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Intersection of disabilities and violence against women and girls in Tajikistan



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Intersection of disabilities and violence against women and girls in Tajikistan

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Contents

Abbreviations	4
Executive summary	5
Literature review	7
Tajikistan	7
Disability	8
Research methodology	10
Data collection	10
Research areas	11
Recruitment of research participants	12
Main findings	14
Basic socio-demographic characteristics	14
Intersection of mental health and violence	15
Intersection of domestic violence and disability	16
Mothers parenting children with disabilities	16
Disability-related stigma	18
Marriage prospects and disability	20
Loneliness and social isolation	22
Access to services	22
Comparison across geographical locations	24
Dushanbe	24
Khorog	24
Bokhtar	26
Conclusions	27
Recommendations	28

Abbreviations

DRC	Districts of Republican Subordination
DV	Domestic violence
FGD	Focus group discussion
GBAO	Gorno-Badakhshan Autonomous Oblast
Oblast	Administrative region/province
PO	Public organisation
SGBV	Sexual and gender-based violence
TJDHS	Tajikistan Demographic and Health Survey
VAWG	Violence against women and girls

Executive summary

International Alert's in-depth research into violence against women and girls in Tajikistan suggests that over 60% of ever-married women aged 15-49 (among the beneficiaries of the Zindagii Shoista project) have experienced different forms of spousal violence during their lifetime, including physical, sexual, or emotional violence. Official figures place this figure at 31%, but it has been acknowledged that this figure is on the rise. In this context, the vulnerability of women living with disabilities and of women parenting children with disabilities in Tajikistan increases significantly due to their dependence on caregivers. Existing stigma and ableism associated with different forms of disabilities (associations with illness, anomaly, ugliness, incapacity to have fulfilling life and/or punishment for sins) exacerbate the situation of these women and girls. This report is a study into the intersection of gender, violence and disabilities, with a focus on the role of disabilities in increasing the risk of sexual and gender-based violence and domestic violence perpetrated against women with disabilities and women parenting children with disabilities in Dushanbe, Bokhtar and Khorog.

The study targeted women and men between the ages of 18-65 living with disabilities or parenting children with disabilities. Field data were collected through 12 focus group discussions (four in each location) divided by age and gender, with men and women living with disabilities or parenting children with disabilities. 30 repeat in-depth interviews were conducted with women and men with disabilities among different age groups, as well as women with children with disabilities.

Women with disabilities are thought to be physically unable to fulfil their gender roles and considered unattractive to their husbands; it is widely believed that they are incapable of conceiving, carrying or parenting children, or that they would give birth to disabled children. Participants reported low education levels, informal employment or unemployment, and physical impairments that restricted individual mobility. Disability significantly reduces women's economic opportunity, increasing their dependency on family members and caregivers. Among the researched women living with disabilities, only 20% were formally employed and 20% had university degrees. People with disabilities are viewed as helpless, dependent and different from the rest of society. Disability-related stigmatisation removes other multiple identities from disabled people, denying them agency and associating them only with the disability. In the longer term, this leads to a more extreme forms of ableism, denying rights to education, employment, personal life choices, marriage, childbirth and parenting. In many instances, different forms of stigma and discrimination had been internalised by the research participants. Mothers of children with disabilities face abuse, isolation and loneliness due to restricted mobility associated with caregiving responsibilities and financial dependency on spouses and in-laws. They face associative disability discrimination and stigma. All women interview participants, as well as the majority of women FGD participants, reported to have experienced or to be currently experiencing different forms of SGBV perpetrated both within and outside the family circle. There is a strong link between mental health and sexual violence in all three locations. Disability increases the likelihood of abuse against married women and significantly increases the probability of divorce, separation, or abandonment. This forces women to either tolerate violence or become second wives to financially sustain themselves and their children. Only 20% of the researched women living with disabilities were currently married as first wives; 20% were divorced or abandoned; 20% were living as second wives; 40% were single.

Persons with disabilities (PWDs) also face discrimination in finding work, and women with disabilities encounter particular barriers to employment. In a Sughd oblast survey of 164 PWDs, 36.6% were employed, with more women than men working.¹ Most women worked in petty trade or as seamstresses, and the majority found work themselves or through friends and relatives. Of those who were not employed, most cited health reasons, but

1 Bureau on Human Rights and Rule of Law, Disabled Women's League Istirok and UN Women, Implementation of the Rights of People with Disabilities in Sughd province, Republic of Tajikistan – Report on monitoring outcomes, Khujand, 2011, p.74 (in Russian)

some cited lack of experience. Women with disabilities were divided about employment quotas for PWDs, but they emphasised enabling PWDs to organise work for themselves, especially as entrepreneurs.² The survey also revealed that women with disabilities receive less pension than men (TJS24–280 compared to men’s TJS30–300 per month).³

Recommendations include making VAWG-prevention approaches more nuanced to geographical and cultural context; deepening research into intersectionality, violence against women and girls, disability and masculinity to provide an evidence base for policy and programming; taking into account the needs of mothers parenting children with disabilities more holistically.

2 Ibid.

3 Ibid.

Literature review

Tajikistan

Tajikistan, located in Central Asia, is an overwhelmingly Muslim country, with 85% Sunnis and 5% Ismaili Shiites, with a large part of the latter living in the Gorno-Badakhshan Autonomous Region (often referred to as GBAO, using the Russian acronym) in the southeast of the country.

Ethnically, the population is 84.3% percent Tajik (includes Pamiri and Yagnobi), 13.8% Uzbek and the remaining 1.9% including Kyrgyz, Russian, Turkmen, Tatar and Arab.⁴ According to the Demographic and Health Survey of 2017 in Tajikistan (TJDHS), almost three quarters of women age 15-49 are married, with 47% married by age 20. About 31% of ever-married women aged 15-49 have experienced different forms of spousal violence during their lifetime, including physical, sexual, or emotional. The prevalence of spousal violence has increased by 7% in the 5 years since the 2012 TJDHS.⁵ The proportion of women reporting experiences of spousal violence varies by region, from 16% in the capital city, Dushanbe, to 28% in GBAO, 43% in Khatlon oblast, 25% in Sughd oblast and 26% in the Districts of Republican Subordination (DRC).⁶

Women with disabilities are at a higher risk of violence and subject to different forms of victimisation both within and outside the family. The literature suggests that disability or disability-related relationships or settings add to the complexity of violence and controlling behaviours, creating a specific form of vulnerability.⁷

A systematic review and meta-analysis of the global prevalence and risk of violence against adults with disabilities published in the *Lancet* in 2012 found that, overall, they are 1.5 times more likely to be victims of violence than those without a disability; adults with mental health conditions are at nearly four times the risk of experiencing violence.⁸ Women with mental health conditions or cognitive impairments might have limited capability to identify abuse, affecting their help-seeking behaviour.⁹

The formative research for the 'Living with Dignity' project of International Alert and the data collected in the baseline research highlighted the role of disabilities in increasing the risk of violence against women and girls (VAWG) and domestic violence (DV).¹⁰ These findings were especially true for disabled women or women who had children with disabilities. The research revealed that women with disabilities are often regarded as a burden by their spouses and close relatives, who are not willing to look after them. Women with disabilities are thought to be physically unable to fulfil their duties around the house and in the field. They are considered unattractive (including to their husbands), which limits their marriage prospects or can result in divorce. Women with different forms of disabilities are traditionally believed to give birth to disabled children or to be unable of conceiving, carrying, or parenting children.

