





POLICY BRIEF

Gender-responsive Financing of Personal Assistants for Persons with Disabilities in Kosovo

Prepared by Ernera Dushica and Nicole Farnsworth for the Kosovo Women's Network

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Introduction

People with disabilities have higher rates of unemployment, economic inactivity, and lack social support compared to people without disabilities. Depending on their disability, some require support from a personal assistant every day, or even 24 hours per day. Governments can support persons with disabilities through personal assistance schemes, enabling their increased participation in society. While official gender-disaggregated data has not always been available, according to traditional gender roles, women historically have tended to serve as caretakers more often than men. Thus, budgeting appropriately for caretakers has broader implications for gender equality and specifically women's economic wellbeing, particularly in instances where care work has not been treated officially as labour, such as in Kosovo.

As a member of the Gender Budget Watchdog Network (GBWN) in the Western Balkans (WB) and the Republic of Moldova, the Kosovo Women's Network (KWN) has analysed the legal framework pertaining to personal assistants in Kosovo and government financing of this scheme in 2019-2021 from a gender perspective. A similar assessment has been conducted in all WB countries and the Republic of Moldova, using a shared regional methodology, supported by the Austrian Development Agency and Swedish International Development Cooperation Agency.³ Secondary data was collected through a review of the Kosovo legal framework, including the Budget; and primary data was collected through data requests, interviews, and a focus group with KWN member organisations that work with diverse people with disabilities across Kosovo.

³ The methodology for this analysis was prepared by Keystone Moldova, a GBWN partner organisation.















¹ United Nations, <u>Disability and Employment</u>. Department of Economic and Social Affairs: Disability, 2007.

² ILO, Women and the Future of Work – Taking care of the caregivers, 2015.

The resulting findings and recommendations presented in this policy brief seek to inform discussions surrounding important, current political and legal processes, including the forthcoming respective draft laws for Assessment, Recognition of Status, Benefits, and Services for Persons with Disabilities; for Social and Family Services; on amending and supplementing the Law No. 04/L-131 on State Funded Pension Schemes; and annual Kosovo budgets.

International Requirements

The United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) is an international human rights treaty ratified by the UN in 2008. In February 2011, it was ratified by 98 state parties and the European Union (EU). The Convention affirms that all persons with all types of disabilities are entitled access to basic human rights. More specifically, personal assistants schemes are foreseen by many internationally recognised conventions and treaties. Article 19 of the UN CRPD explains the importance of personal assistants for independent living and it obliges states, "to ensure access to a range of in-home, residential, and other community support services, including personal assistance necessary to support living and inclusion in the community and to prevent isolation or segregation from the community". Personal assistants are essential for persons with disabilities to feel integrated in their communities.

Additionally, the UN CRPD Article 6 recognises the unique multiple inequalities and barriers that women with disabilities may face and calls on states to provide additional protective services:

- I. States Parties recognize that women and girls with disabilities are subject to multiple discrimination, and in this regard shall take measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms.
- 2. States Parties shall take all appropriate measures to ensure the full development, advancement and empowerment of women, for the purpose of guaranteeing them the exercise and enjoyment of the human rights and fundamental freedoms set out in the present Convention.⁶

While Kosovo is not yet an EU Member State, it has made clear commitments to joining the EU and thus has reason to strive towards fulfilling commitments made by the EU. The European Commission recently adopted the European Disability Strategy 2021-2030, which aims to empower individuals with disabilities and eliminate barriers. Additionally, in the European Commission's Gender Action Plan (GAP) III, an indicator is: "addressing intersectionality of gender with other forms of discrimination", which arguably would include addressing the intersectional discrimination that women with disabilities may face. More explicitly, GAP III states: "The rights of women with disabilities should be at the core of the future strategy on the rights of persons with disabilities for the coming years" 2021-2030.

For Kosovo to meet its EU accession goals, Kosovo's legal framework arguably needs to be harmonised with definitions established under the UN CRPD and in line with European Commission commitments.

