series of workshops, we tried to build mutual trust, confidence, and reflect together on matters which were most relevant and important to them. These regular participatory workshops attempted to enable participants to go deeper into the critical analysis of their social situations and develop a sense of belonging to a community of peers. We had four short cycles of self-reflection, and produced four shot-by-shot films/documentaries/drama and more than 300 videos.

Table 3. Participatory methods used in the research project

Method	Process	Explored issues
River of life	Drawing a river of life on a flip chart to show big things that mattered and changed direction. Each river is then displayed and presented verbally in small groups.	Personal learning about oneself as well as about other participants.
Photovoice (Photography)	Taking photos that reflect situations, conditions, or problems encountered in daily life which are then displayed and presented to trigger group discussion.	Unearthing sensitive or neglected social issues that might not be accessed through other methods.
Role plays and community drama	Taking 'roles' of individuals or institutions involved in disability issues or related situations.	Analysing power relations and identifying changes to be made.
Social (census) mapping	Mapping of populations, social groups, health and other household characteristics.	Identify key social groups (e.g. isolated disabled people) and

		processes, different needs and preferences.
Problem tree	Drawing a tree where pods are the problems; the branches that hold them are immediate causes; the large branches the next level causes; the ground is the political systems and values that are the context for structural causes.	Collective and detailed analysis of causes at various levels of a problem related to disability as a form of a social oppression.
Peeling the onion	Doing problems analysis by drawing three concentric circles where the spaces between circles represent individual, family, community, institutional and systemic levels.	Collective analysis of power issues contributing to the problem and reducing the problem to find ways to change existing situation.

Source: Adapted from Chambers (2002), Loewenson *et al.* (2014), Hunjan and Pettit (2011)

The participatory methods had great potential for building the collective agency of people with physical impairments at the community level, but we also had several challenges. One of the major obstacles encountered was the participatory workshop venue. As discussed in Section 2.4, inaccessibility of public infrastructure and transportation (Bakaeva and Muratova 2015) is one of the biggest barriers for people with physical impairments living in Tashkent. Mahalla committee premises also turned out not to be fully accessible for participants with reduced mobility. Moreover, participants considered mahalla committees as unsafe and unsuitable for open discussions due to possible interventions by mahalla chairpersons or staff. We eventually found a safe space at Sanvikt Arts Centre for Disabled Children which turned out to be an optimal location for many participants. Nevertheless, I had to cover all the transportation costs⁴⁴ or give a lift to many participants in my private vehicle so that they could travel from their homes to the workshop venue and back. Without this transportation assistance, they would not be

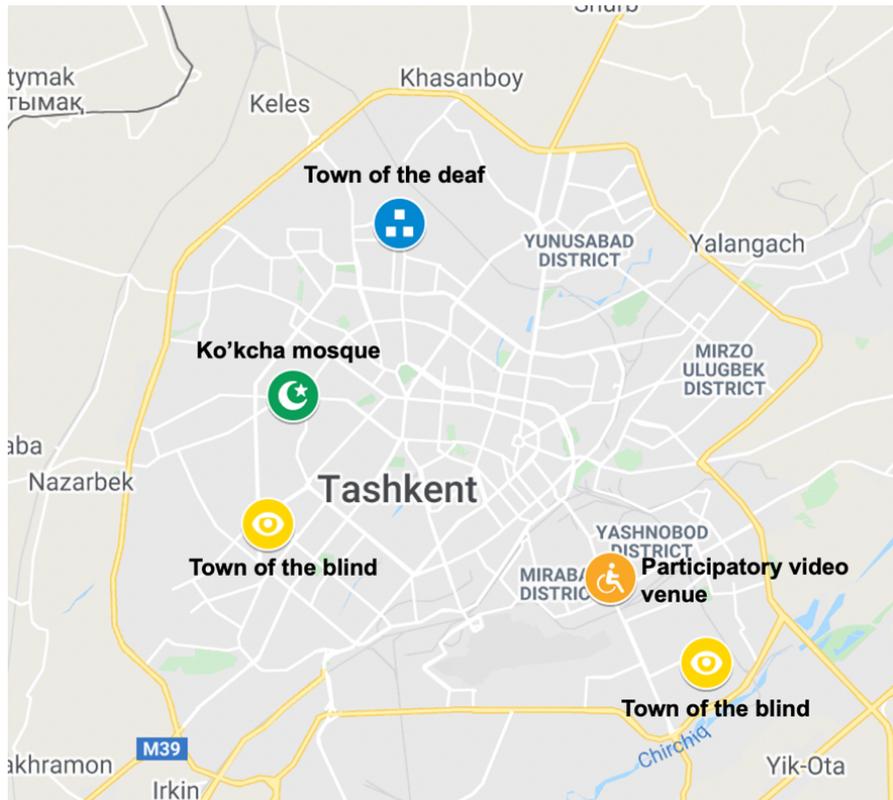
⁴⁴ I received a fieldwork grant as part of the Civil Society Scholarship Award (CSSA) from the Open Society Foundations.

able to participate in the workshops due a lack of private funds to cover expensive taxi services. So far, this section has focused on my participatory research activities with adults with physical impairments. The following section will discuss my interactions with people with visual and hearing impairments during the fieldwork in Tashkent.

Critical ethnography with blind and deaf communities

I used participant observation as a critical ethnography method, thereby treating anything I saw, heard or encountered during fieldwork as research data (Slater, Tacchi and Hearn 2003). I regularly documented detailed observations of private spaces (families and households of disabled people) and public spaces (local community centres, religious spaces such as mosques, shrines, or holy sites), as well as government institutions, during cooperative inquiry and dissemination phases. During both phases of my fieldwork in the summers of 2018 and 2019, I used participant observation as my main method of collecting data by ‘hanging out’ with blind, visually impaired, deaf, and hard-of-hearing people. If in the first exploratory stage I acted more as a conventional ethnographer, in the second phase I conducted critical ethnography and published actively in the local media to advocate for disability rights. I kept a diary where I continuously reflected on my research experiences with disabled co-researchers and participants. As a result, I produced three diaries upon completion of two fieldwork phases in Tashkent city. All field notes were transcribed in English and constitute raw research data. In Tashkent, my field sites were mainly the small, segregated towns of blind people and deaf people in Mirabad, Chilanzar and Olmazor districts of the city (see the fieldwork location map) as well as local mahalla communities, charity events, and so on.

Figure 9. Main fieldwork sites in Tashkent city



Source: Google Maps with author's adaptation.

Major disability organisations such as the Society of the Blind, Society of the Deaf and the Uzbek Society of Disabled (described in detail in Chapter 4) have their central boards in Tashkent and from there coordinate the activities of their regional, city and district branches. I observed that central planning is still a dominant approach to decision-making within DPOs. Members of the three dominant disability organisations have had limited communication and cooperation with each other. During the Soviet period blind and deaf people settled in impairment-specific communities around their specialised production enterprises under their respective organisations and formed so-called '*towns of blind people*' and '*towns of deaf people*' (see Chapter 5 for a detailed analysis of the '*mahalla of blind people*'), while persons with learning and mental impairments have not been really represented by formally registered organisations other than by a few self-help

groups for parents of disabled children. Figure 9 above shows the main sites where I conducted fieldwork phases, adapting research methods to what was appropriate to the different socio-political contexts (see Section 3.2 for a detailed discussion of methodological challenges and limitations).

Moreover, my fieldwork coincided with the start of a project on religious education and raising awareness of deaf and blind people about Islam implemented by the Muslim Board of Uzbekistan (MBU) and the city *khokimiyat* (administration) from early 2018. Therefore, I had an opportunity to participate in weekly meetings and various religious events with deaf and blind people at mosques (mainly Ko'kcha mosque) and the premises of the Society of the Blind. I engaged with these people as a researcher and tried to understand how blind and deaf communities as well as religious institutions and their representatives are creating new concepts of disability and citizenship through Islamic culture and moral values. These spaces also allowed me to interview blind and deaf people, male and female imams (*otin oyi*), and *khokimiyat* officials. I could also listen to various religious lectures related to disability and Islam and participated in Q&A sessions where disabled people and others could put related questions to invited religious experts. Participation in religious meetings with blind and deaf people at mosques, particularly Ko'kcha mosque, provided me with data on how disabled people construct specific forms of citizenship achieved by disabled people through the prism of Islam (see Chapter 7).

Data analysis and reflection

After the first phase I conducted data analysis and reflection on interviews transcribed in Uzbek and/or Russian. Based on the preliminary data I carried out a thematic analysis, “a method for identifying, analysing and reporting patterns (themes) within data” (Braun

and Clarke 2006: 79). I applied an inductive (bottom-up) approach to coding and identifying patterns and themes which captured important facts about the data and enabled responses to the research questions (ibid.). The criteria for identifying relevant themes were not based on their quantifiable frequency in the data but on the extent of their importance to my disabled co-researchers and research participants. I followed the recursive phases of thematic analysis as outlined by Braun and Clarke (2006): familiarising myself with my data; generating initial codes; searching for themes; reviewing themes; defining and naming themes; receiving feedback from disabled co-researchers on the identified themes and producing the dissertation.

Moreover, I used secondary data such as state archives, official documents (such as laws and other legislative acts) related to disability, quantitative data such as official state statistics, grey literature (such as reports and policy papers) from international organisations and NGOs who have worked or are working in the field of disability and development, as well as other sources of relevant information. To assist me in this iterative process of data analysis I used NVivo qualitative data analysis software (Bazeley and Jackson 2013). All the interview transcripts, ethnographic free writing and secondary data constituted raw data that was imported into NVivo 12 and coded (Bazeley and Jackson 2013). In the process of coding and writing empirical chapters I was in regular contact with my disabled co-researchers and participants in Tashkent (via Zoom during the COVID-19 pandemic),⁴⁵ which enabled us to identify the issues of most importance and relevance to them. All the research methods that I have discussed so far raised ethical

⁴⁵ My initial plan to make a follow-up trip to Tashkent in summer 2020 failed due to the outbreak of the COVID-19 and associated restrictions on overseas travel. Therefore, I had to organise online workshops on Zoom to receive feedback and reflect together with my disabled co-researchers and participants.

concerns in the context of my fieldwork in Tashkent which I discuss briefly in the following section.

3.2 Ethical considerations

Ethics in qualitative interviews

Doing research with disabled people in the context of Uzbekistan required careful consideration of ethical principles and standards so that the research was inclusive of participants with various impairments. Reasonable accommodation was provided for participants with physical impairments to ensure that interviews, participatory workshops, and other research activities were accessible for them. For participants with visual impairments the information sheet⁴⁶ was read out loud and their verbal consent was recorded. Where possible, blind and visually impaired participants used their own stamp to sign the consent form. My disabled co-researchers witnessed the process and also signed the consent form. For participants with hearing impairments, sign language interpretation or other communication adaptations were provided and informed consent was gained through a sign language interpreter. For participants with learning disabilities, the information sheet and consent form were explained in easy-to-read formats in a very lay local languages (Uzbek or Russian). In cases where participants had learning disabilities I complied with a professional code of conduct for research with disabled people – the Ethical Guidance for Research with People with Disabilities (National Disability Authority 2009).

⁴⁶ I developed an information sheet and consent form based on the samples provided by the University of Sussex C-REC. These were initially prepared in English and then translated into Uzbek and Russian. These documents provided full information about the research project and what was requested from the participants, potential risks, benefits and exclusion criteria, my personal contact details, and other relevant information. See Appendix #1.

However, widely acknowledged ethical principles such as self-determinism, non-maleficence, justice, and beneficence appeared to be foreign to disabled co-researchers and participants in Uzbekistan. Interestingly, I could not find any information regarding the existence of research ethics committees or even internal codes of ethics within Uzbek academic institutions. Therefore, I was careful when applying these concepts in a politically authoritarian context (Wall and Overton 2006). Self-censorship, which is common within Uzbek society and media (Shafer and Freedman 2003), was another problem as the interviewees, particularly non-disabled elites in the government and mahalla committees, provided socially desirable (Veldwisch 2008) or politically correct answers that were expected from them by powerful groups. Paperwork related to gaining informed consent turned out to be counterproductive with non-disabled elites. As discussed earlier, mahalla chairpersons were reluctant to sign the forms to avoid possible repercussions from the authorities above. However, in most cases there were no such problems with disabled participants who were not afraid to sign the consent form without any payments in return after I provided a full verbal explanation of the research purpose and what was expected from them. Disabled interviewees were not used to being asked for their opinion and therefore it was crucial to establish a mutual relationship of trust between myself, disabled co-researchers and research participants to let them freely discuss issues they were encountering in their daily lives. Given the power dynamics between myself and the participants, I asked them not to respond to any question that they did not feel comfortable with to ensure that they were not coerced and did not overshare their lived experiences of disability.

It turned out that many participants did not know about the concept of securing anonymity and confidentiality in the research. For instance, these ethical concepts were disputed by a blind interviewee, Ulugbek,⁴⁷ from another perspective:

I did not like your interview format. Choice should be made available to interviewees whether they would like to keep their information anonymous or confidential. It does not matter for me because if a person says something he should bear responsibility for the opinion that he expressed. It also affects the quality of research.

In other words, according to Ulugbek, providing anonymity to interviewees would enable them to say whatever they want, thus leading to responses not backed up by evidence.

I felt weird as if I was an ear (*quloq*) [someone who tells secrets] when you provided anonymity and confidentiality. It resembled espionage. I could say whatever I want knowing that my name will be anonymised.

It was also challenging to secure anonymity and confidentiality when I conducted interviews at the homes of disabled participants where other family members could intervene in the process. In some cases, it was difficult to find a neutral venue for the interview and I could not help avoiding the involvement of other witnesses during the interview. For instance, I later realised that conducting interviews at office premises with members of disability NGOs was not a good idea as some interviewees were reluctant to respond to sensitive questions regarding the management of the organisation. I understood that a safe environment plays a crucial role in interviewing disabled people. In the next section I reflect on the importance of safe spaces not only for interviews, but also for co-operative inquiry with people with physical impairments.

⁴⁷ I use his original name as he requested me to do so.

Ethics in co-operative inquiry

As co-operative inquiry is an iteratively evolving inquiry process, providing the information sheet and asking for informed consent at the beginning of the research process was not enough and several other ethical concerns were considered. Together with disabled co-researchers and participants of the co-operative inquiry, we developed a group ethical code which also evolved in the research process. Apart from the ethical considerations in the first qualitative inquiry, I was aware of the ethical stance in co-operative inquiry which can be quite different compared with ethics in conventional qualitative research. Brydon-Miller *et al.* (2003: 15) emphasised that the basic values underlying common practice of action researchers are:

...a respect for people and for the knowledge and experience they bring to the research process, a belief in the ability of democratic processes to achieve positive social change, and a commitment to action.

The core of this practice is participation in democratic processes, the improvement of human life and engagement in morally committed action (Brydon-Miller 2008). Moreover, participatory or emancipatory approaches may be very unfamiliar for people in non-Western contexts such as Central Asia (Katsui and Koistinen 2008). Using visual methods and participatory video raised ethical issues, tensions and challenges which were continuously negotiated between my disabled co-researchers and participants and myself (Shaw 2016). All the participatory video sessions held at Sanvikt Arts Centre for Disabled Children were anonymous and confidential and at the start of the workshops in June 2019 we all agreed on a set of common rules. However, it was difficult to sustain the anonymity and confidentiality of the whole process outside our closed and regular venue for PV sessions. For example, when we made a shot-by-shot documentary at one participant's new house, her neighbours were quite interested in the whole process and were present

backstage. Some of the neighbours approached us and asked us to praise the president's efforts to provide housing for vulnerable people. Similar risks occurred when I involved disabled co-researchers and participants as my co-authors of online publications, which I discuss in detail in the positionality section.

Ethics in critical ethnography

In situations where I acted more as a participant observer, I introduced myself as a researcher to the organisers of religious meetings and other events by providing an information sheet. If it was impossible to get informed consent from all the participants of such events, I asked for their general consent verbally through the organisers. The identity of participants was protected by anonymisation since people were not giving consent on an individual basis. My task was to observe and listen to the debates of blind and deaf communities. However, at times I was asked to report on rather than just observe the problems of disabled communities. Later, I co-wrote several articles for online media with disabled co-researchers and participants. As a result, there was a risk of inappropriate exposure of disabled co-authors and participants mentioned in the critical online publications that become publicly available. To avoid such negative impacts I took several measures to ensure safety of the research participants. Firstly, the research participants were fully informed about possible retaliation from the authorities and others and associated risks. The participants were provided with the drafts of articles in accessible formats prior to publication and were offered the option of anonymising their names and any data that could reveal their identity in the published material. Some research participants wished to remain identified in the publications, while others asked for anonymity. In both cases, the participants were provided with a choice. This section has discussed the ethical issues and concerns raised while conducting qualitative and co-

operative inquiry with disabled and non-disabled people. In the final section of this chapter I reflect on work with disabled co-researchers from NGO 'SHAROIT PLUS' and how this relationship evolved over the research process. I also reflect on my role as a non-disabled privileged researcher.

3.3 Positionality

Working with disabled co-researchers

Critical reflection on my positionality has direct implications for the choice of methodology for researching disability as a social construct in the context of Uzbekistan. Stone and Priestley (1996) warned non-disabled researchers about oppressive theoretical paradigms that conflate disability with impairments, with the risk that social research turns into another form of oppression of disabled people, objectifying them rather than enabling them to become active agents of social change. Therefore, in my research I applied an emancipatory research paradigm treating my disabled co-researchers and participants as equals. I believed they were 'the true knowers' and experts whose reality counts for more than that of rehabilitation experts, development practitioners, social workers or researchers like me (Chambers 1983, 1997). When describing the working class movement, Gramsci (1971) stressed that the representatives of the middle class often developed and controlled ideas and thus opened up a question of the interconnectedness of individual experience with social theory. Gramsci (1971) distinguished between structural (positional) intellectuals and organic intellectuals. These concepts can also be applicable to disability research. For instance, Oliver (1996) argued that to have an impairment means to be an "organic intellectual" within the disability movement and described them as those who are:

less likely to distort the collective experience of oppression and are less likely to sell out to the highest bidder precisely because intellectual work is rooted in personal and collective experience. (Oliver 1996: 167).

However, Oliver (1996) did not mean that those who have no direct experience of impairment and disability oppression themselves cannot contribute to the disability movement. As a non-disabled researcher, I argue that disabled people will not be able to achieve their emancipation without the involvement of allies within the movement. I agree with Oliver that the binary separation of the roles of disabled and non-disabled people in the disability movement would be simplistic and counterproductive. Although emancipatory disability research and critical ethnography approaches to research may address these issues to some extent, I was careful not to drag myself into “exploitative tendencies” mentioned by Oliver (1998) whereby researchers become ‘parasites’ capturing experiences of disabled people to build their academic career rather than to change social oppression (Stone and Priestley 1996a). On the contrary, I tried to build up capacities and transfer skills to my disabled co-researchers and participants to empower them as organic intellectuals who should be considered experts in their lived experiences.

Any disability research should be grounded in the accounts and aspirations of disabled people and I describe my emancipatory approach to research design in Section 3.1 above. In the second phase of co-operative inquiry, I involved one woman with physical impairments, Mukhabbat Rakhimova,⁴⁸ currently a chairperson at ‘SHAROIT PLUS’ as a co-facilitator of participatory workshops. Mukhabbat possessed strong facilitation skills and did most of the interviews with disabled people in the first phase of inquiry. She was

⁴⁸ I am using her real name as I have her permission to do so.

remunerated per diem for her contribution as a main co-researcher. Together with her and other co-researchers we learned about the philosophy of PAR, its approach, and participatory methods. Mukhabbat participated in all stages including research design and planning, data collection and analysis, dissemination of the findings and action. As a result, she managed to build up her research skills such as interviewing, facilitation, thematic analysis, writing up and so on. As Mukhabbat confirmed:

This study served as an impetus for me to gain additional knowledge and skills. This was an opportunity to learn more about our work [in the framework of the organisation]. We applied the research approaches, methods, and strategies we learned in our following projects and witnessed the benefits of them.

In the preparatory workshops in the exploratory phase (June 2018), rather than ‘teaching’ disabled people how to conduct research, we reflected together on how to do it so that it would be beneficial and not harmful for disabled participants. We reflected on the purpose of this study, research questions and ethical considerations, and practised the interview guides with each other. I used the “Uppers and lowers” participatory exercise from [Chambers \(2002: 166–167\)](#) to raise awareness of possible power hierarchies and imbalances and to avoid dominant or subordinate relationships.

Consequently, the presence of disabled co-researchers helped to navigate the challenges of gaining participants’ trust. Together we created an informal friendly environment where interviewees with various impairments could freely share their personal life stories, problems, and concerns. I now realise that the interviews conducted in pairs with co-researchers were more nuanced and thorough compared to those that I did on my own. Mukhabbat explained that a disabled person “would not open to a stranger 100%” particularly if the stranger is non-disabled. As she and other co-researchers already knew

most of the participants with physical impairments from their existing networks at ‘SHAROIT PLUS’ it was easier to gain their trust:

You [referring to me] may not be able to find some questions in the moments where they are needed to be asked. I may ask relevant questions based on my lived experience of disability. Several years ago, I was also shy but when I was interviewed by a Japanese disabled leader who came to Tashkent, I said to myself: “*If they did it, I can also do it*”. (Mukhabbat, co-researcher)

As equal interviewers, disabled co-researchers smoothed over the differences between me and disabled interviewees and helped to create a safer environment for the participants during interviews. Their involvement in the research process had a positive and to some extent empowering impact on disabled interviewees. For example, as a disabled woman who leads a DPO in Tashkent city, Mukhabbat served as a role model for those interviewees who lacked the confidence to lead an active life due to exclusion and segregation. There were also difficult situations where interview participants cried, remembering bitter lived experiences. In such situations, disabled co-researchers were also of great help as they could provide instant peer-counselling services for interviewees in need of urgent support. However, in doing critical ethnographic research with blind and deaf communities I faced several challenges in terms of my positionality which are considered in the following sections.

Insider or outsider?

In terms of positionality I placed myself on the continuum between the insider and outsider extremes as described by Herr and Anderson (2005: 31) and Scheyvens (2014: 7). On the one hand, I consider myself to be an *insider*; as a citizen of Uzbekistan born in Tashkent I have the same cultural identity as my co-researchers and participants. On the other hand, being a PhD student based at a UK university and, importantly, a non-

disabled privileged researcher could move me considerably to the *outsider* extreme of the positionality continuum. In the context of Uzbekistan, I belong to a middle-income group and have not been exposed to poverty, discrimination, or disability oppression like many of my research participants. Therefore, as a non-disabled researcher I tried to regularly reflect on my privileged socio-economic status, associated values, biases and power and how all these individual factors might impact the overall research design, its process and interpretation of findings (Linton 1998).

I took into careful consideration the power asymmetries (Kvale 2006) between me as a non-disabled researcher and my disabled interviewees. As mentioned earlier, equal involvement of disabled co-researchers in the interviews and co-operative inquiry alleviated the power inequalities to some degree. However, it would be idealistic to say that this helped me to get rid of that power gradient altogether. If I compare two summer field trips in 2018 and 2019, I can see a considerable change in my positionality. Although I considered myself as an 'insider' being born and raised in Uzbekistan, speaking Uzbek and identifying myself culturally as Uzbek, I now feel that during the first qualitative phase of my fieldwork I was very much an outsider. It was quite difficult to establish a relationship of trust in a single interview with a disabled person you have never met before. I felt that as an interviewer I was merely extracting information from my interviewees. It was not necessarily an equal conversation and many interviewees accepted more a passive role by answering the questions and fitting into the agenda that was important to me and not to them. One of my disabled co-researchers told me that at the beginning I extracted personal information about lived experiences of disability without revealing much about myself. Only during my second summer field trip did I realise that my relationships with research participants were not equal as I did not open

myself to them. The series of participatory workshops allowed closer relationships with my disabled co-researchers and participants. In the second phase of inquiry, I gradually turned from an outsider researcher into a close friend. The high point of my relationships with co-researchers and participants was when I invited the whole participatory video team and all my co-researchers to my parents' house in Tashkent. The final section addresses my challenges of becoming an advocate and ally on behalf of people with visual and hearing impairments.

The voice of disabled people

During the ethnographic fieldwork, blind and deaf people sometimes asked me to report on challenges they were facing when attempting to claim citizenship within their communities and organisations. Their request was probably related to the fact that I became a columnist on disability and inclusion at a local online media outlet, *Gazeta.uz*.⁴⁹ I published my first op-ed there at the end of November 2018 (Yusupov 2018b). My participation in the CABAR.asia Summer School for Young Researchers⁵⁰ in Bishkek, Kyrgyzstan had served as an impetus to start writing analytical articles for audiences in Uzbekistan and Central Asia. Interestingly, blind people also referred to me as a “journoguy” (in Uzbek *jurnalists bola*) rather than as a researcher. Eventually, through my online publications I became an advocate for disability rights and inclusion in Uzbekistan. I argue that this new role has been compatible with the principles of critical ethnography (Madison 2011; Thomas 1993) discussed earlier in Section 3.2.

⁴⁹ All my articles and op-eds on disability issues in Russian can be found through this link: <https://www.gazeta.uz/ru/authors/dyusupov/>.

⁵⁰ CABAR.asia Summer School for Young Researchers, which was organised with the support of the Institute for War and Peace Reporting (IWPR) and the OSCE Academy in Bishkek in July 2018. All my articles in English can be found through this link: <https://cabar.asia/en/author/dyusupov/>.

Rather than keeping ethnographic data in my field notes, I tried to seek solutions and wrote critical articles for local and regional online media. For instance, I wrote about the injustices during the May 2019 elections of the chairperson at Bayot mahalla committee (which is referred to as the ‘mahalla of blind people’; see Chapter 6), when two blind candidates were not approved by the district *khokimiyat* (administration) to run for the elections (Yusupov 2019b). These kinds of activities eventually changed my identity from being simply a researcher to an advocate for disability rights which had its own implications. Interestingly, turning into such a visible advocate allowed me more access to official spaces which were closed to me during the exploratory phase.⁵¹ For instance, when I published the critical article about the elections at Bayot mahalla (Yusupov 2019b) I was invited to the Mirobod district *khokimiyat* where I had the opportunity to talk to the representatives of the local government. I think if I had approached the *khokimiyat* myself it would have been unrealistic to gain information from them. Thus, critical online reporting allowed me to have additional insights into discriminatory attitudes of state officials towards disabled people. Nevertheless, on many occasions, little or even no reaction followed from the authorities regarding other articles.

However, I further questioned whether as a non-disabled researcher I have a legitimate right to represent the voices of disabled people in online media. I inevitably became an ally of disabled communities with whom I conducted critical ethnographic research. For instance, in the case of the ‘mahalla of blind people’, I took the side of the community of blind people in negotiations with the high-ranking officials who tried to justify their

⁵¹ In relation to difficulties in interviewing representative of the Mahalla Fund and chairpersons of mahalla committees. See previous section on “Qualitative interviews with disabled and non-disabled people”.

ableist arguments for not approving two blind candidates. By becoming an ally, I thought that I was able to show my continuous commitment to my research participants by building sustainable reciprocal relationships. Nevertheless, the question of my legitimacy as a non-disabled researcher who became the ‘voice of disabled people’ has worried me a lot. For instance, a blind participant who later become my closest friend warned me:

After writing extensively on disability issues you have become a ‘disability expert’ who is invited to the table by international organisations. You have become our voice for what I do not blame you. But ideally you should have become our announcer who reads out loud our messages.

Becoming a non-disabled voice of disabled people is problematic if it portrays the disability community as a vulnerable group unable to advocate for its own rights. I felt that I was in an emotional trap as I have been passionately involved in disability advocacy and tempted not to lose the chance to answer the question: What can be done? (Madison 2011; Thomas 1993). However, in such a hustle there is a high risk of diminishing disabled people to passive people whose voices need to be raised on their own behalf. As a solution to my problematic role as a ‘voice of disabled people’, I began writing articles in co-authorship with my disabled co-researchers and participants. In this way, I tried to transfer my skills of analytical writing and reporting to them⁵² so that after I leave the field, they could become independent advocates for disability rights in Uzbekistan. I concluded that as for doing research ‘with’ rather than ‘on’ disabled people, it is also crucial to speak and advocate ‘with’ them rather than ‘for’ them.

Knowing that I could cover issues related to disability rights, many other disabled people contacted me to write about various barriers and discrimination they were encountering

⁵² I co-authored articles with deaf rights activist, Mamur Akhliddinov, and blind rights activist Ulugbek Mamatkhanov as well as chairperson of NGO ‘SHAROIT PLUS’, Mukhabbat Rahimova.

in their daily lives. Although these issues were not always directly related to the purpose of my research project, I agreed to help them out. However, at times, one of the main challenges was saying “no” to myself and those disabled people. I thought that at some point I had to step away from my role as an ally. After returning from the field in September 2019, I kept in touch with my disabled co-researchers at NGO ‘SHAROIT PLUS’ and research participants who fed in the data about what was happening on the ground. I was tempted to go back to the online and offline debates to see if the situation had changed on the ground after I physically left the field. I could not decide what amount of data would be appropriate for conducting this research project as I did not set up the “rules” before I started the fieldwork as to when I would stop data collection. As a result, I was overwhelmed by continuing online disability activism, publishing articles in the popular online media together with disabled participants and co-researchers. I considered that it would be unethical to say “No” to the requests of disabled people to support them in a joint action against disability oppression and discrimination. Thus, I started valuing the continued activism together with them, rather than giving myself a cut-off point and asking my colleagues to wait until I had finished my PhD.

Conclusion

In summary, this study takes an emancipatory disability research approach using multiple research methods with different impairment-specific groups and communities in Tashkent city. I involved disabled co-researchers from a local disabled people’s organisation NGO ‘SHAROIT PLUS’. Together we tried to explore the essence and root causes of disability oppression and discrimination that disabled people experience in their daily lives at individual and collective levels, and the barriers to claiming full citizenship. The fieldwork was divided into two phases and conducted in the summers of 2018 and

2019 using a mixture of qualitative participatory methods with disabled participants and co-researchers. The research data is derived from 73 semi-structured interviews with disabled people, their parents or carers and non-disabled elites; and from more than 20 participatory workshops using participatory video as well as fieldnotes from participant observation. The data collected from interviews and fieldnotes was transcribed in Uzbek or Russian, and coded and analysed using NVivo qualitative data analysis software. This analysis is provided in the following empirical chapters 4, 5, 6 and 7.

Chapter 4. Organisations about them without them: the bitter legacy of Soviet disability policies

To understand the current civil society landscape for disabled people in Uzbekistan, it is important to comprehend the Soviet legacy of disability policies, as they left an indelible mark on Uzbek society and reflect relationships between disability organisations and the state. In Section 1.4. of Chapter 1, I argued that the Soviet citizenship framework for disabled people did not allow the formation of independent disabled people's organisations due to the totalitarian nature of the one-party communist system. As disability organisations were deeply integrated into the communist state structures and ideology, achieving citizenship by disabled people was possible only within the boundaries of the utopian Soviet project. This chapter examines the historical development of dominant Uzbek disability organisations rooted in the ideologies and practices of Soviet citizenship.

I begin with a brief historical overview of the three main impairment-specific disability NGOs established before Uzbekistan's independence. The critical analysis of secondary and primary data collected through ethnographic fieldwork in Tashkent shows that the independent Uzbek state adopted tacit and explicit tools for controlling people with sensory and physical impairments and their public associations. This raises further concerns that the dominant disability organisations are still dependent on and subordinate to the state and cannot legitimately represent the rights and interests of all disabled people. By exploring the NGOs' culture, their organisational structure, and internal debates around the concepts of disability activism and relationship with the state, I argue that the three dominant disability organisations present invisible barriers for asserting citizenship by disabled people.

4.1 The legacy of Soviet disability organising

Historical background of dominant Uzbek disability organisations

Uzbekistan's landscape of disability organisations has been dominated by three NGOs: the Society of the Deaf (OGUz),⁵³ the Society of the Blind (O'zKOJ)⁵⁴ and the Uzbek Society of Disabled People (UzOI).⁵⁵ The first two are the oldest Uzbek disability organisations, inherited from early Soviet times. The All-Uzbek Society of the Deaf and Mute⁵⁶ was founded on 21 May 1929 and in 2019⁵⁷ it celebrated its 90th anniversary. The All-Uzbek Society of the Blind was established three years later in 1932, following the lead of the All-Russian Society of the Deaf (VOG) (Shaw 2011, 2017) and the All-Russian Society of the Blind (VOS) which were established in the mid-1920s. In terms of organisational structure and legal provisions, the first Uzbek disability organisations resembled the All-Russian Societies with central management in Moscow and served as their representative branches in Turkestan.⁵⁸ The All-Russian Societies of the Deaf and the Blind had a strong influence on nascent Uzbek disability organising, and the Russians played an essential role in uniting Uzbek deaf and blind people. In their historical accounts dedicated to the 50th anniversaries of the All-Uzbek Societies of the Deaf and the Blind, Mirkhodjaev (1979) and Primkulov (1983) wrote that based on Leninist internationalism and friendship of peoples the Russian comrades shared their experience with the young Soviet republics. Thus, many Uzbek leaders and members of the two

⁵³ In Uzbek: "O'zbekiston ko'zi ojizlar jamiyati" (O'zKOJ).

⁵⁴ In Uzbek: "O'zbekiston karlar jamiyati"; in Russian "Obshchestvo glukhikh Uzbekistana" (OGUz).

⁵⁵ In Uzbek: "O'zbekiston nogironlar jamiyati"; in Russian "Obshchestvo invalidov Uzbekistana" (UzOI) This organisation works mainly with adults with physical impairments.

⁵⁶ In Russian "Vseuzbekscoe obshhestvo gluhonemyh".

⁵⁷ A deaf blogger and author of the Uzbekistan Deaf Society Blog (www.uzsd.uz) wrote that 21 May 2019 marked the 90th anniversary of the Society of the Deaf of Uzbekistan. However, due to unknown reasons, the celebration was postponed to 17 September 2019.

⁵⁸ Turkestan is a historical term describing the present-day Central Asian republics including Kazakhstan, Kyrgyzstan, Tajikistan, Turkmenistan and Uzbekistan.

societies gained experience and skills from their Russian partners. In the early stages, mainly ethnic Russians were appointed as leaders of the young Uzbek deaf and blind organisations and participated on their behalf in the Congresses in Moscow. For instance, on 21 September 1926 when the First All-Russian Congress of the Deaf was held in Moscow and elected its Central Board and Presidium, Andrei Ippolitov participated as a representative from Turkestan and secretary of the Tashkent section (Mirkhodjaev 1979: 10). The representatives from Turkestan participated in the activities of the All-Russian Societies and were elected as members of their governing bodies.

As a result, the Soviet model of disability organising was imposed on the young Central Asian socialist republics. OGUz and O‘zKOJ replicated the organisational structure of VOG and VOI which were firmly embedded within the communist state and ideology. Before these disability organisations were established, responsibility for issues related to deaf and blind people were distributed among various Soviet state agencies. For instance, the Ministry of Social Welfare was responsible for the provision of pensions and social benefits, the Ministry of Health for preserving remaining eyesight/hearing and preventing vision/hearing loss, and the Ministry of Education worked on printing Braille books. There was no single organisation working across all the spheres of support for people with sensory impairments. Thus, following the Russian societies of blind and deaf people, the Council of People’s Commissars (*Sovnarkom*) of the Uzbek SSR established the Uzbek Societies of the Deaf and the Blind in the form of ‘public organisations’ (*obschestvennaya organizatsiya*). Like their Russian counterparts, they were attached to the People’s Commissariat of Social Welfare⁵⁹ (*Narkomat socobespechenija*) and acted

⁵⁹ Analogue of the ministry that existed 1917-46, which was a central executive state body headed by the People's Commissar and administered the sphere of social welfare. It was first created in April 1918 and existed until 1946 when it became the Ministry of Social Welfare.

under its general guidance (Mirkhodjaev 1979: 16). The Sovnarkom approved the regulations which outlined the organisational structure and legal provisions of the All-Uzbek societies. Although both societies were established in the form of ‘public organisations’ they were considered to be state bodies and functioned under the control and supervision of the Ministry of Social Welfare. Mirkhodjaev (1979) justified this subordinate position to the state by the fact that

members of the Society [of the deaf] who are deprived of hearing and speech are disabled [*invalids*], are registered with social welfare authorities, receive pensions, and enjoy the corresponding benefits (Mirkhodjaev 1979: 46)

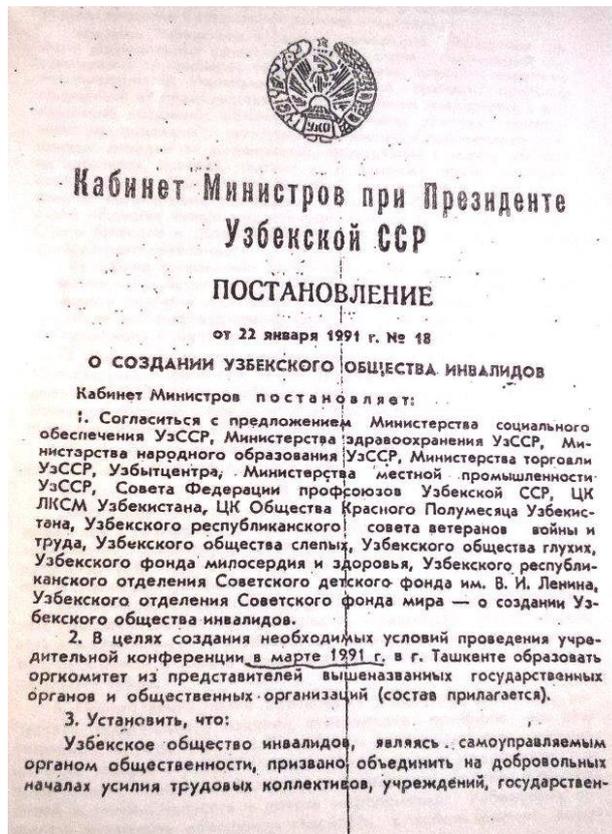
The Uzbek Societies of the Deaf and the Blind and their specialised enterprises received regular state-guaranteed financial support and constant attention from the Communist Party of Uzbekistan, and from trade unions and Komsomol organisations in the centre and at the local level. The societies directed the training and production enterprises (UPPs),⁶⁰ regional boards, primary organisations, cultural and educational institutions; and assisted in the development of ‘socialist competition’, the movement for communist labour, the selection and placement of personnel, and education; and allocated housing, construction, residential and industrial facilities. The Ministry of Social Welfare of the Uzbek SSR primarily oversaw the activities of the societies (Mirkhodjaev 1979: 46), and was involved in every aspect of them, including even the selection and placement of cadres. Therefore, the Uzbek Societies of the Deaf and the Blind could not be considered to be independent disabled people’s organisations (DPOs), but rather government organised ‘public organisations’ that worked as two separate departments under the Ministry of Social Welfare.

