

**PERSONAL ASSISTANCE –
COMPARATIVE ANALYSIS OF THE LEGISLATIVE AND INSTITUTIONAL FRAMEWORK
IN THE AREA OF SOCIAL SERVICES**

Abstract: The paper presents the findings of an external assessment of the current regulatory framework of existing social services and associated services as well as the current regulatory framework regarding the area of social services and employment of persons with disabilities aiming at introducing personal assistance, carried out in the period February-June 2017. The paper aims at reflecting upon the potential future role of the system for personal assistance service provided for persons with disabilities in the Republic of Macedonia, and to estimate the extent to which legal amendments needs to be developed in facilitating this system in the national legislation. An additional purpose is to provide recommendations in a step-by-step approach for initiating the establishment of the system and the legal status, financing, responsibilities and oversight of the work of the service providers and personal assistants, as integral part of the system.

Key words: *legislation, personal assistance, person with disabilities*

ПОПОСКА Жанета

**ПЕРСОНАЛНАТА АСИСТЕНЦИЈА –
КОМПАРАТИВНА АНАЛИЗА НА ЗАКОНОДАВНАТА И ИНСТИТУЦИОНАЛНАТА
РАМКА ВО ОБЛАСТА НА СОЦИЈАЛНИТЕ УСЛУГИ**

Апстракт: Трудот ги презентирани наодите од надворешната проценка на тековната регулаторна рамка на постоечките социјални услуги и придружни услуги, како и актуелната регулаторна рамка во областа на социјалните услуги и вработувањето на лицата со попреченост, со цел воведување на услугата на персонална асистенција, спроведена во периодот февруари-јуни 2017 година. Целта на трудот е да ја претстави потенцијалната идна улога на системот за персонална асистенција за лицата со попреченост во Република Македонија и да го процени степенот до кој треба да се воведат законски измени во олеснувањето на воведување на овој систем во националното законодавство. Дополнителна цел е да се дадат препораки воведувајќи чекор-по-чекор пристап во иницирањето на воспоставување на овој систем и неговиот правен статус, финансирање, одговорности и надзор над работата на давателите на услуги и персоналните асистенти, како составен дел на системот.

Клучни зборови: *законодавство, персонална асистенција, лица со попреченост*

Introduction

The paper understands the Personal Assistance in line with the European Network on Independent Living definition elaborated here. Namely, personal assistance is a tool which allows for independent living and is purchased through earmarked cash allocations for disabled people, the purpose of which is to pay for

any assistance needed. Personal assistance should be provided on the basis of an individual needs assessment and depending on the life situation of each individual. The rates allocated for personal assistance to disabled people need to be in line with the current salary rates in each country. As European Network on Independent Living states “[a]s disabled people, we must have the right to recruit, train and manage our assistants with adequate support if we choose, and we should be the ones that choose the employment model which is most suitable for our needs.”¹ Personal assistance allocations must cover the salaries of personal assistants and other performance costs, such as all contributions due by the employer, administration costs and peer support for the person who needs assistance.

The paper assessing the regulatory framework in the area of social services and employment of persons with disabilities focuses on the following three main legal questions: (i) existing national legal framework in relation to personal assistance service; (ii) role of the service provider in the system for personal assistance service; and (iii) role of the personal assistant in the system for personal assistance service. In addition, international standards in relation to personal assistance service were also assessed and conclusions and recommendations were drafted that should serve as point of reference in designing of specific proposals regarding the amendments to the present Law on Social Protection (LSP) and designing of specific proposals regarding the amendments to the present by-laws.

1. International standards in relation to personal assistance service

1.1. United Nations Convention on the Rights of Persons with Disabilities

The foundation of an independent and inclusive life in the community for persons with disabilities is provided for by the general principles of the Convention on the Rights of Persons with Disabilities (UNCRPD) from 2006, in particular the principles concerning full and effective participation and inclusion in society, and respect for the individual’s inherent dignity, autonomy and independence (Art. 3). According to the Office of the United Nations High Commissioner for Human Rights, full enjoyment of the right to live independently in the community is both the result of, and a precondition for, the combating of stereotypes and prejudices relating to persons with disabilities and the promotion of awareness of their capabilities and contributions to society (Art. 8). Non-discrimination (Art. 5) and accessibility (Art. 9) are essential to ensure that community services and facilities for the general population are available on an equal basis to persons with disabilities and respond to their needs². Furthermore, the Convention recognizes that persons with disabilities have the right to equal recognition before the law (Art. 12) as essential for the effective realization of the right to live independently in the community, to make choices and to have control over their everyday lives, on an equal basis with others³. Inclusive education systems, accessible general and specific health services, the availability of habilitation and rehabilitation programmes, adequate standard of living, and equal opportunities in the open labour market are other examples of interconnected rights that contribute significantly to people living independently in the community (Arts. 24– 28).

More specifically, Article 19 of the Convention on the Rights of Persons with Disabilities provides for the equal right of all persons with disabilities to live independently and be included in the community, with choices equal to others.⁴ The foundation of that right is the core human rights principle that all humans

¹ See: European Network on Independent Living, *Key definitions on Independent Living*, 2013, available from www.enil.eu/policy/.

² See: Human Rights Council, Thematic study on the right of persons with disabilities to live independently and be included in the community, Report of the Office of the United Nations High Commissioner for Human Rights, A/HRC/28/37, 2014, para. 7.

³ See: Committee on the Rights of Persons with Disabilities, General comment No. 1 (2014) on equal recognition before the law, CRPD/C/GC/1, 19 May 2014, para. 44.

⁴ Article 19 of the Convention on the Rights of Persons with Disabilities is connected to provisions in other human rights treaties, including the International Covenant on Civil and Political Rights – Arts. 9, 12, 16 and 17, the International Covenant on Economic, Social and Cultural Rights – Arts. 11 and 12 and the Convention on the Rights of the Child – Arts. 2, 9, 16, 20, 23, 25 and 27. The right to live independently and to be included in the community has also been recognized in regional human rights documents, such

are born equal in dignity and rights, and that all life is of equal worth. This article as many others in the Convention elaborated above, are clearly shifting the paradigm existing from before, stipulating the transition from a medical and charity approach to disability, whereby persons with disabilities were seen as passive objects of care, to a human rights-based approach and subjects of rights. Thus, it is essential for fulfilment of all rights in the Convention the right of persons with disabilities to participate in all areas of mainstream community living, arguing that the capacity of all individuals to make choices in that regard must be acknowledged and enabled by the states.