4 Central Asia: Tajikistan – The World Factbook, US Central Intelligence Agency, <https://www.cia.gov/library/publications/the-world-factbook/geos/ti.html>, accessed 11 July 2019

5 Statistical Agency under the President of the Republic of Tajikistan, Ministry of Health Tajikistan and ICF, Tajikistan demographic and health survey 2017, Dushanbe and Maryland, 2018, <https://www.dhsprogram.com/pubs/pdf/FR341/FR341.pdf>

6 Ibid.

7 M.A. Nosek, C. Clubb Foley, R.B. Hughes and C.A. Howland, Vulnerabilities for abuse among women with disabilities, *Sexuality and Disability* 19(3), 2001, pp.177–89, <https://doi.org/10.1023/A:1013152530758>

8 K. Hughes, M.A. Bellis, L. Jones et al, Prevalence and risk of violence against adults with disabilities: A systematic review and meta-analysis of observational studies, *Lancet*, 379(9826), 2012, pp.1621–29, [https://doi.org/10.1016/S0140-6736\(11\)61851-5](https://doi.org/10.1016/S0140-6736(11)61851-5)

9 Nosek et al., 2001, Op. cit.

10 S. Mastonshoeva, H. Myrntinen and U. Ibragimov, Zindagii Shoista: Living with Dignity – Research report, Formative Research Phase, Tajikistan: International Alert, 2016, <https://www.international-alert.org/publications/zindagii-shoista-living-dignity-research-report>

Families tend to hide children with disabilities to not lessen the marriage chances of other female members of the family. Disability in Tajik society is often associated with poverty, illness, lack of education and, at times, is seen as punishment for sins.¹¹ This type of ableism¹² leads people living with disabilities to internalise stigma and shame. Women and girls living with disabilities experience multiple forms of discrimination, having fewer chances for education, marriage and employment.¹³ Fearing to leave girls without supervision, parents tend to send boys living with disabilities to special boarding schools and keep the girls at home. Families of men with physical, intellectual or mental disabilities often reportedly find prospective brides with or without disabilities from poorer families, expecting them to take care of the men. These indicative results require more in-depth research in relation to VAWG/DV as the issue of living with disabilities in Tajikistan remains largely under-researched.

Disability

Disability refers to the discrimination of a person based on his or her impairments that prevents him or her from fully participating in society. Ignorance, stigma, and physical and communication barriers shape people's marginalisation from society and increase their vulnerability to violence. Historically, the term disability was only defined from a biomedical prospective, i.e. on the body, excluding the social contexts and structures that affect the experiences of people living with disabilities.

The World Health Organisation's newer classification of disability defines it as:

"An umbrella term, covering impairments, activity limitations and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations."¹⁴

Impairments in a person's body structure or function, or mental functioning, limitations of activities such as difficulties seeing, hearing, walking, or problem-solving and restrictions in normal daily activities are an integral part of the new definition. The International Classification of Functioning, Disability and Health recognises functioning and disability as a:

"Dynamic interaction between health conditions and contextual factors, both personal and environmental, emphasizing functional status over diagnoses."¹⁵

Despite the new approach to defining and engaging with disabilities, there is still a tendency in Tajikistan to view disability in terms of physical medical conditions and health measures. Disability is primarily tied to a loss of working capacity and divided into three main categories based on the severity of the condition. Social benefits and protection are tied to official recognition of these three typologies, which is a burdensome and costly process for people living with disabilities. The granting of official 'invalid' status (i.e. disabled, unable to perform, unable to work) is also stigmatising for many people and, in addition to financial constraints and limitations of physical mobility, the stigma associated with the disability status in society prevents people with disabilities from acquiring official status and receiving certain benefits.¹⁶ That said, according to recommendation 90.18 75 of the 2016 report to the Universal Periodic Review, an interdepartmental working group has been set up to undertake a survey of legislation and revise it; consider the feasibility of accession to the Convention on the Rights of

11 The League of Women with Disabilities Ishtirok (a member of the Network of Women with Disabilities), Bureau for Human Rights and Rule of Law (BHR), Nota Bene and International Partnership for Human Rights (IPHR), Persons with disabilities in Tajikistan: Pushed to the margins, Tajikistan, 2018, <https://iphronline.org/wp-content/uploads/2018/12/Tj-disabilities-report-updated-compressed.pdf>

12 Discrimination in favour of able-bodied people.

13 Ibid.

14 Disabilities, World Health Organization (WHO), <http://www.who.int/topics/disabilities/en/>, accessed 11 July 2019

15 WHO, World report on disability, Geneva: WHO, 2011, http://www.who.int/disabilities/world_report/2011/report/en/

16 The League of Women with Disabilities Ishtirok et al., 2018, Op. cit.

Persons with Disabilities; conduct an awareness-raising campaign aimed at overcoming stigmatisation; study the possibility of adopting new criteria for the definition of disability that are in line with international standards.¹⁷

Similarly, women who are caregivers to disabled children are subject to domestic and other forms of violence in Tajikistan. Ryan and Runswick-Cole suggest that mothers of disabled children understand the societal perceptions of their children's devalued bodies and face some forms of disablism¹⁸ themselves, sharing the stigma associated with parenting disabled children.¹⁹ In the Tajik context, women are often solely blamed for giving birth to a child with disabilities and are compelled to take over caregiving responsibilities in full. There are negative stereotypes linked to physical or mental impairments in Tajik society, such as attaching the stigma of having children with disability to women rather than men; for example, it is women are accused of genetic factors leading to disabilities rather than men. As a result, women who have disabled children are often abandoned with their children without support – they are blamed for the disability of their children.²⁰ Most women caregivers of children living with disabilities are forced to stay at home to look after their children without possibilities for employment. In the absence of an adequate, inclusive education system, there is a lack of nurseries or rehabilitation centres for children living with disabilities;²¹ therefore, women parents have to cope with the challenges faced by their children alone. Divorced, separated, or widowed women in Tajikistan are more likely (44%) to have experienced physical violence since age 15 than married women (26%) and never-married women (10%).²²

17 UN Human Rights Council, Universal Periodic Review – Tajikistan, Geneva, 2016, <https://daccess-ods.un.org/TMP/4774187.20722198.html>

18 Discriminatory, oppressive, abusive behaviour arising from the belief that disabled people are inferior to others.

19 S. Ryan and K. Runswick-Cole, *Repositioning mothers: Mothers, disabled children and disability studies*, *Disability and Society* 23(3), 2008, pp. 199–210, <https://doi.org/10.1080/09687590801953937>

20 Bureau for Human Rights and the Rule of Law, the 'From Legal to Actual Equality' Coalition, *Ishtirok League of Disabled Women et al, Tadjikistan 2010–2015: Universal'nyi periodicheskiy obzor po pravam cheloveka, podgotovlenniy obshchestvennymi organizatsiami Respubliki Tadjikistan [Tajikistan 2010–2015: Universal Periodic Review of Human Rights, prepared by public organisations of the Republic of Tajikistan]*. Dushanbe, 2015, http://www.notabene.tj/Doc/Kaz/compl/Report_ESCR_rus.pdf

21 Public Organisation 'Bureau on Human Rights and Rule of Law,' League of Women with Disabilities 'Ishtirok,' Association of parents of children with disabilities of Tajikistan, Association of parents of children with disabilities of GBAO 'Savob,' Association of parents of children with disabilities of Khujand city and Public Association of women with disabilities 'Safoi Konibodom,' *Shadow report on implementation of the International Covenant on Economic, Social and Cultural Rights by the Republic of Tajikistan (with the Focus on Respect of Rights of Persons with Disabilities)*, Tajikistan, 2014, https://tbinternet.ohchr.org/Treaties/CESCR/Shared%20Documents/TJK/INT_CESCR_CSS_TJK_19139_E.pdf

22 Statistical Agency under the President of the Republic of Tajikistan, 2018, *Op. cit.*, p.209

Research methodology

This research is a qualitative study on the intersection of gender, violence and disabilities, with a focus on the role of disabilities in increasing the risk of sexual and gender-based violence (SGBV) and domestic violence (DV) perpetrated against women with disabilities and women parenting children with disabilities. The aim of the study was to gain a deeper understanding of:

- the underlying dynamics and norms leading to different forms of DV and violence against women and girls (VAWG) with disabilities and women with disabled children in the three target areas;
- the needs and wishes of affected women in terms of response;
- support and gaps or challenges in current support mechanisms.

The premise of this study was that disability status is an important consideration in both current and future research on VAWG and designing and implementing and providing VAWG-prevention interventions and services.

In 2015-2019, International Alert in Tajikistan implemented the 'Living in Dignity: Zindagii Shoista' (ZS) project, as part of the global, UK Department for International Development-funded 'What Works to Prevent Violence Against Women and Girls' programme. ZS sought to address DV/SGBV comprehensively by economically empowering women in four target communities in Khatlon and Sughd oblasts of Tajikistan, and by developing DV/SGBV-prevention mechanisms based on the needs and wishes of local women. It worked to change the attitudes of women and men, including community leaders, migrant men and in-laws towards DV/SGBV. The key group of concern was daughters-in-law. Daughters-in-law are expected to serve both their husbands and parents-in-law, and often have little recourse to justice in cases of violence. They are frequently unable to return to their own families in cases of abuse for fear of bringing shame and additional financial burdens upon their families. During ZS, Alert's team discovered links between SGBV and disability – disabled women were regarded as burdens by husbands and close relatives. In rural areas, if women were unable to do manual labour, family members were not willing to sustain them. Disabled women were not considered attractive, which limited marriage prospects or increased the risk of divorce and abandonment. While the link was identified, project funding did not allow for additional research to understand the situation of women and girls with disability in more detail.