⁶⁰ See Chapter 5 for a detailed discussion of the role of UPPs in achieving citizenship by disabled people in Uzbekistan.

Interestingly, until early 1991, there were no public organisations uniting people with physical impairments in the Uzbek SSR. Such an organisation did not even exist in the Russian Soviet Federative Socialist Republic until 17 August 1988, in the form of the All-Russian Society of the Disabled (*Vserossiyskoe obshchestvo invalidov*) (White 1999: 13). People with physical impairments did exist in the Soviet Union but their initiative groups were not allowed to create independent public associations (Fefelov 1986). This was not possible until the emergence of the voluntary sector and democratisation that happened under Gorbachev's political reforms of *perestroika* (reconstruction) in the mid-1980s (White 1999). In the Uzbek SSR, registration of public associations was for the first time prescribed in the Law On Public Associations adopted on 15 February 1991 (GoU 1991). Shortly before the adoption of the first legislation on public associations, the Cabinet of Ministers under the president of the Uzbek SSR established the Uzbek Society of Disabled People (UZOI) (*Uzbekskoe obshchestvo invalidov*) on 22 January 1991. According to the government decree, UZOI was considered to be a 'self-governing public body'⁶¹ (*samoupravlyaemyiy organ obshchestvennosti*) aimed at uniting people with physical impairments.

⁶¹ Resolution of the Cabinet of Ministers under the president of the Uzbek SSR No. 18 of 22 January 1991.

Figure 10. Decree of the Cabinet Ministers under the President of the Uzbek SSR from 22 January 1991 #18 "On Establishment of the Uzbek Society of the Disabled".



Source: Provided by Oybek Isakov, Chairperson of the Association of Disabled People of Uzbekistan

Similar to the Society of the Deaf and Society of the Blind, the Ministry of Social Welfare together with the Ministry of Finance developed a standard list of positions at UzOI and their salaries were paid by the state budget. The founding conference was held in March 1991 in Tashkent to elect an organising committee which consisted of representatives of government agencies and public organisations. The new Society of the Disabled was also represented nationwide through its branches and offices at regional, district and city levels, with the central management board located in Tashkent. After Uzbekistan gained its independence, all three societies (the Society of the Deaf (OGUz), Society of the Blind (O'zKOJ), and the Uzbek Society of Disabled People (UzOI)) received a legal status of 'public associations of disabled people' (*nogironlar jamoat birlashmasi*). Since then, the

independent Uzbek government has treated them as representative of all disabled people due to a supposedly wide organisational structure and large membership on a national scale. Let us now consider the organisational structure of these dominant disability NGOs.

Organisational structure based on ‘democratic centralism’

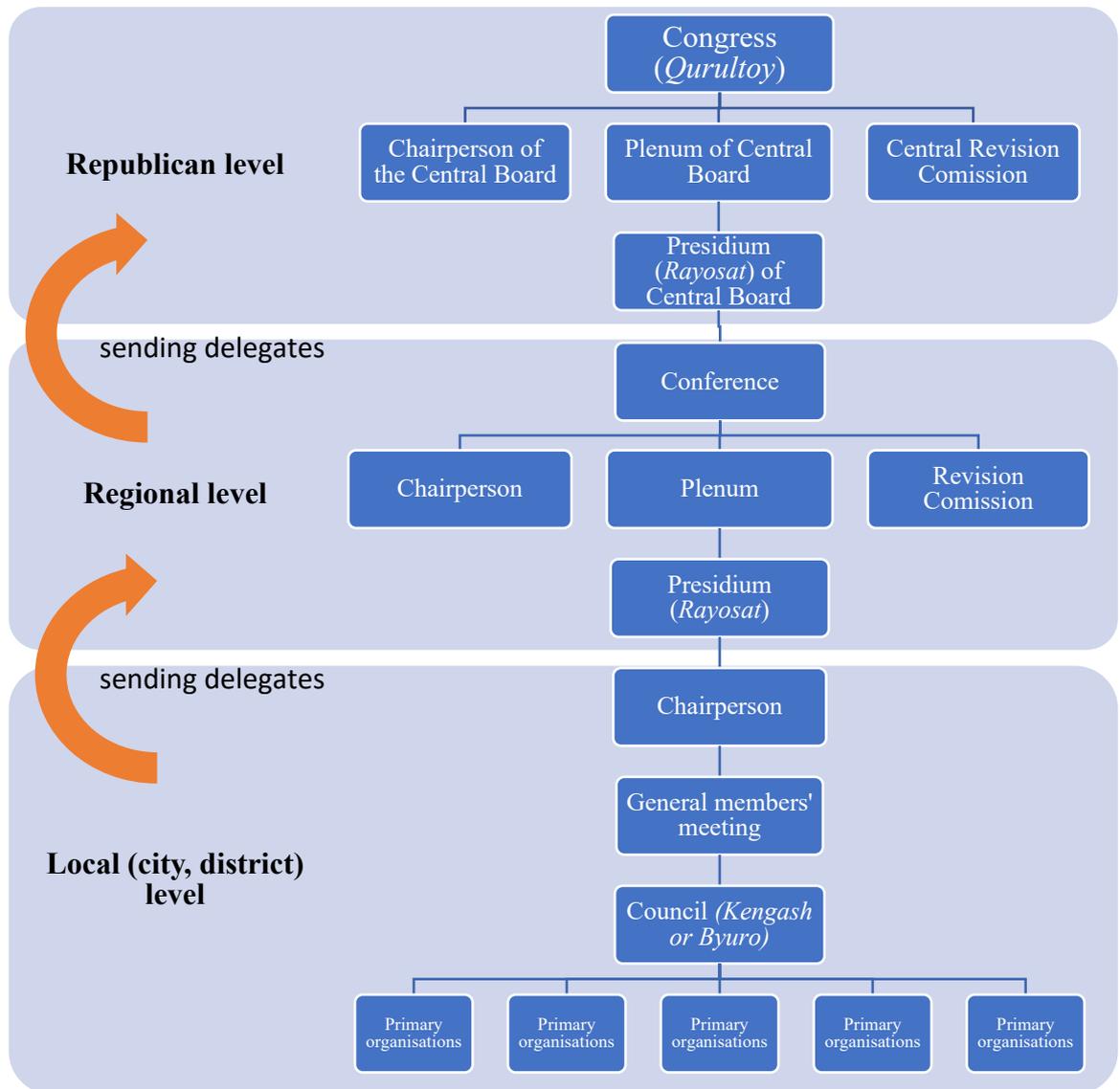
According to the charters (*Ustav*) of the three societies, their mission is to unite citizens with sensory and physical impairments, protect their civil, economic, social, and cultural rights and interests, provide them with social support and rehabilitation, and promote their social integration (*ijtimoiy integratsiyalash*) and full participation in society. For instance, the Charter of UzOI states its main goals and objectives as:

to create equal opportunities for disabled people to address issues of their legal rights, freedoms, and interests, to promote their active participation in public life, to involve them in rational employment [*ratsional mehnat*], to create jobs for them, to provide support in creating social infrastructure [*ijtimoiy infratuzilma*] as well as to prevent their discrimination and to protect their dignity.

Primary organisations (*boshlang‘ich tashkilotlar*) constitute the basis of these societies which identify disabled people at the grassroots level, register them and promote voluntary membership. In the Soviet Union, any public organisation had to form ‘cells’ (*yacheyka*’ in Russian). Similarly, the organisational structure of the Societies of the Deaf and the Blind relied on primary organisations formed at UPPs, educational institutions, as well as state and collective farms with at least five members (Mirkhodjaev 1979: 19). Moreover, such primary organisations were created on a territorial basis uniting deaf and blind people working at home, homemakers, and dependents. These primary units of disability organising formed the foundation of the first disability organisations. Therefore, activities at the grassroots level organised directly with disabled people were of extreme importance. My fieldwork observations showed that OGUz and

O'zKOJ were no longer forming such primary organisations on the basis of UPPs or other subsidiary enterprises, or specialised boarding schools. Instead, they began establishing them on a territorial basis according to place of residence at city or district levels. The diagram below shows the organisational structure of the two main organisations of deaf and blind people.

Figure 11. The organisational structure of the Society of the Deaf and the Society of the Blind



Source: Author's illustration based on the data provided by the Society of the Deaf and the Society of the Blind.

Once in every five years, the local administrative body holds a meeting where the members of primary organisations elect their chairperson and other governing bodies. The presidium (*rayosat*) at the regional level then decides the number of delegates at the local level, which is proportionate to the number of members of the primary organisations. The delegates elected at the regional level (proportionate to the overall

membership at the regional branch) are then eligible to participate in the Congress (*Qurultoy*) which is the highest governing body at the republican level.

Mirkhodjaev (1979) argued that this organisational structure relied on the Leninist principle of “democratic centralism” where all higher governing bodies were elected and accountable to their subordinates, and decisions of the higher bodies were binding for the subordinates. In theory, such decision-making mechanisms should enable members at the local level to be heard and represented in decision-making at the republican level. Each territorial administrative unit at local, regional, and republican level has its Charter and organisational stamp registered at the local justice authorities. As a result, each territorial branch is legally considered to be a separate NGO, even though it belongs to one republican-level organisation. For instance, the Society of the Blind of Uzbekistan has an extensive network of territorial administrations (*hududiy boshqaruvlar*) in 14 regions as well as 178 district and city branches (*bo‘linmalar*) which are all counted as separate NGOs. Therefore, all three societies currently account for 380 disability NGOs, or more than 60% of all NGOs working in the sphere of disability support in Uzbekistan.⁶²

⁶² Based on the NIMFOGO (2018) report there were 613 NGOs in total working in this field. See Section 1.1.

Table 4. Number of territorial branches of dominant disability organisations in 2020

Regions	Society of the Deaf of Uzbekistan	Society of the Blind of Uzbekistan	Uzbek Society of Disabled People
Andijan region	2	17	18
Bukhara region	1	11	9
Jizzakh region	1	13	14
Qashqadaryo region	1	15	9
Karakalpakstan	1	13	15
Navoiy region	1	8	8
Namangan region	1	13	13
Samarqand region	1	17	11
Sirdaryo region	1	12	10
Surxondaryo region	1	15	13
Tashkent region	1 ⁶³	19	19
Tashkent city	0	11	12
Fergana region	1	17	19
Xorazm region	1	11	5
Total branches	14	192	175

Source: State register of non-governmental non-profit organisations in 2020, Ministry of Justice of the Republic of Uzbekistan, <http://e-ngo.uz/front/registry>. Author's calculations.

As mentioned in Section 2.2, based on the official data from 2017 there were 613 registered NGOs working on protection of the rights and legitimate interests of disabled people out of a total of 9,205 NGOs registered in Uzbekistan (NIMFOGO 2018: 11). However, this number of 613 includes all branches of republican NGOs working at regional, district and city levels. It would be more meaningful to consider all regional branches as single republican NGOs because all the territorial branches are managed by central boards (*Markaziy Boshqaruv*) located in Tashkent. According to publicly available information, there are more than 76⁶⁴ NGOs supporting disabled people in Uzbekistan, not counting branches as separate legal entities.

⁶³ The Tashkent regional branch of the Society of the Deaf is responsible for Tashkent city area including the city districts.

⁶⁴ This number frequently appears in the media: <http://uza.uz/ru/society/s-zabotoi-o-lyudyakh-s-ogranichennymi-vozmozhnostyami-10.06.2014-28941>. Disabled people also confirmed this number stating that the Ministry of Justice provided this data on request.

This organisational structure and an extensive network of territorial branches represent the Soviet legacy of disability organising, where all the territorial units aimed to ensure the implementation of decisions of the CPU and Soviet state bodies, as well as decisions of their central boards. In Chapter 5, I argue that instead of promoting the bottom-up principle of ‘democratic centralism’, this inherited organisational structure has become a barrier for internal representation of the rights and interests of ordinary disabled members and UPP workers. I further argue that, despite the collapse of the Soviet Union and the adoption of NGO legislation, the independent Uzbek government continued to intervene in the decision-making processes through proxy chairpersons imposed in a top-down manner. Before proceeding to examine the internal barriers within these dominant disability NGOs, it is important to understand who their members are and how they sustain their activities.

Membership and financial sustainability

According to the law on NGOs in Uzbekistan (GoU 1999), only individuals over the age of 18 may become members of the Societies of the Deaf, the Blind and the Disabled.⁶⁵ Moreover, until recently, the Society of the Deaf and the Society of the Blind have accepted only adults in the first and second group of disability as their members.⁶⁶ Individuals who are ineligible to become members due to their age, or who meet all the membership requirements but have not yet become members are registered by primary organisations at a local level. On paper, membership of the Society of the Deaf and Society of the Blind reaches almost 50% of all registered deaf and blind people in

⁶⁵ If an organisation is registered as a youth NGO, the members can be aged 14 or older. If it is a children’s NGO, the members can be aged 10 or older. The Medical Labour Expert Commissions consider disabled children to be those who are under 16 years old.

⁶⁶ See Section 2.3 in Chapter 2 for the discussion on disability groups.

Uzbekistan. The Society of the Disabled also boasts about almost 250,000 disabled members which seems like a reliable number considering that in total 693,900 disabled people were registered in Uzbekistan. However, as I argued in Section 1.2, many disabled people are left out of the official statistics (Yusupov 2018a). Thus, the reported membership coverage of the societies relates to only those disabled people who managed to register and gain a formal disability status. Moreover, disabled members' level of engagement in the organisational structure and activities of these dominant disability organisations raises further questions. The table below shows the reported membership coverage of the three dominant disability NGOs in Uzbekistan.

Table 5. Membership of the Societies of the Deaf, the Blind and the Disabled in 2020

	Society of the Deaf	Society of the Blind	Society of the Disabled
Members	10,216	22,679	238,763
Registered disabled people	21,212	46,152	N/A
Membership coverage (as % of registered individuals)	48.2%	49.1%	N/A

Source: Based on the information provided by the Societies. Author's calculations

Since their establishment the societies' funds came from annual membership fees; donations from institutions, organisations and individuals; grants from government and public institutions and organisations; and income from products made by disabled people, public gatherings, concerts, lectures, and performances (Mirkhodjaev 1979). Deaf and blind workers of UPPs comprised the core permanent membership in the Societies of the Deaf and the Blind and they regularly paid membership fees. However, due to the deterioration of the economic situation at the UPPs and increasing level of unemployment among deaf and blind people, the Societies' members are failing to pay their fees. As a result, it has become difficult for the organisations to rely on annual membership fees as

a source of funding for their activities. For example, out of 10,216 members of the Society of the Deaf, only 1,456 paid fees in 2019 (only 14.2% of all members). The Society of the Blind has the broadest coverage of people with visual impairments in Uzbekistan and has 22,679 members with visual impairments. Before 2019, the employed members of the Society of the Blind had to pay 10% of the minimum monthly wage and the unemployed paid 5%. However, according to the new Charter the employed are now paying 4% (8,920 soum or about \$0.87) of the basic calculation value (BCV),⁶⁷ and the unemployed 2% (\$0.44), while students have always been exempt from paying membership fees. The 60% fee reduction is related to the inability of the members to pay regularly due to their socio-economic condition (see Section 1.3). Unable to maintain collections, chairpersons of the Societies decided to considerably reduce the fees in order to avoid imposing a heavy burden on their members.

In addition to the membership fees, an important source of funding comes from the UPPs and subsidiaries operating under the Societies, which produce goods and provide services via the manual labour of disabled people.⁶⁸ They transfer a fixed proportion of the prices of sold goods and services to the accounting balance of the central boards. For instance, the UPPs of the Society of the Blind still transfer 2.5% of the stated prices of their realised goods and services to the account of the central board. Of the total 2.5% deductions, 2% are then transferred to the central management, while 0.5% goes to the relevant territorial administrations, such as the district/regional branches of the Society. The enterprises

⁶⁷ Based on the decree of the President Shavkat Mirziyoyev 'On increasing sizes of wages, pensions, scholarships and allowances' adopted on 12 July 2019 since 1 September 2019 instead of the minimum wage the basic calculation value was introduced which as of January 2020 amounts to 223,000 soum (less than \$22).

⁶⁸ See the following Chapter 5 to understand the role of UPPs in achieving citizenship by disabled people.

established under the territorial and local branches specify the amount allocated to the founders of that enterprise in constituent documents. In other words, the organisational budget of the Society of the Blind is comprised of 2.5% deductions from the production at its enterprises. This money mainly went to paying salaries of the Society's staff members at territorial administrations and local branches, their office costs, as well as on projects supporting the social protection of their members, providing them with rehabilitation equipment and encouraging them with material and moral support. This model of financial sustainability was also inherited from the Soviet Union. However, during the post-socialist economic, political, and social transformation in Uzbekistan, this model suffered heavy damage and as I argue in Chapter 5, it proved unsuitable for the new economic and political realities. To conclude, the analysis of the historical background, organisational structure and membership of the three dominant disability NGOs in Uzbekistan shows that they inherited the Soviet model of disability organising. The Uzbek government has presented them as organisations which represent the rights and interests of all disabled people in the country. However, based on data on the membership coverage and territorial presence across the country, I argue that in practice they may represent only about 50% of all registered disabled people in Uzbekistan. In the following section I shed light on the ongoing crisis of representation within these dominant government-organised disability NGOs.

4.2 State takeover of the dominant disability NGOs

State interference in the organisations of deaf and blind people

Undoubtedly, losing a privileged political and economic status within the structures of the communist state presented enormous challenges for the financial sustainability of the Societies, as they could not guarantee government orders and subsidies in the post-Soviet

period. But the hard times at the UPPs can be explained not only by external factors, but also by accumulated internal organisational issues within the Societies of the Deaf and the Blind that may not be visible to the public. In contrast to the initial Soviet citizenship framework for disabled people which I discussed in Section 1.4 of Chapter 1, the Societies of the Deaf and the Blind *de jure* became independent ‘public associations of disabled people’⁶⁹ based on the law ‘On Public Associations’ adopted on 15 February 1991 (GoU 1991). Later they also gained a legal status of NGOs according to the law ‘On Non-government Non-commercial Organisations’ adopted on 14 April 1999 (GoU 1999). It was a significant step towards recognising the independence of the disability NGOs from the state, as under the communist regime the voluntary sector was non-existent up until the mid-1980s (White 1999) and the Societies of the Deaf and the Blind had to operate under the supervision of the Uzbek SSR Ministry of Welfare.

Furthermore, the Society of the Disabled was established in January 1991 to unite persons with physical impairments who were left behind during the Soviet times. The Society of the Disabled tried to replicate the UPP system by setting up several subsidiary enterprises to employ mainly people with physical impairments. The Ministry of Social Welfare that controlled the activities of the Societies of the Deaf and the Blind during the Soviet era ceased to exist in 2001 when the functions of social protection were transferred to the newly established Ministry of Labour and Social Protection of Population in February 2001. In February 2016 it was transformed into the Ministry of Employment and Labour Relations, while responsibility for social protection of disabled people was transferred to the Ministry of Healthcare and the Agency for Medical and Social Services which was created under it at the end of 2018. Unlike the Soviet Ministry of Social Welfare which

⁶⁹ In Uzbek ‘*nogironlar jamoat birlashmasi*’; in Russian ‘*obshchestvennoye ob’yedineniye invalidov*’.

directly controlled the activities of the societies, the Ministry of Healthcare did not retain such supervisory functions but largely contributed to medicalisation of disability.

By law the three main organisations of disabled people became independent from the state, but the collected ethnographic evidence revealed that *de facto* they are still subordinate to the government through written and unwritten regulations. For instance, paragraph 5.10 of the Charter of the Society of the Deaf re-registered at the Ministry of Justice on 21 January 2010 explicitly mentioned that the candidacy of the chairperson of the organisation

shall be agreed with the Complex at the Cabinet of Ministers of the Republic of Uzbekistan, which presides over the Society of the Deaf of Uzbekistan.⁷⁰ (Society of the Deaf of Uzbekistan 2010: 10)

Apparently, the charter documents of the societies were drafted based on the Soviet templates and institutional memory. The so-called ‘complex’ (*majmua* in Uzbek) at the Cabinet of Ministers turned out to be a kind of union of several departments which controlled the activities of the societies of deaf, blind, and people with physical impairments. A representative of the Society of the Deaf who I anonymised as Alisa confirmed this:

There is a **curator at the Cabinet of Ministers**. All Societies of the blind, deaf and disabled have one curator. Of course, the candidacy of the chairperson must be coordinated with the curator. Not off the street. (emphasis added by the author)

Based on the organisation’s charter, candidates for the position of chairperson should be citizens of Uzbekistan, have higher or secondary specialised education and have worked at the Society of the Deaf for over 15 years. The candidacy of the chairperson of the

⁷⁰ I provide the original Uzbek text: “...uning nomzodi O‘zbekiston Respublikasi Vazirlar Mahkamasining O‘zKJ ga rahbarlik qiluvchi majmua bilan kelishiladi”. (Society of the Deaf of Uzbekistan 2010: 10)

central boards of these Societies must be agreed in advance with the curator so that the chairperson is ‘not from the street’⁷¹ (in Russian ‘*ne s ulitsy*’) but a proven person. According to Alisa, this procedure was outlined in the old Charter and it was more about the agreement of the curator who even requested a list of at least three reserve candidates for the position, in case there was a need for an urgent replacement. Thus, even if delegates within the Societies choose their chairperson of the Central Board, his candidacy should be agreed by the curator. This was also confirmed by representatives of the Society of the Blind who said that they had opportunities to be in contact with the curator.

My collected evidence has shown that so far there have been no self-nominated candidates during the elections for the chairperson of Society of the Deaf. The representatives from the Cabinet of Ministers and the Republican Trade Union Committee have always proposed the candidates the delegates should vote for at the congress. Alisa suggested that this top-down agreement procedure is required to ensure that the candidate for the leading position at the Society has proper education, is intelligent, articulate, and has no criminal record, so that he or she can properly represent and talk on behalf of the Society at the official state meetings, communicating the tasks set up by the government. She tried to legitimise such a top-down intervention in the elections of the chairperson by the fact that the societies of deaf and blind people have had vast material resources, real estate properties and production units that once belonged to the all-encompassing Soviet government. Therefore, to monitor these resources the Cabinet of Ministers preserved strict control over the societies through so-called

⁷¹ Meaning that this person should not be an outsider who is out of the system, but a person who is insider and knows the system from within.

‘curatorship’ (in Russian ‘*kuratorstvo*’): direct involvement in personnel policy. Alisa explained this accordingly:

The Cabinet of Ministers took curatorship [kuratorstvo] over large Societies with production enterprises. This [referring to the Society of the Deaf] is not a Society of beer and plov lovers. Large businesses, and taxes, and production!

I agree with Alisa’s argument that monitoring and audit of the properties and financial flows of these dominant disability NGOs is important. However, such explicit state intervention in the internal affairs of the NGOs of disabled people contradicts the legislation of Uzbekistan on public associations and NGOs (GoU 1991, 1999). Specifically, this contradicts Article 4 of the law on NGOs which states that:

interference of state bodies and their officials in the activities of a non-state non-profit organisation, as well as interference of a non-state non-profit organisation in the activities of state bodies and their officials **is not allowed**⁷² (GoU 1999: online).

Further evidence confirmed that in theory the societies were legally proclaimed as independent public associations and NGOs, and have been showcased to the local and international public as ‘disabled people’s organisations’ (DPOs). However, in practice they have remained strictly controlled government-organised NGOs (GONGOs). Therefore, I argue that these two disability GONGOs are not genuine and independent grassroots organisations *of* disabled people. This applies also to the Society of the Disabled which, unlike the Societies of the Deaf and the Blind, did not have a nationwide system of production units like UPPs.

⁷² Emphasis added by the author.

Appropriation of the Society of the Disabled

Top-down government interference in the organisational structure of UzOI (the Society of the Disabled) began in the early stages of its establishment in 1991. The initiative group of people with physical impairments who stood on the threshold of the establishment of UzOI in the early 1990s said that the Uzbek Soviet government tried to impose its own candidate during the elections of the chairperson. But due to the pressure from the grassroots level by the activists with physical impairments, they managed to elect their own candidate. Because of the rejection of the state-backed candidate and insubordination to the authorities, activists with physical impairments that I talked to during fieldwork argued that UzOI had been truly independent from the government. However, they had to pay for their independence as the organisation was deprived of any state support in the form of subsidies, state procurement contracts or a monopoly right to produce certain types of goods like the societies of blind and deaf people did during the Soviet times. Moreover, in the new realities of transformation into a market economy, and the economic crisis in the 1990s after the collapse of the Soviet Union, the UPP system was deemed unfeasible for the Society of the Disabled which ultimately could not build up a substantial resource and production base. On the other hand, low financial turnover and a lack of properties made the Society of the Disabled less attractive to the Uzbek government. Indeed, a person with a long experience of working at the Society of the Disabled said that they have never had a ‘curator’ in the Cabinet of Ministers.

However, even UzOI could not withstand the onslaught of direct state intervention in its organisational structure. Until 2009, the Society of the Disabled was led by a chairperson with physical impairments, Oybek Isakov. But under pressure from the higher authorities, he had to quit in favour of a non-disabled professor from the Medical Labour Expert

Commission (VTEK), A. Abdusalomov, who worked as chairperson until 2011. After this term ended, Oybek Isakov put his candidacy back to the Congress and became chairperson again. Nevertheless, in 2012, there was another direct intervention from the Ministry of Justice and this time Isakov was asked by a state official, Nabirayev, to let his acquaintance⁷³ Suyarjon Kurbankulov become a temporary chairperson of the Society of the Disabled. Kurbankulov was not a disabled person himself and never worked in the field of disability. When Kurbankulov left his position in 2015 another non-disabled person, Komil Abdullayev, became chairperson and is the incumbent. This prevalence of non-disabled people in the higher management was a result of direct state intervention in this independent NGO of people with physical impairments, even though the initial charter of the organisation did not legally allow a non-disabled people to become a chairperson of the Central Board of the UzOI (Society of the Disabled). Subsequently, it lost its capacity to advocate for full citizenship of people with physical impairments. The organisation turned into a government-controlled NGO like the Societies of Deaf and Blind people. Another significant question relating to such top-down control over the main disability NGOs is whether a non-disabled chairperson can represent the rights and interests of disabled people. The following section discusses the challenges of deaf people who have been struggling to take their rights back from a hearing chairperson of OGUz.

⁷³ Apparently, based on the information from the witnesses of that events, Mr Nabirayev received a bribe of \$5,000 to appoint Mr Kurbankulov as a chairperson of the 'Mahalla' fund, but due to the failure fulfil the promise, Mr Nabirayev decided to temporarily give the position of chairperson of the Society of the Disabled to Mr Kurbankulov.

“The deaf are ruled by the hearing”

A religious community of deaf and hard-of-hearing people with whom I did participant observation at mosques in Tashkent⁷⁴ expressed their discontent with the leadership of the Society of the Deaf. This pious deaf community understand ‘disability’ through a moral perspective to achieve so-called ‘spiritual citizenship’ which I discuss in detail in Chapter 7. The group of over a hundred deaf and hard-of-hearing Muslim men and women was led by a young Uzbek deaf man in his 20s, Jasur.⁷⁵ At one of the religious meetings at Ko’kcha mosque, he addressed the audience with a joint letter addressed to President Mirziyoyev on behalf of the deaf community. In this letter, they complained about the acting chairperson and representatives of the Central Board of the Society of the Deaf. The deaf participants of that religious meeting were unanimous in the view that the main public association of deaf people was unaware of problems and difficulties people with hearing impairments were facing in their daily lives. Deaf participants were united in thinking that the seizure of power at OGUz (the Society of the Deaf) by non-deaf people was the reason for the lack of accountability of the Central Board towards their needs and aspirations. Below I provide an excerpt from their letter:

Because absolutely healthy people⁷⁶ have left the state of affairs [at the Society of the Deaf] in a terrible condition acting for the sake of their interests. The rights of deaf-mute people are in the hands of absolutely healthy non-disabled people. **Deaf-mute people who are members of the Society of the Deaf of Uzbekistan do not possess their rights at**

⁷⁴ See Chapter 7 for a detailed discussion of the role of Islamic culture and religious institutions in constructing a distinctive form of citizenship by disabled people in post-Soviet Uzbekistan.

⁷⁵ I am using a pseudonym.

⁷⁶ In Uzbek they used *to’rt muchasi sog’ odam*, thus emphasising entirely able-bodied healthy people in comparison with a person with impairments who is believed to have issues with their health. This is the term used by the research participants which I am critical of as disability should not be conflated with illness but accepted as part of human diversity.

all, and everything is being held tightly in the hands of non-disabled people.⁷⁷

The manifesto of the deaf religious community outlined that they were not enjoying their rights at the Society of the Deaf, and that non-deaf people were accessing them instead. Importantly, the letter concluded that the prosperity of their Society could be possible only if “a fundamental change happens in the management system of the Society of the Deaf”. Indeed, in 2013, a hearing chairperson Javokhir Rikhsiev took over the leadership of the Central Board of the Society of the Deaf. Before him, from 1999 to 2013, a hard-of-hearing woman Farida Paramonova served as chairperson of the Central Board, and before that she worked as a director of the Cultural Centre for the Deaf, as well as chairperson of the Tashkent regional branch of the Society of the Deaf. In 2013, she moved to Russia for a permanent residency and handed over her position to her hearing deputy chairperson Mr Rikhsiev. The pious deaf activists struggled to communicate with him, and their manifesto was aimed primarily at him, criticising his lack of transparency and accountability to the deaf community.

Alisa, a representative of the Society of the Deaf who I mentioned earlier, also confirmed that all directors at the UPPs of the Society of the Deaf were at that point hearing businessmen. In the same vein, Shaw (2017) in his book on deaf people in the USSR notes that the profitability of the All-Russian Society of the Deaf attracted hearing bureaucrats who eventually took over the organisation and were not eager to work with deaf people. At the same time, all chairpersons and delegates participating in the Congress (*Qurultoy*) of the Society of the Blind have always been blind and visually impaired people. But only three deaf chairpersons of the regional branches of the Society of the

⁷⁷ Emphasis added by the author.

Deaf remained, in Namangan, Fergana and Khorezm regions. Alisa told me that all other leaders and delegates from local and regional levels of the Society of the Deaf were hearing persons who did not communicate in sign language.

All UPP directors are all healthy. And there are many hearing people among chairpersons of regional boards. All of them are included as delegates at the Congress. We are trying to include deaf people as well. But with each Congress, it becomes more difficult to choose deaf people. Because they do not work at UPPs and do not understand why and where they were chosen [as delegates].

She explained that with each conference and congress, it was becoming more and more challenging to elect deaf and hard-of-hearing chairpersons and delegates who could be involved in the work of the higher governing bodies. Alisa complained about the lack of smart and active deaf candidates for the leadership positions and roles, due to their lack of interest in the activities of the Society or in working at UPPs. Interestingly, her perception mirrors Jasur's demands for accountability and transparency (as a young member of the Uzbek deaf community). In the final section of this chapter (4.4), I argue that this inconsistency is due to different understandings of deaf activism and citizenship held by various groups within the deaf community. During the Soviet times, working at UPPs played an important role in climbing the ladder from an ordinary worker at the sheltered workshop to managerial roles at the Society of the Deaf. But how can the younger generation of deaf activists be blamed for a lack of interest in UPPs if the whole system of segregated employment is in deep crisis and is not able to offer decent jobs? In the context of the collapse of the UPPs and lack of integration of deaf people in mainstream industries, labour contribution can no longer serve as a means to achieve Soviet citizenship. Therefore, since 1991 there has been an increasing prevalence of hearing people in leading managerial positions both at UPPs and within the Society of the Deaf, which as I argue has already turned into the 'Society of the Hearing'.

OGUz has an outdated electoral procedure which is heavily dependent on the approval of controlling government entities. The complex at the Cabinet of Ministers is restricting involvement of ‘outsiders’ in the governing bodies of the Society of the Deaf while enabling hearing people to occupy positions of power. For instance, in 2013 the candidacy of the hearing chairperson had been put forward by the Cabinet of Ministers and approved unanimously by the delegates of the congress. Alisa also warned that the current hearing chairperson, Rikhsiev, had relatives working in various positions at state organisations. For instance, she mentioned that his brother worked at the prosecutor’s office, and his son worked at SNB.⁷⁸ Therefore, Alisa thought that it was useless to oppose Mr Rikhsiev due to his powerful connections. One could assume that by agreeing on the candidacy of Rikhsiev, the government was trying to ensure that the property of the NGO is not squandered, misappropriated or embezzled by unknown people. However, I do not agree with this interpretation: such overprotection by the state leads to a situation where young deaf people like Jasur are excluded by the organisation which should protect their rights and interests. The top-down procedure of reconciliation with the curator at the Cabinet of Ministers puts restrictions on independent elections of the chairperson at the Congress (*Qurultoy*). However, it is not clear whether the powers of the unnamed curator include rejecting any candidate that they deem unsuitable for leadership positions. In other words, if Rikhsiev’s candidacy was already approved by the curator, it would be quite difficult to compete with him as the elections would not be fair. Such top-down imposition of non-disabled candidates suitable to the government undermines the right of deaf members of the Society to choose their own leader. Therefore, the principle of ‘democratic centralism’ is not working in practice.

⁷⁸ The National Security Service (SNB) is a national intelligence state agency in Uzbekistan, a successor to the KGB affiliate in the Uzbek SSR which was renamed as the State Security Service in March 2018 during Shavkat Mirziyoyev’s presidency.

4.3 Failure of the principle of ‘democratic centralism’

Voices of young disabled activists are not heard

In Section 4.1, I showed how the principle of ‘democratic centralism’ should work in theory. But what is it like in practice? In this section, I provide ethnographic accounts of how elections are organised at the Society of the Blind to see whether ‘democratic centralism’ allows the voices of all members to be heard. At the Central Board of the Society of the Blind, which is the headquarters of the organisation, I interviewed a member of staff called Izzat.⁷⁹ He is blind young man around the age of 30 who worked at the organisational and social department of the Central Board. As I interviewed him, it was clear that Izzat’s involvement in the Society of the Blind was quite controversial. He was born after Uzbekistan’s independence in 1991 and presented himself as an ambitious independent activist for disability rights. He saw no prospect of serious reform within the Society of the Blind. His scepticism was driven by his unsuccessful attempt to get elected as chairperson of the Tashkent city branch of the Society. In early May 2019 when I had just started my second summer of fieldwork in Tashkent, I met him at the Palace of Culture of the Blind in Cho‘pon ota mahalla where the metropolitan office of the Society of the Blind is located. On that day each district branch sent its own elected delegate to participate in the conference (*konferentsiya*) at Tashkent city branch. For instance, if in Mirabad district of Tashkent city there are about 210 registered members, then one delegate is elected by open voting to represent 30 members, which means that in total seven delegates represent this district. Izzat himself was elected as one of the delegates

⁷⁹ All names used in this chapter are pseudonyms. During my doctoral research Izzat became a good friend of mine and I managed to build a strong relationship of trust with him. Otherwise, he would not be able to talk openly with me about the ongoing issues at the Society of the Blind. The first interview with him was rather sanitised with ‘politically correct’ answers. Moreover, the interview took place in the premises of the Central Board which might have put additional pressure on him.

from the Mirabad and Bektemir inter-district branch. In total 39 delegates⁸⁰ participated in the Tashkent conference but Izzat said the outcome of the vote was predictable as Rustam Askarov, an older partially sighted man who had managed the Tashkent city branch since 2012 was re-elected to the position thanks to the majority votes of 27 delegates. Twelve delegates voted for Izzat's candidacy which was recommended by one of the delegates at the conference. However, Izzat was not satisfied with the outcome of the elections and blamed the election commission for a lack of transparency and impartiality. He argued that the members of the election commission were quite loyal to the acting chairperson and worked closely with him at the cultural centre.

