



Seminar 'Moving towards independent living and community-based care - EU funding instruments to support the development of community-based services for persons with disabilities: personal assistance and personal budgets'

Thematic Comparative Paper – Slovakia

Examples of personal assistance schemes in Europe – lessons learned

Bratislava, Slovakia, 21 May 2019

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Directorate-General for Employment, Social Affairs and Inclusion

Seminar on "Moving towards independent living and community-based care for adults and children with intellectual disabilities in Romania"

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Executive Summary in plain language

This report is about personal assistance.

Personal assistance is support provided to people with disabilities from specially trained workers.

Sometimes people with disabilities are forced to live in institutions away from their families and communities.

Personal assistance allows people with disabilities to move out of institutions and live in their local community.

Personal assistance is organised differently in the different countries.

This report describes how personal assistance works in the following countries: Sweden, Bulgaria and the Czech Republic.

The report tells how personal assistance needs to be organised to be in line with the Convention on the Rights of Persons with Disabilities.

The Convention on the Rights of Persons with Disabilities is a document about the rights of people with disabilities.

It says that people with disabilities should be supported to live in the community, like everyone else.

Personal assistance is in line with the Convention when people with disabilities can decide how their assistance is organised.

This means that people with disabilities can choose who, where, when and how to provide their assistance.

1 Introduction

1.1 Objectives

This paper focuses on personal assistance as a tool that can be used in the process of deinstitutionalisation to enable people with disabilities to live and participate in the community, in line with the requirements of the UN Convention on the Rights of Persons with Disabilities (CRPD) and the priorities of the European Disability Strategy 2010-2020. It presents personal assistance schemes from three European countries – Sweden, Czech Republic and Bulgaria – all of which have more than 10 years of experience with assistance services, and in the case of Sweden – more than 25 years. The strengths and limitations of each scheme are discussed from the perspective of the CRPD and general recommendations are formulated to assist policy-makers and other stakeholders with the development of assistance schemes that enable independence and inclusion of people with disabilities.

1.2 European legal and policy context to personal assistance

1.2.1 The UN Convention on the Rights of Persons with Disabilities

Access to personal assistance is essential to ensure that people with disabilities can fully enjoy their right to live independently participate in the life of the community. This right is set out in Article 19 of the CRPD (2007), which has been ratified by both the European Union and Slovakia. It requires that 'all persons with disabilities, regardless of the type or degree of the impairment or the level of support necessary, have the right to 'live in the community, with choices equal to others'. In line with Article 19, all State Parties to the Convention are obliged to ensure that people with disabilities have 'access to a range of in-home, residential and other community support, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community'.

1.2.2 European Disability Strategy 2010-2020

The European Commission also emphasises the importance of 'quality community-based services, including access to personal assistance' for achieving 'full participation of people with disabilities in society', which is one of the overarching EU-level objectives set out in the European Disability Strategy 2010-2020. The Strategy also promotes the use of EU funds for the development of 'personal assistance funding schemes' as part of the efforts to achieve transition from institutional care to community-based services.

1.3 Key elements of personal assistance

In the General Comment on Article 19, the UN Committee on the Rights of Persons with Disabilities (2017) defines personal assistance as 'person-directed/"user"-led human support available to a person with disability'. While the Committee recognizes the diversity of assistance models, it outlines the key elements of personal assistance, that distinguish it from other similar services, including:

- i. Funding for personal assistance is based on an individual needs-assessment and is allocated to the person with disability.
- ii. The person with disability has control over the service and can decide whether to contract it from a variety of providers or employ their own assistant/s. They can custom-design their service and choose by whom, where, when and how to be provided.
- iii. Personal assistants should be recruited, trained and supervised by the person who was granted the assistance.
- iv. Even when the service is contracted out, the person with a disability remains in the centre of all decisions concerning their assistance.
- v. Control over assistance can also be exercised through supported decision-making¹.

The Committee underlines that only services that allow for choice and control of people with disabilities over their assistance are compliant with Article 19.