Subsequently, Alert, with support from Swedish International Development Cooperation Agency, decided to conduct this small-scale study on the links between disabilities and VAWG, the gendered dimensions of disability-related violence and its consequences on the lives of women. The study was conducted in three cities of Tajikistan: the capital city – Dushanbe; the administrative centre of Khatlon oblast – Bokhtar; the administrative centre of GBAO – Khorog. The study targeted women and men between the ages of 18-65 living with (different kinds of) disabilities or parenting children with disabilities. The methodology of the current study was developed based on the 'ecological framework'.²³ This framework helps to research violence through the examination of individual, relational, societal and socio-cultural factors. It provides a basis for the analysis of contextual influence on behavior and the reciprocity of individual behaviors, including victims and perpetrators with their surrounding environment, and combines individual level-risk with familial, societal, communal and cultural factors.

Data collection

Field data were collected through 12 focus group discussions (FGDs) with men and women living with disabilities or parenting children with disabilities, with 4 FGDs in each research location divided by age and gender. Repeat

in-depth interviews using the 'life history' approach were conducted with 12 women and 6 men with disabilities among different age groups and/or who have children with disabilities, amounting to a total of 30 interviews. Life-history approach is a method of qualitative research, often, but not exclusively, used in anthropology and in the health sciences. As an alternative to empirical methods, the life history approach helps to collect data from people who are asked to tell the story or document their lives over a period of time in their own words. FGD questions were geared towards understanding gendered community attitudes and beliefs regarding different forms of disability and associated violence, individual beliefs and experiences of men and women of various ages living with disabilities or parenting children with disabilities, assessing the suitability of any available response mechanisms and the degree of support and/or victim-blaming extended to abused women/girls or mothers parenting children with disabilities.

The interviews took the form of a verbal conversation designed to allow participants to discuss their experiences freely. It started with brief questions on socio-demographic information and a broad, flexible scope of inquiry for women and men living with disabilities and/or women and men having children with disabilities.²⁴ Interview questions used in ZS were adapted to take into consideration the more diverse experiences of research participants with disabilities. Socio-demographic information was collected during these interviews, detailing the age of participants; acquisition, type and nature of impairment; living arrangements; educational level; marital status; number of children; employment status. Open-ended questions were used to collect information on research participants' experiences of living with disabilities, their intimate partnerships and experience of caring for and parenting children with disabilities. Following this, there were questions on gender inequality, disability stigma and community safety, and how these experiences shaped their lives, which helped researchers to understand the social and cultural layers of violence associated with disabilities. Questions on lifetime experiences of different forms of violence incorporated modified questions from the 'Adult Abuse Assessment' tool to probe for information on disability-specific violence;²⁵ for example, being denied care or help, having one's assistive device removed, or control over money by caregivers. Participants were also asked to share experiences of care and support and personal protection strategies.

Both FGDs and interviews were conducted in the language spoken by research participants (i.e. Tajik in Bokhtar, a mixture of Tajik and Russian in Dushanbe, and Shugni (a dialect of the Pamiri languages spoken in GBAO) during data collection in Khorog). Repeat interviews were conducted 3-4 weeks after initial interviews, allowing for the building of rapport between the data collectors and participants; this helped data collectors to return to issues raised in previous interviews. Each interview lasted approximately two hours. Field research assistants took notes during the interviews and FGDs in the language spoken/used for discussions; interviews were later transcribed and translated into English and/or Russian.

Research areas

The selection of the research locations of Dushanbe, Bokhtar and Khorog was to allow for the specific collection and analysis of diverse experiences of men and women living with disabilities in urban and rural parts of Tajikistan. The urban population predominantly lives in Dushanbe (27% of the total population), with the remaining 73% living in rural areas. Rural areas have, comparatively, less access to services and interventions for people living with disabilities.

24 Annexes can be provided upon request. These include a consent form for FGDs, a consent form for IDIs, FGD template, a template for interviews with women living with disabilities, a template for interviews with men living with disabilities, and a template for interviews with women parenting children with disabilities and interviews with men parenting children and/or married to women living with disabilities.

25 J. McFarlane, R.B. Hughes, M.A. Nosek et al., Abuse assessment screen-disability (AAS-D): Measuring frequency, type, and perpetrator of abuse toward women with physical disabilities, *Journal of Women's Health and Gender-Based Medicine* 10(9), 2001, pp.861–66, <https://doi.org/10.1089/152460901753285750>.

Dushanbe is the capital and largest city in Tajikistan with a population of approximately 679,400 people. Under the Soviets, Dushanbe grew rapidly and was endowed with many industrial enterprises and cultural institutions. The city had a multi-ethnic population due to an influx of (primarily Russian-speaking) workers from other parts of the Soviet Union. During the 1990s, with the collapse of the Soviet Union and the Tajik civil war from 1992-1997, Dushanbe became dilapidated and its inhabitants were impoverished. Most ethnic Russians and other minorities fled during this period, and have been slow to return. Today, Dushanbe city has a large expatriate community working for various developmental and international organisations which started functioning in the country in the post-war period.²⁶

Bokhtar (formerly Qurghonteppa), is a city in southwestern Tajikistan, the capital of Khatlon oblast. Bokhtar is the largest city in southern Tajikistan, located 100 kilometres south of Dushanbe. The population of the city is close to 102,000, making it the third-largest city in the country. The population fluctuates depending on season (as a result of Tajik migrant workers who leave to work in the Russian Federation). Similar to Dushanbe, Bokhtar is demographically more diverse than other larger Tajik cities – ethnicities residing in the city include Tajiks, Uzbeks, Russian, Tatars, Ukrainians and others.²⁷

Khorog is the administrative centre of the Gorno-Badakhshan Autonomous Oblast (GBAO).²⁸ The province is almost entirely mountainous, with almost no level or arable land. The largest ethnic group living in GBAO is known as Pamiri, who are closely ethnically and culturally related to the Tajik people and speak many different dialects of the Persian language. Pamiris are primarily Ismaili Shiite Muslims, whereas most Tajiks are Sunnis. Although the province makes up 45% of the land area of Tajikistan, it represents only 3% of the population (approximately 200,000) with approximately 30,000 living in Khorog.²⁹

Recruitment of research participants

Alert worked with its local NGO partners³⁰ to identify and invite FGD and interview participants. Criteria for selection included individuals who were at least 18 years of age and reported mild-to-moderate or severe functioning difficulty on one or more items listed in WHO's *Disability Assessment Schedule*³¹ or who had children with different degrees of disabilities classified in the WHO schedule.

A limitation of this study is it did not include people with severe disabilities, who may be at a higher risk of experiencing violence and who are less likely to be able to access services and interventions to prevent SGBV. Additionally, the study did not include participants living with severe cognitive or communication difficulties. On the other hand, interviews and FGDs did include parents with children with severe disabilities of all forms, including cognitive or communication difficulties.

Interviewers and interviewees were the same sex to facilitate talking openly about gender issues. Life history interviews were triangulated with other data collected in ZS and other information from Tajikistan and internationally to help interpret the data.

The research was conducted in partnership with three local NGOs that have experience of working in VAWG prevention and disabilities in Tajikistan, and that support parents with disabled children. The NGOs supported the research by securing local government approval for the research through formal letters, logistics and other arrangements during data collection. They identified double the required number of participants for FGDs and

26 Dushanbe - Capital of Tajikistan, OresCA, <https://www.oresca.com/tajikistan/dushanbe.htm>, accessed 11 July 2019

27 Kurgan-Tyube, Tajikistan, OresCA, <https://www.oresca.com/tajikistan/kurgantube.htm>, accessed 11 July 2019

28 Badakhshan is split across two countries: Tajikistan to the north and Afghanistan to the south.

29 Gorno-Badakhshan Autonomous Oblast (GBAO), OresCA, https://www.oresca.com/tajikistan/regions/gorno_badakhshan_region.htm, accessed 11 July 2019

30 PO 'Ghamkhori' in Bokhtar, PO 'Ruzbeh' in Khorog and PO 'Nerubakhsh' in Dushanbe.

31 WHO disability assessment schedule 2.0 (WHODAS 2.0), <http://www.who.int/classifications/icf/whodasii/en/>, accessed 11 July 2019

interview participants based on the criteria. Final participants were randomly selected by the lead researcher and field research assistants.