Thus, States parties shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community. More particularly, Article 19 (a) requires States parties to ensure that persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement. In light of this, institutionalization is incompatible with the Convention, and it is an obligation of States parties to make alternatives available⁵. Article 19 (b) provides that the States parties should enable access to persons with disabilities 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. In this light, support provided in segregated settings to continue institutionalization is therefore not compliant with the Convention. At the end, Article 19 (c) stipulates that community services and facilities for the general population should be made available on an equal basis to persons with disabilities and should be responsive to their needs. To concluded, Article 19 encompass three main elements, as follow: choice for the individual with disabilities in the type and supply of services, individualized support to enable the inclusion of each person with disabilities, and, availability and accessibility of the general services to all, including persons with disabilities. For this paper most important is Article 19 (b) that will be elaborated here more in details. Namely, Article 19 (b) includes a reference to a range of services that can involve different providers, but certain criteria needs to be met based on the shift from “care” to “rights”. As implied by the Office of the United Nations High Commissioner for Human Rights in its Thematic study on the right of persons with disabilities to live independently and be included in the community from 2014, all persons with disabilities should have equal access to, an equal choice of, and control over support services that respect their inherent dignity and individual autonomy and aim to achieve effective participation and inclusion in society (para. 29).

As to the personal assistance as one of the services that should be made available for persons with disabilities necessary to support their living and inclusion in the community, should be noted that this service should be available to all persons with disabilities, irrespective of one’s income and type of impairment and independent of one’s place of residence⁶ (first characteristic). Eligibility criteria for access to support services need to be defined in a non-discriminatory way. Provision of access to personal assistants for persons with intellectual and psychosocial disabilities is essential to moving from a medical to a social approach concerning mental health issues with respect to personal autonomy. However, in many countries the personal assistance service it is available only to persons with certain impairments and thus the Committee on the Rights of Persons with Disabilities has expressed concern at such limitations. Second characteristic for providing the personal assistance is that this service should be adequate i.e. appropriate, accessible, affordable, accountable and responsive to the needs of the persons with disabilities. In this context, persons with disabilities must have control over the support provided and be the ones who hire,

as the European Social Charter - Art. 15, and the Inter-American Convention on the Elimination of All Forms of Discrimination against Persons with Disabilities - Art. 4, para. 2 (b).

⁵ See: Committee on the Rights of Persons with Disabilities, Concluding observations on Austria, CRPD/C/AUT/CO/1, China, CRPD/C/CHN/CO/1, and Spain, CRPD/C/ESP/CO/1.

⁶ A range of personal assistance approaches, including peer support and advocacy, crisis respite and planning, non-medical support to deal with altered perceptions, assistance to meet practical needs of everyday life, advocates for decision-making support and living support networks to help make connections in the community, have proved particularly beneficial to persons with psychosocial or intellectual disabilities.

employ, supervise, evaluate and dismiss their assistants. The possibility to choose between different service providers is a way to make the services more accountable, increase control by the user and provide protection against the risk of abuse. In certain contexts training is essential, in order to ensure that support is in conformity with the standards of the Convention and responds to needs and respects the individual's will. Payment to users rather than providers contributes to ensuring that the support is person-centred and respects the preferences of the person with disabilities. Finally, the services should be structured in a way to enable users to enjoy access to effective redress and remedy against the service provider. Third and final characteristic of the personal assistance is the modality of funding. Namely, there are different options for covering the costs of support services. Some States cover the entire budget for service delivery and provision, while others share costs with beneficiaries. Sometimes services are provided directly by organizations of persons with disabilities, which can receive co-financing by State or local government, or can raise their own funds. The Committee on the Rights of Persons with Disabilities repeatedly calls on States to allocate adequate resources for support services that enable persons with disabilities to live in their communities⁷. Should be noted that austerity measures have had a significant negative impact on the financing and provision of support in many countries; thus raising important concerns in relation to the States' obligations of non-retrogression, non-discrimination and compliance with minimum core obligations.

The Law on the Ratification of the Convention and the Optional Protocol was unanimously adopted by the Assembly of the Republic of Macedonia on 5 December 2011, and officially entered into force on 22 December 2011. In the Initial report on the Convention on the Rights of Persons with Disabilities (2015), under the part specific rights of the Convention, under Article 19, the Republic of Macedonia does not mention concretely personal assistance as a service. However, the National Strategy for Equal Rights of Persons with Disabilities (Revised) 2010 2018 clearly mention introduction of the personal assistance service.

1.2. Council of Europe

Persons with disabilities are entitled to have access to and enjoy the full range of human rights safeguarded by the European Convention on Human Rights and the European Social Charter (Revised), in particular Article 15 in relation to the right of persons with disabilities to independence, social integration and participation in the life of the community, and Article E providing that the rights of the Charter shall be secured without discrimination on any ground. In addition, the Council of Europe Disability Strategy 2017-2023 titled "Human rights: a reality for all" succeed the Council of Europe Disability Action Plan to promote the rights and full participation of persons with disabilities in society: improving the quality of life of persons with disabilities in Europe 2006-2015. The overall goal of the Council of Europe Disability Strategy 2017-2023 is to achieve equality, dignity and equal opportunities for persons with disabilities. This requires ensuring independence, freedom of choice, full and effective participation in all areas of life and society, including living in the community⁸.

1.3. European Union

The European Union (EU) acceded to the UN Convention on the Rights of Persons with Disabilities in December 2010 according to its Article 44, as the first Regional International Organization. In addition, 27 EU Member States have ratified the Convention. The European Union, implements the UNCRPD

⁷ See: Committee on the Rights of Persons with Disabilities, Concluding observations on Australia, CRPD/C/AUS/CO/1, Austria, CRPD/C/AUT/CO/1, Argentina, CRPD/C/ARG/ CO/1, China, CRPD/C/CHN/CO/1, Hungary, CRPD/C/HUN/CO/1 Peru, CRPD/C/PER/CO/1, Spain, CRPD/C/ESP/CO/1, and Republic of Korea, CRPD/C/KOR/CO/1.