Izzat's distrust of the voting process also stemmed from his blindness as he could not see the result of voting by a show of hands in an open vote. In other words, although for sighted people a show of hands can be considered 'open voting', for Izzat it was in a sense a secret ballot as he did not know who voted for whom. I asked him whether it would be better for the Society of the Blind to introduce accessible methods of open voting for blind and visually impaired people (for example, by asking delegates to pronounce the name of the candidate they are voting for when raising their hands), but he pointed out that it is not stated in the Charter. Moreover, Izzat thought there was a downside to pronouncing names when voting as it may cause political confrontations among delegates if they are reluctant to say the names of the candidate when casting their ballot. He provided an example of elections in Navoiy region where the delegates did pronounce the names, and it turned into a brawl. As a result, although the blind and visually impaired people call it as 'open voting', it is inherently a secret ballot. Commenting on the

⁸⁰ There were in total 43 delegates who were elected to participate in the Tashkent conference, but four could not come.

inclusivity of these elections Izzat mentioned that there have been no delegates who could represent blind and visually impaired menial workers from UPPs (he called them ‘black workers’, or *qora ishchi*) which I discuss in detail in Chapter 5. Moreover, the youngest chairperson of all the district branches in Tashkent was born in 1982. Thus, the rights and interests of the younger generation remain underrepresented within the largest NGO of blind and visually impaired people in Uzbekistan.

Izzat told me that during the Karimov era, when 2008 was declared ‘The Year of the Youth’ (*Yoshlar yili*), the blind youth began to unite under the Central Board of the Society of the Blind, initially as a student group. They wanted to establish an organisation separate to the Society of the Blind, and founded a new independent NGO called Tashkent City Centre of the Blind Youth (*Toshkent shahar ko’zi ojiz yoshlar markazi*). Registering a new NGO of the blind was quite complicated (Yusupov and Isakov 2020a), and the Tashkent city branch of the Society of the Blind provided necessary legal and other forms of support in the process. When an initiative group of citizens submits application documents for the registration of an NGO, the justice authorities check the founders and the future governing body of the organisation through the special services in order to exclude ‘suspicious’ and ‘unreliable people’ from getting into the leadership. But this is all done behind the scenes, and if something is ‘wrong’ with the candidacy of the head of the NGO, they will ask to replace him under some pretext. This practice is used in many countries of the former USSR. The state reserves the right to define ‘unreliability’. Therefore, one needs to have a guarantor within the established NGOs or even government agencies which would confirm the reliability of the initiative group. Currently, about 140 blind young people are members of this NGO which mainly engages in distributing notebooks in Braille, organising excursions and question-and-answer

sessions through its group ‘Clever Students’. But Izzat says that the younger generation of the blind should also be blamed for not doing more to mobilise their peers within the Society of the Blind to represent their interests through the established organisational structure. However, I argue that participation of young people in the decision-making process is difficult due to the dominance of older bureaucrats with visual impairments. As a result, young people with visual impairments who were born after independence are acutely underrepresented within the Society of the Blind. This situation points to generational tensions between older blind leaders who tend to think through the prism of the Soviet citizenship framework and a younger generation who would like to invent new approaches for supporting employment, education, and recreation with their blind and visually impaired members.

Exclusion within the Society of the Blind

On 26 September 2019 the XVIIIth Congress (*Qurultoy* in Uzbek) of the Society of the Blind was held in the Tashkent headquarters of the organisation. 112 delegates⁸¹ from all over Uzbekistan participated in the elections of a new chairperson of the Central Board. The *Qurultoy* is held once in every five years and according to the Charter it is the supreme governing body of the Society of the Blind. The leader is elected not through direct voting by the members, but via elected delegates who represent each territorial branch. The elections are organised at each level starting with the district, then the city, and finally the republican level (see Section 4.1 for the overview of the organisation structure). The Plenum of the Central Board decides the number of delegates for each territorial unit. In total there were about 80-90 delegates (or 70-80% of all delegates) who

⁸¹ 109 delegates were present at the *Qurultoy*, and six delegates could not come to Tashkent due to unexpected circumstances.

participated in the 2019 *Qurultoy*. Among them were the chairpersons of the territorial administrative branches, directors, and deputy directors of the UPPs and other functionaries of the administrative apparatus. Only one blind delegate out of a total of 112 delegates was under 30: a 22-year-old young man with a visual impairment representing Tashkent region. Other delegates of the Congress were predominantly elderly veterans with visual impairments. Blind and visually impaired women were not present at the Congress, neither are they present in any current managerial positions at the Society of the Blind. The founding chairperson of the Society of the Blind, Quدرات Primkulov (1983) warned that a “dangerous question” of why there were very few women among the historical figures of the Society of the Blind might naturally arise:

Were there no blind women among Uzbek girls and women? Or did fate smile more at women rather than men?

Primkulov (1983) continued that, of course, that was not the case, and in Uzbek families, both girls and boys suffered from the same diseases. Due to the lack of timely medical care, poverty and unsanitary conditions, the children of many poor people became blind from infancy. Primkulov (1983) argued that:

all the trouble was that the Shari'a law (Shariyat) had deprived Muslim women of all human rights.

He mentioned the efforts of the Soviet government to put an end to ‘rich feudal treatment’ of girls and women. It seems that after the collapse of the communist regime, blind female members have not been equally represented in the higher governing bodies of the organisation. Izzat said that only one ‘healthy’ (*sog'lom* in Uzbek⁸²) woman participated in the XVIIth Congress, and all other delegates were blind or visually impaired and male. Consequently, there is a lack of representation of female and younger blind voices. Thus,

⁸² Meaning sighted women.

I argue that the principle of ‘democratic centralism’ is not working as expected in the new realities of post-Soviet Uzbekistan. Nonetheless, one important organisational feature that the Society of the Blind preserved in the post-Soviet context is that blind and visually impaired people have retained most of the leadership positions within the organisation. However, the Central Board has usually appointed sighted men as directors of the UPPs. This section has showed that there is a lack of inclusion, participation, and representation of young and female members with sensory impairments within the governing bodies of the societies of deaf and blind people. The Society of the Blind has remained the only organisation of disabled people meeting an essential criterion of a genuine and independent DPO – the chairpersons of territorial branches and of the central board are all blind and visually impaired people, while the delegates elected from the local and regional levels are also blind with a few exceptions. In other words, the affairs of the blind are handled by blind people based on the principle of a global disability rights movement ‘*Nothing about us without us*’ (Charlton 1998). Unfortunately, this is not yet the case at the Society of the Deaf or the Society of the Disabled where decision-making power currently belongs to non-disabled people. This situation is further exacerbated by contested concepts of disability activism among various groups of disabled people. As well as considering state intervention, it is important to ask what kind of perspectives on disability and citizenship their disabled members hold. The final section in this chapter argues that due to the failure of ‘democratic centralism’, all three societies turned into government-controlled disability NGOs, which presents barriers for alternative formal representations of deaf people in the current civil society landscape.

4.4 Societies as barriers for disability advocacy and citizenship

Debated concepts of deaf activism and advocacy

One of the members of the religious group of deaf people, Anvar,⁸³ has become my closest friend and co-author of several articles on the barriers faced by the Uzbek deaf community. He was born in 1979 in the Chimkent region in Kazakhstan. At the age of five, he moved to the then Uzbek SSR and lived in Jizzakh region. Anvar attended a mainstream school for about two to three months, but due to illness and consequent hearing loss, he went to the specialised boarding school No. 102 in Tashkent city and completed ten grades. In 1997 he entered the Republican Technical Vocational School under the Ministry of Social Welfare⁸⁴ and in 1999 completed a full course as a mechanic for the repair of radio and television equipment – a very common profession for a disabled man in Uzbekistan. However, as the vocational school lacked suitable conditions for deaf children, he could not get a proper professional education and began working as a photographer. He considers himself to have been a full member of the Society of the Deaf since 2002. In 2016-2017, he studied English and American Sign Language (ASL) courses at LaGuardia Community College in New York and had been a vocal advocate for the rights of deaf and hard-of-hearing people through his blog.⁸⁵ Since 2019, like another young deaf activist, Jasur, Anvar has been studying at the University of Journalism and Mass Communications thanks to the 2% quota for disabled students.⁸⁶

⁸³ I am using a pseudonym.

⁸⁴ The Ministry of Social Welfare ceased to exist, but social welfare departments are still functioning.

⁸⁵ It is difficult to anonymise him as he is the only deaf blogger in Uzbekistan.

⁸⁶ See Section 2.4 in Chapter 2 for more information on these types of policies in the field of education of disabled people.

In March 2020 he wrote a letter to the hearing chairperson of the Central Board, Javokhir Rikhsiev, asking him to provide detailed information about the organisational and financial activities of the Society of the Deaf and its UPPs. Despite confirmation of receipt of his formal request by the chairperson's secretary, no response followed. Moreover, his request to get a copy of the Charter of the Central Board remained unsatisfied and he was disappointed:

If members of the Society of the Deaf, which was created to protect their rights and interests, cannot get the necessary information about the activities of their own organisation, then what is the need for such an organisation?

Indeed, it was quite challenging to obtain any information about the work of the Society of the Deaf as it has no organisational website or even a webpage on social media. The hearing chairperson is hardly approachable and is usually silent at public meetings. It seems that he does not really engage with the deaf community. The only available webpage with some information was found on the Regional Secretariat of the World Federation of the Deaf in Eastern Europe and Central Asia,⁸⁷ which indicated that out of more than 22,000 citizens with hearing and speech impairments registered by the Society of the Deaf, 10,291 people are members over 16 years old (reflecting a membership coverage of 45.4%). Based on the information provided by Alisa, there were 75 primary organisations of the deaf, but a thorough review of the NGO registry of the Ministry of Justice did not provide any information about such primary organisations. The numbers on membership and primary organisations are doubtful, given that deaf and hard-of-hearing people feel a sense of alienation and a lack belonging in relation to the Society of the Deaf as discussed above.

⁸⁷ <http://eemars.org/>. The website is currently not working as of May 2022.

In sharp contrast, Alisa, a veteran of the Society of the Deaf in her mid-60s, has a different perspective on deaf activism and membership of the Society. Alisa is a deaf chairperson of the Tashkent regional branch⁸⁸ who has been working at the Society of the Deaf since 1974. In 1970 she completed secondary education at a public school and in 1973 she graduated from a public vocational-technical school (*tekhnikum*). She grew up and studied among hearing people in Angren, but when her condition worsened and she completely lost her hearing, she was forced to sit at home for about one year. She could speak like a hearing person but became totally deaf. In 1974, Alisa suddenly saw a job announcement in the newspaper '*Pravda Vostoka*' (The Truth of the East⁸⁹) that the UPP No. 1 was recruiting deaf and hard-of-hearing students to the specialised enterprise and came to the Society of the Deaf. She then started working at the training and production enterprise of the deaf UPP No. 3 in Tashkent. It became part of her everyday life as she was accepted by a community of people like herself (*svoya sredi svoih*). She criticised the deaf blogger Anvar for his critical reporting of the situation in the Society. To her mind, Anvar's critique that the deaf youth are not given a way to take the lead was only 'beautiful words' (*krasiviye slova* in Russian). According to Alisa:

All the deaf are indignant that the Society [of the Deaf] did not give them anything personally. I accidentally saw one quote by John F. Kennedy "Don't ask what your Motherland gave you. Ask yourself what you gave your Motherland." To paraphrase this, you can ask the dissatisfied [deaf people], what have you given to the Society?

Alisa continued that the term 'Society' itself implies active participation of members in the life of the Society, and this is written in the Charter. Alisa defines deaf activism as

⁸⁸ Unlike the Society of the Blind there is no Tashkent city branch of the Society of the Deaf and Alisa is responsible for working with deaf and hard-of-hearing people residing in Tashkent city as well.

⁸⁹ The newspaper has been published since it was founded in 1917 under the name *Nasha Gazeta* (Our Newspaper). In 1924, it switched to its current name 'The Truth of the East' and was considered to be one of the prominent newspapers in the Uzbek SSR published in Russian.

participating in deaf sports, amateur art activities and performances (*hudozhestvennaya samodeyatel'nost'*)⁹⁰ or visiting the library of the deaf where they could have an opportunity to interact with other members of the Society. She felt that the younger generation of deaf people do not understand what social activism (*obshchestvennaya deyatel'nost'* in Russian) implies:

Young people do not understand what social activism is like in a Komsomol.⁹¹ For example, I tried to include young people in my team. I issue an invitation to the Plenary meeting once a year. And they question me, what is it? Or they say they are busy, they need to go to the hospital, they can't or make up any excuse. Such young people we have.

Although Alisa tried to include deaf youth and issued invitations to the Plenum meeting once a year, she felt they did not understand the purpose of the event, why they were chosen to participate, or they made some excuses for not coming. Alisa accused them of not taking part in the activities of the Society:

If he [Anvar] have been more active, he would have understood both the Charter and the system. All elective bodies of the Society elect only Society members. He does not want to be a member of the Society; he cannot be included in the members of the elected body of the Society.

In her eyes, Anvar is not an active member and is just registered with the Society of the Deaf. She supposed that probably he only needed a certificate (*spravka*) from the Society proving that he is actually deaf. Alisa explained that she sees all the deficiencies and challenges in the Society, but she has been following the principle:

⁹⁰ Amateur performances and arts activities of deaf people emerged and were popular during the Soviet Union. Nowadays they include drama and musical groups (feeling the music through the vibration), and various ensembles (performing national dances in traditional costumes, singing in sign language) involving deaf and hard-of-hearing people who usually practise at the Culture Centre for the Deaf also known as the 'Palace of Culture of the Deaf' (*Dvorec kul'tury gluhih*).

⁹¹ The All-Union Leninist Young Communist League was briefly known as Komsomol and was a political youth organisation during the Soviet era.

You are not able, and it is not within your power to change the world,
you should change your attitude to the world.

While Alisa's words may contain elements of truth, there is a strong counter-argument that there are already many young deaf activists like Jasur or Anvar representing a new generation of deaf and hard-of-hearing people who openly criticise the current non-disabled leadership of the Society of the Deaf. The outdated concepts of deaf activism embedded in the Soviet legacy have become a barrier to the development of new forms of citizenship being claimed by the new generation of disabled activists in Uzbekistan.

Is there a place for an independent deaf people's organisation?

Feeling that it would be difficult to reform the outdated management system and the concepts of deaf activism at the Society of the Deaf, the young deaf leader Jasur sent a similar complaint to the Virtual Reception of the President Shavkat Mirziyoyev.⁹² Like the manifesto I analysed in Section 4.2 it was also read out loud at the religious meeting. Apparently, the activist group of deaf people never heard back from Mr Abulhasan, the senior religious official they initially addressed regarding the problems with the chairperson of the Society of the Blind.⁹³ This time Jasur's petition was directed to the Agency of Medical and Social Services under the Ministry of Health which in its turn redirected the appeal down to the Society of the Deaf. The petition addressed to the president read:

⁹² This was an innovation of the new president which was launched at the end of September 2016 to provide an opportunity for citizens to send a question, opinion, or complaints directly to President Mirziyoyev (Starr and Cornell 2018: 178). It can be accessed at <https://pm.gov.uz/>. Since the launch of the virtual reception in September 2016 more than 3.2 million appeals have been received and based on the website almost all of them have been reviewed.

The Virtual Reception of the President of the Republic of Uzbekistan was launched at the end of September 2016 to provide an opportunity for citizens to send a question, opinion, or complaints directly to President Mirziyoyev (Starr and Cornell 2018: 178). It can be accessed at <https://pm.gov.uz/>.

⁹³ Probably, the reason that Jasur did not hear back from him was because he left his job at the Committee on Religious Affairs and started working on terrorism and extremism at the Ministry of Internal Affairs.

Our goal is to radically reform the management system of people with hearing and speech impairments in our country, which has been disrupted for various reasons. Because **we consider it appropriate that disabled people should be led by a person who has a deep understanding of concerns and problems of deaf-mute people and who has been raised among themselves** [o‘zlarining ichidan yetishib chiqqan].

In the letter, the deaf activists emphasised that deaf and hard-of-hearing people can be themselves part of the problem due to their illiteracy and lack of education. Nevertheless, they put the biggest blame on the current non-disabled leadership of the Society of the Deaf which could not build a good working relationship with deaf people. They referred to a stereotypical image of an Uzbek deaf person who is immediately conflated with illiteracy and probably is not congruent with the image of a chairperson that is held by the curator at the Cabinet of Ministers. I could feel the strong sense of anger, disappointment and despair while reading the letter:

We have tried many times, but our numerous attempts have been in vain. The reason is that we are deaf and mute.⁹⁴ We cannot complain to anyone. Even if we complain, no one understands us, or does not want to understand us, or rejects us by giving various excuses.

The deaf activists asked the president to provide them with the opportunity to self-govern with due dedication and responsibility. It seems that the letter never reached the president himself, but was read by the current hearing chairperson, Rikhsiev, who invited the representatives of the initiative group of deaf people to his office. Jasur explained all his recommendations and plans, but the chairperson rejected all of them. Rikhsiev made various excuses including the fact that supposedly Jasur and other active and young deaf people were not members of the Society of the Deaf and therefore they could not legally claim anything from the Society. Ridiculously, a hearing chairperson of the Society of the Deaf showed the deaf activists the door, arguing that they were not the members of

⁹⁴ They used an interesting expression in Uzbek to illustrate their condition: *‘bizlarning qulog‘imiz og‘ir va zabonsiz ekanligimizdir’* which translates as "our ears are heavy and that we are mute".

the Society of the Deaf as they were not paying membership fees. The paradox is that due to alienation from the Society, deaf people are reluctant to pay membership fees as they do not like to work with hearing leaders who do not care about them. As my co-researcher Anvar put it honestly:

Nobody wants to work with such leaders. Even I do not want to become a part of the Society [of the Deaf], the membership certificate is lying somewhere with several years of unpaid membership fees. There are a lot of people like me in the Society, unfortunately.

The unsuccessful one-to-one meeting with the hearing chairperson did not make the initiative group of deaf people give up, and another deaf activist made an official complaint to the prosecutor's office about his dissatisfaction with the staff members of the Central Board of the Society of Deaf. However, the prosecutor's investigation showed that the chairperson of the Central Board accepted them in person and listened to their suggestions. The prosecutor's letter also indicated that "the proposals were not submitted in a written form". Moreover, the prosecutor's response referred to clause 4.1 of the Charter of the Society of the Deaf, which the deaf activists have never had access to. Apparently, the prosecutor was hinting that the deaf activist was not a member of the Society of the Deaf and was not paying membership fees.

After all these unsuccessful grievances, deaf activists decided to establish a new organisation of deaf and hard-of-hearing people. In their joint address to state officials and government bodies, the religious deaf community indicated that if a fundamental change in the management system of the Society of the Deaf does not happen, then they would like to establish a new organisation. They named it '*the Association of the Deaf of Uzbekistan*' and announced their willingness to elect their own leader who would deeply understand the concerns and problems of persons with hearing impairments. However,

all their attempts to register a new public association of deaf people failed, and when they applied for legal support for the registration of their NGO at the Ministry of Justice, they were told that the Society of the Deaf and the Sports Federation of the Deaf already existed. The reaction of judicial authorities further confirmed my assumption that the Uzbek authorities do not see any necessity or even interest in giving way to the establishment of new and independent DPOs, arguing that disabled people could already join the three societies of deaf, blind, and people with physical impairments. In other words, the existence of these big disability NGOs presents a barrier for the emergence of genuine grassroots DPOs in Uzbekistan, which would advocate for the rights and citizenship of disabled people on the ground. Apart from the Centre of the Blind Youth mentioned in Section 4.3, young deaf activists could not register their own NGO. But any restriction of freedom of association contradicts the Constitution⁹⁵ of Uzbekistan and registration of the new Association of the Deaf can be legally refused only if an NGO with the same name was previously registered. So far, this chapter has showed that deaf and blind people in Uzbekistan do have critical agency to advocate for equal representations of their rights and interests. The ongoing state intervention in the dominant disability NGOs and the impediments to formal recognition of their self-initiative groups are constraining their bottom-up struggles for citizenship. The critical ethnographic evidence analysed in this chapter confirms that the legacy of the Soviet citizenship framework for disabled people is affecting opportunities of emerging disabled leaders for bottom-up advocacy, and social and political participation. The privileged positions of the three societies are inhibiting the formation of new grassroots disabled people's organisations, and suppressing the aspirations of a new generation of disabled

⁹⁵ Article 34 of the Constitution of the Republic of Uzbekistan states that "Citizens of the Republic of Uzbekistan shall have the right to form trade unions, political parties and other public associations, and to participate in mass movements" (GoU 1992).

activists to construct new frameworks of citizenship and play a more active role in the nascent Uzbek disability movement.

Conclusion

During Soviet times, the Societies of the Deaf and the Blind were integrated into the structure of the communist state and heavily relied on government support. These two organisations of people with sensory impairments possessed vast resources and the system of specialised enterprises which functioned under the Soviet Ministry of Social Welfare. Nevertheless, they could live only within the boundaries of the definitions of ‘social activism’ imposed from top-down. This allowed them to develop distinctive disability identities and communities through promotion of cultural and sports activities among deaf and blind people. Since Uzbekistan gained its independence in 1991, the societies of blind and deaf people have developed an extended network of branches across the country. They turned into leading NGOs dealing with disability issues and core state partners in channelling financial and other types of support from the government and other sponsors. As a result, they monopolised the right to represent disabled people across the country in decision-making processes at the national level.

However, tacit relationships between the societies and government bodies make them reliant on state authorities in issues related to the election of leadership positions at these organisations. The ongoing intervention of the Uzbek government in the dominant disability NGOs does not allow them to adhere to the internal principle of ‘democratic centralism’ and deprives ordinary members of the right to nominate their own candidates to positions of power. Thus, despite the collapse of the Soviet citizenship framework for disabled people, state interference in disabled people’s organisations is ongoing and is

being implemented via the appointing of non-disabled proxies as chairpersons at the leading disability organisations. Based on my ethnographic accounts I argue that two of the societies are entirely controlled by a small group of non-disabled people linked to the Uzbek government. The Society of the Deaf and the Society of the Disabled could not withstand state intervention and their leadership has been taken over by non-disabled people; this makes it hard to refer to these two societies as organisations of disabled people. The Society of the Blind seems to have retained some essential features of a disabled people's organisation, being led by a chairperson with visual impairments and having a majority of members with visual impairments in the governing bodies. However, I argue that lack of inclusion, democracy and equal representation of the rights and interests of ordinary members (in particular, the younger generation of deaf and blind activists, as well as women and girls within these organisations) undermines their legitimacy to function on behalf of disabled people. In other words, the existing civil society landscape in post-Soviet Uzbekistan presents barriers for disabled people to enact their citizenship through the dominant disability NGOs.

Therefore, operationalising the liberal approach to citizenship through disability organisations as happened in Western democracies discussed in Section 1.2 can be problematic in the current political context of Uzbekistan unless new and genuine organisations *of* disabled people are allowed to formally register as NGOs and provide the necessary channels for enactment of citizenship in a relationship with the state. In summary, I argue that the mere existence of the three disability NGOs discussed in this chapter does not necessarily mean that these organisations are protecting the rights and interests of all disabled people in Uzbekistan. The excluded groups within these organisations have not been able to make the heavy bureaucratic machine accountable

and transparent to them, which might have also caused the ongoing downturn in the specialised training and production enterprises (UPPs). In the next empirical chapter, I analyse the situation within the UPPs of the Society of the Blind and the Society of the Deaf which once served as important institutions for achieving Soviet citizenship through the active labour contribution of people with sensory impairments.

Chapter 5. Enterprises about them without them: the struggle for Soviet citizenship continues

This empirical chapter builds upon the argument presented in Chapter 4 that the dominant disability NGOs are inhibiting disabled people's bottom-up advocacy efforts towards citizenship. By drawing on the previous works in disability studies in socialist and post-socialist contexts (Mladenov 2011, 2017, 2018; Phillips 2009, 2010; Shaw 2017; Zaviršek 2014), I argue that the legacy of Soviet functional and productivist approaches to achieving citizenship is still present in Uzbekistan. In this chapter I look deeper into the role of specialised training and production enterprises (UPPs) operating within the NGOs. The ethnographic evidence presented in this chapter shows that deaf and blind people are not able to operationalise the Soviet citizenship framework discussed in Section 1.4 which allowed them to claim a sense of belonging to the communist project through their active labour participation. This approach, which proved to be successful during the Uzbek SSR, has faced considerable economic challenges in the post-Soviet Uzbekistan.

Based on the lived experiences of UPP workers, this chapter problematises the Soviet approach to achieving citizenship through exploitation of disabled people's working capacities. This chapter challenges the suitability of this productivist approach in post-socialist Uzbekistan. I argue that the gradual demise of the Soviet citizenship framework for disabled people precipitated by the ongoing crisis of the UPP system is related to organisational factors rather than external political or economic shocks following the collapse of the Soviet Union. I explain this downfall by the lack of democratic development within the dominant disability NGOs and their lack of accountability and transparency towards workers in UPPs. The findings presented in this chapter contribute

to the overall argument of the thesis that the Soviet legacies of disability organising are affecting the opportunities of disabled people, particularly the younger generation, to promote new ways of achieving citizenship in Uzbekistan.

5.1 From active builders of communism to disenfranchised citizens

Brush with death: collapse of the UPP system

As indicated by Figure 1 in the Introduction, I visited a training and production enterprise (UPP) “CHYOTKA” which belongs to the Central Board of the Society of the Blind. It has specialised in manual production of industrial brushes to clean impurities from cotton. There was a time back in the 1980s (see Figure 12) when this brush business thrived and employed more than 1,500 blind and visually impaired workers. But nowadays, less than 40 blind workers are formally employed. Looking at the dusty equipment it was clear that this specialised workshop was on the verge of bankruptcy. Although we visited the workshop on a working day, we could not see anyone at the worn-out tables, as the UPP could not secure a state procurement contract for brushes that year.

Figure 12. The brush workshop at the training and production enterprise of the blind LLC “CHYOTKA”



Source: author’s photo

UPP “CHYOTKA”⁹⁶ is a limited liability company which was established in 1956 by the Society of the Blind. In an interview the former workers referred to the manual production process as “brush knitting” (*cho’tka to’qish*) because the Russian word *shyotka* (brush) entered the Uzbek language. The mode of production has not changed since Soviet times and has been based on manual labour of blind workers whose wages were calculated based on the number of brushes they manufactured per month. There were no production limits and the more they produced, the more they earned. Therefore, the blind workers had the motivation to perform and earned decent salaries compared with non-disabled workers in similar industries.

⁹⁶ In Uzbek, “CHYOTKA” o’quv ishlab chiqarish korxonasi MChJ.

Figure 13. Old wooden industrial brushes at the training and production enterprise of the blind "CHYOTKA"



Source: author's photo

The UPP system was the cornerstone of the financial sustainability of the societies of deaf and blind people, as they were dependent on income from the sheltered workshops. Their organisational activities were financed by the profits from the UPPs and subsidiary enterprises, as well as by retail and wholesale trade of products and services produced by persons with sensory impairments. As of 2019, there were 45 UPPs of the Society of the Blind operating in all regions of Uzbekistan including the autonomous Republic of Karakalpakstan and the capital city Tashkent. Nowadays, these specialised enterprises produce mainly mattresses, bedding, pillows, car covers, denim, cotton, threads, ropes, towels, sewing products, brushes, brooms as well as polyethylene pipes, plastic products, printing and stationery products, corrugated paper, cardboard boxes, metal products and even roasted sunflower seeds. The Society of the Blind has had a long history of working in the cotton production industry. The Uzbek SSR accounted for about 70% of Soviet

cotton production and the communist state strictly controlled the cotton industry (Zanca 2010). But after the collapse of the Soviet Union the UPPs lost their privileged status to have a monopoly right to produce certain types of goods which were then purchased by the government. Recently, producing mattresses and cotton-related products has become seasonal work. The Society of the Blind now depends on the occasional government orders for its goods and services or must compete with other enterprises through tender procedures.

I talked to two unemployed workers who recently lost their jobs at the UPP “CHOYTKA” and one of them, Jaloliddin aka,⁹⁷ regretfully said: “The brush has died” (*cho ‘tka o ‘ldi*). For him the brush embodied his sense of belonging to the collective through which he enacted his citizenship back in Soviet times. Moreover, regular employment at the UPP was a source of vital income to sustain his household on top of his miserable monthly disability benefit. Jaloliddin aka belongs to disability group I and received a disability pension of about 900,000 Uzbek soums (less than US\$90). There were about 40-60 blind and visually impaired residents in the Bayot mahalla who had not yet reached retirement age⁹⁸ and who were willing to continue working at the brush factory. Importantly, nowadays many blind employees of the UPP “CHYOTKA” exist only on paper and in reports by the Society of the Blind; in practice they are not getting their salaries on time, or are already formally recognised as unemployed. The brush business is on the brink of permanent shutdown due to political, economic, technological, and other factors that the Society of the Blind has had no control over following the collapse of the Soviet Union.

⁹⁷ I am using a pseudonym and referring to him using ‘aka’ which indicates a polite address to an elder.

⁹⁸ As at June 2020, the retirement age in Uzbekistan was 60 for men and 55 for women.

In the post-Soviet realities, the segregated UPP system has proved to be ineffective as the Society of the Blind could not hold a privileged monopoly position and a subordinate relationship with the Uzbek government. In the process of transformation from the planned and heavily centralised economy, UPPs of the blind had to compete as equals with other private companies of non-disabled people. As an example of these new realities, Jaloliddin aka explained that on 11 March 2019 the state cotton industry company UzPaxtaSanoat held a public tender to buy industrial brushes, but the bid put forward by the UPP “CHYOTKA” was not successful. One of the main reasons for the decline of the UPP system is that it has mostly used manual labour and could not modernise its facilities and modes of production (see Figure 14). Manual assembly has proved to be loss-making by default as it increased the costs of production which inevitably affected the final price of the brushes, thus making UPP products less competitive compared with those produced by automated machines. For instance, one brush which is produced manually by two to four blind workers at the UPP “CHYOTKA” is now easily and more cheaply produced by automated Chinese equipment imported into Uzbekistan.

Figure 14. A working space at the training and production enterprise of the blind "CHYOTKA"



Source: author's photo

A similar situation was observed at the Society of the Deaf where only 10 UPPs are left functioning across Uzbekistan. They currently employ only about 240-250 adults with hearing impairments. A representative at the Central Board of the Society of the Deaf told me that the biggest UPP is UPP No. 1 in Tashkent city which employs about 80 deaf and hard-of-hearing people. UPPs in the regions are small and provide jobs for about 20 deaf people on average when they are not working to their full production capacity. Another problem is that most of the UPPs are in regional centres and large cities like Tashkent, Kokand, Namangan, Samarkand, Bukhara and Karshi, and there are no sheltered workshops in distant rural areas. When I interviewed deaf people in Tashkent, many complained about an acute lack of decent jobs in the UPP system. Although there were some vacancies at the UPPs, the interviewees were unhappy with the wages and working conditions. Similarly, the working conditions of blind people employed at the specialised

enterprises were deplorable. The maximum monthly salary they can receive is about 700,000 soums (about \$70) which is not paid regularly. The representative of the Tashkent regional department of the Society of the Deaf, Alisa, who I mentioned in Chapter 4, said that even if there were jobs at the UPPs, deaf and hard-of-hearing people would not be willing to work there:

I offered them work at the UPP. But they are not satisfied with the working conditions: a 10-12-hour working day, a salary of about 1 million soums. They have more income in the parking lot [working as informal parking attendants]. And we cannot blame them for this. A person looks for where it is better. Deaf people should not be blamed for the fact that they have had such a time - the transition to market conditions.

She remembered the Soviet times when up to 450 deaf people used to work at such large industrial enterprises as the Tashkent Aviation Production Association named after V. P. Chkalov.⁹⁹ The Tashkent Plant of Agricultural Machinery (Tashselmash) employed about 250 people and Tashkent Tractor Plant (TTZ) recruited about 70 deaf and hard-of-hearing workers. Moreover, about 500-700 people worked at the Tashkent UPP No. 1. Members of the Society from rural areas who moved to the cities in search of jobs were provided with dormitories near to the UPP infrastructure. But nowadays UPPs, particularly those in the regions, do not have enough resources to provide accommodation for deaf and hard-of-hearing workers who are migrating to urban areas due to rampant unemployment in the regions. Having discussed the ongoing crisis in the UPP system, I now turn to the negative consequences resulting from a functional approach to asserting citizenship by disabled people.

⁹⁹ Currently, Tashkent Mechanical Plant (TMZ).

Functional model of disability as an impediment to citizenship

The ongoing crisis of the segregated model of employment of persons with sensory impairments at specialised UPPs shows that neither the Society of the Blind nor the Society of the Deaf can provide decent job opportunities even for their members. This contributes to the overall argument that the dominant disability NGOs are not able to provide decent opportunities for disabled people to achieve Soviet-type citizenship through active labour contribution. For instance, the Society of the Blind in an official correspondence to its workers explicitly admitted its powerlessness to ensure their employment. The reason is that its UPPs are functioning on average at 10% of their production capacities. The Society of the Blind highlighted that its UPPs are involved in social entrepreneurship (*ijtimoiy tadbirkorlik*) but without any state support they would be unable to survive. As a result, disabled workers of specialised enterprises found themselves in a helpless position where neither the state nor their societies could support them in sustaining livelihoods.

According to the Society of the Blind there are 65,000 blind and visually impaired citizens living in Uzbekistan. This includes 7,221 children up to 16 years old and 8,331 individuals between 16 and 30 years old. As of January 2019, out of 65,000 blind people only about 1,000 were working and more than 30,000 blind people were unemployed. The Society of the Deaf states that 21,600 people with hearing impairments were officially registered in the country in 2019, and 10,100 of them were members of the organisation. Given that only about 240-250 persons with hearing impairments work at the UPPs of the Society of the Deaf it becomes clear that the level of unemployment of deaf and hard-of-hearing people is quite significant. Deaf and hard-of-hearing adults are involved in informal types of work such as parking attendants, or sellers of flags and key

fobs at crossroads. Deaf women sit with floor scales in underpasses offering paid weighing services to passers-by. Importantly, the actual number of formally unemployed blind and deaf people could be higher. The officially reported data might exclude those who are not members of the organisation or those who even did not register at VTEK to get an official disability status.

The problem of the segregated employment model is that the societies and even their members still believe that blind and deaf people could not work at any other general enterprise, as if they cannot compete in the open labour market as equals with non-disabled workers. The generally accepted perception is that people with visual and hearing impairments can work only at specialised UPPs established for them during Soviet times. In other words, both the apparatchiks at the Societies of the Blind and the Deaf and their members internalised public attitudes and stereotypes and are thus practising self-stigma, believing that disabled people can and should work only in their own specialised settings. Moreover, the abundance of labour and younger people aged 18-30 in Uzbekistan and the high unemployment rate make it quite challenging for disabled workers to find decent employment opportunities. The ongoing crisis of the UPP system means that many blind and deaf people are unemployed, with some exceptions who have managed to find jobs outside the established system of segregated employment, which is quite difficult considering the institutionalised discrimination based on disability in the open labour market. The scope of jobs available to those with visual impairments in the general labour market is limited to specific professions such as teachers at secondary schools, librarians, or staff at cultural centres. The general industries would prefer to hire young non-disabled workers rather than recruiting deaf and hard-of-hearing people, which would require adaptation of the workplace and communication difficulties.

I argue that the functional model of disability which underpinned the Soviet disability policy has in fact become the biggest barrier facing blind and deaf people who seek to claim their labour and citizenship rights. This model failed in the new realities of political and economic transformation in Uzbekistan due to systemic changes in the citizenship framework discussed in Section 1.4. After the collapse of the Soviet Union, the Society of the Deaf and the Society of the Blind were turned *de jure* into non-government organisations and had to cope with economic difficulties on their own with limited support from the independent Uzbek government. Despite the ongoing crisis in the UPP system, both societies are still trying to operationalise the Soviet citizenship framework for disabled people by supporting segregated employment practices and facilities. However, there has been little success in reviving the Soviet approach to integration of deaf and blind people through their active labour contribution at the UPPs or in mainstream heavy industries. The functional model of disability (Phillips 2009; Završek 2014) has been exploitative in nature as it was based on the evaluation of labour capacity and productivity of persons with sensory impairments. Their emancipation from disenfranchised people to Soviet citizens was dependent on their labour output.