FGDs and interviews were conducted after ensuring written consent from participants. Due to difficulties in accessing public transport or other means of travel for people living with disabilities in all three cities, separate transportation was budgeted and arranged for all FGD participants to ensure their participation. With regard to the individual interviews, transportation was arranged depending on where they wanted to be interviewed; if respondents wished to remain at home, the field research assistants visited them and interviewed them in their homes. Interview and FGD participants did not receive any financial remuneration for participation in the research except for transportation and light refreshment. In line with Tajik traditions, when visiting interview participants in their homes, the field research team brought bread and fruits as a courtesy.

Main findings

Basic socio-demographic characteristics

Interview participants ranged from 26-52 years old among female respondents and 29-60 years old among male respondents (see Table 1). Male and female participants of FGDs ranged from 20-63 years old. The majority lived in contexts of economic difficulty and poor infrastructure. Among 12 interviewed female respondents, five have been living with disabilities, including one also parenting a child with disabilities. The remaining seven female interview respondents are parenting children with disabilities. Among female respondents living with disabilities, only two have university degrees and formal jobs. In terms of family life, only one is currently married, with the rest of the respondents either single or divorced, which demonstrates how disability (both physical and other types) directly impacts family lives of women, reducing their chances for marriage and a personal life.

Among the seven women parenting children with disabilities only three have university or college degrees; only one is employed. The rest of the respondents do not have any formal or informal jobs due to their complete commitment to caring for their children. Four of the seven women are currently married and living with their spouses; however, the caregiving responsibilities over children living with disabilities sit fully with the women.

(Continues overleaf)

Table 1. Basic socio-demographic characteristics of the research participants

Categories	Men living with disabilities		Women living with disabilities		Women parenting children with disabilities	
	N=6	100%	N=5	100%	N=7	100%
18-35 years old	2	33%	3	60%	3	43%
36-65 years old	4	67%	2	40%	4	57%
Married	5	83%	1	20%	4	57%
Divorced	0	0%	1	20%	1	14%
Single	1	17%	2	40%		
Widowed	0	0%		0%	1	14%
Second wife			1	20%	1	14%
Spouse without disabilities	4	67%	1	20%	4	57%
Spouse with disabilities	2	33%	0	0		
University education	4	67%	2	40%	3	43%
Formal employment	0	0%	2	40%	1	14%
Informal employment	6	100%	0	0	0	
Congenital disabilities	3	50%	4	80%		
Acquired disabilities	3	50%	1	20%		
Have children	4	67%	2	40%		
Have children with disabilities	1	17%	1	20%	7	100%

Among men respondents, all six respondents are living with disabilities and one is also parenting a child with disabilities. Four of the respondents have university degrees and all the respondents are engaged in informal and/or seasonal work. It should be noted that gender norms and expectations are also strong for men in terms of providing for the family – these expectations are not compromised in the face of disability. The male respondents in rural areas reported to be mainly engaged in very low-paid seasonal jobs in the market or in begging. Five of the male respondents are married, with two of them married to women living with disabilities.

Generally, participants reported low education levels, informal employment, or unemployment. Most participants reported physical impairments that restricted individual mobility and dexterity. Impairments were either congenital or acquired through illnesses such as polio, osteomyelitis, epilepsy, diabetes, apraxia, car accidents, and stroke or brain injury, as they result in paralysis, amputation, scarring, or sight impairment.

Intersection of mental health and violence

The research revealed an alarming tendency of disability-related violence against women and girls perpetrated by men and women family members, husbands, in-laws and other men in the target communities. Research respondents across all groups were especially concerned about the vulnerability of mentally disabled girls and women to sexual violence. Parents of disabled girls expressed strong fears about the future of their daughters and the threats of sexual violence. Often, women and girls with mental disabilities are forcefully isolated by family members and kept inside the home to both minimise threats of sexual and physical violence against them and lessen the likelihood of associated communal stigmatisation.

“My 25-year-old neighbour is mentally disabled. She [tries to] run away from her house and her family chains her up inside the house. She left the house once and teenagers hit her on the head with a shovel. Her face was covered with blood. When her brother went to the houses of the boys in the neighbourhood, the neighbours said that they should keep her at home.”

FGD participant among young women living with disabilities, city A³²

“Life is difficult for disabled men and women, but for women it is even more difficult. Disabled women are sexually assaulted and abused by men, especially women with mental disabilities. For example, there is a [mentally] disabled young woman usually walking in our bazaar.³³ She is very beautiful. The men in the bazaar sexually [ab]use her in turn. She does not understand anything and no one can prevent these men from doing [this] to her.”

FGD participant among young women parenting children with disabilities, city B

“I am very afraid for my daughter; she is in bed and can’t move without support. I don’t leave her alone even with the men in my family, I have this dreadful fear for her. I will never forgive myself if something happens to her. I have this dreadful fear, what will happen to her?!”

FGD participant among older women parenting children with disabilities, city A

“Sexual violence against mentally disabled girls and women happens in our city. Often it is gang rape. One of these incidents happened recently. Several men raped a mentally disabled young woman. As a result, she got pregnant, the baby died during childbirth. Her family took her from the hospital immediately. Her parents did not even try to prosecute the perpetrators. I am worried every afternoon for my daughter, I am worried if she will come back home from school or not.”

Interview respondent among older women parenting children with disabilities, city C

32 To protect the identity of respondents, particularly those from small communities, the locations of quotes have been kept anonymous.

33 Local market.

Intersection of domestic violence and disability

The research revealed high levels of violence within domestic settings against women and girls living with disabilities and women parenting children with disabilities. Perpetrators include direct family members for unmarried women, including extended family members; for married women, perpetrators are primarily spouses and in-laws. Women and girls face both emotional and psychological abuse, neglect, humiliation, financial and material deprivation, forced isolation, and physical and sexual abuse. Although, in some rare cases, women with disabilities marry men without disability, the majority are victimised within the family. Men, including men living with disabilities, conform to gender roles and stereotypes of controlling and punishing women which puts these women at risk. Fearing additional stigmatisation if divorced, being dependent financially on husbands and other family members and lacking any possible support system outside marriage forces women and girls to tolerate abuse and humiliation.

“All my problems started when I got married. He said before the court that he does not want to live with disabled woman. I regret marrying him so much. My family members forced me to marry him, they did not want me to live with them. I dream of meeting someday someone who would love me, even if I am disabled. I want to be happy.”

Interview respondent among older women living with disabilities, city A

“Due to my disability, I was not able to fulfil all my responsibilities around the house and my mother in law forced me out of the house. I told her that she can’t [kick me out], my husband is in Russia. She said that I am giving you three talaq³⁴ instead of my son, you can leave now. Neither my parents nor other relatives allowed me to live with them after I [had to leave] my ex-husband’s house. Then I had no other choice but to marry for a second time, [marrying] a man who is 35 years older than me.”

FGD participant among older women living with disabilities, city B

“When my husband is drunk, he beats me, humiliates and insults me, calls me names because of my disability. He then goes to my parents’ house and causes them lots of trouble, insults them. My father told him that if he does not want to live with me, then we should separate.”

Interview respondent among young women living with disabilities, city C

Mothers parenting children with disabilities

Women who give birth to children with disabilities face specific vulnerabilities in Tajik society throughout their parenting experience. Tajik families place extreme emphasis on the motherhood experience and the need to pass family names and legacy from generation to generation. Sons are traditionally considered the connectors of this intergenerational link; their birth into families is demanded, expected and celebrated. On the other hand, the birth of daughters can be controversial and is often considered a more difficult parenting task due to the risks girls face in society. This same attitude exists towards disabled boys and girls, with girls facing significant ableism.

34 *Talaq* is a form of divorce in Islam whereby a Muslim man can divorce his wife by pronouncing *talaq* (the Arabic word for divorce) three times.