Kosovo's Legal Framework

Kosovo's legal framework does not include a consistent definition of disability in accordance with the UN CRPD. The Law on Amending and Supplementing the Law on the Training, Professional Rehabilitation and Employment of Persons with Disabilities defines disability as a "restriction in access

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⁴ United Nations, Convention on the Rights of Persons with Disabilities (CRPD).

⁵ Ibid.

⁶ Ibid.

⁷ European Disability Strategy 2021-2030.

⁸ European Union, <u>EU Gender Action Plan III:</u> An Ambitious Agenda For Gender Equality And Women's Empowerment in EU External Action, 2020.

⁹ Ibid.

and usual activities in everyday life of a person as a result of physical, sensory, intellectual or mental impairments that prevent him/her to participate in everyday life activities." ¹⁰ The definition is limited to three types of disability and does not define other types. Psychological disabilities, autism, and down syndrome are not included explicitly in this definition. The vague definition of disability contributes to unclarities that may hinder persons from accessing personal assistance.

The Law on Family and Social Services, which provides for direct social care services, does not contain any definition of disability. This narrows the scope of who is eligible for personal assistant funding. The current laws do not provide any definitions or provisions for women with disabilities and do not adequately integrate intersectionality into the provision of services for persons with disabilities. Thus, the laws are not aligned with the intentions of the UN CRPD.

Personal assistance is not defined explicitly in Kosovo's legal framework. Rather, the Law on Social and Family Services defines "Direct Social Care" as "the provision of help with domestic duties, personal care, mobility, communication or supervision. It can be provided in a person's own home, in a specialist day centre or in a residential home." According to this Law, a person in need is also a "person" in the territory of Kosovo, regardless of status or place of origin, that needs social services because of physical illness or disability. The application process for direct social care is not detailed in the Law, but it appears that the Centre for Social Work (CSW) in each municipality is responsible for identifying persons who are eligible for receiving social care and for coordinating social care. According to the Law on Social and Family Services, CSWs in each municipality are responsible for maintaining a list of those in need of social services:

Centres for Social Work with the consent of the individuals concerned will maintain a register of people in need of social services who are resident in their territory and who lack family or other community support and who have difficulty maintaining themselves, or are at risk of self-neglect, exploitation or abuse by others or of any other form of harm. The Centre for Social Work shall arrange for those people in need who are on this register to be visited on a regular basis by a responsible person, in order to monitor their safety and well-being.¹³

The government is responsible for monitoring the quality of direct social care services under Social and Family Services, which is regulated by the Department of Social Welfare. While this Department used to be located within the Ministry of Labour and Social Welfare (MLSW), amid a government reshuffling in 2021, the Department is now within the Ministry of Finance, Labour, and Transfers (MFLT). The Law on Social and Family policies has established a council that is responsible for the maintenance of professional standards and discipline in the area of Social and Family Services. This Council acts as the licensing and registration authority for professionals working in this field. According to Article 5.3 of this Law, the Council is responsible for:

Holding the register of Social and Family Services professionals who are licensed to practice in Kosovo. It has authority to decide who may hold a license, and who may hold a license as a specialist Social and Family Services professional. It determines what continuing professional development is required by Social and Family Services professionals.¹⁵

Thus, professionals providing direct social services must be licensed and registered by this Department. Professionals working in municipalities as well as in non-governmental organisations (NGOs) may provide direct social care services. However, to date, neither the Law nor secondary legislation has

¹⁰ Law on Amending and Supplementing the Law No. 03/L-019 on Training. Professional Rehabilitation and Employment of Persons with Disabilities.

¹¹ Law on Social and Family Services.

¹² Ibid, Article 1.3, e.6.

¹³ Ibid, Article 7, "Role of the Centre for Social Work".

¹⁴ Ibid, Article 5.2.

¹⁵ Ibid, Article 5.3.

specified the minimum expertise and professional requirements that personal assistants must have to be licensed and provide these services.

