

# ► Empowering for Independence: Building High Quality Personal Assistance Services for Persons with Disabilities

February 2024

Persons with disabilities may need support in doing their daily life activities, such as going to work or school, doing household chores, or meeting their friends. Support can take many forms: some people may require assistive technology, such as a wheelchair, a screen reader, or a hearing aid, while others may need personal support or combine these and more. A common form of personal support that persons with disabilities need is personal assistance.

Personal assistance is the direct, one-on-one support a person with disabilities requires to achieve the same range of self-determination, choice and control, opportunities, and activities as a person without disabilities. Personal assistance is essential for persons with disabilities to lead their own lives, and to enjoy all the rights under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD),<sup>1</sup> particularly the right to independent living, as defined in General Comment No. 5 of the UNCRPD Committee<sup>2</sup> and in the Guidelines on deinstitutionalisation, including in emergencies.<sup>3</sup> Personal assistance may benefit people with a diverse range of impairments and of different ages, including children with disabilities, supporting their and their families' independence and reducing reliance on informal care.<sup>4</sup>

At the global level, there are growing discussions on care and support, and on the necessity to improve the situation of care and support workers. Support workers often experience poor working conditions, such as low wages or unstable employment, which leads to a low quality of life and a heightened risk of abuse and neglect for both the providers and the users. However, the perspective of people with disabilities remains excluded from these discussions. A gender perspective with an intersectional approach focused on women with disabilities is also missing, despite the disproportionate rates of abuse and neglect women with disabilities experience.

This factsheet focuses on the provision of personal assistance, as a support service that enables persons with disabilities to take an active role in its provision and that has a long-lasting impact on their rights. Looking into personal assistance services globally may shed light on how to structure care and support services to reduce inequalities.

---

1 United Nations Convention on the Rights of Persons with Disabilities, available at [United Nations Convention on the Rights of Persons with Disabilities \(UNCRPD\) | Australian Human Rights Commission](#)

2 Committee on the Rights of Persons with Disabilities (2017). General Comment 5 on Article 19 - the right to live independently and be included in the community, available at <https://www.ohchr.org/en/documents/general-comments-and-recommendations/general-comment-no5-article-19-right-live>

3 Committee on the Rights of Persons with Disabilities (2022). Guidelines on deinstitutionalization, including in emergencies, available at <https://www.ohchr.org/en/documents/legal-standards-and-guidelines/crpdc5-guidelines-deinstitutionalization-including>

4 Westberg, Kenneth (2010) Personal Assistance in Sweden, available at: [https://www.independentliving.org/files/Personal\\_Assistance\\_in\\_Sweden\\_KW\\_2010.pdf](https://www.independentliving.org/files/Personal_Assistance_in_Sweden_KW_2010.pdf)



This factsheet is based on the report “Towards Dignity and Autonomy: A Comprehensive Look at Personal Assistance Policies for Persons with Disabilities Worldwide”, co-produced by the International Labour Organisation and the European Network on Independent Living. The report focuses on personal assistance services in Costa Rica, Thailand, Japan, Republic of Korea, Taiwan, Serbia, Bulgaria, England, Slovenia and Sweden. This report was built on desk research and interviews conducted with experts and personal assistance users in these countries.

## ► Building quality personal assistance services

---

Personal assistance services that are high quality are those that enable full choice and control of persons with disabilities. National personal assistance provision systems that have a positive impact, are sustainable, and create impact in society, should have the following elements: **direct payments, equal provision and promotion across the country, coverage of all costs, flexibility, persons with disabilities in charge of service design**, and an **alignment with the principles of independent living**.<sup>5</sup>

### 1. Direct payments to maximize choice and control

Direct payments refer to when persons with disabilities directly receive the funds to cover the costs of personal assistance. This is how assistance is organised in countries like Japan, England, and Sweden. Managing the funds means being able to employ assistants or choose the provider directly, with training and support if necessary, resulting in more choice and control.