The experience of parenting disabled children, especially girls, adds to the existing vulnerabilities of Tajik women; therefore, the likelihood of different forms of violence to be committed against them increases. In a context in which women are seen as vessels for progeny, the 'inability' to perform this singular function puts them at considerable risk of abandonment and violence. Mothers of disabled children experience different forms of associated stigma and share, to a certain extent, the different forms of disablism against their children.³⁵ This shared disablism is especially strong in Tajik society due to the subordinate and discriminatory position of women, and the strong societal expectations of 'decent motherhood and womanhood', e.g. giving birth to healthy children.

According to the research respondents, women are primarily blamed for having disabled children and are solely responsible for taking care of them, in addition to fulfilling other traditionally assigned roles in the family.

"I faced lots of abuse [from] my mother-in-law. If I was not able to do something around the house on time, she would insult me. She did not allow [me] to spend money on my son's treatment. My husband blames me for my son's disability. He insults me and hits me if I say something."

Interview respondent among older women, parenting children with disabilities, city B

"I was married off to my cousin and both of my children were born with sight impairments and both cannot walk... My in-laws [then] forced me out of the house. My mother has mental disabilities, I faced a lot of difficulties in my parents' house as well. I had no other choice but becoming a second wife to a man who pays the rent of my apartment and helps me financially to take care of my children. I am always depressed when I see other children in the street. My children are trapped in the house the whole day, I cannot even take them out onto the street."

Interview respondent among young women parenting children with disabilities, city B

"I gave birth to my daughter shortly after my husband died. My daughter couldn't talk and walk. I sold all my belongings and organised treatment for her; she talks now but is not able to walk. My in-laws forced me out of my husband's house after they discovered my daughter had multiple forms of disabilities. They were [insinuating] that I might have been made pregnant by [an]other man."

Interview respondent among older women parenting children with disabilities, city A

"My husband always blames me for my son's disability. My son was sitting on my lap and my husband told him to not sit on my lap, he called me a cow. Yesterday I was exercising with my son, he needs to do [certain] exercises. My husband passed by and suddenly kicked me really hard in the chest. My son was so scared. I feel that all my attempts to rehabilitate my son are useless, because he continually witnesses violence in our house."

Interview respondent among older women parenting children with disabilities, city C

The parenting experience of mothers of disabled children in Tajikistan is made more problematic due to the lack of inclusive service provision for people with disabilities. Frequently, mothers with disabled children are not able to financially sustain themselves. They have to spend most of their time taking care of their children and are desperately looking for treatment options, schooling opportunities and other ways to integrate them into society and socialise with their peers. This requires considerable time and travel which the mothers do not have (and which is exacerbated by poor infrastructure and transportation).

The birth of a disabled child does not automatically remove other responsibilities from a mother, i.e. those associated with her role as a wife and daughter-in-law. For men, however, the experience is different, as they are not expected to take on caregiving roles. Based on respondents' information, men tend to separate from

women after the birth of a disabled child without hesitation or fear of societal disapproval. Family pressure from family members on men to distance themselves from the woman and child can cause extreme stress and the most common outcome is that men succumb to the pressure and leave their families after only a short time of parenting disabled children.

The impression across the different groups and geographical locations involved in the study suggests that there is little shame and societal judgment associated with the act of men leaving their family in the case of the birth of a child with a disability. On the contrary, this decision is justified by the necessity for men to have their needs fulfilled by their wives – with a disabled child a woman cannot, supposedly, cater to all her husband’s needs as all her time is dedicated to the child, thereby causing problems in the relationship. Furthermore, men feel the need to have a healthy child who will continue the family legacy, whereas women feel strongly obliged to take care of their disabled children alone and fear societal disapproval of being considered unable to adequately fulfil their motherhood responsibilities (even if families question the ‘worth’ of the child).

“Even though both parents should be involved in the process of raising and caring for a disabled child, a mother is more caring and is able to give [him or] her more love and be more tolerant than a father.”

FGD participant among older women living with disabilities, city C

“I have a disabled child. When I plan to take my child to the children’s health and learning centre, my husband quarrels with me, he does not allow me to go anywhere. But if I only stay inside the house with my child, his health conditions will never improve. Men do not believe that disabled children have the capacity and the need to study and learn something.”

FGD participant among younger women parenting children with disabilities, city B

“I gave birth to a girl with Down’s syndrome. After I came home from the hospital my husband said that my daughter did not look like him and left us. I was living in Moscow at that time. I took my daughter and came back home. When I first saw my family members, I told them right away about my daughter’s syndrome. I was so afraid of their reaction. Fortunately, they accepted me and my child. Their attitude brought hope back to my life. But for three years I was not able to go out of my house, did not attend weddings, birthday parties. I did not see any of my friends or acquaintances. The birth of a disabled child and the subsequent divorce utterly shocked me, I only recovered, came back to life, after three years.”

FGD participant among older women parenting children with disabilities, city A

Disability-related stigma

The research revealed a high degree of stigmatisation of both men and women and girls and boys living with disabilities in all three locations. Stigmatisation of women is often linked to the societal expectation of women’s roles in the family and the focus on physical attraction, especially for girls and unmarried young women.

“My daughter is 25 and she does not want to go out of the house. She is embarrassed of her physical appearance; her appearance does not conform with societal expectations. She used to go out before, but then she heard bad things from people and now she refuses to go out, she tries to avoid meeting people.”

FGD participant among older women, city C

Among male respondents, some agreed that women with disabilities suffered greater stigma in their communities.

“I think it is easier for a disabled man than disabled women to live in my city. Women are always shy and try to hide, [try] not to be noticed. In our city we have some men who have no leg[s] but walk in the streets without any concern. If a girl doesn’t have a leg, she would be depressed to be seen with a walking stick, especially if she is an unmarried girl. For girls in schools it is still a big issue even to have glasses because they would be [singled out] and called upsetting names!”

Interview respondent among young women living with disabilities, city C

People with disabilities are viewed as helpless, dependent and different from the rest of society. Disability-related stigmatisation removes other multiple identities from disabled people, denying them agency and associating them only with their disability. In the longer term, this leads to more extreme forms of ableism, for example denying disabled men and women’s rights to education, employment, personal life choices, marriage, childbirth and parenting. Among the research participants, often different forms of stigma and discrimination had been internalised.

“Some people do not even use my name, when they talk about me, they will say ‘that disabled girl’ or ‘that sick girl’. After all, disability is not the only thing I have. I also have a name.”

FGD participant among young women living with disabilities, city C

“Disability becomes a barrier for women to marry. Firstly, because men will always prefer to marry women without disability. Secondly, disabled woman cannot give birth to healthy child[ren] and cannot fulfil [their] obligations [and] household chores.”

FGD participants among young women living with disabilities, city B

Disability-related stigmatisation affects women’s mobility severely; it often results in isolation and loneliness.

“If you compare disabilities between men and women, for women it is more difficult. For example, a man with a disability can appear in public places, but for women it is a kind of taboo. If a man with a disability falls in the street, he is not shy and can deal with people’s attention, but for women it is hard.”

FGD participant among older men living with disabilities, city B

Societal stigmatisation often translates into stigmatisation within the family. This is most pronounced for women and girls with disabilities. In some cases, family members of disabled people feel associative stigma.

“I have a very bad relationship with my nephews. My older nephew does not allow me to go out of the house. He says, if I go out, I should not come close to him because he is embarrassed of me. My father thinks I am not able to do any work around the house. If my mother is not in the house, he even refuses to drink the tea that I make, he feels it is a disgrace to drink it.”

Interview participant among young women living with disabilities, city A

Men with disabilities are often stigmatised as a result of hegemonic masculinity norms. In Tajikistan, these norms dictate the primary responsibility of a man – to provide for their families and protect them from any outside threat.

"I have the fear that, because of having only one hand, I may not be able to find the right girl to marry. I am always worried that I will not achieve my goals as normal people would. When applying for jobs I fear that I will not be hired due to my condition."

Interview respondent among young men living with disabilities, city C

"Healthy men can work and provide for their family. However, a man with a disability, especially those who are in bed and cannot walk, will not be able to work. Therefore, he is not able to marry and have a family. Even if a man with a disability marries, he will not be able to financially sustain his family."

FGD participants among young women living with disabilities, city B

Many disabled men internalise societal stigma associated with their disability and struggle with depression and anxiety as a result.

"My only happiness in life is my wife. She is very kind and supportive. As a man I feel so sorry that I am not able to do for her what I could do if I were not blind. She is really the only person who really cares for me. I am so thankful to God that, instead of my eyes, he gave me such a wonderful wife. She values me even though the only income I have is from begging in the street."