2 Personal assistance budget in Sweden

2.1 Background

In January 1987, a pilot project started in six municipalities in Stockholm, involving the provision of direct payments for user-led personal assistance. The project was initiated by an organisation of people with disabilities – the established in 1984 Stockholm Cooperative for Independent Living (STIL). According to Ratzka (2003), the founder of the Cooperative, the participants in the pilot were 22 people, representing a wide range of ages, family and housing situations and disabilities. STIL administered the service for them, functioning as a subcontractor to the municipality. The pilot project ran until the beginning of 1989. In June 1989 the Stockholm municipality decided to make the model permanent by granting people with disabilities in Stockholm the right to receive direct payments and organise their assistance, allowing other co-operatives and private companies to become subcontractors.

Meanwhile, in 1988 the government set up a commission to evaluate the support provided for people with extensive support needs and to formulate recommendations for improvement. Bengt Westerberg (2013), the Swedish Ministers of Social Affairs between 1991 and 1994, notes that the Commission found out that the quality of home care and clustered housing services was poor. Based on the analysis of the pilot project, the Commission came up with a proposal to introduce personal assistance. The report of the Commission served as a basis for the 1993 reform of disability services, part of which was the introduction of personal assistance budgets at national level.

2.2 Legal Framework

Personal assistance in Sweden was initially regulated by two laws – the Act Concerning Support and Services for Persons with Certain Functional Impairments (LSS), and the Assistance Allowance Act (LASS). Both were adopted in 1993, as part of the reform in the disability services but recently the Assistance Allowance Act was incorporated in the Social Insurance Code. The Act Concerning Support and Services for Persons with Certain Functional Impairments legally entitled some people with disabilities to a

¹ Supported decision-making is an arrangement where people with disabilities are supported to understand, make and communicate their own decision, instead of having someone else deciding for them (substitute decision-making). Supported decision making is an alternative to guardianship.

number of special support measures, including personal assistance. Its main goals were to enable people with disabilities to have good quality of life, to live independently and participate fully in the life of the community, with respect for their right self-determination. The Assistance Allowance Act set out the rules concerning the provision of personal assistance budget for people who need more than 20 hours of assistance with their basic needs per week.

2.3 Institutional framework and funding arrangements

The responsibility for administration and funding of personal assistance is divided between the local and the central government and depends on the amount of assistance required. Försäkringskassan, the Swedish Social Insurance Agency, administers the service for those people with disabilities who require assistance with their basic needs for more than 20 hours per week. It also covers the costs for the hours above 20 per week, while the municipality pays for the first 20 hours. The municipality is also responsible for the administration and the funding of the service for people with 20 or less hours of personal assistance per week.

Overall, most of the personal assistance is funded and administered at the national level. In December 2015, there were 16 142 people receiving personal assistance allowance from the state (Försäkringskassan, 2017) and 4 295 people receiving assistance services from the municipality (Socialstyrelsen, 2017).

The assistance allowance paid under Assistance Allowance Act, is basis on a flat rate per hour, which is determined by the government and revised each year. In 2015, the rate was SEK 284 (approximately 30 EUR²) per hour but people with specific needs, for example who require a specially trained assistant, were able to apply for a higher rate, up to SEK 318 (34 EUR) per hour (Försäkringskassan, 2017). The personal assistance budget paid from the municipalities (under LSS) is not regulated at national level and each municipality can determine the hourly rate, following the guidance of the National Insurance Agency and ensuring that it covers all reasonable expenses.

According to the guidance of the Insurance Agency the hourly rate should cover all assistance related costs, including: assistants' salaries and relevant taxes, insurance contributions and benefits, administration of the service (e.g. office, equipment, insurances and accounting services), trainings for people using the service, assistants and office staff, measures related to safety and work environment and staff's health and well-being, and costs of assistants accompanying the user outside of their home, such as transportation, meals or entrance tickets (Försäkringskassan, 2003 cited in Westberg, 2010). Employment related costs are expected to be covered by around 87% of the flat rate, and the remaining 13% can be used for administrative and other costs. However, each provider can decide how to divide the funding among other assistance related costs.