However, direct payments are far from being the norm. In most countries, private or public organisations provide personal assistance directly to the users. Persons with disabilities must then accept the services they are offered and have lower influence over the design of personal assistance. In Slovenia and Bulgaria, there is an alternative option, where persons with disabilities can recruit the assistants, and service providers support with recruitment, payroll, and administration. This can help increase choice, where direct payments are not available, but does not provide the same level of autonomy.

### 2. Personal assistance is provided equally across the country

When personal assistance is provided differently among regions, provinces or municipalities in the same country, persons with disabilities have unequal access to the support they need and experience restrictions due to persisting inequalities and discrimination. For example, in Serbia, where the funding is managed by the municipalities, the service is only available in 26 out of 145 municipalities.<sup>6</sup> Even when provided by the national authorities, inequalities can persist. In England, although the service is centralized at national level, there are significant differences in funding levels and regulations, leading to inconsistencies in quality.

### 3. All costs related to personal assistance are covered

There are several costs associated with the provision of personal assistance: salaries, taxes, administration costs (recruitment, payroll, training...) and additional expenses such as travel costs. Financial coverage of these costs is vital for ensuring high quality services. Limitations to funding often result in persons with disabilities resorting to additional informal support, placing a higher burden on family— particularly on women, and requiring excessive out-of-pocket costs that may lead to catastrophic expenditure. When no informal support is available, the only option may be living in an institution, in contradiction of the UNCRPD obligations.

Employment-related and administrative costs are usually covered, but if funding for it is insufficient, it can restrict choice. In Bulgaria, the limited allocation for administrative costs results in users only being able to use the services provided by the municipalities, so they cannot choose non-state provider. Travel and transportation costs often have limitations. This highly impacts recruitment, especially in rural and remote areas and in cases where assistants work split hours. To mitigate this, some countries like Taiwan offer a highly hourly rate for assistants in remote areas, while Slovenia provides a fixed extra payment for commuting expenses.

---

<sup>5</sup> More information on the principles of independent living may be found at <https://enil.eu/wp-content/uploads/2022/06/Principles-of-Independent-Living.pdf>

<sup>6</sup> Data for 2022, provided by the Republic Institute for Social Protection.

Costs ceilings may further limit options, as they restrict the number of hours people with disabilities can access. In some countries, there is a requirement for users to contribute financially in the form of co-payment systems; for instance, in Taiwan, if an individual earns more than the determined amount, they must cover 30% of the cost of the assistance. This can make personal assistance unaffordable, especially to those with higher support needs.



Antonella is 27 years old, from Italy, and a wheelchair user. Her personal assistant, Alice, is 28 years old and she is also from Italy. Antonella moved to Brussels from Italy to do a traineeship at the European Parliament. Thanks to having access to personal assistance, she could move to another country to achieve her career goals, living independently without her family.

---

“Being supported by Alice, my personal assistant, helps because I live in a non-wheelchair accessible environment. Without her, I would miss many opportunities to participate in meetings or trainings, and leisure activities with friends. (...) I feel more independent, responsible and happy in my life.”

Alice believes that her role as a personal assistant is to support Antonella to have the same opportunities as everyone else. For her, her profession is gratifying and never boring, and she sees how she can make a difference in Antonella’s daily life.

However, Antonella does not receive funds for personal assistance. She pays for her assistance through her disability allowance and her family’s support. She struggled to find an assistant in the past and was supported by her family. In Antonella’s opinion, obstacles to find a personal assistant are even greater for those experiencing multiple and intersecting discrimination, and for those living in rural areas.

[You can watch the full interview here](#)