The Law on Social and Family Services also states the obligations of the Municipality in overseeing social services, usually through its relevant Directorate within each municipality: "Directorates deliver Social and Family Services within their territory through the activities of Centres for Social Work or by providing financial or other assistance to NGOs to enable them to do so". ¹⁶ The Directorate within the Municipality is responsible for ensuring that CSWs or NGOs are providing direct personal care for all who are eligible. The Law on Social and Family Services includes a provision regarding the importance of NGOs in providing necessary social services; NGOs can provide social services to vulnerable groups through a contract with the Municipality or through their own initiatives. ¹⁷ To provide these services, these NGOs must first be licensed by the Department of Social Welfare and adhere to all regulations, directives and procedures relating to their activities as laid down by the Ministry. ¹⁸ To date, no specific minimum criteria exist for NGOs or their staff members providing personal assistants.

Two key laws relevant to persons with disabilities and personal assistants presently are under review for amendment, the Draft Law for Social and Family Services; and Draft Law on amending and supplementing the Law on State Funded Pension Schemes. Meanwhile, a new Draft Law for Assessment, Recognition of Status, Benefits and Services for Persons with Disabilities will be soon available for public consultation. MFLT representatives anticipate that the legal amendments and secondary legislation to follow will establish clearer, more inclusive definitions regarding which persons with disabilities will qualify for professional assistants and the minimum qualifications that personal assistants will need to fulfil to be licensed. Indeed, clarifying legal definitions, ensuring access for diverse persons with disabilities based on their needs, and establishing clear minimum qualifications within the legal framework for personal assistants will all be essential for ensuring quality services in the future.

The Kosovo Program for Gender Equality 2020-2024 also recognises the differing needs of women with disability as well as the care work performed by women for people with disability. One of its activities towards increasing the employment of women and girls is the "provision of access to quality social and family services, residential care centres for day care for the elderly and people with disabilities". The Program does not refer explicitly to personal assistants, however, in terms of improving women with disabilities' access to the labour force. Nor does the National Strategy on the Rights of Persons with Disabilities in the Republic of Kosovo mention personal assistants.²⁰

As per the Regulatory Impact Assessment, the Government of Kosovo should ensure that a Gender Equality Impact Assessment is conducted to inform all draft laws.²¹ This Assessment is important for identifying the ways in which a law may impact diverse women and men differently, so as to inform the drafting of a law that will contribute to furthering gender equality. The Agency for Gender Equality in the Office of the Prime Minister of the Republic of Kosovo has provided clear guidance regarding what this Assessment should contain.²² Yet, the Government of Kosovo seems not to have conducted a Gender Equality Impact Assessment to inform the aforementioned draft laws yet, which is needed prior to finalising the laws.²³

Personal Assistance Users

Kosovo does not have official data on the total number of persons with disabilities since not all are registered officially. However, based on estimations, more than 200,000 people with disabilities live in Kosovo, approximately 10% of the population²⁴.

¹⁶ Ibid, Article 6.

¹⁷ Ibid. Article 8.

¹⁸ Ibid. Article 8.3.

¹⁹ KWN interview with MFLT official, April 2022.

²⁰ Kosovo Office for Good Governance, National Strategy on the Rights of Persons with Disabilities in the Republic of Kosovo 2013-2023.

²¹ Government of Kosovo, <u>Better Regulation Strategy 2.0 for Kosovo 2017-2021</u>.

²² Agency for Gender Equality, <u>Gender Equality Impact Assessment Manual</u>.

²³ KWN interviews with officials, April 2022.

²⁴ Interview with the Department of Pensions, Ministry of Finance, Labour, and Transfers.

Two main categories of persons with disabilities are eligible to apply for personal assistants: paraplegic and tetraplegic (PTTP) beneficiaries and blind persons. Both of these categories are further divided into two groups. PTTP Group I includes persons with an 80% or more degree of disability, and Group 2 includes persons with a degree of disability lower than 80%, based on a medical report. Whereas, Group I for the category of blind persons includes those with sight 0 to 0.2, and Group 2 includes those with sight over 0.2, based on a medical report. Both groups from both categories receive a disability pension from the government. However, only Group I beneficiaries from each category are eligible for personal assistants.