2.4 Overview

2.4.1 Eligibility

To be eligible to receive assistance budget, a person has to belong to one of the following three groups:

- people with intellectual disabilities, autism and similar conditions;

² The exchange rate used is based on information from the Swedish bank about the annual average for 2015.

- people with considerable and lasting intellectual disabilities acquired in adulthood;
- people with other significant and lasting functional impairments, not as result of normal ageing, who have considerable difficulties in everyday life and comprehensive need for support or services.

In addition, to be eligible to receive their budget from the state, a person must require assistance with their 'basic needs', such as personal hygiene, getting dressed and undressed, eating, communicating or other assistance that requires detailed knowledge of the person's specific impairment, for more than 20 hours per week.

Assistance budget can be used by both children (from the age of 0) and adults. If a person is under 65 when they are first granted assistance budget, they can continue to receive it after this age without an increase in the number of hours. If after the age of 65 their needs of assistance increase, they can complement the assistance budget with other available support services.

2.4.2 Organisation of assistance

Assistance budget is granted in number of assistance hours per week, based on an assessment of individual's needs of support. There is no ceiling to the number of hours granted as there are people who may require assistance 24 hours a day, 7 days a week or who may need more than one assistant at the same time. In 2015, the average number of assistance hours per week was 127 (Försäkringskassan, 2017). The hours, when covered at state level, can be used flexible within a six-month period, meaning that unused hours can be transferred from one month to the other.

While eligibility is assessed based on a person's basic needs, other needs are also taken into account when determining the overall assistance budget. They can include, for example, assistance with shopping, cooking, cleaning the house, looking after children, and work or leisure activities.

The personal assistance budget is paid directly to the person with disability who can decide whether they would like to employ assistants themselves or contract provider of their choice – municipality, a user cooperative or a private company. In 2015, 65% of the people were using service provided by a private company, 25% - by municipality, 7% - cooperatives and 3% employed their own assistants (Assistanskoll, 2019).

When people with disabilities employ their own assistance, they need to register a company and administer the service, including assistants' contracts, payments of insurances, financial reporting and other. When using the service from a cooperative, the cooperative is responsible for its administration and the contract is concluded between the cooperative, assistant, the person using the service. Cooperatives also offers individual and group peer-support for people using the service to prepare them for their role as managers of their assistance. Various trainings are also available to personal assistants; however, it is responsibility of each person to train their own assistants, according to their needs. People with disabilities can recruit, train, manage and supervise their assistance, with support from the cooperative. Private companies can also organise trainings and peer support for users, although this depends on the company.

It is possible to have a member of the household as an assistant, but they will need to be employed by the municipality or an assistant provider. Supported decision-making is available to people with intellectual disabilities wishing to use the service.³

2.5 Strengths and limitations

Overall, through a combination of different elements, the system has allowed people with disabilities to have a great deal of choice and control over the service. They can custom-design their support and choose their preferred degree of control. The training and peer-support have also been important for enabling people with disabilities to organise and manage their service effectively. The provision of additional support to people using the service was made possible by taking into account various assistance-related costs in the hourly rate.

According to Westberg (2010) one of the key outcomes from the personal assistance system in Sweden has been that it has replaced care provided in institutional form (for example, in nursing homes or clustered housing) with community support, allowing people with disabilities to leave institutions and live independently in the community. He also points out that assistance service has allowed parents of children and adults with disabilities, to the labour market. In addition, personal assistance has turned out to be more cost effective than the home helper service, which involved in-kind provision of services. It is estimated that it has saved taxpayers around EUR 3 billion since 1994, compared to the home-helper services (Zero Project, 2015).

The main limitation of the Swedish system currently is the needs assessment process (Mladenov et al., 2019). In the recent years the interpretation of what constitutes a 'basic need' has been revised, which led to many people losing their assistance or having their assistance hours reduced (CRPD Committee, 2014). The cutbacks of assistance affect negatively the quality of life of people with disabilities and risk leading to re-institutionalisation.