## 4. There is sufficient flexibility to determine the number of hours

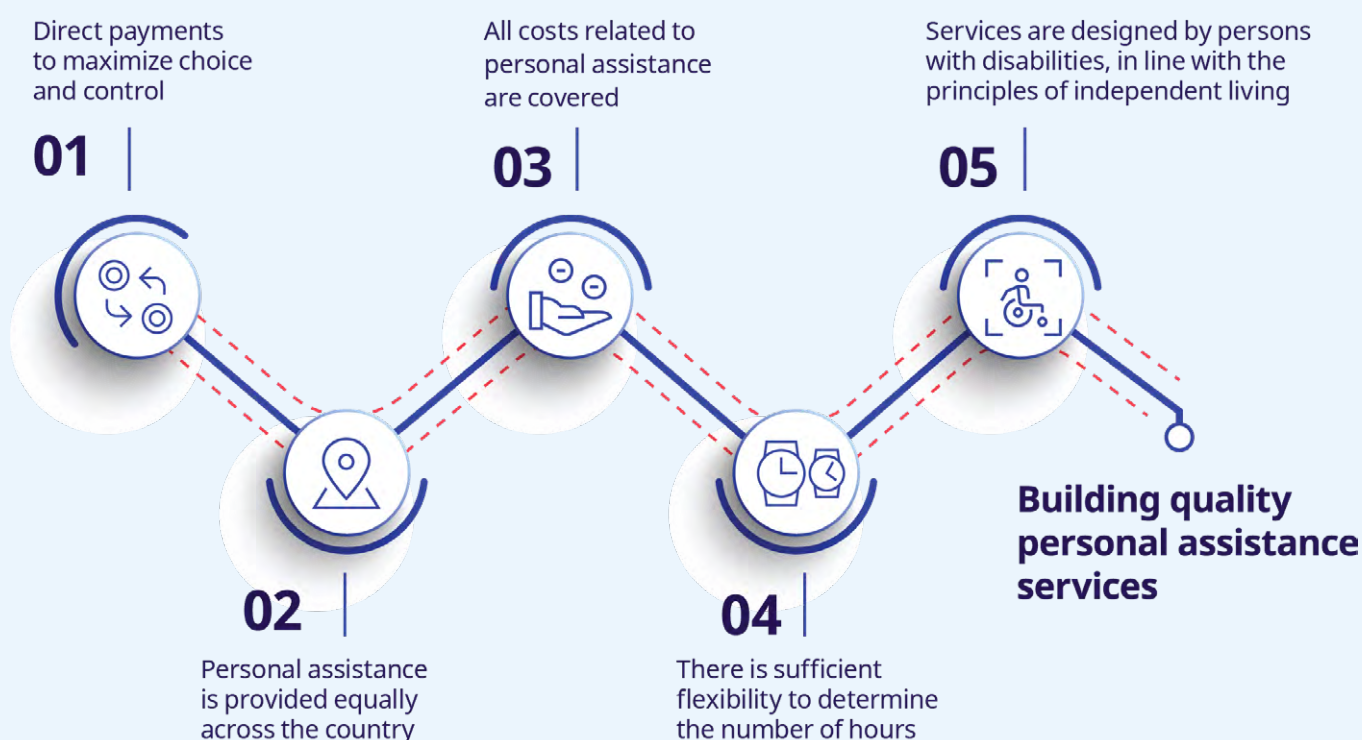
The number of hours is often determined through an assessment process. The evaluation differs from country to country: in Japan, Korea and Taiwan, the assessment considers medical and psychosocial needs, daily living skills, and environmental factors, resulting in a plan that details types of services needed – including the hours of personal assistance. In Bulgaria, Slovenia, and Sweden, they only focus on determining the number of personal assistance hours. In Taiwan, the assessment formally includes peer support, as a peer with disabilities is employed to guide and support the process.

In most cases, needs are detailed by creating a check list that sets out the activities the person may need support with. This method does not allow sufficient flexibility to meet the needs of persons with disabilities, as they may vary from person to person, and can also change in time. Rigid scheduling of brief time slots can also impact recruitment and the quality of services.

## 5. Services are designed by persons with disabilities, in line with the principles of independent living

Having the ability to design support, thereby choosing when, where and by whom it is provided, is a key element of personal assistance and one of independent living principles. But many countries set restrictions in this regard. In Thailand and Taiwan, providers recruit the assistants and assign them to the user. In Bulgaria, services can only be used in the municipality, not allowing the person to relocate. In other cases, hours are restricted, only being available at standard working hours. When providers impose additional restrictions, such as planning or controlling daily activities of the users, the autonomy of persons with disabilities is further reduced. These restrictions make personal assistance resemble traditional home care, instead of a service that allows persons to decide over their own lives.