⁸ See: Council of Europe, Human rights: a reality for all, Council of Europe Disability Strategy 2017-2023, 2017, para. 16.

principles through its legislation, including the EU Charter of Fundamental Rights, the EU Disability Strategy and the developing body of decisions by the Court of Justice of the European Union. Articles 21 and 26 of the Charter of Fundamental Rights of the European Union explicitly prohibit discrimination on the grounds of disability, and recognise and respect the right of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community.

The European Disability Strategy 2010-2020 consists of eight areas: accessibility, participation, equality, employment, education and training, social protection, health and external action. One of the main areas for action of the strategy is the participation, where the European Union aims to achieve full participation of people with disabilities in society by *inter alia* providing quality community-based services, including access to personal assistance⁹. The EU's monitoring framework with regard to the UNCRPD is actively working on the basis of its Work Plan to promote, protect and monitor the implementation of the UNCRPD in the EU. The European Union Fundamental Rights Agency (FRA) is developing indicators and benchmarks and carrying out comparative legal and social research with regard to disability and the implementation of the UNCRPD in the EU Member States.

2. Existing legal framework in relation to personal assistance service

2.1. Legal framework in relation to personal assistance in daily living

The Law on Social Protection (LSP) regulates the system and the organization of the social protection, the rights from the social protection, the financing of the system and the procedure for realization of the rights from the social protection (Art.1). Pursuant to the LSP, the social protection is defined as a system of measures, activities, and policies for preventing and exceeding the basic social risks on which the citizen is exposed during his/hers life, reducing poverty and social exclusion and for strengthening its own capacity for social protection (Art.2 para.1). The Law enumerates the following social risks: a. health (illness, injury and disability), b. old age, c. single parenthood, d. unemployment, losing income, e. poverty and f. other risks related to social exclusion (Art. 2 para. 2). The LSP establishes a positive obligation for the state to take care for the social protection of its citizens in line with the principle of social justice (Art.3 para.1). The state establishes the system for social protection, secures its function, provides means and measures for realization of the social protection and develops measures for self-help as stipulated in Article 3 paragraph 2. State organs responsible for the social protection in the Republic of Macedonia are: the State, the municipalities and the city of Skopje, including its municipalities (Art.3 para.3). The social protection function is of public interest (Art.5). The social protection is realized through the following forms: a. social prevention, b. institutional protection, c. non-institutional protection and d. financial rights from social protection (Art.6). The LSP refers to the term "invalid person" defining it as a person with mental or physical disability (Art. 17). The LSP also provides an opportunity for a civil society organization (CSO) or individual to perform certain tasks and activities from the social protection under conditions and procedure stipulated with the LSP (Art. 18). It can be concluded that the model of personal assistance in daily living, as described and defined in the Rationale for and type of personal assistance service in Macedonia¹⁰, is in line with the basic provisions of the LSP and could be introduced as a special right from the social security without the need of amending its basic provisions significantly; only introducing an article elaborating on the personal assistance, and be embedded under the non-institutional protection.

Furthermore, the non-institutional protection that is implemented in or through the Center for Social Affairs include, *inter alia* the right to a home care and assistance to individual and family (Art.26). The right to a home care and assistance is stipulated for the following categories of beneficiaries: a. elderly, b.

⁹ See: European Commission. European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe, COM(2010) 636 final, 2010, p. 7.

¹⁰ See: Jankovic M. Rationale for and type of Personal Assistance service in Macedonia - draft document, Skopje, 2016.

decrepit, c. persons with physical disability and person with moderate and d. severe and deep mental disability. In order to qualify for the right to a home care and assistance, the persons that fall under the previously mentioned categories, must not be capable to take care for themselves and due to that are in need for care and assistance in meeting their existential needs (Art. 30 para.1). Whether the person in need for care and assistance lives with family is not relevant for realization of this right (Art.30 para.2). The LSP does not contain any definition of the term home care and assistance nor provides the clarification in a bylaw. Even though, the right to a home care and assistance as stipulated in the LSP is complementary with the model of personal assistance in daily living, still the distinction can be made between the two of them. The personal assistance should not be care-oriented, but enable independent living. Namely, the benefits of the personal assistance are as follows: independence for the individual, independence for the family, prevention of institutionalisation, visibility in the community, and changing of the attitudes of the society. The analysis shows that due to the national context as well as the social model of disability the Personal assistance should be embedded under the non-institutional protection and distinguished from the right to a home care and assistance. According to Article 157 the home care and assistance could be provided by an association (CSO) that fulfill the predefined criteria in the LSP and are enlisted at the registry with in the Ministry for Labour and Social Policy (Arts. 152-162). This service could be also provided by an individual if it fulfill the following criteria: a. Possess appropriate vocational education (at least secondary), b. Full legal capacity, c. Its parental rights are not terminated, d. In general good health and e. Possess appropriate space and necessary equipment (Art.164)¹¹. The LSP even provides the opportunity for the individual provider of this service to employ additional three persons for provision of home care and assistance (Art.167).

Finally, the LSP establishes the following monetary allowances that as a condition require certain type and level of disability: a. Permanent Monetary Assistance, b. Monetary Assistance for Care and Nursing from other Person, c. Allowance for Hearing Impairment and d. Allowance for Visual Impairment and Mobility. It can be concluded that main issue that is arising when analyzing these provisions of the LSP in the context of whether the personal assistance should be a monetary right is the fact that it could be considered as already existing right. The Allowance for Visual Impairment and Mobility's purpose is clearly defined as "creating conditions for equalizing the opportunities for inclusion into the everyday life of the community". Having in mind that the purpose of the personal assistance is similar in its goal of enabling full inclusion, it is more than certain that the parallel existence of both, the allowances and the personal assistance as a monetary right could not be properly justified.