Interview respondent among older men living with disabilities, city B

Marriage prospects and disability

The differentiated impact of disability on men and women is particularly evident in terms of marriage prospects (and perspectives). This came out as one of the strongest trends across the three cities and groups of all ages and gender. According to the respondents, women living with disabilities have fewer chances of getting married than men with disabilities; the chances of marrying men without disabilities are minimal. Among five interviewed female respondents living with disabilities, only one is currently married (her husband also has disabilities), whereas the rest of the women are divorced or single.

Men with disabilities, however, often marry women without a disability; in fact, parents of men with disabilities may well demand that a daughter-in-law does not have disabilities. This is linked to the traditional caregiving roles of women in Tajik society, where women are fully responsible for the household in terms of cleaning, cooking and serving the husband and his family. The subordinate role of women and superior role of men within Tajik families does not change, even if a man living with disabilities marries a woman without disabilities; nor does it serve as a factor for any positive change in the position of daughters-in-law vis-à-vis their mothers-in-law and other family members. Among the five interviewed married men living with disabilities, three are married to women without disabilities.

"In our society the attitude towards disabled women is extremely different from the attitude towards [disabled] men. Young men with disabilities can marry women without disabilities and no one will see anything unusual in it. However, if a woman with a disability wants to marry a man without a disability, the parents and the entire avlod³⁶ would be against it."

FGD respondents among young women living with disabilities, city A

36 Large extended family members in Tajik society is collectively called *avlod*, which plays a prominent role in decision making especially in terms of marriage of younger members of the *avlod*.

"I told my father that I want to get married, but he kept refusing everyone who came to ask for me. He said to me to keep quiet, he says that he will not let me marry if he is alive. He thinks I will not be able to maintain family relationships and will become an even greater burden for him."

Interview respondent among young women living with disabilities, city B

"When I gave birth to my third daughter, my husband got sick and eventually became disabled. I spent one year with him in the hospital taking care of him. While I was there, my father-in-law took my children to the orphanage. They spent three years in orphanage before I was able to take them back home. My in-laws do not allow my husband to live with us anymore. They told my husband that while he was in the hospital I was dating other men and was [only] willing to live with my disabled husband to inherit his house."

Interview respondent among young women married to disabled man, city A

The poor marriage perspectives of women with disabilities was also underlined by men living with disabilities or parenting children with disabilities both during FGDs and individual interviews. In all three cities, men generally agreed that women with disabilities ended up without a family, a husband, or children. The significantly lower chance of marriage was the most commonly expressed disability-related consequence for women, mainly as a result of patriarchal gender norms and expectations.

If women with disabilities do marry, it is mostly either to men with disabilities or to significantly older men as second wives. In the case of the latter, this is driven by a lack of financial independence and the strong societal expectations of marriage and childbearing as the primary role for women, affecting their status and defining their existence. Marriage is also a mechanism by which responsibility for the woman with a disability can be passed on in the case that something would happen to the parents or caregivers, thereby ensuring their 'survival' and, to a lesser extent, the possibility for a more independent life (and also a means of escaping judgement and violence within the family home). However, the shedding of the 'burden' of caring for women with disabilities is a clear motivating factor for marriage and these women can be forced into it.

"Due to my disability I was married off to a man whose wife died. He is older than me. I gave birth to a disabled child. Now, my stepsons do not allow me to get pregnant anymore. My stepsons forced me to go through an abortion the second time I got pregnant. I really want to have a healthy child, who can take care of me when I grow old."

FGD participant among older women living with disabilities, city B

"If, by any chance, a young woman with disabilities owns an apartment or other property [or land], this increases her chances of getting married. Sometimes, the family of a disabled girl [would] buy her an apartment to increase her marriage prospects."

FGD participant among older men living with disabilities, city A

"Some parents who have a disabled girl always think about how to marry her [off]. They think once she gets married the problem is solved, [but] with marrying her off they only shift the responsibility to another family. However, think about the girl – how can she satisfy the needs of her husband's family? If she is lucky, her husband will support her, otherwise she will not be happy."

FGD participant among older men living with disabilities, city B

Loneliness and social isolation

Female research participants living with disabilities or parenting children with disabilities expressed feelings of loneliness and social isolation. The factors for this isolation included restrictions in physical mobility due to inadequate infrastructure and transportation, the need to be accompanied (which becomes a burden for family members), the need to take care of a disabled child (for parenting mothers), social neglect from family members and those on whom they are dependent, stigma, gender norms, gendered spaces restricting women's socialisation and mobility and forceful confinement at home (by family members). Men living with disabilities and parenting children with disabilities in all three cities acknowledged this social isolation.

"It is more difficult for women with disabilities. You see, our society can hardly accept the need of women without disabilities to have a social life, to go out, etc. Just imagine now the situation of women with disabilities. Women with disabilities have limited chances to socialise."

FGD participant among older men living with disabilities, city A

Women living with disabilities are forced by family members to stay inside for various reasons. According to research participants, this can be due to safety concerns, societal perceptions of disabilities and the attached stigma, and the lack of time and willingness of loved ones and family members to accompany disabled people. As a result, the education, potential employment and personal life of young women living with disabilities is compromised, leading to feelings of loneliness, worthlessness and hopelessness. These women are physically, socially and financially dependent on family members and must comply with the imposed restrictions on mobility to be able to continuously rely on family and caregivers for their survival.

"My aunt takes care of me; she does not allow me to go outside. I did not attend school; she never allows me to go outside. She goes for my pensions herself. I don't have parents."

FGD participant among older women living with disabilities, city B

Mothers of children with disabilities also face isolation and loneliness due to the restricted mobility associated with full-time caregiving responsibilities; it also depends on the family situation and the type of impairment with which the children are living. In all three cities, some mothers have organised themselves into associations and groups where they can learn and share with their peers about the conditions of their disabled children and ways to support them. However, it is not always possible to participate in such groups as a result of mothers' heavy household responsibilities or husbands' (and other relatives') controlling behaviours (over their movement). Beyond that, social stigma associated with parenting disabled children and mobility restrictions due to inadequate infrastructure prevent women from being in public together with their disabled children. As stated previously, social stigma often translates into stigma and associative stigma within the family against women and girls with disabilities.

"I live with my parents and my daughter has physical impairments. When everyone leaves for a birthday party, I am told directly that I must stay with my daughter. Sometimes I also want to go to weddings or visit relatives. I don't remember when I last went to a wedding. My family members leave their children with me as well while they go to weddings. Why should I look after every child? Because my daughter is disabled? Why do they never look after my daughter and allow me to go out sometimes as well?"

FGD participant among older women parenting children with disabilities, city A

Access to services

Research participants mentioned a number of barriers to accessing basic services. Due to the current regulations on eligibility for the provision of social benefits to people living with disabilities, official registration of disability through medical examination and provision of written medical statements is necessary. Services include monthly small allowances, free routine medical checkups, reduced utility payments, quotas for young men and women living with disabilities to acquire higher education, and others. While the registration process is problematic for many people with disabilities, even those who possess the necessary documentation face other challenges specific to their conditions.

“I have visual impairments and I always need someone to accompany me. I can’t even go and receive my monthly allowances because the terminal (automated teller machine) does not have a Braille system. I am forced to ask someone to bring me my money, I am forced to give them the pin code from my card.”

FGD participant among older women living with disabilities, city A

“There is [an] issue with [cash] machines. They are too high for people in wheelchairs to operate. We [are forced to] ask someone else. It is dangerous to share our pin codes [with strangers] or to give them our cards because they can just run away. That said, we have no other choice.”

FGD participants among older women living with disabilities, city A

In general, married women with disabilities facing domestic abuse do not seek help outside of close family circles. Due to their increased vulnerability and dependence on family members, they are more likely to tolerate violence and abuse. In order to conform with the accepted social norms on marriage and deference to in-laws, women with disabilities try to take over all the responsibilities usually assigned to (non-disabled) women, even if it affects their health negatively.