Alternatively, having Centres for Independent Living (CILs) as service providers can offer more flexibility and autonomy to persons with disabilities, better supporting self-led service providers and facilitating all the elements to put personal assistance in place. They are organisations run and controlled by persons with disabilities and promote the principles of independent living and the UNCRPD.



## ► Providing decent working conditions for personal assistants

---

The profession of a personal assistant remains unknown, undervalued and underpaid. Existing data shows that most assistants are predominantly female and born outside the country where they work. The intersection of gender and migrant status further puts personal assistants at risk of exclusion. Therefore, ensuring decent working conditions and reducing inequalities is of great importance. For this, personal assistants need stable employment contracts, decent wages, promotion and recognition. This would lead to an increase in the number of personal assistants to cover demand.

### 1. Stable employment contracts ensure the same rights as other workers

Typically, personal assistants are engaged either through employment contracts, or through service contracts as self-employed workers. This varies from country to country: in Bulgaria and Slovenia, the legal framework stipulates that personal assistance must have employment contracts, while in other countries, both options are possible. However, due to lack of funding, this may lead to a higher percentage of self-employed personal assistants: in Serbia, around half of the assistants are self-employed.<sup>7</sup> Personal assistants engaged as self-employed workers often have fewer statutory protections and benefits than other workers, leading to difficulties to receive sick leave or unemployment benefits, and therefore resulting in a higher turnover rate.

Migrant workers experience even more precarious situations, due to uncertainties regarding their work permit. Anti-immigration policies have further exacerbated this, making it increasingly difficult for migrant workers to stabilize their situation. Following the 2023 Labour Immigration Law in Sweden, the earnings threshold for migrant workers to obtain a permit was tripled, making many personal assistants lose their right to work in Sweden. In England, following Brexit, the number of vacant posts in adult social care increased by 52%.<sup>8</sup>

Similarly, it has been reported that assistants that are part of social reinsertion programmes, including migrants and people that have not finished basic education, may also experience unstable contracts with lower quality conditions. This also leads to a lack of motivation due to the perception that they did not choose the profession themselves but were instead pushed into it, as personal assistant trainings may be offered in the programmes.

### 2. Decent wages improve retention and quality of life

Too often, personal assistants' salaries are low or declining. In Thailand, they are insufficient to cover living costs,<sup>9</sup> while in Taiwan, they are lower than those of workers in similar sectors. On the contrary, in Europe, the salaries are comparable to those of workers in similar occupations, but inflation has impacted their real income. For instance, in Slovenia, the hourly rate has remained the same since 2019. This impacts the quality of life of personal assistants, makes the job less appealing, and greatly contributes to the generalized workforce shortage of personal assistants.

---

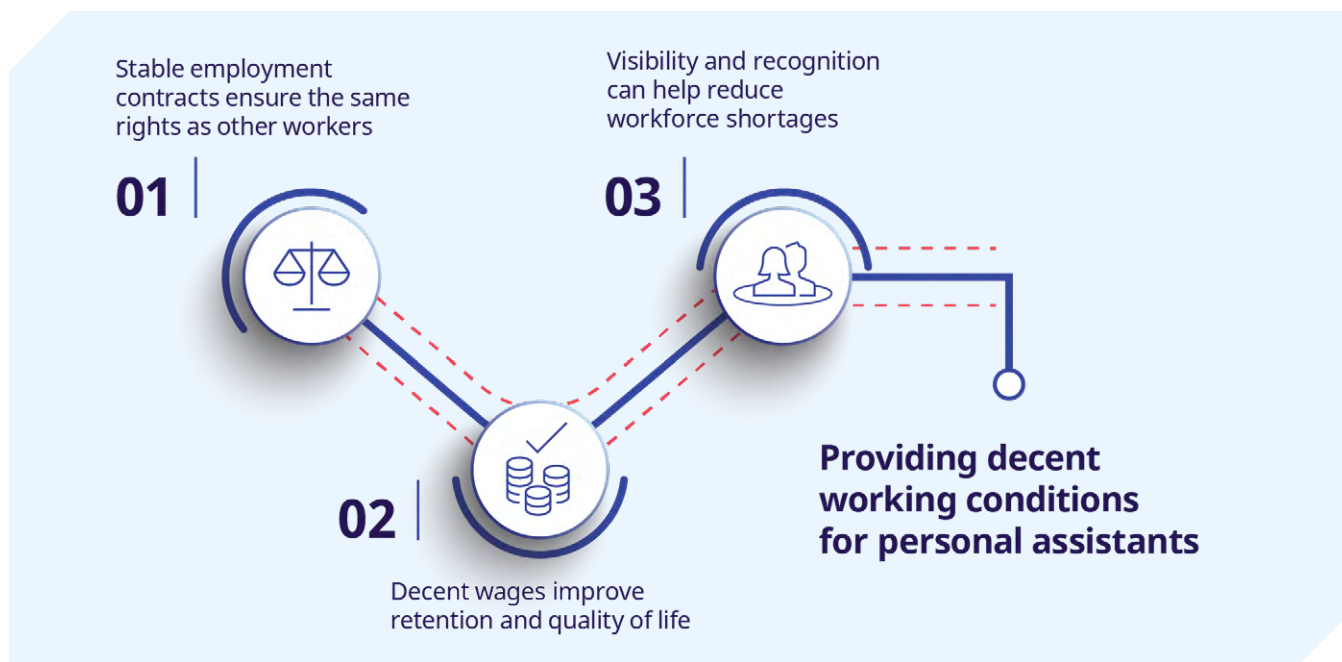
<sup>7</sup> Data provided by the Republic Institute for Social Protection.