The by-laws in the national legal system are a form of secondary legislation that regulates in detail and operationalizes the provisions of the Laws adopted by the Parliament. As such they are not independent and they draw their legal power from the provisions of the Law/s. If those provisions are annulled or amended the by-law loses its legal force. With regards to the Law on Social Protection the main role of the by-laws is detailed regulation of the conditions for realization of certain rights, the procedure for their realization and the necessary documentation. The by-laws in the area of social protection usually have the form of a Rulebook (мк. Правилник) and are adopted by the Minister of Labor and Social Protection. It should be also noted that by-law can be adopted only if the Law contains specific provision mandating the Ministry to regulate in detail certain subject matter stipulated in the law. Currently there are 42 Rulebooks deriving from the LSP. It can be concluded that in addition to changes of the Law on Social Protection, the introduction of the personal assistance service will require an adoption of special by-law in the form of a Rulebook. The Rulebook should regulate in detail the conditions that the individual should comply with, the necessary documentation, the scope of the personal assistance etc. There will be a need for amending the Rulebook on the manner and procedure for allocation of funds to the association of citizens for

¹¹ According to the author many of these criteria can be disputed as discriminatory; however elaboration on all of them is not the purpose of this paper.

implementation of certain activities from the social protection, in order to comply with the new personal assistance service that will be provided by the CSO's and individuals.

2.2. Legal framework in relation to work related personal assistance

Relevant in regard to the work relations of persons with disability is the Law on Labour Relations and the Law on Employment of Persons with Disability as *lex specialis*, elaborated below. The Law on Labour Relations (LLR) is a *lex generalis*, governing the overall employment relations in the country. The Law regulates the working relations between employees and employers established by signing an employment contract (Art.1), and does not make a difference between employees in the public, from the private sector (Art.3 para.1), nor between part-time and full-time employees (Art.8 para.3). However, the LLR does not protect volunteers. In addition to the general provisions, the LLR foresees special protection, *inter alia*, for the persons with disability. Namely, the issue of employment of persons with disabilities is only partially mentioned with prohibition of discrimination on this ground, exemption from overtime, night shifts and possibility for shorter working hours for a parent of a child with disabilities. Article 6 of the LLR unequivocally prohibits discrimination, *per se*, including disability-based discrimination done by natural or legal persons in both the public and private sector. The LLR prohibits all forms of discrimination, including direct (Art. 7 para.2), indirect (Art. 7 para.3) and harassment (Art.9 and 9a) of the employment candidate and the worker. In addition, Article 25 provides that in concluding a contract of employment, the candidate shall not be obliged to submit a proof of their health condition, unless the employer sends the candidate to an examination at own expense (para. 5), complemented by the following provision: "[t]he examination of the knowledge or skills, or the determination of candidate's health condition shall not pertain to circumstances unrelated to the work on the given position which is the subject of the employment contract" (Art.25 para.6). Furthermore, Section XII from the LLR titled "Specific protection" (Arts.161-162, 164 and 169) aiming to protect the health of persons with disabilities provides that persons with disabilities are specific and risk group and the employers needs to have this in mind before delegating work tasks and major change in the working conditions. In addition, if a risk is assessed and established that cannot be eliminated in another way, the employer is obligated to change the working conditions or working hours or to offer adequate alternative job position to the employee under risk. If a person is disabled due to work injury or professional disease, he/she can use vocational rehabilitation and/or new employment position maintaining the pay that was received before the injury/disease (Arts.177-178). It can be concluded that unfortunately, the Law on Labour Relations does not mention explicitly the possibility of introducing personal assistance. However, the law does not prohibit it either. It is up to the legislator to choose to specifically regulate this or not.

The Law on Employment of Persons with Disability (LEPD) regulate the specific conditions for the employment and work of persons with disabilities in performing their occupation independently, under an employer or an acting employer, as well as the conditions establishing a trade company for employment of persons with disabilities – sheltered company, and the benefits thereof (Art. 1). Article 2 stipulates the personal scope of protection of the LEPD by enlisting which persons with disabilities falls into this category. Practice shows that it fails to cover all categories of persons with disability, especially those performing their occupation or profession independently, that is, they work in the capacity of: lawyer, doctor, notary, and the like, thus being unable to realise the benefits ensuing from the law. In addition, persons with mental health problems, persons with psychosis are not specified as persons with disabilities in the sense of this act. These persons need to have an access to vocational rehabilitation, as well as to personal assistance, because, due to the nature of their illness, i.e. they are often not able to perform daily tasks and take care of themselves, their children, or to perform a job in a way that would be possible if there was no illness without an appropriate support. The LEPD foresees a great number of incentives aimed at improving the conditions for employment of persons with mental and physical disability, such as: a. awarding of non-refundable funds for full-time employment of persons with disabilities, accommodations of the position designated for the disabled person, should there be a need and procurement of equipment

according to the criteria and modality established by an act adopted by the Minister of Labour and Social Policy, b. tax exemption and securing funds for pension and health insurance, and c. financial assistance in working (Art. 4). The incentives are valorised into a number of monthly pays as non-refundable funds paid from the Special Fund formed in line with this Law. These are basically solid solutions, which have been classified as positive action.