Globally, the specific needs and vulnerabilities of women living with disabilities are not adequately covered by existing violence-prevention interventions.³⁷ In Tajikistan, existing services available to women facing different forms of violence lack inclusivity in terms of addressing the specific needs of women living with disabilities or women parenting children with disabilities. This includes outreach – there is a low level of help-seeking behaviour among affected women. Existing programmes and interventions for children living with disabilities often do not include approaches on engaging with parents’ emotional and mental health, especially mothers.³⁸ Mothers of disabled children experience anxiety, depression and hopelessness when faced with the challenge of providing their children with adequate education and care. There are a limited number of schools with inclusive education; mothers struggle to negotiate with schools, teachers and other parents to accommodate their children with special needs. The stigma associated with disability adds to the already complicated and difficult lives of mothers and children who must overcome discrimination and exclusion every day. Tailored psychosocial support to mothers of disabled children is not available and the psychological trauma they endure is not addressed. During interviews, mothers of disabled children revealed their deep-seated distress and desperation to the field research team, adding that that this was the first time that anyone had listened to their problems.

“I have tried to kill myself several times – I always wanted to kill myself. I want to tell you the truth, I have always had suicidal thoughts...I told myself that, if I am a bad wife, I need to leave this world so that he can marry someone else. Then my daughter was born with disabilities and now I don’t think about suicide. However, I think maybe this is a punishment for my previous thoughts and [suicide] attempts.”

Interview respondent among young women parenting children with disabilities, city C

37 I. Van Der Heijden, What works to prevent violence against women with disabilities, Pretoria: Medical Research Council, 2014, <https://www.gov.uk/dfid-research-outputs/what-works-to-prevent-violence-against-women-with-disabilities>

38 F. Martin, W. Clyne, G. Pearce and A. Turner, Self-management support intervention for parents of children with developmental disorders: The role of gratitude and hope, *Journal of Child and Family Studies* 28, 2019, pp.980–992, <https://doi.org/10.1007/s10826-018-01308-1>

Comparison across geographical locations

The research sites were selected to allow for the collection of diverse experiences of people living with disabilities and women parenting children with disabilities. The diversity of experiences was dependent on the level of urbanisation of the living settings, the availability of adequate transportation and infrastructure, access to services (urban vs rural), availability of employment opportunities, diversity of population (including ethnic diversity and people living with disabilities), and the communal factors which serve both as triggers and protective features in disability-related violence.

Overall, despite the comparative differences in access to services and other socio-economic indicators, gender-differentiated, disability-related violence against women and girls came out strongly in all three cities. Respondents shared feelings of stigmatisation and low levels of acceptance and inclusion in their communities. Indeed, the strong links between mental health and sexual violence against women and girls, disability and marriage prospects, disability and SGBV/DV, and disability and stigma are present in all three research locations; however, they vary in degrees of severity and other characteristics.

Dushanbe

Both FGD and interview participants living with disabilities and/or parenting children with disabilities had relatively higher awareness of their rights, the existing state-funded services available to them, interventions funded through donors and international organisations, and the norms of legislation and policy governing issues related to disability.

Research participants in Dushanbe enjoyed better economic perspectives in relative terms, including access to higher education and formal employment due to the better economic situation in the city in general.

Developments in infrastructure in Dushanbe in recent years mean that people living with disabilities have better access to transportation than in Bokhtar and Khorog. This increases their physical mobility and sense of belonging, which contributes extremely positively to their mental and psychological state of health.

The comparative demographical diversity in the city, including a larger number of people living with disabilities, has a potentially positive role to play in contributing to a gradual reduction in stigma related to disability. This might explain why research participants from Dushanbe were more open and confident in sharing their life experiences during FGDs and interviews. They spoke without fear of their stories being recognised if told publicly or by their family members, including potential perpetrators. However, despite relatively better opportunities, disability-related stigma and violence remain persistent in Dushanbe. Women and girls living with disabilities are extremely vulnerable to harmful gender norms exacerbated by the presence of a disability.

Khorog

Khorog, and GBAO in general, are geographically more isolated, with considerably less coverage by VAWG-prevention interventions funded by international donors. Due to this geographical isolation and difficult political access to the region, GBAO has been least researched in terms of DV/SGBV and other cross-cutting topics.

There is a misconception among both national and international stakeholders that DV/SGBV is not as much of a problem in GBAO when compared with other regions in Tajikistan. This is believed to be due to more 'liberal' attitudes among the population of GBAO, in part due to the Ismaili traditions of acknowledging and encouraging women's and girls' education and employment. However, patriarchal gender norms and roles remain strong in GBAO despite moderately 'liberal' views, higher levels of education and, comparatively, higher financial independence among women and girls. At the communal level, masculinity is linked to toughness and male honour. Male dominance is persistent and enforced through peers and larger family members, especially among the younger generation and millennials. Indeed, in Khorog, as in the other two locations, disability-related VAWG was stressed by research participants across all age and gender groups.

That said, in comparison to the other research sites, research participants in Khorog were the most reluctant to disclose experiences of violence and discuss disability-related stigma. This added complications during the identification of participants and required additional sensitivity from the research team to build rapport with FGD and interview participants. Based on our analysis, Alert's previous experience with DV/SGBV research and the observations of the research team, this behaviour can be explained through the considerably stronger community ties between the inhabitants of Khorog and indeed GBAO as a whole. Despite increasing internal migration of people coming to Khorog from other parts of GBAO and Tajikistan, the town is very small, with a majority Pamiri population – almost everyone knows each other and everyone is linked with a certain *avlod*. Therefore, respondents were more reluctant to share personal experiences of violence as they feared being identified and being accused of bringing shame on their families or community for sharing sensitive information. The sharing of this information could result in family violence or stigmatisation by the larger public.

Residents of Khorog identify themselves as 'Pamiri' Tajiks and represent a minority population with a distinct language, traditions and adherence to a different branch of Islam (Shia). There are positive attributes associated with representing a distinct, rich minority culture with progressive views; however, there is also an adverse tendency among minority groups within a larger majority population which is to keep problems undisclosed, especially on sensitive issues like SGBV. Alert observed the same tendency during ZS in Uzbek-majority villages, where, during FGDs in particular, participants tried to demonstrate the difference of their villages when compared to the rest of the country and denied occurrences of SGBV.

All the female and male interview participants in Khorog who disclosed experiences of violence and disability-related stigmatisation to the field research team had never told anyone about their situation. Participants asked field research assistants to interview friends or relatives with similar experiences. The difficult experience of women and girls living with disabilities and women parenting children with disabilities in Khorog is more acute due to the lack of adequate health, transport and infrastructure services, and high levels of unemployment.

The level of education among the researched women and men was considerably higher than in Bokhtar. In Khorog, women and girls with disabilities and women parenting children with disabilities received higher levels of financial, mental and emotional support from their family members; stigma around women returning to their parents' house if divorced or separated is not as strong as in Bokhtar and Dushanbe. This adds a certain level of protection and confidence for women if they face separation and/or divorce. Unlike in Dushanbe and Bokhtar, all four interviewed women (one living with disabilities and three parenting children with disabilities) were currently married.

However, this marital status did not necessarily translate into securing assistance and support from spouses in terms of caregiving for children living with disabilities; the caregiving role, as in other parts of Tajikistan, continues to be strongly associated with women's gender roles. Additionally, the lower stigma around separation and divorce does not prevent psychological, financial and physical violence being perpetrated by husbands and other in-laws.

Unlike other research sites, especially Bokhtar and, to a lesser degree, Dushanbe, sustaining families financially is not considered the responsibility of men alone. As such, in addition to caregiving roles and household chores, there are also expectations that women contribute financially to the family budget in Khorog. In the absence of adequate financial income and the lack of formal and informal employment opportunities, women living with disabilities and women parenting children with disabilities can be targets of humiliation and abuse due to financial dependency. According to FGD participants, stronger community ties between residents of Khorog, the town's relative homogeneity and small social circles (i.e. everyone knowing one another) can create safe spaces within the community for people living with disabilities and reduce the risk of violence being perpetrated by people outside the family circle; however, these do not prevent violence being committed within the family circle, an extremely sensitive topic.

Bokhtar

Levels of disability-related violence against women and girls in Bokhtar are higher and more severe than in Dushanbe and Khorog. There are certain historical developments which have contributed to higher levels of VAWG in Khatlon oblast. During the Tajik Civil War, the majority of the hostilities and violence against civilians, including gender-based violence, occurred in this part of the country.³⁹ The highest percentage of ever-married women who have ever experienced physical, sexual, or emotional violence by spouse is in Khatlon region.⁴⁰ Female interview participants in Bokhtar reported experiences of violence that led to divorce either due to their own disabilities or the disabilities of their children. Two of the four interviewed women had been forced to become second wives for their own and their children's financial security, and for shelter and protection from violence committed by the wide community, including sexual violence.