3 Personal assistance in Sofia municipality, Bulgaria

3.1 Background

Bulgaria has been developing national-level assistance services since the beginning of the 2000s. Despite these services were called 'personal assistants' or 'social assistants', they offered little choice and control to people with disabilities and mostly sought to secure employment for long-term unemployed people on benefits and to contribute to the income of the families of people with disabilities. Since 2007, the country has also been using EU funds to develop assistance programmes. While these schemes generally have more liberal approach towards the choice and management of assistants, they still offer limited choice to people using services and the sustainability of the provision is not ensured (Centre for Independent Living, 2009).

Sofia Municipality began to provide assistance services from the beginning of 2008 under a scheme entitled 'Assistants for Independent Living'. The framework for the scheme was originally developed by an organisation of people with disabilities – the Centre for Independent Living – Sofia. It was based on the organisation's experience

³ For more information about organisation of assistance for people with complex support needs, see People with complex disabilities – JAG, Sweden (Angelova-Mladenova, 2019).

with managing personal assistance under a pilot externally-funded project. The project, which ran between 2001 and 2003, sought to develop a model for user-led personal assistance, drawing on the experience of countries like Sweden and the United Kingdom. Within the project, 30 people with disabilities used assistance services for an average of 14 months. The assessment of the project showed that it had a very positive impact on people using the service, their families and assistants (Dakova, 2004). Based on the assessment of the project and following an active lobbying and advocacy of the Centre of Independent Living, Sofia Municipality decided to allocate funding for the provision of assistance service.

3.2 Legal framework

'Assistants for Independent Living' scheme was set up through a special ordinance, adopted by the Municipal Council of Sofia municipality in July 2007. The Ordinance, which determined the conditions for the provision and funding of the service, has been amended several times, since its adoption.

3.3 Institutional framework and funding arrangements

The service is funded and administered by Sofia Municipality, through the respective local Bureaus for social services. At the end of each year, the Municipal Council decides about the amount to be allocated for the service, based on annual activity reports and needs forecast for the next year. In 2019, there were just above 1 400 people using the service, including 714 adults and 719 children⁴.

The service can be provided by the municipality or by other organisations, as long as they are registered in the Register of service providers or have the relevant licence to work with children. When the service is managed by a private provider, the hourly rate of assistants' payment is increased by 2% (changed in 2008 from 7%) which can be used to cover administrative costs. However, since the start of the scheme, there have not been any private organisations involved in the provision of the service, because this 2% have not been enough to cover their administrative costs.

Initially the hourly rate for assistance was linked to the minimum salary but in 2010 a fixed rate was set, which has not been revised since. As a result, assistants' hourly rate went down from three times the minimum wage in 2008, to just above the minimum wage in 2019.

3.4 Overview

3.4.1 Eligibility

To be eligible for the service, people need to satisfy the following conditions:

- be above five years of age and under the retirement age, unless they continue to work under employment or related contracts;
- have 90% or more 'permanently reduced ability to work requiring additional support' (in the case of children 50% and above 'reduced ability for social adaptation, requiring additional support)

⁴ For details, see: https://www.sofia.bg/web/guest/news/-/asset_publisher/1ZIMReQfODHE/content/id/3977897 [in Bulgarian].

- have permanent address in the municipality, or in the case of students – current address;
- do not use similar social services under other programmes.

3.4.2 Assessment and organisation of assistance

People wishing to use the service need to submit an application to the local Bureau for social services and have their needs assessed by social workers from the Bureau. The applications are submitted annually. When the scheme started, the needs assessment was made in number of hours of assistance, but in 2011 this was changed to points. Different areas of assessment have different maximum amount of points – from 10 in the area of family environment, up to 80 in the area of social and educational activities. The points serve to rank the applicants and determine the ones that will get access to the assistance service – those with the highest ranking. The points are then transferred into assistance hours by a specially established commission. At present the maximum number of hours a person can get is 300 per month, which is approximately 10 hours per day. However, even people who need assistance for more than 300 hours per month are not awarded the maximum hours, to allow more people to take part in the scheme (Tsenova, 2018).