The LEPD clearly stipulates that the employer cannot employ or transfer from one to another job position a person with disabilities that does not fulfil the general and specific criteria for the concrete position, i.e. a person that is not qualified to do the job (Art. 4-b). But, the Law provides for an obligation of the employer of a person with disabilities stating that "[i]n hiring a person with disability, the employer shall create proper work conditions and adaptations to the work place depending on the position, the type and level of education, and the type and level of disability of the disabled person being hired" (Art.5 para.2). The legislator fails to elaborate this provision in more detail, thus omitting to point out the type of conditions the employer ought to create. For example: whether they should encompass accommodation to the interviewing process in employment, accommodation to the working hours and practices, and even provision of a professional vocational trainer and personal assistant. By not clarifying the provision, it is left to the courts to delineate the borders of these legal practices. The legislator, furthermore, does not give a detailed explanation as to the kind of adaptation to the work place to be made, but, nevertheless, this has been better elaborated in the Rulebook on the criteria and means to award non-refundable funds from the Special Fund for improvement of the conditions for employment and work of persons with disabilities¹². Pursuant to Article 7 para. 2 of this Rulebook, the adaptation encompasses accommodation to the working and utility rooms, to the equipment, working resources, devices and other technical aids. A positive aspect is that besides the obligation to reasonable accommodation, the Rulebook also provides for funds secured through a Special Fund for improvement of the conditions for employment and work of persons with disabilities (Arts.8 and 20). Here is very important to stress that the inclusion of work related personal assistants could be performed without the need for a significant legislative changes/amendments to the LEPD. Namely, Article 5 can be amended stipulating the creation of appropriate working conditions and the adaptation of the workplace, by introducing the work related personal assistant as a supporting measure for employees with disabilities. Detailed regulation could be made by adding additional provisions to the Law or by adoption of a specific by-law. The only risk that should be taken into account is the funding. Special conditions and incentives for providing employment for persons with disabilities are regulated by the LEPD and the Regulations for criteria and the way for assigning funds of the Special Fund for improvement of the conditions for employment and work of persons with disabilities. The amount of funds in this Fund, are decreasing through time and there is a risk, if the legislator decided to cover the work related personal assistance from this Fund, that there will be no sufficient funds for this. It can be concluded that there is an opportunity to include work related personal assistant by amending the Article 5 of the LEPD stipulating the creation of appropriate working conditions and the adaptation of the workplace, by introducing the work related personal assistant as a supporting measure for employees with disabilities.

3. Role of the service providers in the system for personal assistance service

3.1. Legal framework in relation to service provider of personal assistance

The Law on Associations and Foundations (LAF) regulates the modality, conditions and procedure for establishing, registration and ceasing to exist of the associations, foundations, unions ... and *inter alia* the status of organizations of public interest (Art. 1). The LAF provides that 'organizations of public interest' is an organisation that obtains public interest status according to this law (Art. 3 para. 1 line 15).

¹² See: Rulebook on the criteria and means to award non-refundable funds from the Special Fund for improvement of the conditions for employment and work of persons with disabilities. Official Gazette of the Republic of Macedonia No. 156/2008.

The Law provides that organizations of public interest enjoy tax and customs benefits according to law (Art. 7 para. 2). One of the main principles of the work of associations is the non-profit work. However, the LAF provides that organization can carry out activities which can gain profit if the activity is related to the goals established by statute of the organization, but if this is the case than the profit must be used for implementing those goals (Art. 12). As to the sources of income the following are stated in Article 48 of the LAF: membership fee, founding contributions, voluntary contributions, donations, gifts (in money, goods, property rights), inheritance, legacies, rents and leases, as well as incomes from investments, dividends, interest, loans and other income in accordance with the law and statute. The associations can receive funds from the State budget, budget of the municipalities and city of Skopje (Art. 49 para. 1) and the funds should be used for implementing the goals of the organization stipulated in the statute and the programme (Art. 50 para. 1), The employees are entitled to salary and allowances according to the law and the collective agreement (Art. 50 para. 5). It can be concluded that the LAF regulates in detail the procedure for gaining the status of organizations of public interest as per Section XI of the LAF titled “Status of organizations of public interest”. According to Article 73 from the Law, the organisations can gain a status of public interest if they conduct activities in public interest, implement programmes and projects on central and/or local level, independently or in cooperation with state bodies or municipals bodies, municipalities in Skopje and city of Skopje, as well as use of funds for implementing activities. Among activities in public interest the Law in its Article 74 provides that such activity *inter alia* is ‘assistance/care and protection of persons with physical or mental disability, person with disabilities in development and persons with special needs’. In addition, the LAF in its Article 90 provides that organization can be entrusted with performing public power/authorization by transferring this competence from a state body, municipal body or other institutions with public authority in accordance with the law.

CSOs and individuals are eligible to provide services in the area of social protection in accordance with the provision of the LSP and the applicable by-laws. Section V from the LSP includes provisions that are regulating the CSO’s and individual as providers of such services. An association can implement certain activities from the social protection, stipulated in the LSP, if is registered for realization of objectives and tasks in the area of social protection (Art. 152 para.1). The LSP defines the objectives and tasks are considered as social protection related to: a. social prevention, b. development and provision of services from the social protection to individuals, families and groups of citizens exposed to social risk, c. development and improving of the social protection and d. development and improving of the voluntary work in the municipality (Art. 152 para.2). The Ministry of Labour and Social Policy (MLSP) keeps a registry of the associations working in the area of social protection (Art. 153 para.1). The procedure for registration includes submitting request to the MLSP with the following supporting documents: registration documents, statute and program (Art. 153 para.3). Additionally, the association must provide documentation in support of the following additional criteria: a. track record of activities in the area of social protection or social policy at least three year since the establishment, b. implementation of at least three project in the area of social protection or social policy, c. secured space and staff, and d. annual financial report (Art. 154). The association will be erased from the registry under the following circumstances: a. upon own request, b. cessation of the association, c. failure to fulfill and maintain the criteria prescribed in the LSP, and d. failure to use appropriately or misuse of state allocated funds (Art. 156). The association *inter alia* is authorized to implement the following work from the area of social protection relevant for the personal assistance: a. social services to individuals, families and groups of citizens exposed to social risk, and b. Home care and assistance to individual and family (Art. 157). For provision of these services the MLSP could participate with allocating part of the funds in a procedure determined by the LSP. The allocation is done on the basis of public call (Art. 158). Those associations that will be selected will sign a contract with the Minister of Labour and Social Policy determining the rights and obligations of the parties (Art. 160). The supervision and oversight of the implementation of the contract is done by the Minister (Art. 161).

3.2. Responsibilities and financing the work of the service provider

The association enlisted in the registry could provide the following services from the social protection: a. research in the area of social protection, b. social prevention, c. education, counseling and professional support to individuals exposed to social risk, d. counseling and training for volunteers, e. homecare and assistance to individual or family, f. daily and temporary care for beneficiaries of social protection in the daily center from Articles 139-142 and Article 146 and the center from the Articles 143-145 and Article 147 of the LSP, g. development and promotion of the volunteering in the municipality, h. development and promotion of the social protection, i. organized living with support, and j. protection of victims of domestic violence (Art. 157).