Persons in need of personal assistants first must apply for pensions within their municipalities. A Health Committee comprised of health experts and representatives of MFLT review these applications. The MFLT Division for Pensions is responsible for distributing disability pensions for both those who qualify for personal assistants and those who do not. Based on medical reports, the Division decides whether Group I beneficiaries from the aforementioned categories qualify for personal assistants. The pension for PTTP persons without personal assistants is €150 per month and €375 in total for those requiring personal assistants, anticipating that persons with disabilities would receive €225 and their personal assistants would receive €150 per month. Blind persons receive €125 per month and €250 if they require a personal assistant, suggesting a compensation of €125 for the personal assistant per month. The government distributes monthly the full amount of pension and compensation for the personal assistant to the registered, qualifying person with a disability. Thus, personal assistants do not receive any payment directly from the government. The person with a disability is responsible for selecting their personal assistant, whether the person is a family member or not.

There were 3,831 officially registered persons with disabilities who had personal assistants in Kosovo in 2019, 3,629 in 2020, and 3,499 in 2021 (see Table 1). Consistently, women have comprised approximately 45% of personal assistant users, whereas men have comprised 55%.

Table 1. Total Beneficiaries with Personal Assistants, 2017-2021										
Year	PTTP	Blind	# and % of Persons with Personal Assistants by Gender							
			Women	%	Men	%	Total			
2019	2,238	1,593	1,717	44.8%	2,114	55.2%	3,831			
2020	2,161	1,468	1,619	44.6%	2,010	55.4%	3,629			
2021	2,108	1,391	1,576	45.0%	1,923	55.0%	3,499			

Table 1. Total Beneficiaries with Personal Assistants, 2019-2021

Several persons who may need personal assistants, like those with mental disabilities, other physical disabilities, or the deaf are not mentioned explicitly in the legal framework as eligible. While ostensibly they may apply with the claim that they have a disability of at least 80%, the legal framework does not clearly provide for them to receive a disability pension or personal assistant.

Personal Assistants

Persons with disabilities chooses their own personal assistants. The personal assistant can be a family member or someone suggested by the CSW. Regardless, anyone serving as a personal assistant must be contracted by the person with a disability. Contracting is done through a notary office and the government is not engaged in this process. Thus, the government does not employ anyone to serve as a personal assistant. Nor does it assign personal assistants, though the CSW can make referrals.

As mentioned, the legal framework currently does not require personal assistants to have any specific qualifications to perform this work; anyone can become a personal assistant. It is important that persons with disabilities have the right to select their own assistants so that they feel comfortable with those persons. Meanwhile, in some situations, personal assistants reportedly have not had sufficient qualifications for this work, which has led to physical injury, burnout, and other challenges.²⁵

Depending on the level of disability, some persons with disabilities require personal assistants for only a few hours during the day, while others require 24-hour care. Notably, the compensation provided to personal assistants is the same regardless of the number of hours they work or that they

²⁵ KWN focus group with CSOs working with people with disabilities, April 2022.

must be available to assist persons with disabilities. The fact that personal assistants are not treated officially as employees leaves ample opportunity violations of their labour rights, including substantial unrecognised overtime work. Moreover, the amount that individual personal assistants receive does not cover their basic expenditures. Their compensation is less than the minimum wage in Kosovo (\in 170). As their work is not treated as labour, personal assistants do not receive any pension contributions. This can contribute to their poverty later in life, particularly if they are unable to take on other work because they provide full-time care. Such low compensation and poor working conditions for personal assistants contributes to difficulties in finding persons willing to sacrifice their time, physical health, and financial wellbeing to provide these services. ²⁶

KWN requested data from MFLT on the number of women and men engaged as personal assistants, but never received it. MFLT may not have this data available because the person with a disability receives the payment and then pays the contracted personal assistant directly; the funds are not transferred from MFLT. Considering traditional gender norms and their role as caregivers, qualitative evidence suggests that women are more prone to serve as personal assistants than are men.²⁷ Often family members, including mothers and sisters, care for persons with disabilities. Non-recognition of personal assistants' labour as formal employment thus potentially contributes to women's staggeringly low employment rates in Kosovo (i.e., only two in ten women are formally employed);²⁸ and to gender inequalities, particularly women's comparatively weaker economic position within families and the society. Again, the informal work of personal assistants may also contribute to the feminisation of poverty among retired women, as they have not paid into the pension savings system.