The money for the provision of the service are not paid to the person using the service but to the service provider. Since the municipality is the only provider, the money remains in the municipality. The provider is responsible for the administration of the service and the payment of the salary of the assistant, including the relevant taxes and insurances. The salary is paid on the basis of a report about the hours of assistance worked, which needs to be signed by both the assistant and the person using the service.

Even though the service provider is the legal employer of the assistants, people using the service can choose their assistants, determine their tasks and working time and decide when to dismiss them. It is possible to have more than one assistant (not at the same time) and to have a member of the household as an assistant.

3.5 Strengths and limitations

From the perspective of the CRPD, one of the main strengths of the municipal scheme is that people with disabilities have significant control over their assistance – they can choose when, where, by whom and what kind of assistance to receive. It is also positive that the scheme covers people with various impairments and that it does not exclude, at least legally, private providers from service delivery.

Together with this, there are several limitations in the organisation and funding of the scheme that affect its effectiveness as a tool for independent living, including:

- The ceiling on the number of hours means that people with more extensive support needs are forced to go to residential institutions as they are not able to live in the community without significant additional informal support.
- The needs assessment process is complicated, and it is not clear how the decision about the number of hours to be granted is made. In addition, assessment prioritises person's engagement in employment or education, which creates a paradox as it means that to be eligible to receive assistance, one needs to demonstrate that they can cope without assistance (Mladenov, 2012).

- The choice of providers and assistants is restricted by the allocated funding. On the one hand, the hourly rate of personal assistants is currently very low, which makes it difficult for people with disabilities to find assistants outside the family circle. On the other, the insufficient amount for administrative costs discourages private organisations from becoming providers. The lack of a choice of assistants and providers means that people may not be able to find an arrangement suitable for their individual needs. This will affect negatively the potential of the service to support the inclusion and independence of people with disabilities
- The access of people with disabilities to the service is restricted by the geographical coverage (Sofia municipality). In addition, not all eligible people who apply are able to use the service because of the limited funding that the municipality can allocate.

4 The Czech Republic's care allowance

4.1 Background

At the end of the 2007s, a radical change took place in the funding of social services in the Czech Republic towards direct payments. In 2007 a new financial instrument was introduced – care allowance – where cash payment was provided by the state to all eligible people with disabilities, rather than to service providers, to cover the costs of their support. This change was motivated by the desire to move from institutional care to support in the community (Siska, 2009). It was also expected that the care allowance would enable people with disabilities to become clients, i.e. to choose among a variety of providers and purchase services according to their individual needs and preferences. This was expected to lead to services, which are of better quality and are better tailored to the person's individual needs, while unsuitable services would fade away (Barvíková and Österle, 2013).

4.2 Legal framework

In the Czech Republic, the provision of support to people with disabilities is regulated by the Social Services Act No.108/2006 Coll. Among the main principles of the Act are: support for social inclusion, provision of services based on individual needs, and respect for human rights. The Act, which came into force in 2007, details the eligibility criteria and the mechanism for granting and controlling the use of the care allowance. It also defines a range of social services available to people 'in adverse social situations'. The provision of the care allowance is further detailed in the relevant implementing regulation – the Decree implementing the Social Services Act (505/2006 Coll.).

4.3 Institutional framework and funding arrangements

The personal assistance service is funded by the state and currently administered by the Labour Office – a national level administrative authority under the Ministry of Labour and Social Affairs. The Labour office, through its regional branches, accepts applications and carries out the initial assessment (social investigation – 'sociálnímu šetření'). The District Social Security Office is responsible for conducting a detailed assessment of the person's 'degree of dependence', and based on that the Labour office makes the final decision about the allowance. The Labour office also pays the allowance and controls its use. Until 2011, when the functions and the role of the

Labour Office was redefined with (Act 72/2011 Coll), the allowance was administered by the municipalities.