The MLSP participate in funding the provision of services in the area of social protection by the CSO in accordance with the LSP (Art. 158 para.1). The funds are allocated on the basis of public call for proposals published in at least two daily newspapers available on the whole territory of the country (Art. 158 para. 2 from the LSP and Art. 2 from the Rulebook on funding of CSOs¹³). The public call includes the types of the activities for which funding can be provided, the amount of the available funds, the necessary documentation, the timeframe of the procedure for allocation of funds and the timeframe for implementation of the necessary activities (Art. 158 para.3). The CSO applicant beside the requested documents listed in the public call must submit among other things detailed description of the activities and detailed budget (Art. 3 from the Rulebook).

The procedure for the publication and the implementation of the public call is conducted by a Commission for Cooperation with Associations. This Commission gives an opinion on the submitted application in 30 days from the closure of the public call and on the basis of it the Minister of LSP renders a decision on granting funds (Art. 159). The Commission evaluates the submitted evaluation with regards to their: relevance to the objectives of the public call (0-10 points), internal capacity and experience of the applicant (20-30), points and consistency of the proposed objectives and activities including measures for sustainability of the project (45-60 points) (Art. 6 from the Rulebook). The decision can be appealed in a time limit of 8 days to the State Commission for Deciding in Administrative procedure (Art. 159 para. 3). The Minister signs a contract with the association outlining the mutual rights, obligation and responsibilities (Art. 160). The contract contains provisions regulating: the objective of the grant, timeframe and date of entering into force of the contract, project related responsibilities of the contracting parties, reporting, liability in case of damage, the amount of the grant, ineligible costs, method of funding, audit and monitoring and cessation of the contract (Art. 8 from the Rulebook). As a conclusion, the LSP provides the possibility for funding the services in the area of social protection through launching public calls and it governs the procedure. The mechanism for funding is through direct contracts between the Ministry for Labour and Social Policy and the association/CSO. One issue that could impede the process of personal assistance is the fact that the sole responsibility for supervision is vested with the MLSP according to LSP. Lack of regional offices of the Ministry of Labour and Social Policy that could oversee the supervision in the remote areas of the country will be detrimental for the effective monitoring mechanism and potentially can lead to misuse.

3.3. Monitoring and oversight of the work of the service provider

The MLSP oversees the CSOs in the implementation of the activity from the social protection for which it provided the funds (Art. 161 para. 1). If it is founded that the association did not spend the received funds in accordance with the contract, or the activities are not implemented in accordance with the public call, or if it does not begin with implementation in the prescribed time period, the MLSP will cease the future funding of the association. The MLSP will terminate the contract and will initiate a procedure for

¹³ See: Rulebook on the manner and procedure for allocation of funds to the association of citizens for implementation of certain activities from the social protection. Official Gazette of the Republic of Macedonia No. 24/2005.

refund of the grant and compensation for damages (Art. 162 para. 2). The association can be erased from the Registry of CSO in the case of misuse of funds (Art. 156 para. 1).

4. Role of the personal assistant in the system for personal assistance service

4.1. Legal framework in relation to employment of personal assistant

The Law on Labour Relations regulates the working relations between employees and employers established by signing an employment contract (Art.1 para. 1). The working relation is defined as contractual relation between an employee and an employer in which the worker voluntarily engages in organized process of work with the employer for salary and other remuneration, and personally continuously perform the work according to the instructions and under the supervision of the employer (Art. 5 para. 1 line 1). Section II of the Law titled "Employment contract" regulates all the specificities in relation to the contract obligation of the employer as well as the employee including rights, obligations and responsibilities on the basis of conducting a work from the working relations. The LLR in Article 14 specifies the type of employment such as working relation on indefinite time (мак. работен однос на неопределено време) and working relation on specified time (мак. работен однос на определено време). The Law provides that the working relation can be on full time (Art. 116) or part time (Art. 48). Furthermore, the Article 49 allows for the opportunity an employee on part time to sign part time employment contracts with different employers and thus to achieve full time working time according to the law. The LLR obliges the employee, on request from the employer, to work beyond the full time (overtime) but not more than additional eight hours weekly (Art. 117). Furthermore, the employee that works full time can as exception sign employment contract on part time with another employer, for not more than additional ten hours weekly with prior consent from the first employer where the employee works on full time (Art. 121). In addition, the employee can sign a contract allowing his/her to conduct his/her work from home or in premises according to his/her choice out of the working premises of the employer (Art. 50). Finally, for the employee that conducts particularly difficult, demanding and unhealthy work, and whose detrimental effect on its health or working ability cannot be fully removed with protective measures, its working hours can be shortened proportionate to the harmful effects or working ability in accordance to the law or the collective agreement (Art. 122-a para. 1) and in exercising the right to salary and other employment rights, this part-time equals to full-time employment (Art. 122-a para. 2). The Law continues in stipulating that as 'particularly difficult, demanding and unhealthy work' is considered inter alia work with persons with the most severe mental disabilities (Art. 122-a para. 3). The employee that signs the employment contract must fulfill the conditions of conducting the specific work according to law, and the conditions set by the employer (Art. 19 para. 1). Article 28 regulates the elements that the employment contract consists of. There is a set of articles in the LLR that regulates the termination of employment contract amicable (Art. 69) or with a dismissal (Arts. 70-104). For the work the employee will receive a pay in accordance with the law, collective agreement and employment contract that must be monetary and it is comprised of a basic salary, part of the salary for work performance and supplements (Arts. 105-106). In addition, the employee has a right to cover expenses in relation to its work for: a. duty travel, b. field allowance, c. use of a private vehicle for duty travel, d. separation from family, and e. death of the employee or member of his/her family (Art. 113 para. 1). The employee has the right and obligation for continues education and vocational training in accordance with the needs of the working process aiming at retaining or improving the work capacities, and it is the duty of the employer to provide this for the employees (Art. 154). It can be concluded that the LLR is best suited to facilitate the employment of the personal assistant in line with the proposed personal assistance model.