Despite the superficial changes in the organising of disabled people in post-Soviet Uzbekistan, the functional model still constitutes the core of the current Uzbek disability policy. VTEK relies on the functional model for disability assessment and determination (Mladenov 2011, 2015a). According to this model, disability is defined as a partial or complete loss of person's ability to work, and the aim of the disability assessment is to estimate labour capacities and restore them through individual medical and vocational rehabilitation plans (IPRs). VTEK's written recommendations regarding occupation and

employment in the disability certificate provide strict guidelines on what kind of work a disabled person can do, and where. VTEK's disability assessment labels disabled people as those who "can work in specifically created conditions" or even as "unfit for work" by imperatively denying their "right to work, free choice of work, fair conditions of labour and protection against unemployment in the procedure specified by law" enshrined in Article 37 of Uzbekistan's Constitution (GoU 1992). Seeing this label of 'unemployable' on the VTEK disability certificate, a potential employer in the open labour market usually refuses to recruit individuals with impairments. This is institutional discrimination based on disability. If, nevertheless, a person with sensory impairment manages to overcome the above barriers and get a job in the open labour market, then they can be considered lucky, or as blind people put it ironically, '*chosen*' (Abdukhalilov, 2015). Therefore, those with visual and hearing impairments generally have no other option than to work in specialised enterprises under the Society of the Deaf and the Blind, or to seek opportunities in the informal labour market. The following section analyses the causes of the ongoing crisis in the UPP system, and builds on the arguments presented in Chapter 4 regarding the failure of the principle of democratic centralism and further takeover of the UPP by non-disabled entrepreneurs.

5.2 Unheard voices of UPP workers

Lack of state support in making UPPs accountable to its workers

In this section, I explore the ways in which UPP workers are trying to advocate for their labour rights and in doing so assert their citizenship in the context of post-Soviet Uzbekistan. The former blind worker at the UPP "CHYOTKA", Jaloliddin aka, whom I mentioned earlier showed me a thick pile of letters. They were all his complaints to higher authorities (ministries, the Senate, the President's Administration and his virtual

reception, Prosecutor's office and so on) and the Central Board of the Society of the Blind, about the problem of unemployment at his UPP. Despite his endless appeals to the government bodies and the leadership of the society, the voice of the unemployed ordinary worker of the specialised brush enterprise was never heard. Due to his congenital blindness, he contacted the President's virtual reception by telephone to make a complaint that many UPPs for blind people were given out for rent to unknown non-disabled businessmen, and requested state support in providing jobs for blind and visually impaired people in disability groups I and II. In his appeal to the president, Jaloliddin aka asked the government to take over the control of the Society of the Blind. His official complaint was considered by the Ministry of Employment and Labour Relations of Uzbekistan which abstained from interfering in the affairs of the Society of the Blind. The state officials argued that the law on NGOs does not legally authorise them to control or intervene in the activities of NGOs, and in their turn NGOs could not intervene in the activities of state bodies.¹⁰⁰ This official response to Jaloliddin aka appeared to be untenable and hypocritical in the light of explicit intervention by the Cabinet of Ministers in the governing bodies, which I discussed in Chapter 4.

At the same time, the alleged inability of the authorities to intervene in the situation is further complicated, as the specialised enterprises of the Society of the Blind are business entities and supporting entrepreneurs has become a core focus of the economic policies of President Mirziyoyev since he came to power in September 2016. The newly adopted laws and regulations have made it difficult to inspect the activities of private companies, and to request the relevant state bodies to inspect the activities of business entities, one should have a solid proof of violations. In its response to another letter, the Employment

¹⁰⁰ This is stipulated in Article 4 of the Law "On Non-government Non-profit Organizations" (GoU 1999).

Promotion Centre of Yakkasaray district stated that Jaloliddin aka did not have any proof of violations of the law by the Society of the Blind, and none of his arguments (*vajlar*) had any evidence that could be confirmed by documents. The state labour authorities suggested that it would be appropriate if the highest governing body, the Central Board of the Society of the Blind, and the internal control-revision commission of the organisation reviewed his public appeal and undertook necessary action.

In the end, the state bodies forwarded the complaint about the failure of the Society to provide decent employment opportunities for the blind to the Society's Tashkent city branch. Rustam Askarov (a partially sighted head of the city branch), together with the chairperson of the Mirabad and Bektemir inter-district branch of the Society, A. Parmonov, and the lawyer of the UPP "CHYOTKA", R. Matchonov, visited Jaloliddin aka to talk about his appeal to the President's virtual reception. During the meeting Jaloliddin aka accused the representatives of the Society of not providing decent job opportunities for blind people at UPPs of the Society of the Blind across the country. Even if positions were available, they were retained only for the sake of formality. He expressed dissatisfaction about how the Society's central management board did not communicate properly (*muloqot qilish*) with ordinary members of the local branches who had worked at specialised enterprises. According to Jaloliddin aka, renting the territories and industrial premises of the UPPs to suspicious entrepreneurs and using the rent income to maintain the Society's central management apparatus (*boshqaruv apparati*) was unjustified, as the Society members were not benefiting from it. Importantly, Jaloliddin aka said that he did not talk only for himself but for an army of unemployed working age blind and visually impaired people at the national level.

Rustam aka, the chairperson of the Society's Tashkent city branch, asserted that work on the improvement and development of specialised production facilities was taking place to increase the number of job vacancies for the blind. The apparatchiks of the Society of the Blind wanted to close the case immediately and made Jaloliddin aka sign a statement that he had no complaints about the UPP "CHYOTKA" and/or the Tashkent city branch of the Society. The final statement submitted to the Central Board contained false information that Jaloliddin aka was employed and receiving a monthly wage. During the earlier private conversation with me, he indicated the opposite, as he was looking for job opportunities due to unemployment at the "CHYOTKA" LLC. This case shows how the voice of one ordinary blind worker does not win the battle against the heavy bureaucratic machinery of the Society of the Blind, and Jaloliddin aka had no other choice than to accept the situation. Nevertheless, he did not lose hope and turned again to the state authorities, namely to the Tashkent city Prosecutor's office. A pro forma response followed from a senior adviser of justice indicating that the Society of the Blind can engage in business according to its Charter. At the end of the letter the Prosecutor's office underlined that if Jaloliddin aka considered that "his rights or interests protected by the law are violated and he had incurred material and moral damage he has the right to appeal based on article 3 of the Civil Procedure Code to the common pleas court (civil law court)". Moreover, the letter mentioned that if he was not satisfied with the prosecutor's reply, he had the right to make an appeal to the higher standing prosecutor. Other state bodies reminded him of his right to appeal to the higher standing bodies, based on article 33 of the law on the "Appeals of Individuals and Legal Entities", if he was unsatisfied with the response. Such indifference of the government bodies to the grievances of Jaloliddin aka are further aggravated by lack of democratic decision making within the

Society of the Blind. The next section shows that the voices of UPPs workers are not being heard within the existing organisational structure.

Voices of UPP blue collar workers are not heard

As argued in Chapter 4, leaders of the societies of deaf, blind, and people with physical impairments, as well as the Uzbek authorities, claim that they represent all disabled people in Uzbekistan. They base this claim on the reach of their activities across the country and extensive membership coverage, arguing that no other public associations could be representative at such scale. The government bodies usually involve representatives from these three societies when there is a need to include disabled people in high-level policy and decision-making processes. The three societies monopolised the right to represent and speak on behalf of all disabled people in Uzbekistan. But do they have a legitimate right to represent them in policy- and decision-making if they are heavily dependent on the government in terms of the make-up of their organisational leadership? At first glance, the organisational structure of the societies may look as if it is based on the principles of direct participation and involvement of disabled members at the grassroots level. In theory, the principle of ‘democratic centralism’ should ensure participation in decision-making processes through primary organisations and bottom-up elections of delegates and members to governing bodies. Moreover, the term ‘society’ suggests there are ready-made ‘societies’ of separate close-knit communities of people with hearing, visual and physical impairments organised according to principles of equal rights and opportunities. However, such a superficial understanding of the role these three societies play in constructing citizenship of disabled people in Uzbekistan fails to address the state control and associated power relationships happening behind closed doors.

The current study found that ordinary disabled members and workers of the societies and its enterprises are finding themselves in disadvantaged positions. The blind bureaucrats and sighted entrepreneurs within the Society of the Blind are considerably constraining the citizenship of UPP workers. As discussed above, a number of government bodies remained indifferent to Jaloliddin aka's complaints about his livelihood challenges. The leadership of the Society of the Blind did not listen to his appeals either. Thus, ordinary UPP workers like Jaloliddin aka are not finding any leverage over the Central Board to make it transparent and accountable to them. Disturbingly, Jaloliddin aka said:

The management [Central Board of the Society of the Blind] is not working. We [workers at the brush factory] are not getting our salaries for more than 3 months now. Who writes about these issues loses his job, who makes a complaint [*jaloba* in Russian] – faces job cuts [*sokrasheniye* in Russian].

In reality, he should have been treated as a direct beneficiary of the main public association of the blind whose interests and rights to work should be protected by its Charter. The problem here lies in the fact that the blue collar workers of specialised enterprises of blind people are not well represented in the governing bodies of the Society of the Blind. According to Jaloliddin aka, there have so far been no delegates representing the labour rights of workers at the UPPs (*'ishchilardan delegat bo'lmagan'* in Uzbek).

They always choose [delegates] themselves and appoint themselves [to senior management positions].

The electoral procedures are usually predetermined (*'stsenariy tayyor'*) while almost all the delegates are usually directors of the UPPs and white collar bureaucrats. Jaloliddin aka provided his own estimates that about 80% of the delegates who have the right to vote in the chairperson elections of the central board were “their own people” (*o'zlarini odamlari*). This is aligned with Izzat's experience of participating in the chairperson elections at the Tashkent city branch of the Society of the Blind. Therefore, it is important

to understand how the elections within the dominant disability NGOs are organised and whether they are inclusive of ordinary members and workers of the UPPs. The inability of Jaloliddin aka and Izzat to penetrate the higher governing bodies reflects a detachment of the organisation from the interests and concerns of ordinary members. The next section shows the consequences of such disengagement in the form of the abuse of authority by older bureaucrats and their covert relationships with non-disabled businessmen.

5.3 Organised crime societies

The cotton business: a corrupt mess

Given the political and economic importance of cotton production in Uzbekistan and the related cases of corruption referred to as “the Uzbek cotton affair” (Cucciolla 2017, 2020) it is interesting to view it through the lens of disabled people. This section contributes to the overall argument of this thesis that the dominant disability NGOs are not representing the rights and interests of all disabled people in Uzbekistan, but on the contrary are operating in favour of a rent-seeking group of bureaucrats and non-disabled businessmen linked to them. Interestingly, when Jaloliddin aka mentioned 11 directors of the UPPs functioning across the country, he referred to them as a “an organised crime group” (*“uyushgan jinoyatchilik guruhi”*). In the post-Soviet context of formal deregulation of the Society of the Blind as an independent public association of disabled people, and lack of inclusive, fair, and transparent elections of its chairpersons, the organisation has become susceptible to corruption and has become unaccountable to its members. Since independence, the Central Board of the Society of the Blind has enjoyed the privileged status of buying raw cotton at state-regulated prices from the state-owned joint-stock company UzPaxtaSanoat (Uzbek Cotton Industry). Jaloliddin aka explained that if, for example, 100kg was purchased, 30kg of it was used to make mattresses at the specialised

UPPs and the remaining 70kg was sold out in the market at increased prices as a raw material. For this purpose, as well as the UPPs, the Society of the Blind established about 30 subsidiary companies which were used to make money by selling raw cotton.

For example, in 2019 the Society bought 1,500 tonnes of cotton and cotton millpuffs (lint). Cotton and lint are mixed together and become a cotton raw material which is then sold by the subsidiary enterprises of the Society of the Blind at high prices. Izzat explained that if an enterprise of the blind receives a transfer of money to its account from a client purchasing the raw cotton material, the managers of that enterprise also receive money in envelopes. Moreover, if for instance Izzat has an enterprise – a subsidiary under the Society of the Blind – and if he wants to get about 50 tonnes of cotton from the Central Board which allocates quotas for its enterprises, for each tonne of cotton he would have to give a bribe (*soqqa qistirish*) to the chairperson in US dollars. He did not know the exact amount of the bribe for one tonne of cotton, but he remembered that there was a time that each tonne of cotton ‘cost’ US\$1,000 as a bribe to the chairperson of the Central Board. Therefore, the difference between the government-controlled price and market price of raw cotton turns into additional revenue, and its internal distribution among the senior bureaucrats of the Society of the Blind raises concerns about possible corruption cases within the organisation. Izzat said that the cotton business is “a corrupt mess” (*“korrupsiyaga botgan yo’nalish”*) run by the older generation of bureaucrats with visual impairments at the Society of the Blind who colluded with sighted investors with vague backgrounds. Let us now consider how these obscure business relationships evolved in the following section.

The blind “old foxes” and a “gang” of sighted entrepreneurs

Based on the evidence gathered, this section further confirms the arguments made above that a small group of bureaucrats are benefiting from the properties and resources of the dominant disability NGOs in Uzbekistan. Izzat compared this grave situation in the governing bodies of the Society of the Blind with “a gangrene of the hand” from the wrist to elbow, where a human body represents the whole organisational system. As the administrative power is concentrated in the hands of a few veterans, all the resources and external support are being directed to preserve the gangrenous hand. The dead body part represents the collapse of the segregated model of employment in UPPs, the collusion of blind bureaucrats with suspicious non-disabled businessmen and the prevalence of ‘old school’ chairpersons in leadership positions. The central management is preoccupied with preserving the gangrenous hand, which is blocking resources from reaching other body parts. For example, Izzat referred to a recent case when in April and May 2020 the Central Board received a government subsidy of about 136 million soum (more than \$13,200) to cover monthly salaries of organisational staff members during the COVID-19 pandemic and strict quarantine measures. However, in June the central board held a meeting with its staff members saying that they would not be able to pay the salaries in full. Later the chairperson announced that the Central Board was buying a new imported luxury car for administrative use which would cost the Society of the Blind about 340 million soum (more than \$33,000) with all the import duties and taxes.

Moreover, Izzat accused the “gang” (*shayka* in Russian) of non-blind directors of the UPPs, Muhammadkhairullo Kayumjonov (a Tajik-Russian investor at the UPP “CHYOTKA”) and Sherzod Khoshimov (director of “DIZAYN-PRINT” LLC) of making the newly elected chairperson Ergash Narpulatov buy the new vehicle on the

pretext that the old car did not fit with the reputation of the chairperson of the Society of the Blind. It is worth mentioning that many properties and bankrupt enterprises of the blind were transferred to sighted businessmen for the so-called ‘trust management’. For instance, the UPP “CHYOTKA”, which specialised in the production of industrial brushes for the cotton industry, now entirely belongs to Muhammadkhairullo, a sighted businessman of Russian-Tajik origin. Other properties like the Society-owned hotel “Marhabo” were transferred to the balance of “DIZAYN-PRINT” LLC, also managed by a non-disabled director. As a result, at the time of writing, all directors of the UPPs of blind people in Tashkent city are sighted. There are still a few blind and visually impaired directors of UPPs in the regions. Building on the work of Shaw (2017) on deaf people in the USSR, I argue that such control of specialised enterprises by non-disabled entrepreneurs represents the extension of post-Soviet transformations. The privileges provided by the state to the disability NGOs, such as tax benefits, and large bank credit at discounted rates, attract non-disabled businesspeople to make large profits under the veil of the UPP system. Importantly, the involvement of sighted entrepreneurs is limited to the UPP businesses, and within the Society of the Blind it is still widely perceived as inappropriate for sighted people to participate in the management of the organisation or be elected as chairpersons.

According to Izzat, the Society of the Blind has turned into a vertical money-making (“*soqqa qilish*” in Uzbek) organisation with a top-down hierarchical structure, an older chairperson with visual impairments at the top, with non-disabled people in managerial positions at UPPs, involved in business activities. Izzat said that by asking questions about the corrupt management at the Society, I sprinkled salt on his wound, as he feels shameful about working there but has no other option. He does not want to associate

himself with ‘old school’ corrupt chairpersons and non-disabled entrepreneurs with shady pasts. He referred to the elderly chairperson of the Tashkent city branch, to whom he lost in the elections, several older chairpersons of the district branches and the director of the Palace of the Culture of the Blind and other ‘old school’ blind executives as “old foxes” (*qari tulkilar* in Uzbek). Izzat stressed his dissatisfaction with the fact that the six delegates representing Tashkent city in the recent Congress (*Qurltoy*) were represented by old blind bureaucrats. He argues that the “spiritual decay” (*ma’naviy chirish*) in the management of the Society is happening due to the prevalence of senior blind men (*qartang*) who would not easily give up their positions. There is an Uzbek proverb ‘*Qari tulki tuzoqqa ilinmaydi*’ (‘Old foxes do not fall into the trap’) meaning it is tricky to expose the wrongdoings of an old, crafty person. Putting it another way, a considerable gap between the interests and rights of ordinary workers of the UPPs and the central staff of the Society of the Blind has emerged. The Central Board has become unable to escape the vicious circle of opaque businesses that do not really care about the destiny of its blind and visually impaired members. In the next section, I explore the case of a sighted investor who started his own business in a building belonging to UPP “CHYOTKA”.

A shadowy business under the guise of blind people

This section reveals that the intervention of non-disabled entrepreneurs in the UPP system is affecting the livelihood opportunities of blind and visually impaired workers. Jaloliddin aka said that for the last four years the brush business at UPP “CHYOTKA” has been managed by a sighted entrepreneur, Jalol To’xtaev, who is originally from the Republic of Karakaplakstan.¹⁰¹ At the time of my fieldwork he had already quit the job of a director

¹⁰¹ Referred to as ‘an autonomous republic’ within the Republic of Uzbekistan.

at the “CHYOTKA” enterprise, accused by the blind unemployed workers of stealing machine tools and bringing the enterprise to bankruptcy. Jaloliddin aka said Jalol To’xtaev had stolen the equipment, installed it in his private company and was now competing with the “CHYOTKA” enterprise to win government contracts. He had promised to renew the production equipment and carry out repair works at the UPP, but unfortunately, it was done at the expense of the workers. If in 2015 a blind worker received 850 soum (US\$0.089) for one manually produced brush, in 2019 the pay per unit was reduced to 300 sum (US\$0.030). Jaloliddin aka suggested that the funds required for renovation purposes should have been withdrawn from the amortisation fund rather than the salaries of blind employees. The situation was similar at other training and production enterprises of the Society of the Blind across the country. There was no work and, even if formally employed, the blind workers were not getting paid and thus had effectively lost their jobs for good. Affected by the radical change in the political and economic environment during the 1990s, the crisis of the segregated employment model was further aggravated by this untrustworthy abled-bodied manager who betrayed the blind workers at the brush factory, according to the testimony of Jaloliddin aka.

Figure 15. Visiting the training and production enterprise “CHYOTKA” LLC of the Society of the Blind of Uzbekistan



Source: author's photo

During our tour of “CHYOTKA”, the current partially sighted director, Zoir aka, enthusiastically led us to another part of the building. As we walked through the dark corridor, we suddenly saw a light at the end of the tunnel. A thick metal door, on a background of a freshly painted pink wall, appeared in front of us. Zoir aka put his thumb on the door lock to make a quick scan of his fingerprints which made me feel as if we were time-travelling into the future. Stumbling across such a high level of biometric protection in this derelict Soviet building was quite unexpected. We entered the door and saw a sharp contrast to the abandoned brush workshop. It was obvious that the premises were recently renovated, and large investments had been made to purchase modern knitting machines. Two sighted Uzbek workers were manually knitting sweaters under the instruction of a Turkish man. I could not see any blind or visually impaired workers.

The deputy director of the new enterprise, who introduced himself as an ethnic Tajik investor with Russian citizenship, invited us to his office where he showed us a package of sweaters and other types of winter and autumn wear for women which would be sold under the brand tag “Made in Uzbekistan by blind people”. The enterprise was established as a separate subsidiary LLC under the Society of the Blind thanks to credit from the state bank of 5 billion sum (about US\$525,000) to buy Chinese equipment and attract Turkish specialists for personnel training. The new company was able to obtain this level of credit because the Society of the Blind offered the UPP building as collateral with the total estimated value of 10 billion sum. However, according to Izzat with whom I spoke earlier at the Central Board, the building was heavily undervalued and should have been calculated at a minimum of 20 billion soums if not more. He worried that the Central Board was taking a huge risk by permitting the Tajik-Russian businessman to get the large credit.

‘If the era of the brush making is ending our Society leaders are looking for some new opportunities,’ – said Izzat in a private conversation.

He alluded to possible corruption, suggesting that the chairperson of the Central Board should have been rewarded well (*yaxshigina rozi qilish kerak*) for letting the Tajik-Russian entrepreneur receive the credit and start the business. Moreover, Ulugbek revealed that there is a kinship relationship between the director of a printing company, LLC “DIZAYN-PRINT”, another subsidiary company of the Society of the Blind located in Cho‘pon ota mahalla, and the director of the new womenswear manufacturing enterprise.

Later I saw a video report on the main state TV channel *O‘zbekiston 24* which showcased the UPP “CHOYTKA” for its recent success. The news anchor boasted that a new state-

of-the-art weaving workshop, equipped with Turkish and Chinese technologies, able to produce competitive goods meeting market requirements, had been launched at the Society of the Blind thanks to “the financial support of foreign investors”. The new workshop was launched in the two-hectare production facility of the UPP “CHYOTKA”, a building which had not been used for several years. The journalist reported that the new enterprise employed 90 people, of which 70 were blind and visually impaired. Interestingly, the director of the enterprise was presented as an “investor from Russia” although he obtained credit from a local state-owned bank. Zoir aka, the director of the “CHYOTKA” enterprise, spoke on TV as “a leading specialist” (*yetakchi mutaxassis*) and said that “*blind people are used to any work, their senses are very strong*”. However, although I have watched the video several times I did not notice any blind or visually impaired workers at the new enterprise.

Jaloliddin aka, an ex-worker at the “CHYOTKA” enterprise, told me that the Society of the Blind was initially trying to get credit for development of the brush production but in the end the Central Board of the Society of the Blind decided in favour of knitting jumpers for women rather than industrial brushes for the cotton industry. The Society leaders supported the business plan of the Tajik entrepreneur who also offered to open a medical centre at the same building by securing more bank credit on preferential terms for disabled people’s organisations. However, blind people can neither work at the medical centre nor make jumpers at the new sewing enterprise.

‘The most that we can do – is packaging the finished jumpers and that’s it,’ explained Jaloliddin aka.

Thus, the new production enterprise did not offer employment to many blind men and women in the community. I later learned from Jaloliddin aka that the Tajik entrepreneur

employed only five blind workers for the packaging unit and did not create the promised 100 permanent jobs for blind and visually impaired workers.

This incident reflects that, in the context of transition from the planned to market economy, legacies of the Soviet disability organising such as UPPs have been influenced by market-based neoliberal and productivist approaches (Mladenov 2015b, 2017, 2018). This has further undervalued the role of blind and visually impaired workers within the UPP system, and reflects the broader dynamics of the post-socialist transition. The final section in this chapter argues that, as UPPs have become the cornerstone of the societies of blind and deaf people, which are in turn subordinate to the Uzbek government, their advocacy for disability rights and citizenship has been constrained to those issues beneficial only to small groups of bureaucrats and non-disabled business entrepreneurs.

5.4 UPPs as barriers to citizenship of disabled people

Tax strike of blind people: a case of selective disability advocacy

In this final section I challenge the capacities of the Societies of the Blind and the Deaf for grassroots disability rights advocacy. I further question whether excluding disabled members, particularly younger people, women and UPP workers from decision-making processes within these organisations allows for independent advocacy for their rights and interests. Moreover, as organisations heavily reliant on government support and control, it is questionable whether these organisations are capable of independent disability rights advocacy. The evidence collected through participant observation in the Society of the Blind showed that the organisation is mainly involved in selective disability advocacy aimed at sustaining the collapsing UPP system. In 2019, the Uzbek government proposed a new tax code based on which enterprises with an annual turnover of over 1 billion soums

would be taxed while enterprises with less than 1 billion soum of yearly output were not taxed. Because of the large turnover at the corrupt cotton business and UPPs, the enterprises and subsidiaries that belong to the Society of the Blind were due to be taxed in the next financial year. As was mentioned earlier in Section 4.3, the organisation sells raw cotton in large amounts which increases the annual turnover of the Society. For instance, in 2019 the turnover of the Society's enterprises was about 46 billion soum (about US\$4.8 million), significantly above the 1 billion soum tax threshold. As such, it is in the interests of the corrupt blind elite to strongly advocate for tax benefits and use all possible strategies to claim back tax benefits for their UPPs and suspicious subsidiaries making under-the-counter profits selling raw cotton.

The chairperson of the Central Board of the Society of the Blind and most of the directors of the UPPs across the country organised a meeting at the Palace of Culture of the Blind. They managed to invite senior government officials from the State Tax Committee, Ministry of Economy, members of the Senate and a business Ombudsman. I participated in that meeting as an observer because it was held right after the religious meeting with blind and partially sighted members of the society. The acting¹⁰² chairperson of the Central Board, Ergash Narpulatov, started the meeting with a brief review of business activities of the Society. He had visual impairment himself and was partially sighted. I was impressed by his public speaking and leadership skills and the tone of his voice was very strong, infused with anger, seeking to defend his organisation against the new tax reform. Eventually, after a series of negotiations and advocacy efforts he managed to uphold the economic interests of the Society of the Blind and its UPPs.

¹⁰² At the time of my fieldwork in summer 2019 he was acting chairperson of the Central Board of the Society of the Blind until he was finally elected during the Congress (*Qurultoy*) in September 2019.

The most interesting outcome of this successful advocacy effort was that high-ranking government officials and members of the Senate agreed to come to this meeting, held at the premises of the Society of the Blind. Usually, Uzbek government officials attend such meetings in official spaces or at least in a neutral space, but this time they came to the Palace of Culture of the Blind. It was a space where mainly blind and visually impaired bureaucrats and UPP directors of the Society gathered. I felt the awkwardness that the officials in the room felt, as this time they were in a minority, including myself. There was a whole underpinning story which could explain the reason why these high-ranking officials agreed to meet with the members of the Society of the Blind. It turned out that the day before the meeting took place the chairperson encouraged the staff of the Central Board to go on strike in front of the Senate. It was well-planned theatre where staff members would play the roles of angry UPP workers who were not satisfied with the proposed tax legislation. I felt that the UPP workers themselves would not go on a such strike as they would know that all the tax benefits would be used by Society bureaucrats and non-disabled entrepreneurs. Staging a strike was the last resort of the Central Board after more than six months of unsuccessful written complaints to the state authorities to return the tax benefits. Eventually, the strike at the Senate entrance put a lot of pressure on government officials and therefore all of them came to the meeting organised by the Society.

An outsider to the Society of the Blind may think that if the UPPs of blind workers were taxed, there would be no reason for them to recruit blind workers, and employers would prefer non-disabled workers. But what if the taxes and privileges were used mainly by a corrupt elite and non-disabled businesspeople? While advocacy for tax benefits may look

like action by blind people to save their UPPs, it is not that reassuring as only a few members of the Society of the Blind are working, while all the benefits would be received by the sighted entrepreneurs. Therefore, the religious community of blind people¹⁰³ preferred not to take part in the action, as they considered that tax benefits were more likely to be received by bureaucrats with visual impairments and sighted entrepreneurs than by the ordinary members and workers of the UPPs (like Jaloliddin aka who are becoming unemployed and are not getting their salaries on time). Izzat explained that his position at the Central Board obliged him to be part of the tax strike at the Senate and at the same time he believed that he would campaign for the UPPs even if they employed only one blind or visually impaired worker. However, I argue that the Central Board was preserving a ‘gangrenous hand’ while the blood was not reaching other parts of the Society of the Blind. Rather than promoting disability-inclusive employment practices in the open labour market, the dominant organisation of blind people is promoting the segregated and outdated practices of employment within the opaque UPP business. So far, this section has showcased selective disability advocacy by the elites of the Society of the Blind who are benefiting from the state privileges granted to the UPPs. The final section in this chapter proposes the overall argument that the UPPs – as a Soviet and productivist legacy approach to enacting citizenship by disabled people – have become an anachronism which cannot be replicated in the new political and economic realities. UPPs are being used by the Uzbek government and the functionaries of the dominant disability GONGOs to showcase their benevolence to deaf and hard-of-hearing people. However, the question of whether blind workers are benefiting from the UPP system remains open.

¹⁰³ I discuss them in detail in Chapter 7.

Window dressing for the president: who is benefiting from the UPPs of deaf people?

During my first fieldtrip to Tashkent in 2018, the President of Uzbekistan, Shavkat Mirziyoyev, visited the Centre for the Culture of the Deaf. His arrival inspired members of the Society of the Deaf (OGUz) and provided hope that from then on, they would not be left out of the reforms being implemented in the country. The president said that “every person in Uzbekistan is dear to him” (President.uz 2018: online) and urged that special attention be paid to the training of teachers, sign language interpreters and the creation of decent jobs for deaf people. President Mirziyoyev participated in the opening ceremony of a new sewing enterprise on the site of UPPs No. 1 of deaf people. The new enterprise was planned to provide 100 jobs for deaf and hard-of-hearing members of the Society of the Deaf. In two years after the momentous presidential visit, together with Anvar who I mentioned in Chapter 4, we conducted an investigation to understand how the lives of deaf people have changed since then (Akhliiddinov and Yusupov 2020a). The results of our joint inquiry showed that only a few deaf workers were hired at one sewing unit, while the other two industrial units remained closed to them. Moreover, deaf workers experienced delays in the payment of their salaries and they therefore began to gradually leave the sheltered workshop. Furthermore, our investigation (Akhliiddinov and Yusupov 2020a) showed out that on 3 July 2018, less than four days after the president’s visit, by the Decree of the Presidium of the Central Board of the OGUz No. 22, Protocol 6, the Culture Centre for the Deaf transferred 1.2 hectares of adjoining land to the balance of the Tashkent city administration free of charge, reportedly to:

...eliminate empty territorial areas on the balance of the structural units of the Society of the Deaf and reduce costs associated with their maintenance.

Three sewing units were previously created on the donated territory. It turned out that the new owner of the three units was an entrepreneur from Turkey, who launched the

production of construction materials in two production units. Given that the production was close to the infrastructure of the Society of the Deaf, we suggested the entrepreneur hire deaf workers. However, the entrepreneur refused to recruit any person with hearing impairments. The irony of this situation is that despite being located in the former territory of the so-called ‘town of deaf people’, the private company does not want to reserve at least the minimum 3% quota of vacancies for deaf people according to the Law on Social Protection of Disabled People¹⁰⁴ (GoU 2008). Thus, the whole opening ceremony seems to be nothing more than a window dressing for the President. The photo below shows the seamstresses during the President’s visit to the Culture Centre for the Deaf on 28 June 2018. A participant in the ceremony, who wished to remain anonymous, said that a few deaf women were sitting in green uniforms while hearing workers were in red uniform (see Figure 16). It turned out later that hearing workers were temporarily brought from the Yangiyul sewing enterprise and were taken back immediately to their real workplaces after the ceremony ended.

¹⁰⁴ This law was replaced by the new law “On the Rights of Persons with Disabilities” (GoU 2021) which came into force on 16 January 2021.

Figure 16. The new sewing enterprise allegedly built for deaf and hard-of-hearing women



Source: President.uz (2018).

This case study shows that the local government is using the UPPs as a tool to showcase the dubious achievements of the state in providing employment opportunities for people with hearing impairments. However, the Tashkent city *khokimiyat* is more interested in the territorial possessions and properties of the Society of the Deaf than the livelihoods of the community of deaf people. In other words, the vast resources and the UPP system inherited from the Soviet Union have become a cause of rent-seeking behaviour by the dominant disability NGOs which are not advocating for citizenship of their disabled members. The critical findings in this section support the argument that the Soviet legacies of disability organising and achieving citizenship through labour contribution have, in fact, become barriers to new approaches to citizenship outside the established Soviet citizenship framework.

Conclusion

Since the collapse of the Soviet Union the functional approach to achieving citizenship by disabled people has been subjected to various shocks in the process of transformation from a planned to a market economy. The political, economic, technological, and social changes made the previous framework unfeasible in the new realities of post-Soviet Uzbekistan. The public associations of deaf and blind people could not keep up with technological advances and were excluded from the industries. The automation of production processes devalued the manual production which the Societies of the Deaf and the Blind heavily relied on. This chapter has argued that the segregated model employment of persons with hearing and visual impairments has proved to be unsuccessful in the transition period due to a lack of state support, loss of the monopolistic right to produce and sell certain types of goods and considerable reduction in state orders and subsidies.

Despite the ongoing crisis in the UPP system, the leadership of the main organisations of deaf and blind people is not thinking beyond the outdated model of employing deaf and blind people at segregated UPPs. Unwillingness on the part of veterans and bureaucrats in the societies to think and act 'out of the box' has led to the failure to protect the human rights and interest of persons with sensory impairments on equal basis with others. Moreover, the UPPs have become a façade for apparatchiks of the 'societies' of deaf and blind people and a means for unscrupulous non-disabled businesspeople to make money using tax benefits and privileges provided by the state. The large-scale corruption, suspicious business relationships with non-disabled entrepreneurs and the inadequate handling of property and assets of the 'societies' by the central boards made deaf and blind people seek justice elsewhere. The day-to-day indifference of the central

management of these organisations to the problems of its ordinary members can be explained by the obsession of their leaders with the corrupt cotton and UPP businesses, which they treat as a core activity. Although the societies have the organisational potential to fully advocate for and protect the rights of many disabled people across the country, they are applying selective advocacy on issues that are beneficial to a small group of disabled and non-disabled elites. At the same time, the government bodies are avoiding the problems of ordinary disabled citizens. Nevertheless, when it is in their interests, they use double standards and are directly intervening in the work of dominant disability NGOs. In some cases, local governments are even expropriating land and other properties of these organisations in favour of non-disabled entrepreneurs. As a result, these organisations are working for the interests of a small group of state-approved bureaucrats working in the central apparatus, non-disabled directors of the UPPs and the local governments which are seizing their remaining resources and properties.

Chapters 4 and 5 showed the three main organisations of persons with hearing, visual and physical impairments have evolved into government-controlled NGOs (GONGOs). The outdated organisational structures and internal bureaucratic procedures they inherited from the Soviet Union are not inclusive or democratic. These findings are in line with evidence from post-Soviet European countries where lack of transparency and accountability towards their members have turned these disability organisations into mere “extensions of the government” (Holland 2008: 552) that are not representative of the rights and interests of disabled people in Uzbekistan. This view is also supported by Mladenov (2018) who argues that in Central and Eastern Europe, a majority of DPOs have also been integrated into “structures of tokenistic participation” (Mladenov 2018: 83). But the current composition of the civil society landscape and its top-down

relationship with the state is not the only legacy of the Soviet disability policies and institutions. Segregated employment and vocational training practices of the Society of the Deaf and the Society of the Blind resulted in the creation of segregated residential areas, so-called ‘mahallas of the blind’ and ‘towns of deaf people’. These areas were established around training and production facilities to meet the accommodation needs of UPP workers. In the chapter that follows, I explore how disabled residents of a segregated mahalla of blind people are advocating for citizenship at the community level. The critical ethnographic evidence I collected in these disabled spaces shows that they are facing barriers to achieving ‘mahalla citizenship’, due to the interference of local government in the organisational structure of the self-governing bodies of citizens (mahalla committees).

Chapter 6: Communities about them without them: claiming citizenship in mahallas

In this chapter, I explore how blind and deaf people have established segregated communities, ‘mahallas of blind people’ and ‘towns of deaf people’, around the UPP production infrastructure. Building on the existing literature on mahallas in Soviet and post-Soviet Uzbekistan (Abramson 1998; Dadabaev 2013; Rasanayagam 2009, 2011; Sievers 2002) and the multiple evidence I collected with people with sensory and physical impairments in Tashkent city, I argue that the ongoing formalisation (Urinboyev 2011) and state intervention into the mahalla structure (HRW 2003; Massicard and Trevisani 2003) are constraining the efforts of disabled people to claim their political, civil and social rights at the community level.

To understand the roles of the formally recognised ‘mahalla committee’ and ‘informal mahalla’ (or ‘organic mahalla’)¹⁰⁵ (Rasanayagam 2011: 51) in constructing citizenship by disabled people at the grassroots level, I provide a discussion of several unique examples from my fieldwork. I first set up the historical context and discuss the rationale for the establishment of segregated communities of blind and deaf people in the Soviet Union, and explore how they transformed after Uzbekistan’s independence. Then I examine the process of electing a chairperson at the ‘mahalla of the blind’ which sheds light on the government-imposed barriers that blind people are facing in exercising their political rights to elect and be elected to the positions of power at the mahalla committee. Finally, I provide an example from my participatory video work with adults with physical

¹⁰⁵ See Section 2.2 in Chapter 2 to understand the role of the mahalla in the Uzbek society.

impairments which reveal the struggle of a disabled woman to achieve her right to independent living.

6.1 Back to the USSR: abandoned ghettos of deaf and blind people

Town of deaf people: how it all started

As discussed in Chapter 5, the specialised training and production enterprises (UPPs) played an important role in the integration of deaf and blind people in socialist society through their active participation in communist labour. Importantly, UPPs were not only places of work for deaf and blind people but also served as a catalyst for development of deaf and blind communities and their distinctive forms of collective identity. Thus, UPPs were also centres of social life, reflected by the residential infrastructure built by the societies around UPPs. For instance, Mirkhodjaev (1979) described how the Society of the Deaf constructed residential buildings and dormitories in proximity to UPPs so that at the end of the ninth five-year plan,¹⁰⁶ the housing stock of the organisation increased by almost 10,000 square meters within the period of the ninth five-year plan (Mirkhodjaev 1979: 25). Most of the UPPs had their own dormitories and residential buildings which could accommodate deaf workers and their families. Gradually, a complete social infrastructure including amenities such as kindergartens, cultural and sports centres appeared around the specialised UPPs, eventually transforming into small segregated towns of deaf and blind people within Tashkent. The idea of building a whole social infrastructure around the industrial enterprises resembles the Soviet type of urban planning where whole towns and cities were built specifically for workers of one big plant or factory in that region.