The amount of the allowance depends on the age and the degree of 'dependence on care' of the person (see section 4.4. for details about the assessment). Since April 2019, the highest allowance, paid to people with the most significant needs, is CZK 19 200 (EUR 748)⁵ which can cover approximately 150 hours of assistance per month, or around 40 hours per week⁶. The lowest amount is CZK 3 300 (EUR 128) per month for children and CZK 880 (EUR 34) per month for adults, which can buy around 25 or 7 hours of support per month respectively.

Data from the Czech Statistical Office (2018) shows that in 2017 the average monthly number of people receiving the allowance was 351 900. Around 13% of them received the highest amount and 30% - the lowest. Approximately 62% of the people in all categories were above the age of 70 and 8% - under the age of 18. The state expenditures for care allowance were CZK 25 120 million (EUR 978 million).

4.4 Overview

4.4.1 Eligibility

Care allowance can be granted to people who, due to their disability, chronic illness or age, require another person's assistance in dealing with certain 'basic needs'. To be eligible to receive the allowance, the person should require assistance with at least three of the basic needs. In addition, they must be above the age of one.

4.4.2 Assessment and organisation of assistance

People wishing to receive care allowance need to undergo an assessment of their abilities to cope with certain 'basic needs', including: mobility, orientation, communication, eating, dressing, personal hygiene, physiological needs, health care, personal activities and household care. The assessment establishes the degree of person's 'dependency on care', which can be: slight (grade I) – for people who need assistance with 3-4 needs, medium (grade II) – with 4-6 needs, heavy (grade III) – with 6-8 needs, and total (grade IV) – with 8-10 needs. All people in a specific grade receive the same amount of allowance. The money is transferred to their accounts.

The allowance can be used by the person to buy assistance from a close person, a social care assistant, a registered social service provider. When the assistance is provided by a close person or a social care assistant who does not do it as a business activity, no labour contract is required, although a written agreement should be signed between the social care assistant. In both cases, there is no compulsory requirement people with disabilities to report to the relevant authorities how they have used the allowance, unless such report is requested. However, checks are made by the regional Labour Bureaus whether the allowance is actually used by the person to get assistance and whether the assistance is adequate to the established needs.

⁵ The exchange rate used is the Czech's Central Bank monthly average for March 2019 (https://www.cnb.cz/en/financial_markets/foreign_exchange_market/exchange_rate_fixing/currency_average.jsp?code=EUR).

⁶ The number of hours is calculated on the basis of CZK 130 per hour, which is the maximum rate set out by Decree No 5050/2006 Coll.

If the social care assistant provides assistance as a business activity (for example, to more than one person or for more than a certain number of hours per month), they need to be officially registered as a provider. They should also conclude a written assistance contract with the person specifying the scope of assistance, the place and time and the payment. Contract is also required when the assistance is provided through a service provider.

4.5 Strengths and limitations

The main strength of the system in the Czech Republic is that the payment for assistance services is provided directly to the individual, which allows them to choose how to organise their service. The relationships with the assistants are also not bureaucratic, although there are some potential shortcomings in this approach (for example, the lack of safeguards for the person with a disability). It is also a strength that all people with disabilities, regardless of their impairment, place of residence or income, have access to the allowance.

There are also a number of important limitations, which have hindered the achievement of the goals related to transition from institutional care to support in the community and development of better-quality community support services:

- The system indirectly encourages people with disabilities, especially those with more extensive support needs, to 'choose' residential care. There they can have access to care 24 hours a day, 7 days a week, while at home they would be able to get not more than 4-5 hours of assistance per day. For many people this will not be enough to cover their needs, unless they can rely on significant additional informal support.
- The significant informal support required to allow some people with disabilities to remain at home, limits the employment opportunities of their family members, which has a negative impact on the family income. As a result, the person with a disability has no real choice over how to use the care allowance as it is needed to complement the family income. In these cases, the allowance becomes a source of income for the family, rather than a tool for independent living of the person with a disability. Since it is not used to purchase social services as much as expected, it also does not contribute to the development of alternative to institutional services in the community.
- The state funding is not sufficient to cover the costs for the provision of the service. This has been a barrier to the involvement of private providers and has led to insufficient number of providers of assistance services. Since the demand is higher than the supply, providers are often full and there are waiting lists for access to assistance services, which has hindered the access to the service. In addition, the main idea of the scheme – to allow people with disabilities to become clients – is compromised. This has hindered the expected transformation in the structure and availability of institutional care and community support.
- The needs assessment process, which puts people with disabilities in four general categories of 'dependence', does not allow for the actual needs and circumstances of each person to be taken into account. The limited involvement of people with disabilities in the assessment of their own needs and the medicalisation of the assessment, which is currently done by medical experts, deepens the problem.