The Law on Labour Relations in its Section XXV titled "Inspection oversight in the field of labour relations" regulates the monitoring and oversight of the implementation of the provisions from the LLR by the State Labour Inspectorate (Arts. 256-263). The employee, Trade Union and employer can request

inspection oversight (Art. 257 para. 2). If a violation is found the Inspectorate with a decision will order to the employee to adopt or annul an act that would remove the established irregularities and deficiencies (Art. 258 para. 1). The Inspectorate can submit request for initiating a misdemeanour procedure, if concludes that the employer with violation of a law or other act, collective agreement and employment contract committed the infringement (Art. 261). The LLR entrust the oversight of the implementation of its provisions to the State Labour Inspectorate in a detailed described procedure.

The analysis of the LEPD shows that inclusion of work related personal assistants could be performed under the Article 5, thus amending it to stipulate that introducing the work related personal assistant as a supporting measure for employee with disabilities falls within the duty of the employer, while employing a person with disabilities, to create appropriate working conditions and to adapt the workplace. In other words, allowing the work related personal assistant in the working premises for the concrete employee – person with disabilities - can be understand as creating appropriate working conditions or adaptation of the workplace for this concrete employee. For covering these costs the State gives incentives through the Special Fund for improvement of the conditions for employment and work of persons with disabilities (Art. 6). The LEPD in its Section IV titled “Special Fund for improvement of the conditions for employment and work of persons with disabilities” regulates the work of the Fund. The oversight of the implementation of the provision of the LEPD is vested with the MLSP (Art. 19 para. 1). The inspection supervision of the implementation of the provision of this law that regulates the specific conditions for employment and work of persons with disabilities is vested with the State Labour Inspectorate (Art. 19 para. 2). As a conclusion, the LEPD is not best suited to facilitate the employment of the personal assistant in line with the proposed personal assistance model.

Individuals can independently perform the following activities from the social protection as a profession: a. counseling, b. home care and assistance to individual and family, and c. accommodation in foster families. The LSP provides the opportunity to include the individuals as providers of personal assistance services. The LSP explicitly states that individual can provide home care and assistance to individual and family by fulfilling the criteria: a. possess appropriate vocational education (at least secondary), b. full legal capacity, c. its parental rights are not terminated, d. in general good health, and e. possess appropriate space and necessary equipment (Art. 165). In the case of the LSP is much more pragmatic by giving authority to the local Centers for Social Affairs in the process of granting permits and supervision of the individual providers (Art. 169-170). Also one of the most important issue that the current LSP is enabling is the possibility for both, paying for the services by the beneficiary, or if the beneficiary is indigent payment on the basis of contract with the Center.

5. Conclusion

Personal assistance is an effective means to ensure the right to live independently and be included in the community in ways that respect the inherent dignity, individual autonomy and independence of persons with disabilities. International standards provides for the personal assistance to be available to all persons with disabilities, be adequate i.e. appropriate, accessible, affordable, accountable and responsive to the needs of the persons with disabilities, and funded according to the national context with due notice taken on States’ obligations of non-retrogression, non-discrimination and compliance with minimum core obligations. Persons with disabilities should be involved in the planning of new social support services, including *inter alia* person-centred planning, direct payment, personal budget, development of personal assistant network etc. The model of personal assistance in daily living developed in and for the Republic of Macedonia is in line with the basic provisions of the LSP and could be introduced by including an article establishing the personal assistance. The paper shows that due to the national context as well as the social model of disability the personal assistance should be distinguished from the right to a home care and assistance but embedded under the non-institutional protection. Thus clearly précising the benefits of the personal assistance, as follows: independence for the individual, independence for the family, prevention of institutionalisation, visibility in the community, and changing of the attitudes of the society. In addition

to changes of the LSP, the introduction of the personal assistance service will require an adoption of special by-law in the form of a Rulebook. The Rulebook should regulate in detail the conditions that the individual should comply with, the necessary documentation, the scope of the personal assistance etc.

The LLR does not mention explicitly the possibility of introducing work related personal assistance. However, the law does not prohibit it either. It is up to the legislator to choose to specifically regulate this or not. The LEPD provides for an obligation of the employer of a person with disabilities in hiring a person with disability, to create proper work conditions and adaptations to the work place depending on the position, the type and level of education, and the type and level of disability of the disabled person being hired. The legislator fails to elaborate this provision in more detail, thus omitting to point out the type of conditions the employer ought to create, thus leaving to the courts to delineate the borders of these legal practices. The legislator, furthermore, does not give a detailed explanation as to the kind of adaptation to the work place to be made.

The LSP provides the opportunity for CSO's and individuals to act as providers of social services including the personal assistance service. The CSO's must be registered as an association and not as foundations and must fulfil the necessary criteria stipulated in the Law. The mechanism for funding is through direct contracts between the Ministry for Labour and Social Policy and the association/CSO. One issue that could impede the process of PA is the fact that the sole responsibility for supervision is vested with the MLSP according to LSP. Lack of regional offices of the Ministry of Labour and Social Policy that could oversee the supervision in the remote areas of the country will be detrimental for the effective monitoring mechanism and potentially can lead to misuse. Furthermore, the Law on Associations and Foundations regulates in detail the procedure for gaining the status of organizations of public interest. According to the Law, the organisations can gain a status of public interest if they conduct activities in public interest, implement programmes and projects on central and/or local level, independently or in cooperation with state bodies or municipals bodies, municipalities in Skopje and city of Skopje, as well as use of funds for implementing activities. Among activities in public interest the Law provides that such activity *inter alia* is 'assistance/care and protection of persons with physical or mental disability, person with disabilities in development and persons with special needs'. The Law on Associations and Foundations provides that organization can be entrusted with performing public power/authorization by transferring this competence from a state body, municipal body or other institutions with public authority in accordance with the law.