Transforming personal assistants' currently informal labour into formal labour could contribute directly to implementing government commitments to fighting the informal economy. ²⁹ Moreover, it would address recommendations made in the EU Kosovo Report related to addressing informality, increasing employment, safeguarding labour rights, and furthering gender equality ³⁰. Most importantly, by providing better quality care, this could facilitate persons with disabilities' "full and effective participation in society on an equal basis with others" in accordance with the CRPD.

Personal Assistance Financing

Due in part to the fact that Kosovo does not use programmatic budgeting, Kosovo does not have a specific budget line for personal assistants or related services. Pensions for people with disability and their personal assistants is budgeted for by the MFLT Division of Pensions. The main budget lines for this are the budget line "Pensions for Disability", budget line "Compensation for the Blind", and the budget line "Paraplegics and Tetraplegics". The amounts allocated to these budget lines are presented in Table 2. These are all budgeted in the expenditure category of Subsidies and Transfers.

Table 2. Budget Allocated for Pensions for Disability, Compensation for the Blind, and Paraplegics and Tetraplegics

Year	Pensions for Disability	Compensation for the Blind	Paraplegics and Tetraplegics
2019	17,100,000	5,500,000	12,401,000
2020	17,100,000	5,500,000	12,401,000
2021	17,650,000	5,400,000	11,000,000

Table 3 illustrates the number of beneficiaries of disability pensions who had personal assistants in 2019 - 2021 by the genders of persons with disabilities. While the amount provided to personal assistants can be calculated, it cannot be disaggregated by gender due to insufficient information.

²⁷ Ibid.

²⁶ Ibid.

²⁸ KAS, <u>Labour Force Survey</u>, Q1 2021.

²⁹ Ministry of Finance, National Strategy of the Republic of Kosovo for the Prevention and Combating of Informal Economy, Money Laundering, Terrorist Financing and Financial Crimes 2019-2023.

³⁰ EU, Kosovo Report 2021, pg. 6, 28, 51, 85, 95.

Table 3. Beneficiaries of Disability Pension with Personal Assistants Compensation by Gender³¹

						· /							
	PPTP							Blind Persons					
	Women			Men			Women			Men			
Year	#	Amount	%	#	Amount	%	#	Amount	%	#	Amount	%	
2019	1006	€383,125	45.I	1232	€465,625	54.9	711	€188,310	43.8	882	€241,532	56.2	
2020	970	€363,720	44.9	1191	€445,875	55,1	649	€160,375	44.1	819	€202,850	55.9	
2021	955	€370,275	46	1153	€434,595	54	621	€159,050	43.9	770	€202,925	56.1	

As men comprise the majority of pension recipients, they consistently have received a higher percentage of the budget than have women. As no thorough gender analysis has been conducted, it is difficult to know the reasons why more men than women are benefitting from these transfers. Potentially more men than women have disabilities, or perhaps women with disabilities have less access to these services. Only further gender analysis could shed light on the level of need for such services among women and men.

Arguably, personal assistants should be compensated at least at the minimum wage and based on the hours required for their care work, determinable during the application process in accordance with the needs of the person with disabilities, rather than based on universal flat rate. Given the qualifications that personal assistants should have for this work, it would be more appropriate to pay personal assistants in accordance with the average wage. Table 4 estimates the costs that would be affiliated with more appropriate government financing of personal assistants, based on the number of beneficiaries in 2021, previously presented in Table 1. If the government increases the payment of personal assistants to match the current minimum salary, the total estimated cost would amount to approximately €7,137,960 per year. This would require an increase to the budget in the amount of €1,257,060 annually compared to the current budget.