<sup>8</sup> Skills for Care (2023) The state of the adult social care sector and workforce in England.

<sup>9</sup> Suksanguan, C. (2023) 'Addressing social workers shortages for leveraging the impact of Personal Assistance Services for Persons with Disabilities in Thailand', Socialprotection.org, 31 August 2023, available at: <https://socialprotection.org/discover/blog/addressing-social-workers-shortages-leveraging-impact-personal-assistance-services>.

### 3. Visibility and recognition can help reduce workforce shortages

Personal assistants have a lower turnover rate than other professions in the sector, showing that personal assistants are satisfied with their jobs. However, there is an insufficient supply in most countries, which does not match the demand for personal assistants. This is not only linked to working conditions, but also to the low visibility and recognition of the profession. At societal level, the role of personal assistants is not known or understood; even among care professionals, personal assistance is viewed as an unskilled profession.<sup>10</sup> In Sweden, the image of personal assistance has been further impacted by fake news and negative media coverage. Promoting a more positive image of personal assistants can in turn make the profession more attractive and reduce workforce shortages.



## ► Training and support

Personal assistance is highly personalized, as it must adapt to the individual circumstances of the user. Therefore, many perceive that training and support for personal assistants is unnecessary, while others perceive that it increases the attractiveness and safety of the job. In turn, many users need skills to manage their personal assistance as employers. To achieve high quality personal assistance, it is necessary to offer training and support for users, to involve people with disabilities as trainers, and to utilize training and support to prevent harassment and abuse.

### 1. Training and support for users enables choice and control

Access to training and support for users is necessary for many people with disabilities to exercise choice and control. Training can be on a variety of topics, like recruiting assistants, conducting job interviews, managing work and time, managing relationships, conflict resolution, reporting, and legislation. In countries where the medical model of disability still prevails, it is vital to conduct trainings on the social model to empower persons with disabilities.

<sup>10</sup> Woolham, J., Norrie, C., Samsi, K., and Manthorpe, J. (2019) Roles, responsibilities, and relationships: hearing the voices of Personal Assistants and Directly Employed Care Workers. NIHR Policy Research Unit in Health and Social Care Workforce, The Policy Institute, King's College London. Available at: <https://doi.org/10.18742/pub01-005>.

A crucial type of support for the functioning of personal assistance is peer support, commonly offered by CILs. Users of personal assistance can support each other by sharing their experiences, for instance on assessment, recruitment, task design, obstacles, etc.

## 2. Disabled people themselves provide the best training for personal assistants

It is common in many countries to make training for personal assistants compulsory, usually before or within a certain period after they start work. Trainings are often on topics such as independent living, obligations and rights of assistants, communication skills, rolling a wheelchair, etc. Trainings can be delivered by organisations providing assistance services, or by training and accreditation institutions.