The LLR is best suited to facilitate the employment of the personal assistant in line with the proposed model. The Law provides that the working relation can be on full time or part time, and allows for the opportunity an employee on part time to sign part time employment contracts with different employers and thus to achieve full time working time according to the law. The LLR obliges the employee, on request from the employer, to work beyond the full time (overtime). Furthermore, the employee that works full time can as exception sign employment contract on part time with another employer. In addition, the employee can sign a contract allowing his/her to conduct work from home or in premises according to his/her choice out of the working premises of the employer. According to the LLR the employee that conducts particularly difficult, demanding and unhealthy work, including *inter alia* work with persons with the most severe mental disabilities, and whose detrimental effect on its health or working ability cannot be fully removed with protective measures, its working hours can be shortened proportionate to the harmful effects or working ability in accordance to the law or the collective agreement, and in exercising the right to salary and other employment rights, this part-time equals to full-time employment. LLR is not recognizing the employment of personal assistant in daily living and/or work related personal assistance as a specific category of employees. All provisions from the LLR can affect this group of employee in similar manner as the rest of the employees. From another side, the LEPD is not best suited to facilitate the employment of the personal assistant in line with the proposed model. However, possibility exists of inclusion of work related personal assistants under Article 5 of the LEPD, thus amending it to stipulate that

introducing the work related personal assistant as a supporting measure for employee with disabilities falls within the duty of the employer to create appropriate working conditions and to adapt the workplace.

REFERENCES

- [1] Committee on the Rights of Persons with Disabilities, *Concluding observations on Argentina*, CRPD/C/ARG/CO/1.
- [2] Committee on the Rights of Persons with Disabilities, *Concluding observations on Australia*, CRPD/C/AUS/CO/1.
- [3] Committee on the Rights of Persons with Disabilities, *Concluding observations on Austria*, CRPD/C/AUT/CO/1.
- [4] Committee on the Rights of Persons with Disabilities, *Concluding observations on China*, CRPD/C/CHN/CO/1.
- [5] Committee on the Rights of Persons with Disabilities, *Concluding observations on Hungary*, CRPD/C/HUN/CO/1.
- [6] Committee on the Rights of Persons with Disabilities. *Concluding observations on the initial report of the European Union*. CRPD/C/EU/CO/1, 2015.
- [7] Committee on the Rights of Persons with Disabilities, *Concluding observations on Peru*, CRPD/C/PER/CO/1.
- [8] Committee on the Rights of Persons with Disabilities, *Concluding observations on the Republic of Korea*, CRPD/C/KOR/CO/1.
- [9] Committee on the Rights of Persons with Disabilities, *Concluding observations on Spain*, CRPD/C/ESP/CO/1
- [10] Committee on the Rights of Persons with Disabilities, *General comment No. 1 (2014) on equal recognition before the law*, CRPD/C/GC/1, 19 May 2014.
- [11] Committee on the Rights of Persons with Disabilities. *Initial report of The former Yugoslav Republic of Macedonia on the Convention on the rights of persons with disabilities*, CRPD/C/MKD/1, 2015.
- [12] Council of Europe, *Human rights: a reality for all, Council of Europe Disability Strategy 2017-2023*, 2017.
- [13] European Commission. *European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe*, COM(2010) 636 final, 2010.
- [14] European Disability Forum. *EDF input to the CRPD Committee's general Comment on Article 19 CRPD*, 2016.
- [15] European Network on Independent Living. *Key definitions on Independent Living*, 2013.
- [16] Government of the Republic of Macedonia, *National Strategy on Equal Rights for Persons with Disabilities in the Republic of Macedonia (Revised) 2010–2018*.
- [17] Human Rights Council. *Thematic study on the right of persons with disabilities to live independently and be included in the community*, Report of the Office of the United Nations High Commissioner for Human Rights, A/HRC/28/37, 2014.
- [18] Jankovic M. *Rationale for and type of Personal Assistance service in Macedonia - draft document*, Skopje, 2016.
- [19] Law on Associations and Foundations. Official Gazette of the Republic of Macedonia No. 52/2010 and 135/2011.
- [20] Law on Employment of Persons with Disabilities. Official Gazette of the Republic of Macedonia Nos. 87/2005 (consolidated text), 113/2005, 29/2007, 88/2008, 99/2009, 136/2011, 129/2015 and 147/2015.
- [21] Law on Labour Relations. Official Gazette of the Republic of Macedonia Nos. 106/2008, 161/2008, 114/2009, 16/2010 (consolidated text), 50/2010, 52/2010, 158/2010 (consolidated text), 47/2011, 11/2012, 39/2012, 52/2012 (consolidated text), 13/2013 25/2013, 170/2013, 187/2013, 113/2014, 20/2015, 33/2015, 72/2015, 129/2015 and 27/2016.

- [22] Law on the Ratification of the Convention on the Rights of Persons with Disabilities and the Optional Protocol. Official Gazette of the Republic of Macedonia No. 172/2011.
- [23] Law on Social Protection. Official Gazette of the Republic of Macedonia Nos. 79/09, 36/2011, 51/2011, 166/2012, 15/2013, 73/2013, 164/2013, 187/2013, 38/2014, 44/2014, 116/2014, 180/2014, 33/2015, 72/2015, 104/2015, 150/2015, 173/2015, 192/2015 and 30/2016.
- [24] Mental Disability Advocacy Centre, *The right to Live Independently and be Included in the Community*, 2016.
- [25] Operation Identification Sheet, *Promoting Social Inclusion Services*, 2016.
- [26] Rulebook on the criteria and means to award non-refundable funds from the Special Fund for improvement of the conditions for employment and work of persons with disabilities. Official Gazette of the Republic of Macedonia No. 156/2008.
- [27] Rulebook on the criteria for selection of foster care, the types and number of beneficiaries, and the type and the scope of services from social protection that are provided to the beneficiaries. Official Gazette of the Republic of Macedonia No. 15/2013.
- [28] Rulebook on the evaluation of the type and the degree of the disability of the person in the physical and mental development. Official Gazette of the Republic of Macedonia No. 172/2016.
- [29] Rulebook on the manner and procedure for allocation of funds to the association of citizens for implementation of certain activities from the social protection. Official Gazette of the Republic of Macedonia No. 24/2005.
- [30] Rulebook on the nearer conditions with regards to the standards related to the facilities, equipment, professional staff, level of support, methods and the program for realization of the support for independent and organized housing in a separate housing unit. Official Gazette of the Republic of Macedonia No.80/2015.
- [31] United Nations, *Convention on the Rights of Persons with Disabilities*, 2006.