¹⁰⁶ In Russian, “pyatiletka”: a five-year industrial plan in the Soviet Union. The ninth five-year plan corresponded to 1971-1975.

Deaf and hard-of-hearing workers in the UPPs had their own segregated community in Olmazor district of Tashkent which consisted of a cultural centre,¹⁰⁷ a dormitory, other residential buildings, and even a sports centre specifically built for them and their families. For a long time, this segregated area has been referred to as ‘the town of deaf people’ (in Uzbek, *kar-soqovlar shaharchasi*) or more commonly in Russian as *gorodok glukhih* (see Figure 17), as all the social and production infrastructure dates back to Soviet times. The dormitory for deaf people was built to accommodate the needs of workers with hearing impairments employed at the specialised UPPs. There were also some other residential buildings specifically built for the members of the Society. Apartments in this ‘town of deaf people’ were previously provided by the Soviet government for deaf and hard-of-hearing people, but nowadays hearing people live there as well as deaf families.

¹⁰⁷ It was called the Palace of Culture of the Deaf; in Russian *dvorets kulturi glukhih*.

Figure 17. This is a Google map screenshot of the territory of the Tashkent city/regional branch of the Society of Deaf People including the Cultural Centre for Deaf People and residential areas for deaf people.



Source: Google Maps, 2020.

Over the years, deaf families gradually sold their properties to non-deaf people or gave birth to children who did not have any hearing impairments. Thus, the proportion of deaf residents has been decreasing. But many residents still have some direct or indirect links to deafness and the Society of the Deaf. Almost everyone in the ‘town of deaf people’ spoke sign language which marked the significant cultural aspect of these deaf communities. However, unlike the hereditary deafness in Martha’s Vineyard explored by Groce (1988), the high prevalence of deafness in the Uzbek town of deaf people was the consequence of the Soviet disability policy based on segregation of people with sensory impairments. In other words, in contrast with biological reproduction of deafness, deaf culture and community have been socially and culturally reproduced. Using sign

language in the town of deaf people is standard whether you are deaf or not. Not being able to speak Russian Sign Language (RSL), which is widely spoken by the Uzbek deaf communities, I felt myself disadvantaged or even “disabled” without a sign language interpreter.

Mahallas of the blind

During my ethnographic fieldwork, I was also a frequent visitor to the so-called ‘town of the blind’ in Chilanzar district. Every Thursday afternoon, the Muslim Board of Uzbekistan organised religious gatherings with blind men and women at the Palace of Culture of the Society of the Blind. It was an old Soviet-type two-storey building with a recording studio and a large assembly hall on the first floor. The city branch of the Society of the Blind had its head office on the second floor of the same building. This ‘town of the blind’ was established in the early 1960s when the Organisational Executive Committee of the Society of the Blind requested the Uzbek socialist government to provide 10 hectares of land (Primkulov 1983). Consequently, five hectares were allocated for construction of an UPP for the blind and another five hectares were used to build accommodation for blind workers and their families. The construction began in 1959 and by 1964 a four-storey residential building and a dormitory for the UPP workers were completed. In the same year, a new mahalla under name Cho‘pon ota was established based on this social and industrial infrastructure specifically built for persons with visual impairments. In later years, multi-storey residential buildings appeared in this area and the ‘mahalla of the blind’ expanded. Nowadays, the population of Cho‘pon ota mahalla comprises more than 1,500 residents with one of the highest proportions of people with visual impairments and their families across the country. After Uzbekistan gained its

independence, a mosque was constructed on the territory of the mahalla through *hashar*¹⁰⁸ in 1994 to meet the religious needs of the blind residents. Nowadays it is the only mosque in Uzbekistan which is officially called ‘The *Jami* Mosque of the Blind’ (*Ko‘zi ojizlar’ jome masjidi*) (see Figure 18).

Figure 18. Entrance to The *Jami* mosque of the Blind in Cho'pon ota mahalla Chilonzar District in Tashkent.



Source: author's photo.

The imam of the mosque, who is not blind himself, told me in an interview that one of the purposes of building this segregated mosque was to make it easier for the majority

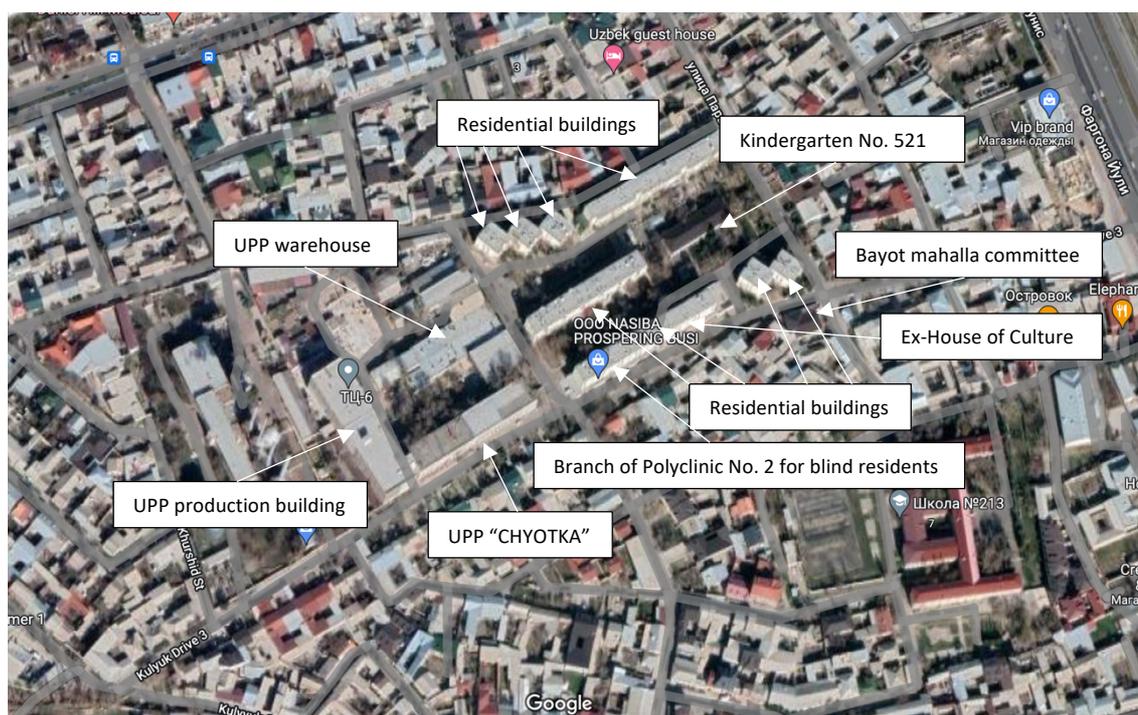
¹⁰⁸ Voluntary community self-help work: a Central Asian tradition of voluntary work in which people gather to clean the streets or help a neighbour with some manual labour in a day of cooperative work (Najibullah 2019).

blind residents so that they do not face difficulties by commuting to mosques in other parts of the city.

In the late 1970s, the Society of the Blind replicated the model of Cho‘pon ota mahalla in a remote area of the city in what is now called Mirabad district. Blind people say that at that time the Society was financially sound and could afford construction of nine four-storey residential buildings for its members including the tenth building intended for the UPP “CHYOTKA” (see Chapter 5), as well as a kindergarten for their children. In the 1980s, families of blind and visually impaired people began to relocate to this area in large numbers. This separate residential area of the blind formed a mahalla called “Matonat” (“perseverance” in Uzbek) which was recently changed to “Bayot”.¹⁰⁹ As in Cho‘pon ota, due to a large blind population it has been referred to as the ‘mahalla of blind people’. As the first-generation of the blind settlers gave birth to children the number of non-blind residents increased, but one can still say that each family in the mahalla has some historical link to blindness and the Society of the Blind. The map below shows nine residential buildings for blind workers of the UPP “CHYOTKA” and their families. The mahalla represents a small town where all the basic facilities for blind residents were in close proximity to each other (see Figure 19).

¹⁰⁹ In 2016 many mahallas in the city were renamed due to the fact that many names were used more than once. Matonat was changed to Bayot. From now on I refer to it as “Bayot mahalla”.

Figure 19. Map of Bayot Mahalla



Source: Google Maps, 2020.

UPP “CHYOTKA” even built a pre-school institution, currently known as kindergarten No. 521, for children of workers with visual impairments. In the past, the kindergarten belonged to the UPP, but it is now owned by the Ministry of Preschool Education. Interestingly, Polyclinic No. 2 even had its own branch inside residential building No. 9, and still provides medical services specifically to residents with visual impairments of Bayot mahalla. Close to this building there was also a House of Culture of the Blind (in Russian *dom kul'tury*) which is currently closed and is on the balance sheet of the UPP “CHYOTKA”. Blind residents complained to me that the UPP directors rented the premises of the cultural centre to non-disabled businessmen.

In 2019, out of more than 1,300 inhabitants, over 160 people were blind and visually impaired while about 110 households had one or more family members with visual

impairments. This constitutes more than 12% of the mahalla population. Official state statistics report that less than 2% of the country's population are disabled. Abbas hoji,¹¹⁰ a retired man with visual impairments in his late 50s, is a long-term resident of Bayot mahalla and a frequent participant in religious meetings at the Palace of Culture of the Blind. He invited me to visit his mahalla where he introduced me to another elderly blind man, Mo‘min aka. He served as an elected ‘whitebeard’ (*oqsoqol* in Uzbek, usually an elderly chairperson) of the mahalla from 2002 to 2005. Because blind people make up a significant part of the community, residents have always elected a blind or at least a person with visual impairments as *oqsoqol* who therefore could understand the problems of the blind residents well. However, in this chapter, I illustrate how the formalisation of the mahalla structure and top-down intervention by the local government (*khokimiyat*) are constraining the efforts of blind and visually impaired residents to assert citizenship at the mahalla level. This happened at Bayot mahalla in May 2019, when the district *khokimiyat* intervened in the elections of the mahalla chairperson. I explore this in detail in the following section.

Bayot mahalla: elections about us without us

This section provides a case study of the recent chairperson elections at the ‘mahalla of blind people’ in Mirabad district of Tashkent. The critical ethnographic evidence suggests that the formalised mahalla committee and top-down direct intervention in the mahalla elections by the local government is suppressing the collective agency of the informal or ‘organic mahalla’ (Rasanayagam 2009, 2011) with its majority of blind and visually impaired residents. The collected ethnographic evidence suggests that mahalla

¹¹⁰ I am using a pseudonym. The title ‘*hoji*’ refers to one who has participated on a hajj.

committees, instead of being inclusive are in practice excluding disabled people from their management. My ethnographic fieldwork at the ‘mahalla of blind people’ coincided with the elections of the chairperson (*oqsoqol*)¹¹¹ of Bayot mahalla on 16 May 2019. It turned out that the proposed candidate with visual impairments was rejected by Mirabad district *khokimiyat* for no reason. I talked to the blind residents of the mahalla to find out how the elections of the chairperson were held. Most blind residents supported the candidacy of a young blind man, Umid,¹¹² and were confident he would be elected. Umid represented a new generation of blind activists who were born just before the collapse of the Soviet Union at the end of 1980s and raised in the Bayot mahalla. He belonged to disability group II,¹¹³ and had a congenital and progressive visual impairment. He graduated from the Tashkent State University of Economics and was an economist by profession. After he left the specialised boarding school for blind children in Tashkent, entering higher education in Uzbekistan was quite difficult as there were limited places available. He was able to enter the university thanks to the quotas for people with visual impairments which allowed him to avoid fierce competition with non-disabled students. Taking into consideration his visual impairment his experience of studying at university would have been very difficult. After graduating and obtaining the diploma of an economist, he had no other choice than to work at the specialised training and production enterprises (UPPs) for blind people as there were no job opportunities for him in the open labour market. He asked the ex-director of the “CHYOTKA” enterprise to recruit him as an economist, but the position was already occupied and instead he was offered work as

¹¹¹ ‘Whitebeard’ refers to an elderly person, local chief, and a leader (chairperson) of the mahalla. *Osqoqol* and chairperson are used interchangeably.

¹¹² I am using a pseudonym for him although his identity might be revealed due to his public action and pre-election campaigning at Bayot mahalla.

¹¹³ See Section 2.3 to see the current disability classification system in Uzbekistan.

a supply agent. However, the director did not honour this offer, and Umid had to go to the Central Board of the Society of the Blind to ask the senior management to give him the job. But they did not help either and the ex-chairperson of the central board told him to wait for three or four years to see if there would be a job opportunity. Finally, through his own social networks in the prosecutor's office, Umid was hired by the UPP "CHYOTKA" not as an economist, but as a blue-collar worker to knit industrial brushes for the cotton industry (see Chapter 5 for a detailed discussion of the crisis in the UPP system).

Despite his young age (30 years old at the time of my fieldwork), Umid tried to run in the mahalla chairperson elections, as the salary was better. He carefully prepared for the elections by drafting his election programme aimed at improving the living standards of blind and visually impaired residents of the community. For him it would have been a win-win situation because he could have sustained his own livelihood and represented the needs of blind people at the community level, as the Society of the Blind was unable to provide livelihood opportunities for its members. As the community of blind people makes up a significant proportion of the mahalla population, residents have always chosen a blind or visually impaired chairperson who was directly familiar with the situation and the problems of the citizens' assembly. Umid, together with a former chairperson of Bayot mahalla who was also blind, put forward their candidacies.

These mahalla elections were held based on the new law¹¹⁴ (GoU_2018) and the government promised it would be "the most transparent, free and democratic" (Radio

¹¹⁴ On 15 October 2018 President Mirziyoyev approved the law 'On the Elections of the Chairperson (oqsoqol) of the citizen's assembly'.

Ozodlik 2019: online). Nevertheless, two days before the day of the election a conflict arose between the community of blind people and the local governor (*hokim*) of Mirabad district who did not allow Umid to run, without providing any concrete reasons for his decision. Based on the new legislation, the district and city *hokims* should approve candidates for the post of the mahalla chairperson, which represents intervention by the authorities in so-called ‘self-governing bodies’. Umid had to pass an interview at the district government office and the *hokim* (governor) said, offensively: “Why is the economist now working as an ordinary worker (*oddiy ishchi*)?”

Obviously, the governor was not aware how difficult it is for a disabled person to find a decent job in Uzbekistan due to discrimination in the open labour market and the ongoing crisis in the brush enterprise “CHYOTKA”. In the end, Umid did not receive any clarity from the *hokim* on the reasons for the rejection of his candidacy. Probably, Umid’s candidacy was not aligned with the stereotypical image of *oqsoqol* as an elderly man with a lot of work experience who has already gained a certain degree of respect and acknowledgement in the community. The new law on the elections of the mahalla chairperson from 2018 (GoU 2018) indicates that *as a rule* the candidates should have higher education, and be a permanent resident in the area for at least five years before the elections. The law also states they should have organisational skills and experience in government bodies, NGOs or entrepreneurship, as well as life experience and authority among the population. The reason for the rejection of Umid’s candidacy was not clear. Until 2019, candidates with visual impairments had successfully contended for the position of the mahalla chairperson. I argue that such challenges to the established status quo at Bayot mahalla are due to the political changes under Mirziyoyev’s regime such as economic liberalisation (Lemon 2019; Starr and Cornell 2018). Mirziyoyev’s approach

to modernisation of Uzbekistan turned out to be less authoritarian than Karimov's (Zanca 2018); his reforms had a more neoliberal spirit (Matyakubova 2020). In the first years of Mirziyoyev's presidency, he also attempted to reform the mahalla system by making the chairperson's position a salaried job – previous chairpersons worked on the basis of altruism.

The restriction of the constitutional right of the blind residents to elect and be elected to positions of power undermines their political rights, which as Marshall described is a form of citizenship (Marshall 1950, 1992). According to residents, the election procedures at Bayot mahalla were accompanied by numerous violations. The local government (*khokimiyat*) proposed a non-disabled woman, Nilufar Mashrapova, who was not previously nominated by the mahalla working group. She had worked as an adviser at Bayot mahalla since 2011 and had voluntarily left her job in mid-April 2019. The blind residents assumed the *khokimiyat* put pressure on her to participate in the elections. The information about her candidacy should have been posted publicly at the mahalla at least five days before the election day, but this did not happen. In addition, general information about the approved candidates, their nominations, the date and place of the election should have been posted on the official website of the Mahalla Council¹¹⁵ (*Mahalla kengashi*) no later than five days before the election. But information about the government-backed female candidate could not be found, either offline or online. The citizens of the mahalla of blind people were deprived of the opportunity to choose their blind candidates. Dissatisfied with the decision of the local government, the blind activists of the mahalla held an extraordinary meeting of the election commission on 14 May 2019 that was fixed by protocol and 41 representatives eligible to participate in the

¹¹⁵ Council for the Coordination of Activities of Self-Government Bodies (mahalla) of Tashkent City.

elections demanded that the Mirabad *khokimiyat* include their blind candidates on the ballot. However, their demand was not fulfilled and as if nothing had happened, the *khokimiyat*, together with the heads of the houses, distributed ballots with no blind candidates on them. As a result, a majority of the blind representatives who had the right to vote in the elections refused to even receive the ballot and opted out of the election.

According to the new law (GoU_2018) adopted during the first years of Mirziyoyev's presidency, the election of the chairperson is considered valid if at least two-thirds of the representatives of residents participated in the elections. There were 67 such representatives with the right to vote in the Bayot mahalla – at least 12% of the total number of citizens. Therefore at least 45 representatives of the citizens' assembly had to take part in the elections for them to be recognised as legitimate. However, according to many blind representatives, due to the boycott only about 15 representatives participated in the elections on 16 May 2019. In order to increase the turnout, uniformed police officers began to pay visits to residents' houses and drove representatives who were eligible to vote in a police car to the polling place. Moreover, the blind activists said that the local government deliberately disseminated false information about the approval of their blind candidates. Finally, some witnesses told me that some teachers and others who were ineligible to vote in the elections cast the ballots.

Dissatisfied with the outcome of the elections at Bayot mahalla, several blind residents wrote official appeals to the city prosecutor's office and the President's virtual reception. One of the members of parliament gave his own version of what happened in Bayot mahalla, and his reasons for why the local government did not provide any official justification for not allowing Umid to run in the mahalla elections. Firstly, he pointed out

that there were already cases in other unrelated mahallas where it turned out that the candidates had a criminal record. Therefore, due to privacy issues, the reason why that candidate was rejected was not publicly disclosed in the mahalla to avoid any harm to his reputation. Umid did not have any criminal record, so it was a spurious justification. Secondly, the member of parliament suggested Umid's dismissal could be related to the overwhelming responsibilities of *oqsoqol* who should work 24/7 which could, he suggested, be a burden to a blind or any disabled person. In other words, the government official assumed that *oqsoqol* should be proactive and inspect houses by "going down to the basement floor, going up to the roof". The representatives of the *khokimiyat* gave a verdict on behalf of blind residents of Bayot mahalla, suggesting the position of the mahalla chairpersons was unsuitable for a blind person. Based on my interactions with local government representatives, I argue that such a top-down position was a result of hyper-protection, imposed 'care' and infantilising of blind people. The blind residents of Bayot mahalla were denied citizenship at the mahalla level and their involvement in the local decision-making process was constrained. Following the social model of disability (Oliver 1990, 1996) I contend that the problem was not in Umid's visual impairments and the intervention of government officials had a disabling impact on the political participation of residents living in Bayot mahalla. In the following section, I build on this argument to show that the formalised mahalla committee has become a barrier for grassroots action of blind people towards citizenship at the mahalla level.

6.2 Inaccessible mahallas: why are people with physical impairments excluded?

No towns for people with physical impairments

As was conceptualised in Chapter 1, besides the right to elect and be elected, another element of the citizenship framework developed by (Marshall 1950, 1992) constitutes the

right to economic wellbeing and a decent standard of living through state-guaranteed welfare and social services. Importantly, access to adequate means of social protection and livelihoods is of crucial importance for disabled people, as disability and poverty are interlinked and serve as causes and consequences of each other (Banks, Kuper and Polack 2017; DFID 2000; Groce, Kembhavi, et al. 2011; Groce, Kett, Lang and Trani 2011; Mitra, Posarac and Vick 2013). In this section, I draw on various types of evidence collected through semi-structured interviews with people with physical impairments living in different mahallas, and also elite interviews with non-disabled chairpersons of mahalla committees in Tashkent city and its suburbs. Moreover, the analysis is based on experiential knowledge and visual data (videos, photos, drawings) co-produced with disabled participants in a series of participatory workshops. These workshops included participatory video as an umbrella methodology (see Chapter 3) with a group of adults with reduced mobilities during two periods of fieldworks in 2018-2019 in Tashkent.¹¹⁶

This section contributes to the overall argument of this chapter by illustrating that mahalla committees hinder grassroots political mobilisation and participation of disabled people. The collected data illustrates that, in practice, mahalla committees are inaccessible, non-inclusive and quasi-state institutions which are constraining citizenship of disabled people at the community level. This evidence counters the idealistic view of mahallas as unique community-led civil society institutions with “a strong social support network based on cultural and family values” (JICA 2010: 7). In line with the existing literature on mahallas in Uzbekistan (Rasanayagam 2009, 2011), I argue that formalised mahalla committees weaken existing support networks at the community level and restrict the

¹¹⁶ See Chapter 3 for a detailed discussion of the possibilities and limitations of using participatory research methods with disabled people in the context of contemporary Uzbekistan.

rights of disabled residents to social benefits guaranteed by the state. In other words, formalised mahalla institutions present a barrier to the upholding of rights of disabled people to adequate social welfare and housing, one of the elements of citizenship in post-Soviet Uzbekistan.

The Soviet legacy of concentration of deaf and blind communities around their specialised production sites had two aspects. On the one hand, segregation of people based on their sensory impairments was related to the efforts of Soviet officials to clean the streets of ‘invalids’ in the post-war period (Fieseler 2014, 2006) . On the other hand, Shaw (2017) argued that concentration of deaf people in the Soviet industry in “deaf brigades” and segregated production and vocational enterprises, as well as in specialised boarding schools for deaf children, cultivated a strong sense of collective Soviet deaf identity. The ‘towns of deaf people’ represented isolated spaces of visual communication and strengthened social networks and bonds within the Uzbek deaf community, where private and public activities were merged (Shaw 2017: 138). Although it may be convenient to study, work, live, and participate in cultural, recreational and sporting activities in one place, it should be noted that deaf and blind people have been isolated from mainstream society for a long time. Throughout this study, I argue that a major reason for such concentration was that it was easier for the Soviet government to control deaf and blind people through the institutions of the Society of the Deaf and the Society of the Blind, which were entrusted to indoctrinate communities with utopian communist ideology and mould Soviet citizens. However, deaf and blind residents saw such segregation as a positive aspect of their lived experiences, contrary to the idea of inclusion promoted by the global disability rights movement (Driedger 1989) and enshrined in the CRPD (2006).

As I discussed in Chapter 4, the Soviet government did not allow persons with physical impairments to register their own organisations until Gorbachev's policies initiated in 1985 (White 1999). One of the dissident disability rights activists who had to leave the Soviet Union for his work, Valeri Fefelov (1986), a wheelchair user with paralysis of both legs, argued that the crackdown on grassroots civil activism by people with physical impairments was related to the intention of the Soviet state to hide persons with physical impairments (such as wheelchair users, those with amputated limbs and deformed bodies) in favour of idealised 'Soviet' bodies:

the state is ashamed of his [a disabled person's] appearance and tries to remove him out of sight! And it is logical: in the society which considers itself ideal, everything should be neat: his clothes, shop-windows, front of buildings. (Fefelov 1986: 87)

As reflected in the famous response "there are no invalids in the USSR" (Phillips 2009) by a Soviet bureaucrat to the question of whether the Soviet Union would host Paralympic Games in the framework of the Moscow Olympics in 1980, the communist state denied the very existence of citizens with physical impairments. Notably, the word 'invalid' itself has connotations which are closer to defining physical rather than sensory or any other impairments. Fefelov (1986) argued that the reply "there are no invalids in the USSR" seemed initially to be a joke, but it indicates the reality of disabled people: indeed, there was no place for people with physical impairments in the 'ideal' socialist society of strong and able-bodied heroic workers, sports champions, and soldiers. Physical impairments were considered to be 'defects' in a heavily standardised and homogeneous socialist system of mass production, urbanisation and state planning and thus were not tolerated or accepted (Rasell and Iarskaia-Smirnova 2014). Unlike deafness or to some extent blindness, physical impairments usually required greater adaptation of the workplaces to

the needs of people with reduced mobility. Therefore, the majority of people with physical impairments were deemed “not fit for labour”, the fundamental element of Soviet citizenship.

Consequently, persons with sensory impairments had more power compared with those with physical impairments, and could build a sense of belonging through the prism of the Soviet citizenship framework for disabled people, which deemed people with physical impairments as less ‘useful’ for industrial production. Moreover, I argue that other reasons for exclusion of persons with physical impairments was the need for adaptation of working environments and accessibility of public infrastructure, which the Soviet Union lacked. Compared with deaf persons who did not even consider themselves as ‘invalids’ or disabled, mobility of persons with physical impairments was severely constrained. The Soviet government did not allow the establishment of the Society of the Disabled until the end of 1980s, and this also restricted persons with physical impairments from self-organising and uniting at the community level to form a distinctive collective identity and agency. Bodies of people with physical impairments did not fit the ideology of a strong and capable Soviet worker and might have corrupted this idealistic image of a Soviet citizen. As a result, people with physical impairments could not establish their own ‘town’ in the form of a segregated community, as was possible for deaf and blind people. On the contrary, the Soviet government tried to hide them in institutions. Such policies of institutionalisation and inaccessibility of physical infrastructure had a severe impact on participation for those with physical impairments in post-Soviet Uzbekistan, and did not allow them to achieve citizenship. Hence, I explored how people with physical impairments could be supported to achieve ‘mahalla citizenship’ through participatory

research, which I discuss in detail in Section 6.4. But first we need to understand the barriers that people with physical impairments are facing in their mahallas.

Inaccessible mahallas as a barrier for residents with physical impairments

A significant aspect of citizenship, particularly for those with physical impairments and reduced mobility, is the right to free movement (Article 18 of the [CRPD 2006](#)). Without this it is not possible to achieve civil, political, and social rights. People with visual and hearing impairments could develop strong social networks and collective disability identity within their segregated communities (see Section 6.1.). Shared residences, collective labour and physical proximity of the vital infrastructure established by the Society of the Deaf and the Society of the Blind allowed blind and deaf people to develop distinctive forms of citizenship (Shaw 2017). As I discussed earlier, by integrating deaf and blind people through labour, the Soviet government excluded people with physical impairments and other disabled groups. The cornerstone of the Soviet disability policy was the functional model of disability (Phillips 2009) which valued labour capacity as a prerequisite for social integration. Therefore, people with physical impairments and all those who were deemed less productive and capable of work were excluded from the Soviet citizenship framework. Unlike deaf and blind people, who could unite under the auspices of their societies, activists with physical impairments were denied the right to freedom of association until late 1980s (Fefelov 1986).

Section 6.2 showed that, besides the organisational channel of the Society of the Blind, people with visual impairments have tried to claim their citizenship through penetration of the formalised structures of mahalla committees. The case of the ‘mahalla of blind people’ showed that residents with visual impairments were able to elect their own blind

and visually impaired chairpersons between the 1980s and 2019. It can be argued that such active political and social participation of blind people in the work of the mahalla committee was possible due to the concentration of blind people in Bayot mahalla, where in 2020 the proportion of residents with visual impairments was 9.77%,¹¹⁷ whereas less than 2% of Uzbekistan's population is registered as disabled (see Chapter 4 for a detailed overview of disability statistics). However, throughout Soviet history and until February 1991, people with physical impairments were denied the ability to register their own Society of the Disabled of Uzbekistan. As a result, no towns or mahallas were specifically established for those with physical impairments and reduced mobility who were scattered around the country. Some exceptions were the specialised residential institutions where activists with physical impairments could make bonds of solidarity during forced placements under the Soviet regime (Fefelov 1986). In contrast with people with sensory impairments, the mobility of people with physical impairments has been considerably reduced. Inaccessible public infrastructure and transport have severely constrained their freedom of movement. Thus, most of the participants with physical impairments who took part in the co-operative inquiry (see Chapter 3) were dispersed throughout Tashkent and were excluded even within their mahalla communities.

A lack of accessibility in the environment and public infrastructure has undermined the right of people with physical impairments to freedom of movement, independent living and full participation in the community life as indicated by Article 9 of the UN Convention on the Rights of Persons with Disabilities (CRPD 2006). The majority of the mahalla committees that I visited were inaccessible for my co-researchers and

¹¹⁷ In 2020, the total population of Bayot mahalla amounted to 1,394 and 136 were officially registered as disabled people with visual impairments.

participants with physical impairments. The lack of ramps for wheelchairs users, narrow doorways, absence of accessible toilets and general lack of reasonable accommodation for mahalla residents with reduced mobility have become a ‘normal’ feature of mahalla committees. About 85% of buildings and social infrastructure facilities in Tashkent are not adapted for use by disabled people (Public Council under Tashkent city *khokimiyat* 2019). Such lack of physical accessibility is comparable with other post-communist countries like Ukraine (Phillips 2010) and Russia (Hartblay 2015) which is due to the Soviet legacy of urban planning. Inaccessible buildings used by mahalla committees indicates these communal spaces are not frequently used by residents with physical impairments. As a result, such environmental barriers inhibit self-organisation of residents with physical impairments as they cannot physically meet and/or easily form relationships with other disabled residents of the mahalla. Moreover, inaccessible public transport is associated with increased costs of transportation due to the need to use taxis (UN Uzbekistan 2019). Lack of accessible and safe urban infrastructure and public transport for people with limited mobility (Bakaeva and Muratova 2015) has also become one of the impediments for achieving citizenship rights by people with physical impairments.

Non-inclusive mahalla structures

Wickenden and Lopez Franco (2021) argued that “accessibility” entails not only removal of environmental barriers but also changes in the attitudes, legal and/or organisational structures which could either promote or impede disability inclusion. For instance, CBM (2012) applies the concept of “comprehensive accessibility” for the identification of physical, communication, policy and attitudinal barriers. The evidence showed the mahalla committees tend to be not accessible enough to enable disabled residents to

participate in community decision-making processes. As I explained in Section 2.2, mahalla committees are run by a chairperson (*oqsoqol*) who oversees the work of mahalla commissions which consist of community members working on a volunteer basis. Interviews with the mahalla staff in Tashkent showed that disability affairs were included in the work of the mahalla commission for the social support of low-income families. Throughout the fieldwork, I did not encounter a mahalla commission which would specifically work on disability issues. This is contrary to the findings of (Pétrie 2004: 243) who listed the commission for disabled people among seven other commissions on weddings and ceremonies, social assistance, women's issues, maintenance, sanitation, and environment. Underrepresentation of residents with physical impairments within the mahalla structure means that decisions related to the allocation of scarce resources within the community are made without the direct involvement of disabled adults, children, and their family members. In the next section, based on the evidence collected through participatory methods with adults with physical impairments, I argue that besides the restrictions of the political rights of disabled people, the mahalla committees are constraining civil and social rights of disabled residents for independent and decent living.

6.3 Mahalla committees as a barrier to realising civil and social rights

Mahalla means testing and poverty targeting

This section shows that the mahalla committees have excluded disabled residents from their activities by viewing them as passive recipients of state welfare and charity. Disabled mahalla residents are not separated as a distinct target group but are vaguely integrated into the work of the Commission to provide social support to low-income families. For the mahalla committee, being a recipient of a disability benefit is perceived

as already being protected by the state social protection system, although the amount of the benefit can be well below the minimum wage and is not even enough for a meagre subsistence. Disability benefits were calculated as a source of household income. Thus, those families who had disabled children and adults could not meet the “low-income” eligibility criterion and were excluded. As people with physical impairments have not been represented within the mahalla structure, a non-disabled *oqsoqol* and other members of the Commission carried out means testing activities on their own without gathering the opinions of disabled residents and families, leading to exclusionary tendencies in the work of the mahalla committees. This important finding also goes in line with Noori (2006) who concluded that decentralisation in the form of proliferating mahalla institutions was ineffective for either alleviating poverty, improving local infrastructure or even as state instruments of control and monitoring, and on the contrary reduced democratic legitimacy and access of the residents to government services.

The Commission on social support of low-income families which is usually chaired by the *oqsoqol* has been responsible for means testing and determination of eligibility for state social benefits. The legal definition of low income has not been compatible with the real living standards. Therefore, the government introduced other concepts like “families in need of social protection” (*ijtimoiy muhofazaga muhtoj oilalar*) for those who did not meet the criteria but were considered to be socially vulnerable.

If you approach the mahalla committee, they will say, “They have a son, they have a breadwinner...” Neighbourhood elders [*oqsoqol*] are afraid to talk. Mahallas help more on a material side, for example, distributing foodstuffs, inviting to pilaf feasts. They think their main help should be more of material assistance. And if a family is not recognised as “low-income” [*kam ta'minalangan*] they will not help it. Even if there is a disabled person, it is considered that family members should look after. [Interview with E10, a representative of a Muslim religious institution]

The experimental evidence from the participatory video exercises with people with physical impairments provides in-depth insights into the exclusionary and patriarchal attitudes of the mahalla staff members towards a woman with physical impairments.

Perpetuation of the charity model by mahalla committees

Besides allocation of state-guaranteed social benefits to vulnerable families, mahalla committees (see Chapter 4 for an overview of mahallas) have also been involved in charity activities. Qualitative interviews with mahalla residents with physical impairments showed that they have been perceived by mahalla committees mainly as passive recipients of welfare and charity. I argue that non-inclusive mahalla committees have exacerbated paternalistic attitudes towards people with reduced mobility through the prism of a charity model of disability (see Section 2.1). This may lead to increased dependency of disabled residents on the mahalla committee. Indeed, to questions about the role of mahalla in the lives of disabled interviewees (see the Appendix for the interview guide) a common response was that the mahalla committee distributes charity goods during holidays.

They would invite me if there was some holiday in the mahalla for disabled people on 3 December or if there would be any other events. **Only during events.** [Emphasis added by the author from the interview with participant with a congenital visual impairment.]

Most disabled interviewees and non-disabled mahalla staff indicated that mahalla committees mobilise local resources to support households with disabled children and adults, particularly during religious feasts and state holidays. For these purposes, mahalla committees usually ask local businesses and entrepreneurs located in the neighbourhood area to provide in-kind and/or financial support, as well as support in organising circumcision ceremonies (*sunnat to'y*) for children in vulnerable families.

We are cooperating with private enterprises in our border areas, which are engaged in trade and commerce. Especially a milk processing company,^[118] provides a lot of practical assistance to our families in need of social protection in our neighbourhood. For example, during the holidays they supported 18 families in need of social protection. They go to these families and distribute their products in their own cars. We also have entrepreneurs in our neighbourhood who support 138 people with disabilities who need social protection in our neighbourhood. (Elite interview with mahalla counsellor on women's issues.)

In an interview a disabled research participant revealed that:

each disabled resident in the mahalla has his/her own sponsor.
(Interview with a woman with physical impairments).

In other words, mahalla committees serve as an intermediary between private donors and disadvantaged families to channel the locally available resources to community residents in need of help. The non-inclusive mahalla space and relational dynamics exacerbate the issues caused by the charity approach to disability when non-disabled chairpersons and mahalla staff make decisions of behalf of disabled residents. Moreover, such charitable support is usually restricted to those who are officially registered as disabled people at VTEK commissions (see Section 2.3. in Chapter 2 for a review of disability assessment and determination in Uzbekistan).

Our mahalla committee by attracting sponsors pays special attention to the social protection of our citizens **who have received this disability group**. (Elite interview with mahalla counsellor on women's issues, emphasis added by the author.)

On the one hand, the existence of such informal practices of support within mahallas hints at the existence of strong social support networks based on the benevolence of private entrepreneurs. But on the other hand, patronising top-down attitudes towards disabled residents further constrain the efforts for citizenship at the mahalla level. Although one-off charity donations intensified during feasts and holidays can be beneficial for families

¹¹⁸ I anonymised the company name.