Table 4. Estimated Costs for Government Financing of Personal Assistants

	Esti	mated Co	st per Perso	on		Total			
	PTTP		Blind		PTTP		Blind		PTTP & Blind
	Per month Per ye		Per month Per year		Per month	Per year	Per month Per year		Per year
Current flat pay rate	€150	€1,800	€125	€1,500	€316,200	€3,794,400	€173,875	€2,086,500	€5,880,900
Current minimum salary	€170	€2,040	€170	€2,040	€358,360	€4,300,320	€236,470	€2,837,640	€7,137,960
Planned minimum salary	€250	€3,000	€250	€3,000	€527,000	€6,324,000	€347,750	€4,173,000	€10,497,000
Average gross salary	€484	€5,808	€484	€5,808	€1,020,272	€12,243,264	€673,244	€8,078,923	€20,322,187

Further gender analysis, however, remains required to better understand potential costs. Some persons with disabilities may only require part-time personal assistance, thereby potentially reducing the compensation for those not providing eight hours of care. Meanwhile, some persons with disabilities require 24-hour care, which would require up to three personal assistants per person to safeguard caretakers' labour rights. Additional persons with disabilities who have been left out of these schemes but deserve equal treatment, such as deaf or mentally disabled persons, must also be considered to arrive at accurate budget estimates. Following further gender analysis, including assessment needs, the government will need to adjust the budget.

Recommendations

• Amend existing laws such as Law No. 02/L-17 on Social and Family Services, Law No. 2003/23 on Disability Pensions, Law No. 05/L-021 on the Protection from Discrimination, and the annual laws on Budget Appropriations for the Republic of Kosovo (each year), to incorporate consistent, internationally recognised definitions of disability. Ensure that these use an intersectional approach to gender, attending to the potentially different needs of diverse women and men with disabilities, as well as intersections with ethnicity, age, and other factors that could hinder access to appropriate care services.

³¹ Official Data from MFLT Division of Pensions.

- Prior to amending and adopting laws, ensure that a Gender Equality Impact Assessment ³² is conducted as part of the required Regulatory Impact Assessment included in the Better Regulation Strategy 2.0 for Kosovo.³³ Assess the number of hours of care that personal assistant users require to better assess budget implications of fairly compensating their labour. Examine underlying reasons as to why men have tended to use personal assistants more than women, identifying any potential challenges that women may face in accessing these services.
- Review the eligibility criteria for personal assistance, as many more persons may need personal assistance than who currently receive it, considering that persons with disabilities that amount to more than 50% also may require personal assistants to participate actively in society.
- Following adoption of laws, specify in secondary legislation the minimum experience, expertise, and qualifications that personal assistants must have to provide qualified services, such as via obligatory training and qualification testing. Regulate continuous capacity-building for personal assistants. Persons should still be selected by and in agreement with persons with disabilities.
- Establish a clear, permanent budget line specifically for financing the Personal Assistance Scheme, distributed to personal assistants who become certified as assistants. Based on aforementioned gender analysis, estimate the actual budget needed considering time required from personal assistants. Meanwhile, increase the amount budgeted per personal assistant from the current €150 for personal assistants of PTTP persons and €125 for blind persons to match at least the minimum salary (currently €170) and ideally the average salary (€484). Plan for likely future inflation.
- While persons with disabilities could still distribute the payments to minimise transfer costs, the government could withhold automatically the 10% pension contribution and place it in the registered personal assistant's pension fund, preventing poverty later in life.
- In order to cover the additional costs of personal assistants, consider improving collection of related revenues, such as implementing increased fines for businesses not ensuring accessible physical locations and services in accordance with laws; those not employing persons with disabilities as per the law³⁴; and those found to have discriminated against persons with disabilities or violated their rights. Consider also imposing taxes on luxury products, such as automobiles, as per KWN's recommendations elsewhere³⁵.
- Throughout the process of drafting the aforementioned laws, including budgets, and secondary legislation ensure meaningful consultation with women's rights organisations working with diverse women and men with disabilities, towards identifying issues and addressing them through the legal framework.

³² See: Agency for Gender Equality, <u>Gender Equality Impact Assessment Manual</u>.

³³ Office of the Prime Minister, <u>Better Regulation Strategy 2.0 for Kosovo 2017-2021</u>.

³⁴ Law No. 03 / L-019 on Training, Vocational Rehabilitation and Employment of Persons with Disabilities states that for every 50 employees, one person with disabilities must be employed.

³⁵ KWN, Gender Responsive Taxation: Removing Taxes for Essential Menstrual Hygiene Products, May 2022.