5 Conclusion

Personal assistance can play an important role in the process of deinstitutionalisation by providing people with disabilities with access to personalised support in the community. However, in order to become a genuine alternative to institutional care, which enables people with disabilities not only to leave long-stay residential institutions but to participate fully in the life of the community, personal assistance should be organised in line with the principles and the spirit of the UN Convention on the Rights of Persons with Disabilities.

Based on the Convention and the experience of the countries presented in the paper, the following recommendations can be made to stakeholders planning to develop personal assistance as a tool for independent living and as an element of the deinstitutionalisation process:

- i. In order to have a service, which is personalised and therefore better able to support inclusion, it is important to ensure that it is not based on the person's medical diagnosis but on their **individual needs of support, presented in hours of assistance** required. It is also important to enable people with disabilities to assess their individual support needs themselves.
- ii. Remove the hidden incentives for people with disabilities and their families to 'choose' institutional care instead of community-based support, by ensuring that the **amount of assistance provided is adequate to the person's support needs**.
- iii. Ensure that the service is funded through a **central source** to allow all eligible people with disabilities, regardless of their place of residence, to have equal access to the service.
- iv. Ensure that the **funding follows the person** with disability and is not paid directly to the service provider.
- v. When calculating the funding for the development of the service, ensure that **all assistance-related costs are considered and adequately funded**, to avoid creating barriers to the effective functioning of the service. In addition to salary-related and administrative costs, it should also cover costs for trainings and peer support for people with disabilities to enable them to manage their service effectively.
- vi. Take measures to make personal assistance an **attractive career path both financially and professionally**.
- vii. Ensure that the system allows for **choice and control of people with disabilities** with regard to the organisation and delivery of the service. For example, they can choose to employ their assistants themselves or contract the service through a variety of providers; they can decide where, when, how and by whom the assistance will be provided.

The above recommendations complement each other. They should **all** be taken into account to ensure that the personal assistance policy is an effective tool for deinstitutionalisation and participation in community. In addition, for the full inclusion of people with disabilities in society, it is important to ensure that personal assistance

is accompanied by a variety of other measures in the areas such as housing, transportation, education, accessibility, etc.

The European Union funding instruments are a valuable resource, which can be used to support the development, piloting and evaluation of personal assistance schemes and other measures in the process of transition from institutional care to community-based support for people with disabilities.

List of reference

Angelova-Mladenova, L., 2019. People with complex disabilities – JAG, Sweden. In: L. Angelova-Mladenova. 2019. *Towards independent living: A collection of examples from Europe*. [online] pp. 19-20. Available at: <https://enil.eu/wp-content/uploads/2019/03/GoodPractice_web.pdf> [Accessed 12 April 2019].

Assistanskoll, 2019. *Statistik om personlig assistans*. [online] Available at: <<https://assistanskoll.se/assistans-statistik.php>> [Accessed 12 April 2019].

Barvíková, J. and Österle, A. 2013. Long-Term Care Reform in Central-Eastern Europe: The Case of the Czech Republic. In: C. Ranci and E. Pavolini, eds. 2013. *Reforms in Long-Term Care Policies in Europe*. New York: Springer. pp. 243-265.

Centre for Independent Living, 2009. Оценка на асистентските услуги за хора с увреждания в България [Otsenka na asistentskite uslugi za hora s uvrejdania v Bulgaria]. [online] Available at: <http://cil.bg/userfiles/nabliudatelnitsa/ocenka_asistentski_uslugi_BG.rar> [Accessed 12 April 2019] [in Bulgarian].