For men, the stigma and stress associated with the lack of possibilities to fulfil their roles as family breadwinners was universal. Unlike in Khorog, the FGD and interview participants among men and women of all ages underlined the strict division of responsibilities between men and women appropriated and condoned by society, with men being fully responsible for the financial wellbeing of the family. Thus, men living with severe disabilities must sustain their families, including through begging in the market and streets, even if their spouses can earn income.

Access to services is not adequate for men and women living with disabilities, and the lack of transportation and relevant infrastructure creates serious barriers for the mobility and inclusion of people living with disabilities. There are, comparably, more VAWG-prevention interventions funded through international donors available for women and girls in Bokhtar and nearby areas than in Khorog. As such, more reports and data are available on the dynamics and experiences of SGBV in Bokhtar.

39 Amnesty International, *Violence is not just a family affair; women face abuse in Tajikistan*, London, 2009, <https://www.amnesty.org/download/Documents/48000/eur600012009en.pdf>

40 Statistical Agency under the President of the Republic of Tajikistan, 2018, Op. cit.

Conclusions

The research demonstrated a strong link between disability and violence against women and girls living with disabilities and women parenting children with disabilities. This is not an unknown issue, but is not being systematically addressed by the national authorities, civil society or international actors focused on preventing violence against women and girls in Tajikistan.

Married women with disabilities facing domestic abuse generally do not seek help outside their close family circles. Due to their increased vulnerability and dependence on family members, they are more likely to tolerate violence and abuse.

To conform with accepted social norms on marriage and deference (and indeed servitude) to in-laws, women with disabilities try to take over all the responsibilities usually assigned to women without disabilities, even if affects their health negatively.

Young women with disabilities face significantly lower chances of marriage as a result of strictly enforced patriarchal gender norms and expectations. Often, women with disabilities marry either men with disabilities or become second wives of significantly older men as a means of securing financial stability, status and fulfilment of their socially assigned roles as women (i.e. marriage and childbearing).

Social isolation of women with disabilities and women with children with disabilities is common in all areas. Reasons given for this include poorly developed infrastructure and inadequate transportation which have a negative impact on physical mobility; the need to be accompanied and the resulting burden on family members; associative stigma related to disability among family members; the time needed to take care of a disabled child for mothers; family members and others limiting possibilities for socialisation; rigid gender norms; restricted gendered spaces; forced confinement in the family home due to safety (and other) concerns. The resulting isolation restricts the education, potential employment and personal lives of young women living with disabilities, and leaves them feeling lonely, worthless and hopeless.

Mothers of disabled children experience anxiety, depression and hopelessness when faced with the daily challenges and discrimination of providing their children with adequate education and care. There are a limited number of schools which are inclusive of children with disabilities. Therefore, mothers struggle to negotiate with schools, teachers and other parents to accommodate their children with special needs.

The focus of the research was VAWG; however, during interviews with men, several issues related to the intersection of masculinities and disability, stigma and discrimination emerged. Disabled men have internalised the social stigma associated with their disability and struggle with depression and anxiety as a result. Men living with disabilities and parenting disabled children were not very comfortable sharing personal histories of stigma and discrimination; Tajik constructs of masculinity dictate that men are expected to deal with stigma and discrimination silently and on their own. That said, there were several occasions where the safe spaces created for male participants allowed them to be more confident and secure in sharing their experiences, including on sexuality.

Recommendations

This study is envisaged as a baseline pre-intervention analysis and be comparable with data from Alert's previous SGBV programming to design an effective project to reduce VAWG with disabilities and women with disabled children. The following recommendations are, therefore, aimed primarily at Alert:

- Different regions of Tajikistan require nuanced approaches for SGBV research or VAWG-prevention interventions. Despite generally similar cultural characteristics and norms, different locations and regions of Tajikistan have important contextual differences and dynamics to consider when planning to prevent VAWG. This is especially true with regard to urban/rural division but also, and more importantly, to under-researched regions, such as GBAO, to dismantle stereotypes and misconceptions, and avoid generalisation.
- Future research on intersectionality and violence is crucial for Tajikistan and its high levels of violence within the family. More thorough analyses of the factors that feed these alarming levels of violence are required to ensure that VAWG-prevention initiatives better take into account the complex, nuanced and intertwined factors that underpin the social norms pertaining to both men and women that enable and condone violence. This will complement the need for an accurate evidence base on which to develop more effective, inclusive national policy on VAWG prevention and more effective internationally funded VAWG-prevention programmes.
- In interventions that aim to support children with disabilities in Tajikistan, it is extremely important to include the needs and vulnerabilities of the mothers of these children in stakeholder analysis and during implementation. The research found that mothers parenting disabled children are extremely vulnerable to different forms of SGBV and experience higher rates of depression and suicidality.
- Knowledge on the intersectionality between masculinity, violence and disability is limited; in future programming this needs to be analysed in greater detail.

This report is also a resource for other national and international stakeholders working to prevent VAWG in Tajikistan. Firstly, it can go some way to correcting the present gap in VAWG programming in Tajikistan regarding women with disabilities and women parenting children with disabilities; secondly, it can act as part of a wider global call to action for inclusion of these vulnerable groups into national and international discourse on VAWG. National and international stakeholders working to prevent VAWG in Tajikistan should:

- **Recognise both disabled women and girls, and women with disabled children as an especially at-risk sub-group:** SGBV-reduction programming must recognise the increased levels of vulnerability of women and girls with disabilities, and women with children with disabilities. Their inclusion should be viewed as of paramount importance. Furthermore, all stages of the project cycle – from proposal development and initial research, to design, to inclusion in programme activities, to dissemination of findings – must consider the extent to which the unique needs of these two groups are integrated. Overall, the experiences of both women with disabilities, and women with children with disabilities, adds to the existing vulnerabilities of Tajik women.

- **Actively mitigate for systemic barriers to their participation:** Both disabled women and women parenting disabled children face additional barriers to participating in SGBV programming, due to greater time and resource poverty. For example, this research showed how women parenting disabled children spend most of their time taking care of their children, looking for treatment options, schooling opportunities, or other ways to integrate them into society and to socialise with their peers. It also highlighted how mothers with disabled children are frequently unable to financially sustain themselves. These time and financial constraints place frequently insurmountable barriers to participating in community-based activities, including SGBV-reduction programming in the community. To guarantee participation of this especially vulnerable group of Tajik women, SGBV-reduction programming must find ways to offer potential beneficiaries support. While the barriers faced by these women will be highly context specific, options including childcare support, travel arrangements, financial reimbursement should be explored.
- **Specifically address the stigmatisation of disabilities within SGBV-reduction programming:** The research revealed a high degree of stigmatisation of both men and women, and girls and boys living with disabilities in all three locations. For SGBV-prevention programming to effectively meet the needs of this vulnerable sub-group, it must explicitly incorporate modules or components that explicitly seek to shift stigma around disabilities. It is tentatively suggested that linking this initiative with the social norm change dimensions of programming might be most effective, particularly in direct relation to explorations of gender norms and expectations.
- **Develop effective outreach mechanisms to engage with beneficiaries with disabilities, or women with disabled children:** The current research outlined how existing services in the country available to women facing different forms of violence lack inclusivity in terms of addressing the specific needs of women living with disabilities or women parenting children with disabilities. Comprehensive outreach activities must be incorporated into SGBV-reduction programming, since there are notably low levels of help-seeking behaviours among affected women with disabilities.

Building upon issues identified within the current research, future research by national and international stakeholders to strengthen SGBV reduction programming should focus on:

- **How to mitigate systemic barriers to participation of women with disabilities, and women with children with disabilities, in the Tajikistan context:** While the current research highlights the barriers to participation faced by women with disabilities and women with disabled children, it was not within the scope of the work to expand on these challenges or outline potential solutions. Exploring the precise nature of these challenges and the ways in which these women can be supported to participate in SGBV-reduction initiatives in the community is a crucial next step.
- **How the experiences of men with disabilities in Tajikistan have an impact on the nature and prevalence of SGBV:** The current research has found that men with disabilities often marry women without a disability and are simultaneously stigmatised as a result of hegemonic masculinity norms and their increased difficulties in achieving the primary responsibility of a Tajik man – to provide for their families and protect them from any outside threat. This research has raised questions round how this experience affects SGBV dynamics and prevalence within these homes.

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