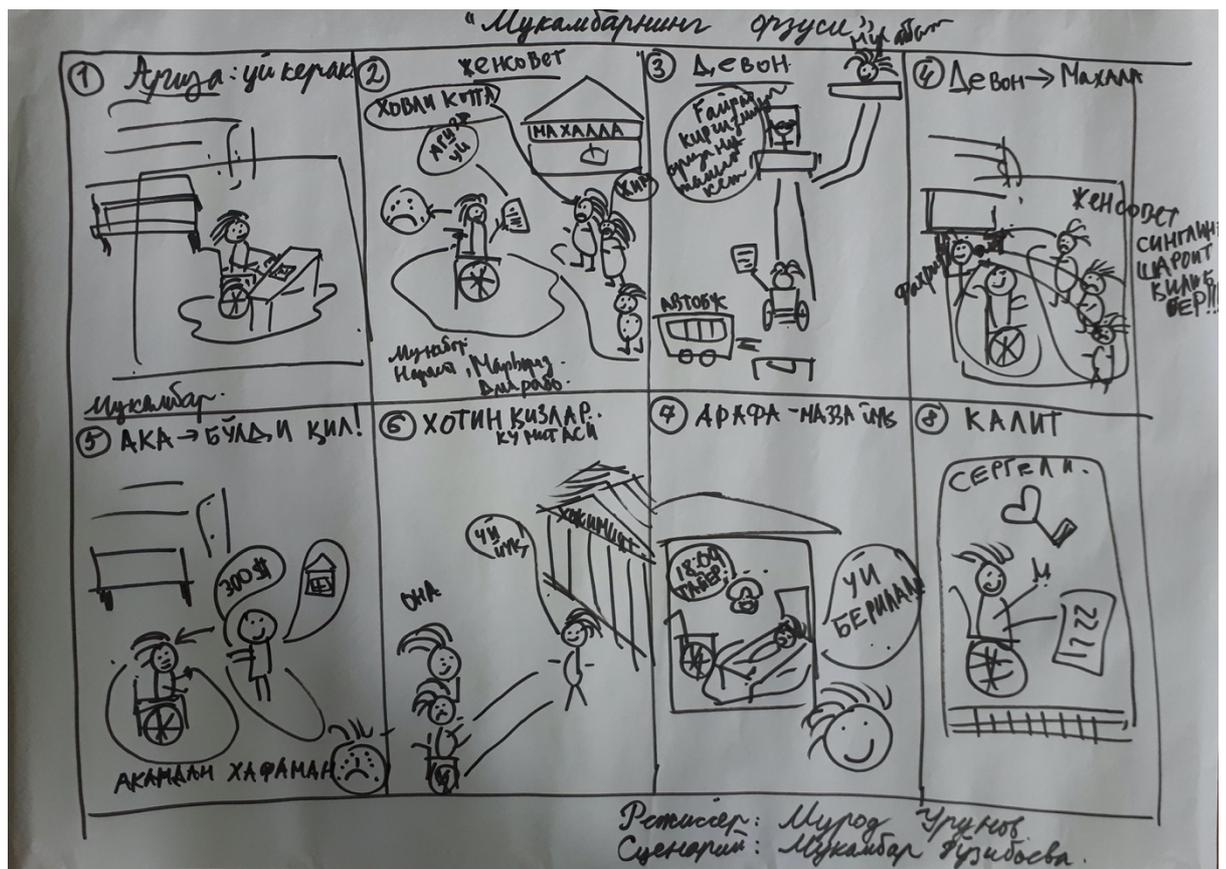
in urgent need, such short-term support is not a sustainable solution for achievement of mahalla citizenship. Such donations make disabled people and their families dependent on external support and often do not meet the exact needs of disabled residents. The case introduced in the final section demonstrates that such a top-down approach to supporting disabled people is experienced in a negative way. The visual evidence collected through participatory video shows that a mahalla committee has become a barrier to independent living for a woman with physical impairments.

Mahalla committees as barriers to independent living

This final section explores another integral aspect of disabled people's citizenship at the mahalla level which is the right to housing and independent living. Article 19 of the CRPD (2006) recognises the equal right of disabled people to independent living and inclusion in the communities. After President Mirziyoyev came to power in late 2016, he initiated several state programmes constructing 'affordable housing' for families needing to improve their living conditions (GoU 2017). The Uzbek government included disabled women among other vulnerable groups such as low-income families who could be eligible to get apartments on the first and second floors of newly built multi-storey affordable housing (GoU 2018b). Interestingly, this social housing was built in a distant Sergeli district of Tashkent city, thus replicating the Soviet social policies of settling people based on their impairments. Recent urban developments under President Mirziyoyev have further divided Tashkent into areas intended for affluent groups, like the newly built business centre 'Tashkent city' (Matyakubova 2020). Such spatial inequality contributes to further segregation of disabled people. Mahalla committees play an important role in the allocation of 'affordable housing' as they were involved as members of the special Commissions established at a district or city level. Based on the

analysis of the visual data from participatory video with adults with physical impairments, this section argues that mahalla committees, instead of realising the right to decent housing and independent living of disabled people, are constraining it, and thus are not enabling disabled women to achieve citizenship at the community level.

Figure 20. Sketch of a shot-by-shot documentary “Marhabo's Dream”



Source: author's photo

To illustrate this, I provide an example that emerged from my participatory video work with adults with physical impairments in Tashkent (see Chapter 3 for detailed explanations of the methodology). Our first shot-by-shot documentary (Shaw and Robertson 1997a) was titled “Marhabo’s¹¹⁹ Dream” and was based on a real life story of

¹¹⁹ I am using a pseudonym here.

Marhabo – a woman with physical impairments aged 40¹²⁰ who uses a wheelchair and who has always lived in Jurabek mahalla.¹²¹ For over three years, she had fought with representatives of her mahalla committee for approval to apply for the state-provided affordable housing programme for disabled and low-income families. Figure 3 above shows Marhabo’s difficult journey towards her dream in eight separate shots that make up her film.

Marhabo’s mahalla Commission on social support of low-income families came to inspect her living conditions and concluded that she was not a low-income person and therefore was not eligible for the affordable housing programme. To apply for this state programme, one should meet certain criteria like the allocation of benefits to low-income families discussed in the previous section. Importantly, disabled women could become part of the preferential housing programme for vulnerable citizens only upon a written recommendation of the special commissions based on the reference of the district (city) mahalla and family support department and the conclusion of the medical association.

In the second shot shown in Figure 20 above, Marhabo showed the members of the mahalla committee inspecting her living conditions, saying that her “yard was big” (*hovli katta*). After bypassing the mahalla committee and appealing to the president’s office (see shot 3) the mahalla committee still exerted pressure on Marhabo’s brother to accommodate his sister (*singlinga sharoit qilib ber*) (shot 4). As a result, Marhabo’s attempts to reach high-ranking officials backfired on her brothers who were blamed for

¹²⁰ As of 2019 when she took part in the participatory workshops.

¹²¹ I do not provide links to these video materials as the consent process for participants did not allow this. All the visual materials produced during the participatory workshops were for internal use only.

not supporting their sister. By imposing such constraints on Marhabo and her brothers, the mahalla committee tried to reduce her problem to the individual and/or family as responsible for care of disabled children and adults. Disabled women like Marhabo, even if they required improvement of their living conditions, were not deemed to fit the ‘social priority criteria’ (*ijtimoiy ustuvorlik mezonlari*). These can be understood as the main indicators of social and housing conditions used by the Commission to select and determine eligibility to participate in the programme. These indicators were developed without participation or even consultation with disabled people and their organisations. This case confirms earlier arguments in this chapter that the mahalla committee excluded disabled community members from support, as it did with its measures to strictly target families in severe poverty. More broadly, this example also shows the state defining the roles and duties of the family and its constituent members. A disabled woman’s individual struggle with bureaucrats of varying power suggests that the Society of the Disabled (see Chapter 5) which ought to protect her rights and interests, was ineffective in advocating for her independent living.

For instance, only single women in disability group I, female wheelchair users with a total living space of less than 23 square meters, as well as women caring for children with severe forms of impairments were considered eligible (GoU 2018b). The appendix to the resolution of the Cabinet of Ministers (GoU 2018b) regulating these procedures contained a list of “diseases leading to severe disability” (*og‘ir nogironlikka olib keluvchi kasalliklar*), thus heavily medicalising disability and conflating it with impairments in contradiction with the social model of disability and CRPD (2006) (see Chapter 2).

The representatives of the mahalla commission argued that Marhabo had three brothers and their families who could take care of her. However, the available living space was not sufficient for Marhabo who wanted to live independently, as about 18 children and adults were already living in the extended household. Marhabo was eager to have her personal space where she could lead an independent and tranquil lifestyle. It took Marhabo up to three years to persuade the mahalla committee bureaucrats that she acutely needed a single room apartment in a multi-storey affordable house. Eventually, Marhabo decided to bypass the mahalla system and travel on inaccessible public transport, which she rarely used, to the new president's administration. There she complained about her mahalla committee and made clear that she would never stop advocating for her right for independent living. In the shot-by-shot documentary, she played herself while other disabled participants were in the roles of the mahalla committee staff. The participatory video process enabled Marhabo to inspire other participants to advocate for citizenship, by telling the story of the challenge she fought to realise her social right to independent living. However, it turned out that the 'affordable housing' she received from the government for lifetime use was not physically accessible for her (Yusupov 2019c).

Conclusion

The aim of this chapter was to critically examine the role of mahalla structures in disabled people's efforts to realise citizenship at the community level in post-Soviet Uzbekistan. The analysis of the collected ethnographic and participatory research evidence has shown that in addition to political rights (Marshall 1992) within the formalised structure of mahalla committees and decision-making mechanisms at the community level, the right to adequate means of social protection and accessible housing is equally important in achieving citizenship by disabled people. The findings suggest that, rather than promoting

such rights of disabled people, mahalla committees have become barriers to community-based political participation and mobilisation. The recent case of the ‘mahalla of blind people’ shows that the segregated blind community is failing to get its needs and interests represented through the formal mahalla structure. Explicit intervention of the local government in the election of the mahalla chairperson in Bayot mahalla and unjustified rejection of the young blind candidate is taking away blind people’s hopes for self-governance and self-representation at the grassroots level. Despite the expectations raised by the new Uzbek government, the mahalla is still a strictly controlled body which is dependent organisationally and financially on the local government. This top-down control echoes the findings of Chapter 4 and 5 where I argued that the dominant disability NGOs were remade into “extensions of the state” (Holland 2008; Mladenov 2018). I argue that the formalised mahalla committees similarly turned into strictly controlled government bodies rather than self-governing bodies of citizens.

The formalisation of mahallas associated with the top-down state intervention and neoliberal policies of Mirziyoyev’s government has had negative impacts on the development of ‘organic mahallas’¹²² of blind people and severely constrained the bottom-up citizenship activism of residents with visual impairments. Consequently, as non-inclusive, bureaucratic institutions, mahalla committees tend to view disabled residents through a prism of the charity model of disability, as passive recipients of social welfare or local donations from private sponsors, rather than as active agents who should be equally involved in the work of the mahalla committees. The qualitative interviews with disabled people and the case of a woman with physical impairments who

¹²² See Section 2.2 in Chapter 2 for the discussion of the concept of ‘organic mahallas’ proposed by (Rasanayagam 2011).

unsuccessfully attempted to claim her right to independent living at her mahalla committee have provided deeper insights into how strict poverty-targeting measures imposed by the mahalla commissions are excluding eligible disabled people from the state-guaranteed social support.

Prior to the formalisation of mahalla in the form of self-governing bodies (GoU 1993, 1999) and long before Soviet rule, the mahalla was organised around Islamic practices (Abramson 1998). Rasanayagam (2011) also found that until the 1960s Uzbek people used the term *masjid qaum* (mosque community) when referring to their mahalla. He further argued that the notion of an informal or ‘organic mahalla’ is constructed in relationship to a mosque (*masjid*) which serves as a catalyst for uniting the community around the practice of Islamic religion. My observations within the religious communities of blind and deaf people reveal that pious disabled people are more likely to find themselves in tension with other groups and the state through interactions with the dominant disability NGOs, specialised enterprises and mahalla committees. In the final empirical chapter of this thesis, I explore how emerging Islamic culture and religious institutions in contemporary Uzbekistan are shaping local understandings of ‘disability’ and generating distinctive forms of citizenship within the pious communities of disabled people.

Chapter 7. Spiritual citizenship: Punished, tested, or blessed citizens?

In Chapter 4, I mentioned the young deaf activist Jasur who criticised the hearing chairperson of the Society of the Deaf for his lack of accountability for the rights and interests of deaf and hard-of-hearing people. Exploring the role of UPPs, I found out that a group of blind people were unwilling to be involved in the strike to claim back the state tax benefits organised by the bureaucrats of the Society of the Deaf (see Section 5.4). In the previous chapter, I introduced Abbos hoji and Umid who invited me to the ‘mahalla of blind people’ to discuss violations during the recent elections of their chairperson. Interestingly, what unites all these people is that I met them all at the weekly religious meetings organised by the Muslim Board of Uzbekistan (MBU). The common religious background of all these disabled people indicates the importance of understanding the role of Islamic culture and religious institutions in the lives of disabled people.

In this final empirical chapter, I explore how disabled people in Uzbekistan are conceptualising ‘disability’ through Islamic knowledge and practices, and mediating their achievement of citizenship through an individual relationship with God and collective relationships with the Muslim community. My findings build on the existing literature on theological and cultural conceptualisations of disability in Islam (Al-Aoufi *et al.* 2012; Bazna and Hatab 2005; Bhatti, Moten, Tawakkul and Amer 2009; Chaim 2019; Ghaly 2010) and focus on the lived experiences of ‘disability’ through religious practices of deaf and blind people in Tashkent city. The ethnographic evidence shows that religious blind and deaf communities are conceptualising ‘disability’ through Islamic morality. However, even in this religious domain the Soviet legacy of top-down state intervention in religious institutions is constraining the achievement of ‘spiritual citizenship’ by blind

and deaf communities. The concept of ‘spiritual citizenship’ emerged from my ethnographic data as I tried to describe how blind and deaf Muslims enact their citizenship through Islamic norms and practices.

7.1 Perceptions of disability in Islam

Disability as a test (*sinov*)

My interest in how disabled people in Uzbekistan perceive ‘disability’ through Islam stems from my prior working experience. At the DET trainings that we organised as part of JICA’s project for disabled people in rural areas I observed some fatalistic notions of disability. To our question “What does disability mean for you?” we frequently received answers like: “Disability is a challenge [*sinov*] sent from God/Allah”. Many Uzbek disabled people believed that their life was already predetermined by *qismat* (fate) which is considered to be a foundation of Islam (Hasnain *et al.* 2008). There is a good expression in Uzbek to illustrate this notion: *pehshonamga yozilgani bo‘ladi* (what is written on a forehead, that is meant to happen). Acceptance of the fact that nothing can be done to change one’s own destiny encourages a disabled person to accept and internalise his/her suffering. Similar findings were reported in Afghanistan (Armstrong and Ager 2005; Coleridge 1999), Pakistan (Miles 1995), and Bangladesh (Burns *et al.* 2014).

However, previous studies have not considered the relationship of Islamic culture to local understandings of disability in Uzbekistan. Zagirdinova (2005, 2009) argued that Islamic norms converted into traditions and customs are shaping negative societal attitudes towards disabled women, who are facing multiple forms of discrimination. However, she only reveals the effects of Islamic culture on disabled men/women rather than doing a deeper analysis of causes, which have their roots in religious values, beliefs and

behaviours. This chapter attempts to fill in this gap by analysing ethnographic data that emerged from my weekly interactions with deaf and blind people at religious meetings at mosques and other spaces for disabled people in Tashkent in 2018-2019. Before going into the analysis I acknowledge the critique of over-deterministic understandings of Islam's influence on culture (Soares and Osella 2009) and argue that Islam does not define attitudes towards 'disability' in Uzbekistan in a one-dimensional way, as there might be an inherent diversity in interpretations of this complex concept within the Islamic tradition. Thus, findings in this chapter present ethnographic accounts of disability through the prism of Islam that I researched within two religious communities of deaf and blind people in Tashkent city.

I learned about these meetings when I interviewed a woman with visual impairments at the Palace of Culture for the Blind in Cho'pon ota mahalla (see Section 6.1). Malika¹²³ was a specialist at the Women's Affairs Department of the MBU, and oversaw organising the regular meetings with deaf and blind communities. Malika invited imams and other religious figures to give talks on various religious issues. One of the dominant discourses on disability was based on the belief that *Allah* tests all human beings in various ways and every test may have its own sacred and hidden wisdom (*hikmat*). Some are tested through impairments, disease, pain, or other forms of sufferings, while others are tested through loss of fortune or loved ones. During the meeting with deaf people at Ko'kcha mosque, one of the invited imams¹²⁴ cited this verse from the *Qur'an*:

We shall certainly test you with fear and hunger, and loss of property,
lives and crops. But [Prophet], give good news to those who are

¹²³ I am using a pseudonym.

¹²⁴ See Section 2.2. for the contextual data on Islam in post-Soviet Uzbekistan where I introduce basic Islamic institutions.

steadfast, those who say, when afflicted with a calamity, ‘We belong to God and to Him we shall return.’ These will be given blessings and mercy from their Lord, and it is they who are rightly guided 2:155-157. (Abdel Haleem 2008: 17–18).

In the same vein, Ghaly (2010) in his book on Islam and disability provides a broader view that “suffering is simply an inevitable concomitant of existence in this life” (Ghaly 2010: 21). In other words, suffering should be taken for granted rather than something that is just possible. Similarly, the deaf participants perceived their hearing impairment as a God’s test (*sinov*). For them the world we are living in now is, firstly, transitory (*o’tkinchi*) or temporary (*foniy*) until a permanent (*boqiy*) afterlife. Secondly, there is no uniformity (*bir xillik*) and there is variability (*har xillik*) – ups and downs over the course of our lives. Blind people who I also met at a separate religious meeting also argued that the world is not static and if our life was monotonous, it would be tedious and lack any meaning. Moreover, according to them, no human being is created perfect, in contrast to *al-Quddus* – the fourth name and quality of *Allah* who is free from any imperfection and deficiencies (*nuqson*).¹²⁵ Therefore, human beings are always tested in this life and are guided to the right path if they show patience and faithfulness to *Allah* in the face of calamities (*musibat*).

Both the disabled communities I engaged with said that God’s tests were not restricted to something that may be perceived as bad but may be good: good health, abundance, wealth, or sudden luck. For example, a rich person is tested to check whether he uses the affluence and resources given by *Allah* in profane or sinful ways or directs it to help others in need. Likewise, *Allah* makes someone poor or disabled to test their patience (*sabr*). Therefore, unlike the functional model of disability (see Section 1.4 and Chapter 5) which

¹²⁵ As retold by blind and visually impaired participants while learning the most beautiful 99 names of *Allah* (*Asmaul Husna*) during religious meetings organised by the Muslim Board of Uzbekistan.

conflates disability with a negative notion related to lack of employability (Phillips 2009; Zaviršek 2014), seeing disability as a test is not to perceive it as something bad. In contrast with simplistic interpretations of disability as a punishment for previous sins or a personal tragedy (see Section 1.1.), a broader view of human life as suffering deflects negative connotations of disability. Although it is predominantly a traditional view of the world, based on my observations, this model of disability is widespread among religious communities of disabled people I engaged with. In the following section I argue that understanding disability as a test in the first place is inextricably linked to a positive interpretation of disability as a blessing (*ne'mat*). In other words, the blessing comes in the form of a test from *Allah* to examine how human beings make use of the blessing.

Disability as a blessing (*ne'mat*)

During the religious meeting, *otin-oyi* (female religious authorities) asked a young blind participant to provide an example of *ar-Rahman's*¹²⁶ mercy. He immediately made a case of his visual impairment as His blessing (*ne'mat*). Blind participants in the religious gatherings believed *Allah* wishes no evil to anyone and their visual impairment is considered as His mercy, as deprivation of vision does not allow them to commit eye-related sins. Perceptions of blindness as a blessing were particularly strong among my blind interviewees who said they were not able to commit visual adultery (*ko'z zinosi*) and in this way they were meant to be closer to *Allah*. For this reason, my congenitally blind interviewee was thankful for his visual impairment and even expressed his unwillingness to be sighted:

¹²⁶ *ar-Rahman* is the first beautiful name of *Allah* out of His 99 names (*Asmaul Husna*) meaning that He is the Beneficent He who wills goodness and mercy for all His creatures.

It is true that this world's landscape is very beautiful. As one scientist put it, the more beautiful this world's landscape is, the more dangerous it is. What is dangerous? The dangerous side of this world is that one will be held accountable tomorrow on the Day of Judgement (*qiyomat kuni*)¹²⁷ for looking at these *nomahram*,¹²⁸ half-naked people or *harom*¹²⁹ things. Therefore, it is very dangerous. But I say *Alhamdulillah*, I am clean (*toza*) from this menace, thank God. I am happy about that. It is a celebration (*bayram*) for me.

He then continued that he did not know what other blind disabled people think but for him personally it is a blessing and every year on 3 December, the International Day of Disabled Persons, he celebrates his blindness. The above perception of blindness as a blessing may not be restricted to blindness but can also be associated with other types of impairments. In this view, speech, hearing, learning, mental and physical impairments may lead to inability to commit certain types of sins. For example, a blind person cannot commit eye adultery, or a deaf person cannot swear. Therefore, in this model impairments are considered to be God's blessing which will alleviate one's position in the afterlife. Although I was not able to get similar accounts from individuals with other forms of impairments, the same blind man explained that speech and hearing impairments hold deaf people free from sins that are committed with one's tongue and ears:

There is a saying "My tongue is my own enemy"¹³⁰...the tongue is a great blessing (*ne'mat*) given by *Allah*. Order is established and decisions are made with it and it is possible to sow the seeds of goodness (*ezgulik*) between people. At the same time with this tongue one can spread conspiracies (*fitna-fasot*) and rumours (*fisq-fujur*) and if necessary one can bring someone to death with it. On the Day of Judgement, they [hearing impaired] will not be questioned about it. They cannot swear with this tongue. They cannot make a grief to others with it...cannot insult speaking with voice...They will not be

¹²⁷ According to religious beliefs, when this world is over, everyone in the other world will be resurrected and gathered for questioning (Begmatov and Madvaliev 2006). Synonyms include *ohirat*, *mahshar*.

¹²⁸ A man and a woman (in relation to each other) who are forbidden to see or to be seen by each other due to lack of close kinship, but those who can get married (Begmatov and Madvaliev 2006).

¹²⁹ Which is forbidden by Islamic law *shariat*.

¹³⁰ He referred to the book "*Major Sins*" by (Adh-Dhahabi 2012).

questioned for their ears as well. They have not heard these filthy rags, insults, destructive words.

Furthermore, those who have no limbs or are physically impaired may be unable to go to dirty (*harom*) places and or hold dirty things. My blind interviewee continued:

The greatest blessing will be on them [physically impaired]. Why? Because they cannot go outside, cannot walk, they are also considered to be protected from eye adultery because they lie in the same place, they cannot go to a dirty (*harom*) place.

One can disagree with this exaggerated argument as it assumes that people with physical impairments are immobile or deaf people are unable to communicate at all. Such perceptions of people with other impairments can be related to limited knowledge and interaction of the blind interviewee beyond the community of people with visual impairments. Similar can be said about perceptions of people with learning disabilities. A question was posted online to the *Fatwa* Board of the Muslim Board of Uzbekistan as to whether children with congenital learning disabilities (*aqli zaiif*)¹³¹ will enter Paradise (*jannat*) without being questioned on the Day of Judgement and whether their parents will have a reward (*ajr*). The answer provided by the Fatwa Board was the following:

Insha'Allah, there will be no questioning for them. This is because it is not obligatory (*farz*) for the mentally retarded to follow the rules of the *Shari'ah* (*shariat*). There are great rewards for parents who raise such children with patience (*sabr*), in the hope of reward (*savob*), without turning to ingratitude (*noshukurlik*).

Impairment can be given as a blessing not only to disabled people but their family members. To illustrate this, I provide this story retold by *otin-oyi* to deaf participants of a religious meeting in a mosque of Tashkent:

A young man who grew up in apostasy (*ma'siyat*) married a pious Muslim woman (*solih* *ayol*). And they had many children. Among

¹³¹ This translates as 'feble-minded' or 'retarded' and was used by the questioner to refer to children and adults with learning disabilities.

them there was a deaf and dumb¹³² (*kar-soqov*) son. The mother paid more attention to her deaf son than to the rest of her children, considered him as God's gift (*omonat*) and took good care of him. She taught him *namaz* and from his earliest childhood she became a reason that his soul (*qalb*) became attached to the mosque. When the boy turned seven, he saw what was going on around him and felt his father falling into the abyss of apostasy. Through signs the son tried to exhort his father and explain him to leave his sins, repent (*tavba*), to go to mosque and would never get tired of repeating his actions. But his efforts were in vain. One day the boy came from the street with a tear in his eye, muttering as something stuck in his throat. And he took the *Qur'an* and put it before his father. He opened *Surah Mary (Maryam)* and put his finger on a verse in it. It read: 'Father, I fear that a punishment from the Lord of Mercy may afflict you and that you may become Satan's companion [in Hell] 19:45 (Abdel Haleem 2008: 193).' Crying the boy looked at his father with hope. The father was deeply moved by the situation and cried along with his son. By the will of *Allah*, the locks of the father's soul were opened because of the righteous child (*solih farzand*). He wiped the tears from the eyes of his son and kissed his forehead and took the steps of repentance towards the mosque...

In this case, the hearing impairment of the devout son was regarded by *otin-oyi* as a reward for the irreligious father who, thanks to his son, was able to repent (*tavba*) in time to avoid God's punishment. The wisdom (*hikmat*) behind this story is that merciful *Allah* did not mean to punish (*jazo*) the father by making his son hearing-impaired but, conversely, He rewarded him with a righteous child who led to the right path (*hidoyat*).¹³³ Therefore, impairment is not regarded as a punishment of *Allah* for the father's misbehaviour but rather as a chance to ask for forgiveness in this world to avoid suffering (*azob*) and God's punishment in the afterlife. In this view, *Allah* creates people with impairments not because He harbours malice against disabled people or members of their families but because He loves them more and gives his mercy and kindness (*mehr*).

¹³² I keep the original translation of Uzbek word *kar-soqov*.

¹³³ The right or true path in Uzbek is *hidoyat yo'li*, in sharp contrast to apostasy (*ma'siyat*).

Acquired impairment is also regarded as a blessing as it serves as forgiveness (*kafforat*) of one's sins in this life. My congenitally blind informant told me that he often encourages those who acquired visual impairment in the following way:

Be happy that *Allah* has forgiven your sins in this world. You might have had a certain sin that *Allah* has forgiven it thanks to the impairment that He has given you. I often tell them that in this world they will no longer suffer from that sin. Because *Allah* does not inflict calamity (*musibat*) on His servants in vain. This is in order not to torment him in the other world and take away the sin he has committed in this world.

Thus, impairment is not considered to be a deficiency but rather an ability to attain a certain degree of purity and innocence (*ma'sum*)¹³⁴ which determines access to the afterlife for individuals with congenital or acquired impairments as well as their relatives or carers. By contrast, people without impairments are deemed to be unable to abstain from committing sins with their eyes, tongues, ears, and physical body, and so are still responsible for them on the Day of Judgement and will be questioned correspondingly. The quality of childish innocence appears to be socially ascribed to disabled people. My blind co-researcher told me that people were surprised or even expressed disappointment about him being a smoker as it is thought to be a vicious behaviour which corrupts the well-established image of an innocent disabled man. Blind men are also often referred to as readers (*qori*) of the *Qur'an* who can follow the proper rules of recitation due to their vocal capabilities. For this reason, when addressing a blind person, it is common to add '*qori*' after his first name. This understanding of disability resembles the affirmation model of disability (Swain and French 2000), a non-tragic view of impairment which embraces a positive religious identity at individual and collective levels. I observed that blind and visually impaired people in particular respond positively to this tendency of

¹³⁴ I did not encounter this word *ma'sum* in speech during fieldwork. It is used more in books and means innocent, sinless.

some Muslims to treat them as being especially virtuous. Having defined the two interlinked definitions of disability through the prism of Islam, I now move onto the moral perspective on disability which was propagated by the religious scholars and representatives of the MBU as well as by some disabled interviewees.

Disability of a soul (*qalb nogironligi*)

A man of learning and piety¹³⁵ told me in an interview that *Allah* makes some of His servants (*bandalari*) visually impaired, and it is considered a test not only for blind people themselves, but also for those ‘with open eyes’ (*ko ‘zi ochiqlar*).¹³⁶ The agony (*azob*) of a ‘sealed soul’ (*muxirlangan qalb*) is considered to be heavier than that of a ‘sealed eye’ as there are many people who, being fully sighted or able-bodied, do not bow down in prayer (*sajda*) to worship *Allah*, study religion, or keep in mind their mortality and subordination to God and how they will show gratitude (*shukur*) for their ‘healthy bodies’ on the Day of Judgment. In contrast, the status of those disabled people, whose souls are believed to have been enlightened with belief in *Allah*, who have endured illnesses, impairments in their bodies and other calamities (*musibat*) with patience (*sabr*) and without complaining, will be raised. Souls of those with impairments are illuminated with light, and angels (*farishtalar*) see them as performing pilgrimages to holy sites (*ziyosat*). In an interview, a representative of the Muslim Board retold us *hadith* (a traditional story) about Imran ibn Husain, one of the *Sahaba* (Companions) of the Prophet, who had *bavosil* (hemorrhoids) for about 30 years and because of the disease was unable to sit or stand. Thus, eating and ablution were all performed lying down:

¹³⁵ I am anonymising the elite interview participant by using the widely used identifier ‘men of learning and piety’ for religious scholars.

¹³⁶ One who can see, sighted people in contrast to blind people.

A man named Mutarraf came to see him with his brother A'lo who cried seeing the condition of Imran ibn Husain. Then he said, "Why are you crying?" A'lo answered, "I am crying because I can't stand seeing your condition, and my heart is broken". "Don't cry, if *Allah* wills me lying like this, there is nothing dearer (*mahbub*) to me than this. So, my favourite thing is to lie in this bed as a patient (*bemor*). I tell you one thing, you will not tell anyone until I die: everyday angels (*farishtalar*) come to visit me, greet me, and I respond to their greetings. They talk to me and then leave."

This story suggests that people whose hearts are enlightened by *iymon* (faith), and those who have endured illnesses, calamities, and impairments in their bodies, will be exalted, their souls will be enlightened, and angels will visit them. They gain ability to see what ordinary people cannot see with their eyes, they start seeing with their 'soul's eye.' Accordingly, there is a differentiation between physical impairment related to a body versus disability of a soul (*qalb nogironligi*).

In the previous story about the father in apostasy who repented thanks to his pious deaf son, the father had a sealed soul and a padlock on it (*qalbiga qulf*). Although the son was deaf, he was able to study *the Qur'an* and practice piety, but his father's soul was disabled. Blind participants of religious meetings also indicated that despite their loss of vision, their soul's eye (*qalb ko'zi*) could see. Moreover, pious blind people are thought by non-disabled people to have exceptional abilities, able to see with their soul's eye what ordinary sighted people cannot see. An imam told me that during the *Qur'an* competition organised among women with visual impairments in Tashkent in 2018, the judges praised a blind girl who won the competition and as an exception she was accepted to the Khadijatul Kubra Women's Secondary Special Islamic School:

Praise to be to our sister, may Allah bless her teachers and parents and put the crown of laurels [*izzat toji*] upon their heads on the Day of Judgement. Rather than having a sealed soul and open eyes it is better for eyes to be sealed and have an open soul like this.

The MBU often applies this concept in its appeal to Uzbek society and refers to pious blind people as “Muslims whose soul’s eye is open”. Islamic clergy refer to them as “His majesty the man” (*hazrati inson*) as they serve an example and a lesson (*ibrat*) for those whose ‘four body parts are healthy’¹³⁷ (*to‘rt muchasi sog‘*). Moreover, in its public appeals the Muslim Board of Uzbekistan (MBU) uses related verses from *the Qur’an*:

We have created many jinn and people who are destined for Hell, with hearts they do not use for comprehension, eyes they do not use for sight, ears they do not use for hearing. They are like cattle, no, even further astray: these are the ones who are entirely heedless. 7:179 (Abdel Haleem 2008: 107)

Referring to unnamed interpreters (*musaffir*) of the *Qur’an*, the Board explains that this verse is metaphorical (*majoziy*). That is, even those who hear the truth do not necessarily comprehend it, those who are able to see the right path (*hidoyat yo‘li*) do not walk it and those who hear admonition (*pand-nasihah*) do not follow it. *Allah* has rewarded human beings with an able body, speech and hearing abilities so that they could use it in the righteous way and be grateful for it. From this perspective, ‘disability’ is not inherent in a body but a soul and is about morality and spirituality. In other words, a truly ‘disabled’ person is someone who despite having an able body is not a pious (*taqvodor*) Muslim and does not fear God. As my blind interviewee put it:

disbelief [*iymonsizlik*] is disability [*nogironlik*], without faith [*iymon*]¹³⁸ that person is truly disabled.

So far, this section has shown that pious communities of blind and deaf people in Tashkent city are conceptualising ‘disability’ through a moral perspective, which has

¹³⁷ When giving a sharp contrast between disabled and non-disabled people the emphasis is added on four or sometimes seven limbs that are healthy which means that a person is ‘absolutely able-bodied’ compared to a disabled person. I criticise this ableist notion in the section ‘A note on disability terminology’.

¹³⁸ In Arabic *Iman* – faith in *Allah* as the central of the five pillars of Islam.

allowed these pious communities to adopt a positive religious identity in contrast to medical or functional models which focus on impairments. Similar to Muslim women activists described by Peshkova (2015, 2020), the Muslim disabled people I have introduced in this chapter project their interpretations of ‘moral disability’ onto the corrupt bureaucrats at disability NGOs, non-disabled leaders of UPPs, and mahalla committees. For these pious deaf and blind people their “moral transformation into better Muslims” (Peshkova 2020: 251) allows them to construct their sense of belonging to *Allah*. Thus, I argue they achieve citizenship not through liberal or functional approaches but through a moral approach through their devotion to *Allah*. In the following section, I show how these religious disabled communities are constructing a new form of ‘spiritual citizenship’ by nurturing their divine relationships through patience, gratitude, and trust in God.

7.2 ‘Spiritual citizenship’ through devotion to *Allah*

Patience (*sabr*)

As mentioned in Section 7.1, a majority of disabled participants of religious meetings treated their impairments as a God’s test (*sinov*), as one of blind man said:

the purpose of this test is for *Allah* to examine how we [disabled people] will overcome the challenge either in anger and dissatisfaction or in gratitude [*shukur*] and devotion to *Allah*. He does not send any tests to those who cannot bear them.

An *otin-oyi* during one of the religious meetings with blind people put it this way: a test (*sinov*) lived through with patience (*sabr*) will result in *ajr*¹³⁹ (reward). *Allah* is to raise

¹³⁹ From Arabic, *ajr* is translated as reward and is a concept in Islam. Based on *the Qur’an*, people will be rewarded in the afterlife for their good deeds in this world. In other words, in return for their meritorious (*savobli*) deeds, Muslims will be rewarded with various ranks (*maqom*) and titles (*martaba*) as well as blessings (*ne’matlar*) in the afterlife (Husniddinov and Ibrohimov 2004).

one's status in the eternal world according to the 'beauty of patience' (*chiroyli sabr*) shown towards a test in this temporary life. As one of my blind interviewees said,

Be patient, the reward of patience is yellow gold^[140] and *Allah* will provide opportunities in the afterlife and even a place in Paradise [*Jannat*] in return for patience in this transient world.

The interviewee concluded that "we should not seek paradise in this world" and no matter how many tests he would face in this life, his only wish was not to be tormented in the afterlife. This probably explains the unwillingness of the religious blind community to be involved in the tax strike organised by the bureaucrats of the Society of the Blind (see Section 5.3). For pious blind people, citizenship is not achieved through labour contribution at UPPs but through their devotion to *Allah*, exercising patience (*sabr*) in their daily lives. This finding is in line with that of Harmsen (2008) who argued that *sabr* served as a path toward empowerment. Similarly, [Khalid \(2014\)](#) argued that the communist regime could be construed as a test for Uzbek believers who relied on God (*tavakkul*) and patience (*sabr*) instead of political or military resistance. The importance of *sabr* was also highlighted by a representative of the MBU who retold *hadith* at one of the religious gatherings with deaf people at Ko'kcha mosque. The *hadith* was about a black woman who experienced epileptic seizures; she secured a place in paradise thanks to her patience:

She went to the Prophet (peace be upon him) and said, "I have epilepsy. During the seizure, my intimate parts [*avrat*¹⁴¹] are exposed. Pray to *Allah* (so He gives me healing)". The Prophet (peace be upon him) said, "If you wish, be patient and you will achieve Paradise. If you wish, I will pray to *Allah* and He will heal you." She said, "I will be patient, but during the seizure my intimate parts are exposed. Pray to *Allah* that

¹⁴⁰ In Uzbek *Sabr qil, sabr tagi sariq oltin*.

¹⁴¹ From Arabic *avrat* means unprotected, weak part; the genitals are the part of the body of a worshipper that should be covered with a garment during worship (religious acts) according to the Shari'ah. In prayer, the part of a man's body from the navel to the knees, and all the parts of a woman's body except her face and palms, even her hair, are considered *avrat* (Husniddinov and Ibrohimov 2004).

they are not exposed.” The Prophet prayed for her. When a woman had a seizure, her intimate parts were not be exposed. (Narrated by Imam al-Bukhari and Imam Muslim).

When confronted with a choice between health in this temporary world and eternal paradise in the Hereafter, the woman in the story preferred the second and, in this way, reconciled herself with her physical impairment. Thus, patience meant enduring hardships, doing what faith (*ymon*) required and agreeing with God’s judgement (*hukm*). The *hadith* implies that disabled Muslims are to submit to the will of *Allah* and come to terms with their impairments, which should be viewed as tests before *Allah* bestows good upon them. In this way, disabled people are not encouraged to seek *shifo* (healing) or cures, but to be patient.