Committee on the Rights of Persons with Disabilities, 2014. Concluding observations on the initial report of Sweden, CRPD/c/swe/co/1. [online] Available at: <<http://goo.gl/1xqFpi>> [Accessed 12 April 2019].

Committee on the Rights of Persons with Disabilities, 2017. *General comment No.5 on living independently and being included in the community*. Available at: <https://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/5&Lang=en> [Accessed 12 April 2019].

Czech Statistical Office, 2018. *Statistical yearbook of the Czech Republic 2018*. [online] Available at: <<https://www.czso.cz/documents/10180/61431878/32019818.pdf/f7a76822-fe74-4caa-8031-6cf5963e125f?version=1.4>> [Accessed 12 April 2019].

Dakova, V., 2004. За чиновниците и хората. [Za chinovnitsite i horata] [online] Sofia: Centre for Independent Living. Available at: <http://www.cil.bg/userfiles/library/otdelni/za_chinovnitsite_i_horata_1_2004.pdf> [Accessed 12 April 2019] [in Bulgarian].

European Commission, *European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier Free Europe*, COM(2010) 636 final. [online] Available at:

<<https://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=COM:2010:0636:FIN:en:PDF>> [Accessed 12 April 2019].

Försäkringskassan, 2017. *Social insurance in figures, 2016*. [online] Available at: <<https://www.forsakringskassan.se/wps/wcm/connect/d9a3498f-ea2a-40a7-a358-80722d13963a/socialforsakringen-i-siffror-2016-engelsk.pdf?MOD=AJPERES>> [Accessed 12 April 2019].

Mladenov, T., 2012. Personal assistance for disabled people and the understanding of human being. *Critical Social Policy*, [e-journal] 32(2), pp.242-261. <https://doi.org/10.1177/0261018311430454>.

Mladenov, T., Pokern, I., and Bulic Cojocariu, I., 2019. *PA checklist – A tool for assessing personal assistance schemes*. [online]

Available at: <https://enil.eu/wp-content/uploads/2019/02/Mladenov_Pokern_Bulic-PA_Checklist.pdf> [Accessed 12 April 2019].

Ratzka, A., 2003. *Independent living in Sweden*. [online] Available at: <<https://www.independentliving.org/docs6/ratzka200302b.html#project>> [Accessed 12 April 2019].

Šiška, J., 2009. *ANED country report on the implementation of policies supporting independent living for disabled people*. [online] Available at: <<https://www.disability-europe.net/downloads/333-cz-8-request-07-aned-2009-task-5-request-template-to-publish-to-ec>> [Accessed 12 April 2019].

Socialstyrelsen, 2017. *Statistics on the functionally impaired – measures specified by LSS 2016*. [online] Available at: <<https://www.socialstyrelsen.se/Lists/Artikelkatalog/Attachments/20545/2017-3-42.pdf>> [Accessed 12 April 2019].

Tsenova, I., 2018. Места има – ако някой умре [Mesta ima – ako niakoi umre] [in Bulgarian]. *Sega* [online] 7 March. Available at: <<http://old.segabg.com/article.php?id=896583>> [Accessed 12 April 2019]

Westberg, K., 2010. *Personal assistance in Sweden*. Translated from Swedish by S. Berg. [online] Available at: <https://www.independentliving.org/files/Personal_Assistance_in_Sweden_KW_2010.pdf> [Accessed 12 April 2019].

Westerbers, B., 2013. Personal Assistance – a revolution for people with disabilities. 7th International conference on social work in health and mental health, University of Southern California, Los Angeles, 26 June 2013. [online] Available at: <https://www.independentliving.org/docs6/Westerberg-Swedish-disability-policy.html#_ftn1> [Accessed 12 April 2019].

Zero Project, 2015. Sweden's personal assistance budget. [online] Available at: <<https://zeroproject.org/policy/sweden-3>> [Accessed 12 April 2019].