Blind people frequently mentioned the story of Abdulloh ibn Ummu Maktum – a blind Muslim man thanks to whom the 80th Meccan sura *Abasa* (He Frowned) was revealed to the Prophet.¹⁴² Ibn Ummu Maktum was one of the closest Companions (*sahoba*) of the Prophet and was chosen as one of the *muazzin*¹⁴³ in Medina. Based on the *hadith* narrated by Imam Abu Dawud from Anas, when the Prophet left Medina to participate in battles, he would leave ibn Maktum in his place despite his congenital blindness. This story was narrated during separate interviews with two blind men:

Abdulloh ibn Maktum faced difficulties commuting to mosque because *kofir* [non-believers] and *mushrik*¹⁴⁴ [idolaters] of Mecca put big stones and glass shards on the road which he walked. No matter how many times he stumbled and slipped on them he kept going to the mosque. In the end, the Prophet’s Companions connected his house and the mosque with a rope so that he could find his way by touching it.

¹⁴² I will talk about this sura in detail in the section on disability and equality in Islam.

¹⁴³ From Arabic, *muazzin* is a person who performs the calls to prayer in the mosque.

¹⁴⁴ From Arabic, *mushrik* were polytheists who before the emergence of Islam among the Arab tribes worshipped various idols, stones, and so on. They also believed in a number of male and female gods thus not recognising God as single (monotheism).

Then the disbelievers and polytheists of Mecca tied blades to the rope and ibn Maktum's hands were full of blood. Seeing this the Messenger of *Allah* peace be upon him cried out in grief and said: "I will pray for you and your eyes will open but on the Day of Judgement you will not be one of the first who can see the face of *Allah* [*Allohning jamoli*].¹⁴⁵ But if you live in this world with blindness until the end you will be the first to see His face and beauty." Ibn Maktum's faith was so strong that he endured many hardships and tests and chose to remain blind.

I posed the same question to my interviewee (who was blind from birth), and he said he would choose the same as ibn Maktum, as this temporary world would pass in several years, but the afterworld is eternal. He added that he was not afraid of living in blindness being surrounded by good people. However, he also mentioned a conflict between his religious position and his lived experience of disability. He mentioned some situations in his daily life, when he is not able to find things, hits something on his way, and gets very upset with himself, saying: "I wish my eyes could see". But afterwards he immediately asks for forgiveness from *Allah* by reciting a short prayer (*Astaghfirulloh*). Parallels can be drawn here between ibn Maktum's sufferings and the difficulties faced by my interviewee in daily life. The life of Abdulloh ibn Ummu Maktum and the lives of the Companions (*sahobalar*) serve as examples for disabled people. According to one *hadith* the Prophet said:

My Companions are like the stars, whichever of them you follow you will be rightly guided.

The notion of *sabr* and divine devotion discussed in this section are also linked with another religious concept of gratitude (*shukur*) which I consider in the following section.

¹⁴⁵ Seeing the face or beauty of *Allah* is considered to be the greatest blessing in Paradise.

Gratitude (shukur)

This concept builds on the notion of *sabr* and is achieved through being grateful to tests and blessings of *Allah*. It constitutes the process of enacting ‘*spiritual citizenship*’ through individual divine relationships. This story was retold in an interview with a representative of the MBU:

One noble man contracted a serious disease – leprosy [*juzom*] which is believed to be common in countries with hot climate. As his limbs leaked out and body parts slowly fell off his family members disgusted by his condition took him out and threw him in the middle of a desert. People passed by and looked at him while crows were pecking out the eyes of the helpless man with no legs to run and no hands to chase away the birds. The man with no limbs and blind was lying in the desert waiting for his death when a passer-by started a conversation with him, “Oh...you have been through such a severe test [*sinov*] and affliction [*musibat*], all your body parts have become useless but nevertheless you are so patient [*sabrli*].

The stranger was surprised by the fact that he was neither complaining nor crying out.

The man with leprosy replied:

“O passerby, are you surprised to see me in such a condition. Praise be to *Allah*, He has given me a tongue to pray [*zibr*],¹⁴⁶ and He has given me a soul [*qalb*] that fears Him, and He has given me a body that will endure afflictions, calamities, and diseases. I swear by *Allah*, my Lord.” Then the man turned to the sky and prayed: “Even if You [God] pour afflictions [*musibat*], calamities [*balo*] and tests [*sinov*] on me like rain...my love [*muhabbat*] for You would only grow.”

This story seeks to illustrate that despite all the God’s tests in the form of hardships the pious man with leprosy is showing his love to *Allah* and expressing gratitude for the

¹⁴⁶ From Arabic, *zibr* means remembrance, and is an Islamic spiritual ritual associated with the remembrance of God in mysticism. *Zibr* is an integral part of *mawlid* and other religious ceremonies and is considered to be a main meditative practice of Sufism. Husniddinov and Ibrohimov (2004: 142) state that *zibr* can be recited aloud (*zibr al-jahriy*) or without voice (*zibr al-xafiy*). The former is quite common in Central Asia where a group of Sufis first sit in a circle, one person (*qavvol*) recites certain phrases in a certain tone, accompanied by some musical instruments. Gradually, people get up and start doing specific movements. During *zibr*, Sufis and dervishes say and repeat the following phrases: “Alloh hay” (Allah is alive); “La iloha illalloh” (there is no god but Allah); “Allohu Akbar” (Allah is the Greatest); “al hamdu lilloh” (Praise be to Allah) and so on. The main purpose of *zibr* is to gain closeness to *Allah*.

remaining bodily functions that he uses to pray and fear God. One of my blind interviewees said that a Muslim person wins in two ways:

when the good befalls him, he shows gratitude [*shukur*] by saying *al hamdu lilloh* [praise to be to God] and receives *savob*¹⁴⁷ [reward].

If the evil befalls him, he shows his beautiful patience and receives reward. The belief that merciful *Allah* tests only those creatures whom He loves was particularly strong among disabled religious communities. Ghaly confirms this notion that being an object of affliction is an important sign of God's love towards His servant and refers to these words of the Prophet:

When God loves a servant, He will visit him with afflictions. When He loves him, with a fully-fledged love, He will preserve him. (Ghaly 2010: 20) what does God do when he doesn't love somebody? are all types of impairment generated/explained in the same way?

Ghaly (2010) also cited some Sufi scholars who believed that God provides His creatures with love only after He tests them through various calamities. An example of young woman with cerebral palsy in a religious interview series titled "Lovers" (*Oshiqclar*) (*Bintu Sodiq 2020*) says that love for *Allah* comes first and foremost from the sense of gratefulness (*shukrona*). She explained that her physical impairment has not caused any problem and she has never been ungrateful for her condition, because when God gives an ailment or illness (*dard*) there can be a hidden meaning and wisdom (*hikmat*) behind it that His creatures might not immediately comprehend. In another religious video (*Al Quranuz - Shayx Alijon qori sahifasi 2020*), a 36-year-old man who has spent 16 years in bed due to his physical impairment shows his love for the *Qur'an* by reciting it. An imam comments on his achievement:

¹⁴⁷ From Arabic, *savob* means reward. Human behaviour and activities consist of the good and the evil, which in Islam is called *savob* and *gunoh* (sin) (Husniddinov and Ibrohimov 2004).

Perhaps he would not have been able to recite the *Qur'an* in this way if he was not in such a condition...Although people have an able body, they can walk, stand up and are busy with their daily routine they cannot or do not read the *Qur'an* given to us by our Lord. Those bedridden know the value of it...

Thus, the man with physical impairments understood that his physical condition strengthens one's devoutness to God while the ability of the 'bedridden' man to recite the *Qur'an* and his ensuing piousness can be interpreted as a sign of God's love. For the young woman with cerebral palsy, a reciprocal divine relationship is established through constant prayers (*zikr*) and gratitude (*shukur*) so that a disabled person unlocks their heart, starts knowing and engaging in conversation with God and eventually falling in love (*oshiq*) with Him.

Thus, the young woman with cerebral palsy whom I interviewed separately told me that expressing discontent is considered to be ungrateful (*noshukur*) to God:

Why was I given this affliction? Why was it not given to another person? What have I done wrong?

A formula proposed by *otin-oyi* during one of the religious meetings with blind people was that if a person is grateful (*shukur*) for a God's blessing (*ne'mat*) he or she will get a reward (*ajr*) in the 'Hereafter'. If blindness is perceived as *Allah's* gift enabling abstinence from eye-related sins then a blind person should be grateful for such a blessing. If the necessity of beautiful patience is stressed in accepting disability as a test, gratefulness for God's mercy is prioritised in terms of defining disability as a blessing. A blind man whom I interviewed recited in Arabic this verse of the *Qur'an*:

Remember that He promised, "If you are thankful, I will give you more, but if you are thankless, My punishment is terrible indeed." 14:7 (Abdel Haleem 2008: 158)

Interestingly, the blind man who participated in the religious meeting with deaf people¹⁴⁸ said that those with hearing and speech impairments had a great impact on him:

Allah Himself gave me tongue to speak [*zabon*] and ears to listen and therefore I am grateful and say “*al hamdu lilloh*” (Praise be to *Allah*).

Based on all the stories mentioned in this section, I argue that ‘spiritual citizenship’ is achieved by disabled people through patience, gratitude, and trust in *Allah* for any tests they believe they have received. It may seem that the above religious cases may embrace the individual model of disability which I reviewed in Section 1.1 of Chapter 1, by placing the problem in the individual and asking for endurance in the face of challenges sent by God. However, this perspective towards disability does not necessarily place the problem within the human body, as disability is not something negative, but a God’s test and a blessing as discussed in earlier sections of this chapter. Thus, it is problematic to impose the individual model of disability which was developed in other contexts for the analysis of how disability is perceived through Islamic interpretations. Moreover, it does not mean that in this approach the individual is deprived of agency. The agency component of the ‘spiritual citizenship’ that I identified through participant observation and participatory methods concerns *tavakkul* (trust in God), which I review in the following section.

Trust in God (*tavakkul*)

*Tavakkul*¹⁴⁹ means submitting oneself to the will of *Allah*, relying only on the sustenance (*rizq*) He provides. Husniddinov and Ibrohimov (2004) say that *tavakkul* practices were

¹⁴⁸ They were held separately with deaf people at Ko’kcha mosque of Tashkent on Wednesday and Sunday mornings and with blind people at the Palace of Culture of the Society of the Blind on Thursday afternoons.

¹⁴⁹ Used interchangeably with the Uzbek word *tavakkal* (risk, at random) means investing one’s hope in someone and believing (Husniddinov and Ibrohimov 2004: 220).

widespread among ascetics and Sufis who, based on the *Qur'an*, linked it with *iymon* (faith). They believed that only a person bound by faith and with true hope in *Allah* was able to renounce the worries of daily life and serve impartially in the way of *Allah*. *Tavakkul* was considered to be one of the starting points (*maqom*) of the Sufi school *tariqat* and was also associated with another *maqom* in Sufism, *qoniqish* (satisfaction) or *rido* in Arabic. In Sufi terminology *maqam* of *tavakkul* means total trust, surrender and submission to God's will by which the Sufi finds joy even in sorrow, and thus cannot be intimidated by calamities and sufferings (Brittanica n.d.). Adherence to *tavakkul* in practice would also mean cessation of almost any labour activity. Referring to major jurists (*faqih*) and theologians (scholars of *ilohiyat*), Husniddinov and Ibrohimov (2004) suggest that *tavakkul* does not always mean a complete abandonment of labour; that is, a person can work and engage in business activities. However, instead of making such work the main goal of life, it is necessary to earn enough to meet today's needs, and not to think about tomorrow.

Disabled research participants as well as imams and Islamic clerics mentioned *tavakkul* at various points throughout my fieldwork in Tashkent. A blind interviewee listed three types and interpretations of *tavakkul*. Firstly, *tavakkul* for him was associated with risk-taking behaviour in the name of God, as he believed everything was in *Allah's* hands. He gave an example of how, after several unsuccessful attempts to find a job, he started a small business by selling imported *mushkambar* (Arabian perfume oils) at a local mosque. In the beginning, he hesitated about whether it would work for him or not, given his visual impairment. But then he submitted himself to fate (*taqdir*), believing that all sustenance (*rizq*) comes from *Allah*, saying in Arabic "Tavakkaltu Alloh" and doing *tavakkul* in God (*Xudoga tavakkal qilmoq*). He explained that the Uzbek proverb *O'ychi o'yini*

*o'ylaguncha, tavakkalchi ishini bitiradi*¹⁵⁰ (while the prudent thinks over his calculations, the risk-taker achieves the desired) is not said in vain. Secondly, he believed a human being does not have any control over when, where and how sustenance would be given by God and that therefore he should have a reverential trust in the Lord and pray solely to Him. Thirdly, if a calamity (*musibat*) occurs, he should leave it to God (*Allohga tashlab qo'yish*) and show patience (*sabr*) in the face of hardships and pain. This is also considered a type of *tavakkul*. All three types of *tavakkul* are interrelated and reinforce each other.

Blind participants in religious meetings agreed that unwavering confidence in God empowers disabled people in various situations and submission to *Allah* encourages their action (*harakat*) to enact their citizenship. A young woman with a physical impairment who was involved in participatory video-making referred to *tavakkul*, when she came to the workshop venue by taking a taxi on her own. She has an acquired physical impairment and due to inability to walk by herself she always needs someone to support her.¹⁵¹ I was surprised seeing her alone and asked whether she was afraid to come on her own. Her response was that whatever happens, *Allah* protects and supports her (*Allohni o'zi asraydi va qo'llaydi*) although she knows that leaving home alone might be a risky affair. In a sharp contrast, we found it difficult to convince another young woman and her mother to come to the workshop venue. Although the young woman was more independent and could move independently using her wheelchair, her mother was very protective of her and did not trust taxi drivers and strangers in the streets. Moreover, her mother thought

¹⁵⁰ The original Uzbek proverb is *O'ychi uyiga yetguncha, tavakkalchi to'yiga yetadi* which is literally translated as: while a thoughtful person reaches his home, a risk-taker (*tavakkalchi*) reaches a wedding.

¹⁵¹ She sometimes uses a wheelchair but usually prefers to walk without assistive devices.

that her daughter would become a burden and disturb others (*malol kelish*) as she needed help to lift her from wheelchair and assistance in getting into the car, and faced many other infrastructural barriers due to the inaccessible environment in Tashkent city. However, they both lacked the sense of *tavakkul* and wasted time considering various risks of travelling which could have eventually led to the young woman not attending our participatory workshops. She did come in the end but the lack of *tavakkul* in both disabled people and their relatives may lead to hyper-protection which may result in further social exclusion. Conversely, strong belief in *Allah* promotes spiritual citizenship of disabled people by helping them sustain their livelihoods and be independent.

Importantly, *tavakkul* does not imply renunciation of worldly life. The *tavakkalchi* woman with the physical impairment who came to our workshops on her own recounted this story to me:

There lived an ascetic devout man [*zohid-xudojo 'y*] who prayed day and night. Suddenly, there was a flooding that occupied the whole valley. People came in a boat and would like to rescue him. But he replied, "God Himself will save me". When the water reached his waist, the rescuers came again and asked him to get on the boat. But the man refused help again and said, "Leave me, God Himself will save me". The third time the rescuers came when the water reached his throat the man refused help again repeating the same words. The man drowned and appeared in front of *Allah* and said, "I lived my whole life in prayer to You and did *tavakkal* to you [*o 'zingga tavakkal qildim*]. Why did not You save me then?" *Allah* replied, "Why do not you understand? Drowning was written on your forehead then as I sent you the boat three times. Why did not you get on it yourself?"

This story suggests that there should be a right balance when submitting oneself to God: one should not become *tarki dunyochi* (one who excludes himself from society for religious purposes and lives in solitude), or forget about one's own choices and responsibilities. A pious disabled person may also find himself in a state of fatalistic apathy like the man who refused help three times and died in the end. In sum, disabled

people achieve ‘spiritual citizenship’ in a divine relationship with God which is stipulated through patience, gratitude, and trust in Him. However, the final section in this chapter shows that even in this spiritual domain, non-disabled representatives of the MBU and charity institutions affiliated to it are intervening in the process of constructing ‘spiritual citizenship’ and exploiting disabled people for the sake of their goals to promote Islam in Uzbek society.

7.3 Religious bureaucracy as a barrier for ‘spiritual citizenship’

The purpose of religious meetings with deaf and blind communities

In previous sections, I described how pious communities of disabled people in Tashkent city are conceptualising ‘disability’ through a moral perspective and achieving spiritual citizenship in a divine relationship with God. They are also developing a sense of belonging to the mosque community (*masjid qaum*). In other words, through organising weekly religious meetings, the MBU has contributed to the establishment of the community where they can express and share their lived experiences of disability. I later learned that the idea for organising such religious meetings first came from the Cultural Centre for the Deaf. Their purpose was to return deaf and hard-of-hearing people to Islam, as many of them joined the Protestant missionary group Iso Masih (Jehova’s Witnesses). Consequently, the MBU, together with the Tashkent city *khokimiyat* took over this initiative and began organising the religious meetings with deaf and blind communities from January 2018. At one of these meetings, I met Anvar, who I mentioned in Section 4.4. He recounted a story about a deaf young man who, in the early 2000s, started going to a Christian church. That church did not discriminate on the basis of religion or ethnicity and a third of the attendees were Muslims. Moreover, sign-language interpretation was provided during their religious meetings. Anvar told me:

As a young man, I kept asking myself if I had done the right thing. Because I am a Muslim, I have to respect my religion [Islam] and learn more about it. Why did we go to church while most of our country was Muslim? Although there were enough mosques at the time, some Muslims like me went to church. As the situation in that church was different, and [deaf] people like us felt we were 'heard'.

Apparently, his guilty conscience was bothering him due to his Uzbek identity because being Uzbek is conflated with being Muslim (Hilgers 2009). A representative of Tashkent city administration (*khokimiyat*) told me:

...regardless of the fact that we live in a democratic state we should not lose our Muslimness.

Being Muslim in the local context is associated with adherence to social norms through customs and traditions around circumcision, marriage and death, which helps to build essential social networks in the communities (Louw 2018: 89). Therefore, complexities emerged when entire deaf families joined Christian missionary groups like Jehovah's Witnesses. Questions were raised by deaf communities about whether it was lawful for a Muslim woman to live with her husband if he had converted to another religion. They believe that their marriages (*nikoh*) broke up after their husbands or themselves joined these religious groups. Therefore, after their return to Islam upon recitation of *kalima* 'La Ilaha Illallah' they immediately requested imams to remarry them in fear of ending up in Hell (*do'zax*). Moreover, intergenerational conflicts appeared to be on the rise among those who choose to be missionaries, particularly young people. For example: a father died as a Muslim and his son, being a converted Christian, resisted the community by saying that he would bury him in a Christian graveyard. A single mother knowing that her daughter was attending church became embroiled in family strife (Pelkmans 2007, 2009, 2017).

As a result, since early 2018, the MBU has been carrying out outreach and awareness-raising activities among deaf communities in Tashkent and other regions. The religious meetings were held twice a week with deaf people and once a week with blind people. This was probably due to the fact that deaf people were in a more disadvantaged position without access to mosques and spiritual enlightenment. Illiteracy and lack of religious education made them an easy target to conversion by missionary groups. The MBU stated that deaf communities fell in the trap of missionaries and went astray in exchange for financial support, food, gifts, livelihood opportunities or even travel abroad. The provision of sign language by the Jehova's Witnesses served as an important motivating factor for deaf communities as they felt included and were able to join their religious activities. Moreover, it turned out that missionaries have been making good use of literal interpretations of verses from the *Qur'an*, trying to discredit Islam in the eyes of deaf communities (Bozorboy qizi 2018). When a young deaf man asked her:

I was really frightened when I read the verse 18 of *Surah al-Baqara* in the *Qur'an*. Will there be no *hidoyat* [right path] for deaf and dumb?¹⁵² Could you please clarify this issue? I have *iymon* [faith] in my soul and my trust in *Allah* is strong but I cannot understand this verse.

Malika explained that verse 2:18 which reads as “deaf, dumb, and blind: they will never return” (Abdel Haleem 2008: 5) has nothing to do with deaf and dumb or blind people and is addressed to *mushriklar*¹⁵³ (idolaters). In other words, the verse is given in a figurative way and is about *ma'naviy* (spiritual) deafness, dumbness, and blindness. Their deafness is that they do not listen to the truth, their dumbness is that they do not speak the truth, and their blindness is that upon seeing the truth they do not confirm it. Another

¹⁵² The original term used in Uzbek language is *kar-soqov* (deaf and dumb).

¹⁵³ From Arabic, this means a person who rejects *tawhid* and one who worships idols.

verse from the same *Surah al-Baqara* was recited by *otin-oyi* during another meeting with deaf people at *Ko 'kcha mosque* in Tashkent:

Calling to disbelievers is like a herdsman calling to things that hear nothing but a shout and a cry: they are deaf, dumb, and they understand nothing 2:171 (Abdel Haleem 2008: 19)

Deaf people who turned to Christian missionaries were deemed to have lost themselves (*o'zligini*), their Uzbek identity and their religion as a Muslim, and to have become spiritually deaf. On its website, the Muslim Board of Uzbekistan stated that because deaf people have been cut off from society for a long time, they have no understanding of Uzbek national values (*milliy qadriyatlar*) and Islam. In an online article by Narzullaev (2018) the imam mentioned *Vatan* (Homeland), *Millat* (Nation), and *Imon-e'tiqod* (Faith) as sacred concepts which cannot be replaced by anything. Thus, missionary work and proselytism are considered as a significant threat to the spiritual security of an individual and the nation in general. For this reason, the MBU began making efforts to 'rehabilitate (*sog'lomlashtirish*) the religious environment' by organising spiritual enlightenment talks for deaf communities with sign language interpretation. Thus, I argue that the primary purpose of these religious activities was to reinstate Uzbek identity and bring deaf people back to Islam rather than to include them in Uzbek society. In the following section, I show how representatives of the MBU are intervening in the construction of religious disability identity.

Intervention in, and instrumentalisation of, spiritual citizenship

Malika, who worked at the Women's Department of the MBU, organised the religious gatherings with deaf people in an attempt to make sign language¹⁵⁴ look more Uzbek.

¹⁵⁴ The sign language used in Uzbekistan is based on the Russian Sign Language (RSL).

When greeting deaf people, she put both her hands on her chest articulating '*Assalomu alaykum*' (Muslim greeting) with her lips and asked them not to use the Russian sign '*Zdravstvuyte*'. Besides, she believed that deaf participants should try to speak so that the muscles of their tongues would not stiffen and asked them to repeat several times '*La ilaha illallah*.' She believed that when one repeats this *kalima* all the muscles around our tongues work and when they are activated *Allah* will definitely bless their tongues with movement and speech in the end. Malika recounted the *Asma-ul Husna* competition where there were deaf people who could not speak at all and said that when everyone started saying out loud the names of God they started speaking. She recommended saying '*La ilaha illallah*' every day after *namoz* (prayer) and trying to emit sound (*ovoz chiqarish*) in pairs and then if *Allah* wills, they will organise the *Qur'an* competitions with them. In other words, rather than accepting sign language as an element of cultural identity, I argue that Malika is imposing her own perceptions on the religious transformation of deaf people.

Moreover, on many occasions, disabled participants at religious meetings were used as objects of religious edification (*ibrat*) to awaken a feeling of gratitude in non-disabled people for their 'healthy bodies'.¹⁵⁵ As a man of learning and piety told me in an interview:

They [non-disabled] are healthy, but they are not eager to bow down in prayer [*sajda*], to study their own religion, to remind themselves of mortality and servitude [*bandalik*],¹⁵⁶ that tomorrow we all have death on our heads. What will they say when they die? How will they express gratitude for their healthy bodies? They do not think about this.

¹⁵⁵ I criticise this opposition between 'healthy' and 'disabled' as disability should not be conflated with illness.

¹⁵⁶ From Uzbek, *bandalik* has two meanings: something that is intrinsic to every mortal, and also means a subordinate position or even slavery. These two notions are quite interrelated.

An imam who was invited to the religious meeting with deaf people could not help crying during his talk as he witnessed the enthusiasm of deaf and hard-of-hearing participants to learn more about their holy religion. The imam suggested those who were able to hear and speak were in negligence and heedlessness (*g'afolat*), far from studying Islam. He then asked the deaf participants to be grateful and praise God for the generosity and courage (*shijoat*) that He had given them. At another meeting with blind people,¹⁵⁷ the same imam gave a talk and I watched the video posted on social media under the title “A heart-wrenching video clip 2” (*Yurakni larzaga soluvchi rolik 2*) ([Mabrur 2019](#)). The first part of this video series was recorded with the deaf community during the religious meeting at Ko‘kcha mosque where I was also present. In the second video, blind men and women of various ages were praying in Arabic and reciting the *Qur'an*, and this verse was added to the description for the video:

Which, then, of your Lord’s blessings do you both deny? 55:13
(Abdel Haleem 2008: 353).

Many comments on the video, which appeared to be from non-disabled people, indicated that blind readers of the *Qur'an* are not actually blind as they could comprehend with their soul’s eye. But instead, those sighted people who do not use their eyes to read the words of *Allah* are truly blind:

In fact, those who cannot read the *Qur'an* with their eyes open should be called truly blind, eyes of these people [blind men and women in the video] can see ([Mabrur 2019](#)).¹⁵⁸

¹⁵⁷ I was not present and watched this video of the meeting titled “Yurakni larzaga soluvchi rolik 2” (Heart-Wrenching video clip 2) ([Mabrur 2019](#)).

¹⁵⁸ According to a representative of the Muslim Board of Uzbekistan who appeared in the YouTube video ([Mabrur 2019](#)).

One commentator pleaded with God to save him from the blindness of soul (*ma'naviy ko'rlik*) rather than from physical blindness. Spiritually blind people are deemed to be those who, while seeing the truth of *Allah* with their eyes and the world full of evidence of His oneness, are not faithful to Him. Other commentators called for gratitude and appreciation of His blessings, including eyesight and other capacities. These verses from the *Qur'an* were used in this context:

Say [Prophet], "It is He who brought you into being, He who endowed you with hearing, sight, and understanding – what small thanks you give!" 67:23 (Abdel Haleem 2008: 383).

Did We not give him two eyes, a tongue, two lips, and point out to him the two clear ways [of good and evil]? 90:8-10 (Abdel Haleem 2008: 422)

The following *hadith* by Al-Mutaffaqun cited by the Muslim Board of Uzbekistan instructs non-disabled Muslims to learn from disabled people:

When it comes to worldly blessings, look at those who are in lower positions than you, and do not look at those who are superior to you, for this will cause you not to be indifferent (be grateful) to the blessings that *Allah* has bestowed upon you.

The *hadith* implies that if a person is ill, they should consider that there are more seriously ill people in this life. If they are poor, they should remember that there are poorer people than them. In this way, they will be grateful for their condition and try to appreciate it no matter what happens to them. However, such attitudes may objectify disabled people as sources of contentment and a sedative for non-disabled people to be satisfied with what they have in life. So, the implication always seems to be that the disabled person is having a hard time even though they say they are not oppressed.

In the article titled 'Value of Time' which was published on the website of the Muslim Board of Uzbekistan there was this statement: "If you want to know the value of 10 years

- ask a 30-year-old man who became disabled in his 20s.” Another story that was also published by the Board (Iminjonov 2018) illustrates this notion very well:

One man started a business. After a while, his business went bankrupt. All his experiments were failed. He was deeply in debt. He faced a big problem. [He] became depressed. It became difficult to live. One day, as he was walking down the road in a depressed mood, his soul full of sorrow, his life covered in uneasiness, he saw a man crossing the road, with both legs amputated and using a wheelchair with both hands. When the distressed man approached the disabled man, the latter said with a smile on his face, *“Good morning! Look at the beauty of this morning! Today is a very happy day, isn't it?!”* The depressed man was ashamed of his condition. He regained his composure and said: *“Alhamdulillah, of course I have healthy legs. I can walk with them, go out with them. So why should I worry?! Why should I bother?! I have a treasure that this man does not have!”*

Treating disabled people as objects of *ibrat* is also based on the notion of purity (*ma'sum*) and spiritual proximity of disabled people to *Allah*: they serve as a moral compass guiding non-disabled people to the right path (*hidoyat yo'li*). It is believed that *Allah's* hidden wisdom (*Allohning hikmati*) is behind the creation and existence of disabled people in this world. But such attitudes towards disabled people may turn them into instruments in the hands of religious leaders for promoting Islam among non-disabled communities. For instance, a young blind man, Izzat, working at the Central Board of the Society of the Blind (who I mentioned in Chapter 4) was critical about this, saying that using disabled people for such purposes may lead to the objectification and stereotyping of all disabled people as virtuous. In addition, such a top-down instrumentalisation of disabled people by the MBU can lead to the perpetuation of the traditional charity model of disability (see Section 1.1) which portrays disabled people as in need of constant support from others.

Conclusion

This final empirical chapter showed that the Muslim communities of deaf and blind people with whom I did participant observation in Tashkent are understanding ‘disability’

through a moral perspective. While I recognise a variety of theological and cultural interpretations of this complex concept through Islam are possible, I identified dominant religious discourses promoted by the Muslim Board of Uzbekistan presented by men and women of learning and piety which were then received by disabled people who produced their own understandings of disability. These religious groups look at 'disability' from a broader perspective of human suffering and present disability as another divine test which should be overcome through devotion to *Allah*. Moreover, they perceive disability not as something negative as suggested by medical or other deficit models of disability, but as a God's blessing which makes people with various impairments virtuous and closer to *Allah*. In this sense, they construct a positive religious disability identity, similar to what Swain and French (2000) called the affirmation model of disability which promotes a non-tragic view towards disability.

Building on these religious conceptualisations of disability, deaf and blind communities are constructing a new form of citizenship, which I refer to as 'spiritual citizenship'. In contrast to liberal notions of citizenship where the relationship of disabled people and their organisations with the state is analysed, or the functional approach of Soviet citizenship where labour contribution plays an important role, pious disabled people are developing their sense of belonging in relationship to God. As well as their individual transformation into better Muslims, they are also projecting their moral perspectives on disability and citizenship onto perceived injustices taking place within their civil society organisations, training and production enterprises and mahalla institutions. However, even within the religious sphere, the ongoing top-down intervention of the MBU and religious bureaucracy is constraining the process of individual and collective construction of spiritual citizenship by Muslim disabled communities. So far, this thesis has shown

that disabled people in post-Soviet Uzbekistan are not a homogenous group but diverse not only in terms of their impairments, but also in their social, economic, cultural, and religious backgrounds. To be able to analyse this complex reality, in the final chapter I present 2 which allows us to analyse how different groups of disabled people operationalise their forms of citizenship.

Chapter 8. Conclusions and recommendations

This research shows that disabled people in post-Soviet Uzbekistan are enacting their citizenship in various ways: through civil society organisations, specialised training and production enterprises, mahalla institutions and Islam. This final chapter presents a conceptual framework for systemic analysis of the relationship between disability and citizenship in post-Soviet Uzbekistan. I present below a product of my bottom-up reflection process upon conducting fieldwork and analysing the empirical data.¹⁵⁹ Based on this conceptual framework, I argue that the endeavours of disabled people towards achieving citizenship in Uzbekistan do not follow a linear process. It is, rather, a complex and iterative process of negotiating distinctive understandings of disability and forms of citizenship in the post-socialist context. It shows the barriers that people with various impairments face while navigating complex power relationships and hierarchies within the dominant disability NGOs, production enterprises, mahalla committees and religious institutions.

Importantly, these processes happen not only in a tension with the state as in the liberal approaches to citizenship by disabled people discussed in Chapter 1 but also within their organisations, communities and religious institutions which all serve as proxies of state control. I further argue that neither of the existing conceptualisations of disability, developed predominantly by scholars and activists in other parts of the world, fully grasp the complexity present in a post-socialist Central Asian state like Uzbekistan. Therefore, one of the main contributions of this thesis is to provide a conceptualisation of disability and citizenship based² on the lived experiences of disabled people in Tashkent city.

¹⁵⁹ See Chapter 3 for methodological considerations.

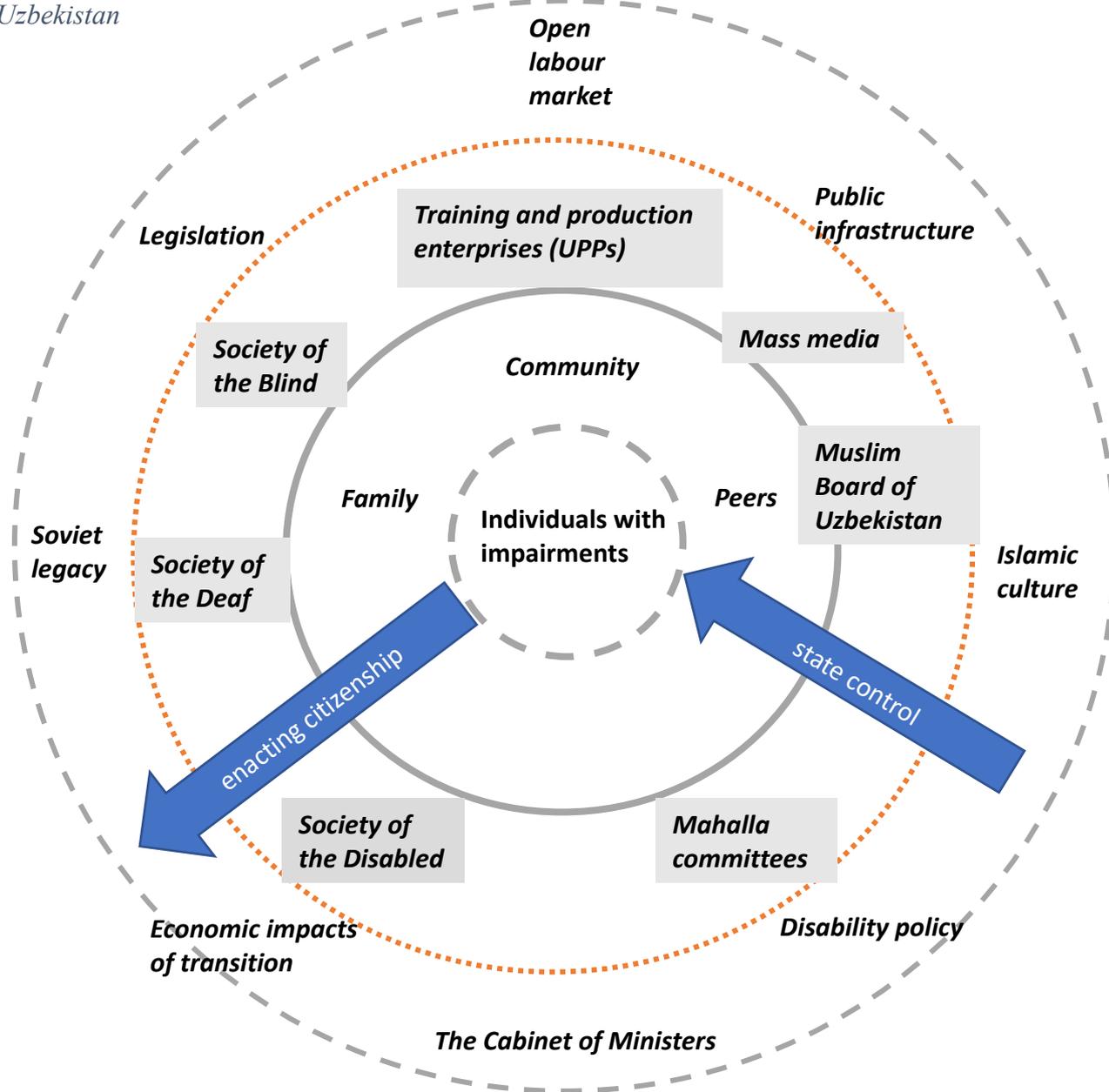
Besides this conceptual contribution, I argue that an emancipatory approach to disability research can bring deeper insights into the hidden barriers that disabled people are facing on their individual paths to asserting citizenship.

8.1 Conceptualising disability and citizenship in post-Soviet Uzbekistan

A citizenship framework of disabled people in Uzbekistan

After the collapse of the USSR in 1991, the Soviet citizenship framework for disabled people presented in Section 1.4 (see Figure 3) was no longer applicable for the analysis of the ongoing social, economic, and political transformations in contemporary Uzbekistan. However, Chapters 4 and 5 showed that the legacies of Soviet disability policies and organisations for disabled people are still deeply embedded in institutional and ideological perspectives towards disabled people. To critically examine how disabled people construct their forms of citizenship and a sense of belonging in Uzbekistan, I have developed a conceptual framework which I discuss in this section. This is a product of a reflective and reflexive practice with disabled co-researchers and participants in the field. The idea behind developing this framework was inspired by the power method called *'peeling the onion'* from [Hunjan and Pettit \(2011\)](#) which we used during the participatory workshop with disabled people. This conceptual framework (see Figure 21) allows us to analyse various complex ways in which disabled people in Uzbekistan construct distinctive disability identities and forms of citizenship. It showcases the unique socio-cultural, economic, and political context of a post-communist Uzbek state with a majority Muslim population. It enables navigation of its complexities, and explores the distinctive ways in which disabled people in post-Soviet Uzbekistan are constructing their disability identities and forms of citizenship.

Figure 21. *Conceptual framework of citizenship of disabled people in post-Soviet Uzbekistan*



Source: author's illustration

Figure 21 illustrates a simplistic model of Uzbek society, where each layer of this framework represents different social levels. Individuals with various forms of impairments are placed in the middle of the framework where they are surrounded by their immediate environment like family, peers, or community. Importantly, this conceptual framework is not rigid and the boundaries between the layers are porous. The

reality is complex, prone to change over time and unique to each individual with a certain type of impairment, and their immediate environment. For instance, some disabled Muslims discussed in Chapter 7 would put their mosque community (*masjid qaum*) first as it significantly influences their lived experience of disability. Civil society institutions have been placed on the layer between the state and disabled people. This layer represents formally recognised public associations of disabled people and their training and production enterprises, mahalla committees and religious institutions. Importantly, the boundary between the civil society and state layers is blurred given the implicit or explicit interventions by the Uzbek government in the dominant disability NGOs (Societies of the Deaf, the Blind and the Disabled) examined in detail in Chapter 4. The final layer contains government structures, dominant belief systems and ideologies which underpin each layer of the analysis.¹⁶⁰

The preliminary formation of an individual understanding of disability is initiated by people with impairments in their daily interactions with their families, peers and community or their immediate surroundings.¹⁶¹ In the early stages, perceptions of ‘disability’ as a social or cultural issue, rather than an individual problem of a medical or tragic nature (see Section 1.1.), serve as catalysts for establishment of the communities of similar people. This was explored in Chapter 6, in the unique context of ‘mahallas of blind people’, where the Soviet legacy of urban segregation allowed residents with visual impairments to develop a collective disability identity to advocate for their political rights in contestation with the state-controlled mahalla committee. In Chapter 7, understanding

¹⁶⁰ The detailed overview of the contextual elements of this conceptual framework is provided in Chapter 1 and 2.

¹⁶¹ For instance, it can be an institutional setting where children or adults with impairments can develop a collective identity of being a member of one institution.

disability through the prism of morality embedded within the daily practice of Islam facilitated the formation of a pious collective of disabled Muslims who share similar religious perspectives towards ‘disability’. As a result, such individual transformations occur towards the upper layers of this system, which include civil society and state institutions. This process drives disabled people in an outward, critical direction towards the political, economic, legal, and cultural foundations of Uzbek society. Thus, the process of claiming citizenship by disabled people can be defined as an outward force from the inside-out, where individuals with impairments develop critical understandings of ‘disability’ that enable them to graduate from their own ‘bubble’ and move on to the next level of interaction with societal structures. However, to claim citizenship, individuals with impairments need to overcome attitudinal, environmental, and institutional barriers at each layer of the system. It resembles the ‘ripple effect’ of a stone being dropped in a pond, causing the spread of ripples across the water. In other words, a disturbance in the heart of the system causes transformation of the whole system.

State and civil society institutions in each layer of Uzbek society, as well as inherent belief systems and values, influence these processes of construction of citizenship by disabled people. Chapter 4 showed that, due to the Soviet legacy of disability organising, the state may explicitly intervene in the organisational structures of the dominant disability NGOs, thus making them unrepresentative of the rights and interests of disabled people on the ground. Moreover, the state institutions impose top-down perceptions of disability by treating disabled people as mere recipients of charity, welfare, or medical care. Independent groups of disabled people are not welcomed in these “structures of tokenistic participation” (Mladenov 2018: 83). Therefore, the dominant disability NGOs serving as “extensions of the state” (Holland 2008) constrain the bottom-up efforts by

disabled people towards achieving citizenship. As a result, the exclusion of disabled people and erosion of their citizenship is illustrated by a force exerting pressure from the outside. In other words, the authoritarian state is trying to put individuals with impairments back in their 'bubble' by operationalising control through personal tragedy, charity, individual and medical models of disability. Using the analogy with the stone and a pond, the Uzbek government tries to freeze the water, to prevent the 'ripple effect' and the ultimate disruption of the whole system by disabled activists and their allies. Thus, I argue it is in the interests of the state to reduce the problem of 'disability' to within the boundaries of the individual domain rather than allowing grassroots action by disabled people. This conceptual framework of achieving citizenship by disabled people will be further unpacked and operationalised in the following section to critically examine three distinctive forms of citizenship of disabled people in post-Soviet Uzbekistan.

Forms of citizenship of disabled people in post-Soviet Uzbekistan

Building on the critical findings in Chapters 4, 5, 6 and 7, I argue that the conceptualisation of citizenship based on liberal values and rights which are achieved in contestation with the state, may not be directly applicable to the post-socialist context of contemporary Uzbekistan. The authoritarian nature of this post-Soviet state constrains the civil space available for such a contestation, which eventually has to take implicit forms of struggle for citizenship. As a theoretical contribution to the existing debates, I offer an important argument that the struggle for citizenship occurs not only on a macro level between disabled people, their organisations, and the state. Instead, it is a continuous bottom-up process which is initiated through reconceptualisations of disability and transformations of these reconceptualisations into collective action on the ground. Thus, the struggle for citizenship takes place at each societal level starting from a disabled

individual, their surrounding community (mahalla), self-help groups and civil society organisations, and their institutional and ideological environments. Ultimately, I argue that analysing disabled people's citizenship only through the liberal paradigm of 'civil society – state' tension is ambiguous in post-socialist contexts. The reason is the nature of a post-Soviet state, which tries to sustain its control and constrain the field for grassroots civic action through its proxies in the form of government-organised NGOs, mahalla committees and Islamic institutions.

This study shows that in order to support the endeavours of disabled people for citizenship in Uzbekistan we need to identify the internal tensions within disabled people's organisations and their tacit relationship with the state. The conflicts within the dominant disability NGOs, UPPs and mahalla committees that I described in previous chapters occur between various groups of disabled and non-disabled people who share different views on 'disability' and 'citizenship'. Such perceptions stem from the Soviet legacies of functional approaches to disability and top-down disability organising which was allowed within the boundaries of the utopian communist project. Moreover, in the context of the post-Soviet transition, 2 are emerging under the influence of the mahalla and Islamic institutions in Uzbekistan. The table below presents three different forms of citizenship of disabled people that I identified based on the findings discussed in the empirical chapters.

Table 6. *Forms of citizenship of disabled people in post-Soviet Uzbekistan*

Type of citizen	Underpinned by normative expectations	Provides access to	Models of disability and implications	Ambivalences in relationship to disability
Soviet citizen	To contribute to labour and build a communist state.	Social benefits, vocational training and employment, medical rehabilitation.	Functional model – disability is lack of employability and capacity to work).	Limited to adults with sensory impairments (visual and hearing), segregated employment, no choice given; judging people by their labour productivity.
Mahalla (community) citizen	To support self-help, build a community of peers and define sense of belonging.	Self-determination and taking control over one's own life through mahalla structure, social benefits, and charity.	Charity model, personal tragedy – disability is a personal tragedy that can be resolved through charity giving.	Segregated communities of impairment-specific groups.
Spiritual citizen	To devote oneself to <i>Allah</i> , accept disability/impairment as a test and mercy of God.	Self-determination through divine relationship, new forms of livelihoods.	Religious model – disability is a divine test and blessing.	Religious identity taking over disability identity, instrumentalisation of disability by the religious institutions to promote their own agendas which can promote a charity model of disability.

Source: author

Each of the forms of citizenship presented in the table above provide a snapshot of previous discussions in the empirical chapters. For instance, Chapter 4 and 5 showed that blind and deaf people are still struggling to operationalise the Soviet citizenship through the Society of the Blind and the Society of the Deaf. However, in the political and economic realities of post-Soviet Uzbekistan, it has been challenging for them to revive this form of citizenship. Based on the ethnographic accounts of experiences of UPP workers, I argue that such a productivist understanding of citizenship undermines the citizenship claims of those disabled people who are considered by the system to be less capable of work. Interestingly, this Soviet legacy of segregation of blind and deaf people resulted in the formation of unique disability communities which I described in Chapter 6. For example, blind people in Bayot mahalla developed their sense of belonging to one

disability community, seeking to claim their ‘mahalla citizenship’ through penetration of the formalised mahalla committee structure. Finally, in Chapter 7, I examined how Muslim disabled people understand ‘disability’ through the prism of Islamic principles of morality and justice which enables them to achieve ‘spiritual citizenship’. These findings may help us to understand that being a diverse population, segregated groups of disabled people in Tashkent city are actively asserting various forms of citizenship. However, the common problem is that top-down intervention of the state in the disability NGOs, their enterprises, mahallas and Islamic institutions is undermining their efforts.

Therefore, there is a definite need for reforming the organisational structure of the dominant disability NGOs by minimising the state’s control over the organisations; such control contradicts the legislative norms on NGO regulations in the country. Civil society organisations *of* disabled people should be able to register and run their own independent NGOs while the Uzbek government should formally recognise them as representative of the rights and interests of excluded disabled groups. Instead of promoting segregated employment practices through the training and production enterprises (UPPs), the Uzbek government should promote disability-inclusive employment in the open labour market. Moreover, we need to limit the interference of local governments in mahalla structures to make them inclusive, through involvement of disabled people in the daily work of the mahalla committees and the establishment of a separate mahalla commission to work with disabled community members. Greater efforts are needed to ensure that mahalla spaces are accessible for people with various forms of impairments, in terms of both physical environments and attitudes of the mahalla staff and higher-standing authorities. In general, the Uzbek government should implement all the provisions of CRPD (2006) after its recent ratification in 2021. The authorities should not treat disabled people as passive

recipients who lack agency and control of their own lives but provide freedom of association and ensure non-intervention in the activities of their NGOs, mahallas and religious communities. As this research shows, disabled people in Tashkent city are trying to actively assert their citizenship through various ways. It would be impossible to conceptualise the three forms of citizenship without active involvement of my disabled co-researchers and participants in this study. The following section shows how an emancipatory approach to disability research can bring deeper insights into the lived experiences of disabled people and support their struggles for citizenship in Uzbekistan.

8.2 Contributions to research methodologies with disabled people

Potentials of working with disabled co-researchers

In the process of conducting this research I realised that disability research should be grounded in lived experiences and aspirations of disabled people, and not constrain or narrow down their various perspectives. Having disabled co-researchers from the DPO ‘SHAROIT PLUS’ was both a challenging and rewarding experience of reciprocal learning. I shared my research skills with them and in return could get deeper insights into the lived experiences of disabled participants by gaining their trust and creating safe communicative spaces for their expression. Through this process my disabled co-researchers could improve their skills of interviewing, facilitation, and analysis. As one of my co-researchers confirmed:

This study served as an impetus for me to gain additional knowledge and skills. This was an opportunity to learn more about our work [in the framework of the organisation]. We applied the research approaches, methods, and strategies we learned in our following projects and witnessed the benefits of them.

One of the practical outcomes of this research project was an enduring legacy of sustainability, as ‘SHAROIT PLUS’ members were able to learn from this hands-on

experience and get skills and equipment for participatory video-making (Shaw 2015b; Shaw and Robertson 1997b) in community development work in Tashkent. All the equipment used in this research was transferred free of charge to the 'SHAROIT PLUS' organisation, and was consequently used in new participatory video projects it initiated.¹⁶² The long-term presence of the organisation in the field allowed continuous engagement with the research participants who eventually became members of 'SHAROIT PLUS' and participants in its new projects. Moreover, as Shaw (2015) argued, the learning outcomes from the participatory video project may unfold in the post-project activities that are not usually reflected in the recorded video materials.

This organisational change that took place after my study was also accompanied by positive impacts on individual research participants. Their involvement in the participatory workshops has led to a positive individual transformation in their understandings of disability, as not an individual or medical problem but more a shared issue apprehended together with their peers. The participatory workshops allowed them to build a small community of adults with physical impairments and showed the potential of participatory video in community development. However, I recognise the reality is quite complex and to create social change with a short-term intervention of this kind is quite difficult in a country like Uzbekistan. The situation within the government-organised disability NGOs, mahallas and the Islamic institutions is a good example of a context that is hard to change, characterised as it is by institutional barriers that disabled people are accustomed to facing in their daily lives.

¹⁶² After I left the field, NGO 'SHAROIT PLUS' initiated its own participatory video project and managed to receive external funding from the Eurasia Foundation of Central Asia to work with women with physical impairments in Tashkent. Recently, they received another grant from the Helsinki Foundation for Human Rights to implement a participatory video project with single mothers of disabled children in Tashkent.

Potentials of critical ethnography with disabled people

In Section 3.4, I argued that during my ethnographic fieldwork with blind and deaf communities in Tashkent city, I became an ally of the emerging disability rights movement in Uzbekistan. Thus, when I started advocating for disability rights and inclusion by writing extensively for online media, I inevitably became a so-called ‘voice of blind people’, ‘voice of deaf people’ or more generally a ‘voice of disabled people’. The conceptual framework of citizenship of disabled people in post-Soviet Uzbekistan also includes mass media as one of the elements in the civil society layer. As I mentioned earlier in Chapter 6, my observations of violations of disability rights during the elections at the ‘mahalla of blind people’ encouraged me to undertake some action. My reflections about the injustices perceived by the community of blind people at the elections for Bayot mahalla in May 2019 urged me to think about how I can be of help to the community of blind people. As a result, I ended up writing an article for *Gazeta.uz* (Yusupov 2019b). I later learned that being an advocate for disability rights while doing research with disabled people contributes to the ongoing struggles for ‘mahalla citizenship’. Moreover, such an activist approach to inquiry creates additional spaces for contestation with government representatives. Importantly, such spaces allowed me to understand the positions of state officials which were otherwise difficult to access through elite interviews (see Section 3.2.).

However, as I reflected in Section 3.4, becoming ‘a voice of disabled people’ also had its own challenges. My attempts to promote disability rights through publications in the online media appeared to have turned me into ‘an expert of disability’ which is not the case. I argue that disabled people themselves are true experts of their lived experiences.

Therefore, to tackle this issue I started writing together with my co-researchers and participants. This has also led to reciprocal learning and contributed to joint action to achieve citizenship by disabled people. For instance, I co-authored several articles on deaf people's rights with deaf blogger Mamur Akhliddinov; we wrote about the dire state of affairs at the Society of the Deaf (Akhliddinov and Yusupov 2020a). Moreover, our recent article "Nothing About Us Without Us: we deaf people are ruled by the hearing?" (Akhliddinov and Yusupov 2020b) resulted in the ousting from power of the hearing chairperson of the Central Board of the Society of the Deaf, Javokhir Rikhsiyev, whom I mentioned in Chapter 4. Such online publications contribute to raising awareness of the rights of disabled people. However, due to the complexities of the political regime in Uzbekistan it is challenging to solve deep-seated institutional problems through such online awareness-raising campaigns alone. As I mentioned earlier, there is a need for radical reform of the organisational structure of the dominant disability NGOs to make them inclusive of all groups of disabled people. Nevertheless, our publications in the online media contributed to raising issues in the public domain which were not spoken about before.

Limitations and future areas of research

Looking back at the research questions (see Introduction) I now realise that each of the four sub questions could be answered within the scope of separate thesis, as they all present important directions for future research. Further separate studies with a deeper focus on the role of disabled people's organisations, mahallas and religious institutions in the lives of disabled people in Uzbekistan are required. One of the main limitations of this study was that it was conducted in the urban areas of Tashkent city, which is more developed compared with the regions. People in Tashkent enjoy better living standards,

whereas rural areas, even in the outskirts closest to the capital, are comparatively poorer, lacking basic infrastructure (gas, electricity, clean drinking water, roads, and so on). Therefore, there is a need to understand the situation in the rural areas. Moreover, regions other than the city of Tashkent have been subject to less scrutiny by international organisations and NGOs in the sphere of disability and development. Lived experiences of disabled people in peri-urban and rural areas may be quite different as they may face additional barriers to achieving citizenship. It appears that the sense of community and Islamic culture is likely to be much stronger in rural areas and therefore such field sites represent interesting contexts for exploring the relationship between Islamic culture and disability and wellbeing, and for exploring the role of formal/informal community and social networks in promoting or constraining citizenship of disabled people. Thus, further research should be undertaken to investigate the perspectives on disability and citizenship in rural areas of Uzbekistan.

Moreover, as this study has focused mainly on people with sensory and physical impairments there are still many unanswered questions about the barriers people with intellectual and mental impairments face in claiming citizenship. Further research could usefully explore how children with learning disabilities and their parents, as well as those with multiple impairments (such as deafblind people), are self-organising to advocate for their citizenship, and what challenges they are facing when establishing their public associations in Uzbekistan. For instance, a lack of organisations for parents of children with learning disabilities affects their representation within the emerging disability rights movement in Uzbekistan. This can also be related to the Soviet legacies, as disabled children appeared on the agenda of the communist state only in the 1980s (Rasell and Iarskaia-Smirnova 2014). In addition to underrepresentation of disabled children within

the wider debates over Uzbek disability policy, less attention is given to girls and women with disabilities. As I discussed in Chapter 4, disabled women are not represented within the dominant disability NGOs. For instance, the reason why blind female members of the Society of the Blind are still not active and not equally represented in its higher governing bodies remains an open question. Further research is needed that would specifically focus on gender and disability issues in Uzbekistan.

Conclusion

In this thesis I explored how disabled people seek to achieve citizenship in post-Soviet Uzbekistan to build a distinctive conceptual framework for the analysis. The findings show that the relationship between these two concepts is complex and tied to various institutions. This study shows how disabled people are claiming citizenship through institutions such as disabled people's organisations, training and production enterprises, mahallas and Islam. Based on the analysis of the role of these social institutions I argue that 'disability' is socially, politically, and culturally constructed through the everyday lives of disabled people in Tashkent city. I argue that neither of the existing conceptualisations of disability developed predominantly by scholars and activists in other parts of the world can fully grasp the complexity present in a post-socialist Central Asian state like Uzbekistan. This complexity is further exacerbated by the differences between disabled people's groups based on impairment types, age, gender, and religious identity, due to the ongoing fragmentation and lack of cross-disability coordination among these groups.

The ratification of the CRPD (2006) by Uzbekistan in 2021 signified the acceptance and commitment of the Uzbek government to implement the universally applicable principles

and provisions of the Convention. Although the emerging disability movement in Uzbekistan is not framing its activism through the social model of disability and human rights-based approach to disability, it does not necessarily mean that there is a strong tension with the Convention. As Zagirtdinova (2005) mentioned earlier, the social model is still widely unknown in Uzbekistan. However, in recent days one may find it appearing frequently in public discourses such as presidential speeches and legal documents. But even if the Uzbek disabled activists do not refer directly to the social model they still see and understand deeply that the problem is not in their bodies but in the institutional, attitudinal, and environmental barriers they are facing in their daily lives. The ongoing grassroots struggle of disabled people in Uzbekistan is driven by the sense of justice and morality understood through the prism of the daily practice of Islam and associated spiritual interpretations of 'disability' as a divine test and blessing. Liberal subjectivities entailed in universalistic approaches to disability and citizenship are applicable in the specific context of Uzbekistan. For instance, the liberal notions of civil, political and social rights as integral elements of active citizenship (Marshall 1992) still inform the politics of the emerging Uzbek disability movement. However, the Soviet legacies of disability conceptualisation and organising intertwined with the post-socialist economic, political, and social transformations ask us to be cautious in imposing universalist approaches to disability action. This study shows how a distinctive bottom-up approach to the disability movement is emerging from historically and culturally specific experiences of disabled people in Uzbekistan.

The Soviet legacy of disability policy embedded in productivist approaches to disability is still an important aspect of current organising of disabled people in Uzbekistan. Sheltered workshops for people with visual and hearing impairments served as

mechanisms for achieving citizenship through active labour contribution in the Soviet times. However, other groups of people with physical impairments and learning disabilities were excluded by this system which considered the working capacities of disabled people as the main eligibility criteria for their Soviet citizenship. On the other hand, the segregated communities of blind and deaf people which emerged around this specialised production infrastructure allowed them to gain a sense of belonging to their grassroots communities at the cost of inclusion into the general society. In the context of the post-independence period, such Soviet disability organising turned out to be problematic due to internal corruption and the acquisition of UPPs and properties of the Society of the Blind and the Deaf by non-disabled entrepreneurs. This process has been further exacerbated by the insufficient representation of the voices and aspirations of excluded groups of disabled people within their respective organisations and barriers to their political participation at the mahalla level.

Importantly, the Soviet legacies of disability policies entangled with the barriers of the post-Soviet era are not allowing the formation of a grassroots movement of disabled people in Uzbekistan, thus affecting their chances for achieving citizenship. As such, it is difficult to translate the slogan of the international disability rights movement “Nothing About Us Without Us” (Charlton 1998) into the realities of post-Soviet Uzbekistan. In practice, the critical findings of this study reveal that the civil society institutions which ought to represent the rights and interests of disabled people have been instrumentalised by the state. As a result, we have organisations about disabled people without their participation and representation in governing bodies; training and production enterprises of disabled people belonging to non-disabled businesspeople who are using all the state benefits and privileges; communities about them without their involvement in decision-

making at mahalla committees; and mosque communities of disabled people led by non-disabled men and women of piety and learning.

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Appendix 1. Ethics forms



PARTICIPANT INFORMATION SHEET

Invitation to take part

You are being invited to take part in this research project on **'Exploring the Potentials of Community-based Inclusive Development with Disabled People in Uzbekistan.'** Please take time to read the following information carefully before you decide whether or not to take part as it is important for you to understand why the research is being done and what it will involve.

About the project

This research project is being conducted by a doctoral researcher Dilmurad Yusupov as part of his PhD in Development Studies from 2017 to 2021 under academic supervision of Dr Jackie Shaw at the Institute of Development Studies, University of Sussex, who are happy to be contacted if you have any questions (see contact details on page 2).

Purpose of the project

The purpose of this study is to explore potentials of community-based inclusive development in Uzbekistan by examining various cultural, social, economic and political factors which are shaping understandings and experiences of disability by people with physical, visual, hearing and learning disabilities. The research also aims to examine the perspectives of disability held by non-disabled people. The research outcomes will be used to raise awareness of the issues that disabled people are facing in their daily lives which may influence state policies aimed at supporting them.

Why have you been invited to take part?

You have been chosen to take part in this study as you fit in the criteria of a potential research participant i.e. either you have physical, visual, hearing or learning disability and considered as a disabled person or you are a non-disabled person who have worked with disabled people. It is estimated that in total about 70 people will participate in the study, out of which 50 are disabled people and 20 are non-disabled people.

Do I have to take part?

It is up to you to decide whether or not to take part in this research project. If you do decide to take part you will be given this Information Sheet to keep for your records and be asked to sign a Consent Form. If you decide to take part, you are still free to withdraw at any time without giving any reason and all the information obtained from you will be removed from the pool of research data. You will be given a period of 1 month to withdraw from the study.

What will happen to me if I take part?

You will be invited to take part in an interview which will last approximately from one to two hours where you will be asked to reflect on your understanding and experience of disability or working with disabled people. The researcher may contact you to invite to a

participatory workshop discussions and/or further research activities, although there are no expectations from you to participate further and it will depend solely on your willingness.

What are the possible disadvantages and risks of taking part?

If you are a disabled person especially who has recently acquired an impairment you may be prone to a certain degree of psychological stress while reflecting on your understanding and experiences of disability. For a non-disabled participant any potential harms, disadvantages or risks of taking part in the study are not anticipated by the researcher, except for his/her time involved in the research activities. Your decision not to participate in this study will have no negative impact on you.

What are the possible benefits of taking part?

You may benefit from reflecting on your understanding and experiences of disability as it might help you to get more support. As a disabled person you will perhaps be also interested in meeting other disabled participants during focus group discussions and sharing your experiences with them.

Will my information in this study be kept confidential?

All the information collected about you will be kept anonymous and strictly confidential (subject to legal limitations). Your name will be coded using ID numbers and kept separate from other details about you. Electronic data will be stored on a password-protected computer and hard-copies will be stored behind a locked door. No one else except the researcher will have access to this data.

What will happen to the results of the research?

The results of this research will be used to write a PhD dissertation and/or for publications in peer-reviewed journals, conference papers, presentations and book publications.

Who is funding the research?

This research has been funded by the Wenner-Gren Foundation for Anthropological Research Wadsworth International Fellowship.

Who has approved this research?

This research has been approved with reference number ER/DY65/1 by the Social Sciences & Arts Cross-Schools Research Ethics Committee (C-REC) of the University of Sussex and the Institute of History of the Academy of Sciences of the Republic of Uzbekistan. If you have any ethical concerns, please contact the project supervisor (see contact details below). University of Sussex has insurance in place to cover its legal liabilities in respect of this study.

Contact for further information

Dilmurad Yusupov
 Doctoral Researcher
 Institute of Development Studies
 University of Sussex
 Brighton
 BN1 9RE UK
 Tel: +44 (0)7380 496699
 Email: D.Yusupov@sussex.ac.uk

Dr Jacqueline Shaw
 Research Fellow
 Institute of Development Studies
 University of Sussex
 Brighton
 BN1 9RE UK
 Tel: +44 (0)7947 025039
 Email: J.Shaw@sussex.ac.uk

Thank you for your time and effort to read this information sheet!

Date



CONSENT FORM FOR PROJECT PARTICIPANTS

PROJECT TITLE: Exploring the Potentials of Community-based Inclusive Development with Disabled People in Uzbekistan

Project Approval Reference: _____

I agree to take part in the above University of Sussex research project. I have had the project explained to me and I have read and understood the Information Sheet, which I may keep for records. I understand that agreeing to take part means that:

- | | | |
|--|------------------------------|-----------------------------|
| I agree to be interviewed by the researcher and/or his co-researchers. | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| I agree to allow the interview to be audio-taped. | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| I agree to make myself available for a further interview if required. | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| I agree to make myself available for further research activities. | <input type="checkbox"/> Yes | <input type="checkbox"/> No |

I understand that my participation is voluntary, that I can choose not to participate in part or all of the project, and that I can withdraw at any stage of the project without being penalised or disadvantaged in any way.

I understand that if I decide to take part I am still free to withdraw at any time without giving any reason and all the information obtained from me will be removed from the pool of research data. I understand that I will be given a period of 1 month to withdraw from the study.

I consent to the processing of my personal information for the purposes of this research study. I understand that such information will be treated as strictly confidential and handled in accordance with the Data Protection Act 1998.

I understand that any information I provide is confidential, and that no information that I disclose will lead to the identification of any individual in the reports on the project, either by the researcher or by any other party.

I understand that confidentiality cannot be guaranteed for information which I might disclose in the focus group discussions.

_____	_____	_____
Name of Participant	Date	Signature

I believe that _____ understands the above project and gives his/her consent voluntarily.

_____	_____	_____
Name of Witness	Date	Signature

Appendix 2. Disabled participants interview guide

GUIDE (programme) to conduct interviews on the topic: “Exploring the Potentials of Community-based Inclusive Development with Disabled People in Uzbekistan”

Target group

Persons with physical, visual, hearing and learning disabilities.

Control group

Individuals are selected based on their age, gender, standard of living, type of impairment (congenital or acquired), place of residence (urban/rural) and other factors.

Location

In the neighborhoods of Tashkent city and Tashkent region (one of the districts may be Parkent or Boka or any other district).

Number of interview participants

About 50 people in total (25 people from the urban, 25 people from the rural areas).

1. Opening (10-15 minutes)

A. Introduction

Introduce yourself and after explaining in detail the participant information sheet ask whether he / she agrees to participate in the interview using a consent form.

B. Purpose of the interview

Exploring the lived experiences of disabled people and their perceptions of disability. The results of the research will be used to develop proposals for their support, together with raising public awareness of the problems they face in their daily lives. Your opinion is very important to us.

C. Process of the interview

Answers to questions are conducted in a relaxed atmosphere: everyone can express his point of view. That we did not miss a single opinion, our conversation will be recorded on the recorder (if you certainly agree with this). I remind you once again that the interview is anonymous and confidential, and no one other than the researcher will have access to your data and your name and contact details will not be indicated in the research reports. Therefore, we ask you to express your opinion freely and be honest.

We are primarily interested in your opinion based on your own experience. There are no good or bad, right or wrong answers. Feel free to say what you think is right. It is very important for us to hear everyone's opinion. Do not be shy if you have something to say.

Questions

I. Understanding and lived experience of disability (30-45 minutes)

1. Before we start, tell us about yourself, your family or your neighborhood.
2. Do you consider yourself to be "disabled", "a person with a disability" or "a person with limited opportunities"? If so, what does "disability" mean to you?
3. Do you consider yourself "different" compared to others? Why? In what sense? Why not? What change does this mean for you?
4. How can you describe your daily life experience? Can you tell us about any issues or challenges you face in your daily life? Why do these issues/challenges exist? What do you think are the reasons for their origin?
5. What conditions or opportunities have been created or not yet created for you in our society? What would you do if given these conditions or opportunities? How would you use them?

II. The role and attitude of society towards disability (30 minutes)

1. Who helps and supports you on a daily basis? (e.g., family members, self-help groups, mosques, entrepreneurs, international and local NGOs, neighborhood, authorities)?
2. What can be done to improve the lives of disabled people in your neighborhood?
3. Can you assess the role of society in your inclusion and creation of equal opportunities?

III. Final questions (5-10 minutes)

1. Do you have an unfulfilled dream or goal? What should be done to achieve them?
2. Do you have any suggestions or questions you would like to ask?
3. Are you interested in further reflection and analysis of these issues later as a group member (Step 2: Invite to Group Research)?

Thank you very much for participating in the interview. All your comments and suggestions will be taken into account.

Appendix 3. Elite participants interview guide

GUIDE (programme) to conduct interviews on the topic: “Exploring the Potentials of Community-based Inclusive Development with Disabled People in Uzbekistan”

Target group

Chairpersons of mahallas, representatives of the religious community (imam of the mosque), service providers (rehabilitation and prosthesis centre for disabled people, employment and social protection departments), entrepreneurs, officials, representatives of international and non-governmental non-profit organisations.

Control group

Persons who worked with disabled people and provided them with various services, and generally provided them with support and social protection.

Location

Tashkent city and Tashkent region

Number of interview participants

In total about 25 people

1. Opening (10-15 minutes)

A. Introduction

Introduce yourself and after explaining in detail the participant information sheet ask whether he / she agrees to participate in the interview using a consent form.

B. Purpose of the interview

Exploring the attitude of society towards disabled people. The results of the study will be used to develop recommendations on social protection and support for disabled people in Uzbekistan. Your feedback is very important to us.

C. Process of the interview

Answers to questions are conducted in a relaxed atmosphere: everyone can express his point of view. That we did not miss a single opinion, our conversation will be recorded on the recorder (if you certainly agree with this). I remind you once again that the interview is anonymous and confidential, and no one other than the researcher will have access to your data and your name and contact details will not be indicated in the research reports. Therefore, we ask you to express your opinion freely and be honest.

We are primarily interested in your experience of social protection and support for disabled people. There are no acceptable and unacceptable, correct or incorrect answers. Tell us that you feel comfortable and presumptuous. It is important for us to listen to everyone's opinion.

Questions

I. The concept of disability (30-45 minutes)

1. What do you imagine when you hear the word “disability”? If possible, can you express this concept in your own words?
2. What is your experience in social protection and support for disabled people? What services or assistance have you provided to them or providing now?
3. In your opinion, what issues or problems do disabled people face in their daily lives? Why do these issues/problems exist or may arise? What are the opportunities for them in our society?

II. The role and attitude of society towards disability (30 minutes)

1. What role do the family, mahalla, religious sphere, private entrepreneurs, international and non-governmental non-profit organizations play, and also the government in inclusion of disabled people into our society? (The interviewer asks the interlocutor to answer this question by adjusting to the situation)
2. What solutions would you advise to improve their lives and create equal opportunities for them?
3. Have you heard about the strategy of the World Health Organization (WHO) on “Community-based Rehabilitation” (CBR) or currently known by its new name “Community-based Inclusive Development”, which is implemented in developing countries. If you have heard about this, could you assess the potential for implementing this strategy in Uzbekistan?

III. Final questions (5-10 minutes)

1. Do you have any additional suggestions or questions?

Thank you very much for participating in the interview. All your comments and suggestions will be taken into account.

Appendix 4. List of interviewed disabled participants and their relatives

#	Gender	Impairment	Type	Year of birth	Interview date
1	female	Learning	Congenital	1983	19/06/2018
2	female	Physical	Acquired	1977	20/06/2018
3	female	Physical	Congenital	1943	21/06/2018
4	male	Learning	Congenital	1985	21/06/2018
5	female	¹⁶³	-	1959	21/06/2018
6	male	Physical	Acquired	1993	23/06/2018
7	female	Physical	Acquired	2002	23/06/2018
8	female	Physical	Acquired	1976	23/06/2018
9	male	Physical	Acquired	1976	24/06/2018
10	male	Physical	Acquired	1967	24/06/2018
11	female	Physical	Acquired	1988	24/06/2018
12	female	Physical/Learning	Acquired	1982	24/06/2018
13	female	¹⁶⁴	-	1956	24/06/2018
14	male	Visual	Acquired	1992	25/06/2018
15	male	Visual	Acquired	1990	26/06/2018
16	male	Visual	Congenital	1964	26/06/2018
17	male	Hearing	Acquired	1996	26/06/2018
18	female	Hearing	Congenital	1983	27/06/2018
19	female	Hearing/Learning	Congenital	1990	27/06/2018
20	female	Physical	Congenital	1977	27/06/2018
21	male	Hearing	Congenital	1987	27/06/2018
22	female	Physical	Congenital	1983	30/06/2018
23	female	Physical	Congenital	1982	30/06/2018
24	female	Physical	Congenital	1997	02/07/2018
25	male	Physical	Acquired	1984	02/07/2018
26	female	Physical	Congenital	1984	03/07/2018
27	male	Physical	Acquired	1976	03/07/2018
28	female	-	-		03/07/2018
29	male	Visual	Congenital	1988	04/07/2018
30	female	Visual	Congenital	1993	05/07/2018
31	female	Visual	Congenital	1985	05/07/2018
32	female	Visual	Acquired	1977	05/07/2018
33	male	Visual	Congenital	1999	06/07/2018
34	male	Visual	Acquired	1977	07/07/2018
35	female	Physical	Acquired	1960	21/07/2018
36	female	Hearing	Congenital	1975	21/07/2018
37	female	Deafblind	Acquired	1974	24/07/2018
38	male	Learning	Acquired	1985	27/07/2018

¹⁶³ Mother of participants #1 and #4.

¹⁶⁴ Mother of participant #12.

39	female	_165	-		27/07/2018
40	male	Physical/Learning	Congenital	1998	28/07/2018
41	female	_166	-		28/07/2018
42	male	Visual	Congenital	1998	28/07/2018
43	female	Hearing	Acquired	1960	28/07/2018
44	male	Learning	Congenital	1999	01/08/2018
45	female	_167	-		01/08/2018
46	female	Physical/Learning	Congenital	1993	01/08/2018
47	male	Visual	Congenital	1963	09/08/2018
48	female	_168	-		10/08/2018
49	male	Hearing	Acquired	1996	19/08/2018
50	male	Physical	Congenital	1993	24/08/2018
51	male	Hearing	Acquired	1993	26/09/2018
52	female	Visual	Acquired	1969	27/09/2018
53	female	Physical/Epilepsy	Acquired	1991	02/10/2018
54	female	Learning	Congenital		03/10/2018
55	female	Deafblind	Acquired		
56	male	Blind	Congenital	1998	27/06/2019
57	female	Blind	Acquired		29/06/2019
58	male	Deaf	Congenital		1/07/2019
59	male	Blind	Congenital		11/07/2019

¹⁶⁵ Mother of a child with Down Syndrome.

¹⁶⁶ Grandmother of participant #40.

¹⁶⁷ Mother of participant #44.

¹⁶⁸ Mother of a child with Down Syndrome.

Appendix 5. List of interviewed elite participants

#	Gender	Position	Interview date
1	Male	Chairperson of mahalla "Iftixor" Yunusabad District	21/06/2018
2	Male	UNDP Social Policy Advisor, Team Member of the Situation Analysis (SitAn) in Uzbekistan	21/06/2018
3	Female	UN Resident Coordinator/UNDP Resident Representative	02/07/2018
4	Female	Maslaxatchi of mahalla "Bobodehqon" Yunusabad District	04/07/2018
5	Male	Imam of the Cho'pon Ota Mosque for Blind People	06/07/2018
6	Male	Pension Department Ministry of Finance of Uzbekistan	17/07/2018
7	Male	Assistant of Imam of the Mosque "Masjidul Xayr" of Bobodehqon Mahalla of the Yunusabad District	28/07/2018
8	Female	Tashkent city Khokimiyat	02/08/2018
9	Female	Tashkent city Chief Otin Oyi	15/08/2018
10	Female	UNICEF SitAna Project Manager	22/08/2018
11	Female	A representative of the Muslim Board of Uzbekistan	28/09/2018
12	Female	An expert from SmartGov Consulting	03/10/2018
13	Male	A representative of the Muslim Board of Uzbekistan	16/08/2019
14	Male	Chairperson of mahalla "Iftixor" Yunusabad District	21/06/2018