In Bulgaria, England and Sweden, there is no formal qualification or training requirement, so persons with disabilities themselves train their assistants according to their own needs and preferences. There can also be on-the-job training, where a new assistant works alongside a more experienced one. The experiences from these countries show that formal qualification does not lead to better employment and retention rates, but focusing on personal qualities and behaviour has greater levels of success.<sup>11</sup> In England and Sweden, even though there is no compulsory training, it is also possible for assistants to take part of external trainings, if agreed with the users. Ideally, these trainings should be covered by a user-directed budget, to have more control over training and development of the assistants.

## 3. Preventing harassment and abuse through training and support

It is critical to prevent and address harassment and abuse, to ensure a safe environment for both assistants and users. Some strategies that can be used for this are trainings, follow-up meetings, support arrangements, as well as criminal record checks.

As the first step, trainings are useful to raise awareness about identifying, preventing, and responding to situations of harassment and abuse. They can include topics such as forms of abuse, signs of violence, support services available, etc. Secondly, where assistants are not employed directly, service providers can schedule regular follow-ups with users and assistants. These are some of the measures to ensure the safety and well-being of both parties. In addition, organisations such as CILs can offer services for advice and support in case of problems, with a designated contact person and multiple channels for reporting and support. The continuity of the service must be guaranteed in case of a replacement being needed, to ensure users do not feel threatened to lose their personal assistance if they report abuse. Finally, there are other strategies, such as criminal record checks, specific arrangements for assistants working with people known to be abusive, or personal assistants' registers – which are controversial, as they limit control over the selection of assistants.



11 Skills for Care (2023) Individual employers and the personal assistant workforce. Available at: [www.skillsforcare.org.uk/topics](https://www.skillsforcare.org.uk/topics).



## ► Recommendations

### Put people with disabilities in control...



... **of the funding**, through direct payments, so they can make their own decisions regarding the hiring, management, and evaluation of personal assistants.

... **of the services**, by ensuring they have choice and control over when, where, how, and by whom they receive personal assistance.

...**of the qualifications**, letting the users decide over the required qualifications, so they are better suited to their needs.

### Ensure that personal assistance is financed...



...**centrally**, to reduce inequalities across regions and municipalities.

...**fully**, covering all related costs including administrative, employment-related and transportation costs, with no cost ceilings and co-payments.

### Promote quality personal assistance services through...



...**24/7 availability**, to adequately meet the support needs of users.

...**training and support**, including from peers, to recruit and manage personal assistants, understand their rights and responsibilities, and manage conflicts.

...**assessment-based impact on users' rights**, as the best determinant for quality services is how they enable persons with disabilities to access education, employment, leisure, participation, etc.

...**decent working conditions**, with adequate pay rates, stable employment, support, and access to training and development, in balance with control and flexibility of the services.

### Work together for better...



...**data collection and research**, including disaggregated data and information on the number of personal assistants, and further research on centres for independent living and personal assistance cooperatives.

...**understanding of independent living**, to ensure personal assistance is in line with the UNCRPD.

...**visibility of the personal assistance profession**, for higher recognition and wider awareness of a rewarding career with economic benefits to society and a positive impact on the rights of persons with disabilities.

## About the International Labour Organisation

The International Labour Organization (ILO) is the United Nations agency for the world of work. It was founded on the conviction that universal and lasting peace can be established only if it is based on social justice. The ILO brings together governments, employers and workers from its 187 member states in a human-centred approach to the future of work based on decent employment creation, rights at work, social protection and social dialogue. The ILO's tripartite membership drafts, adopts and monitors the implementation of international labour standards -ILO Conventions and Recommendations- on key world of work issues

## About the European Network on Independent Living

The European Network on Independent Living (ENIL) is a Europe-wide network of disabled people, with organizational and individual members throughout Europe, and beyond. ENIL is a forum for all disabled people, Independent Living organizations and their non-disabled allies on the issues of Independent Living. ENIL represents the disability movement for human rights and social inclusion based on solidarity, peer support, deinstitutionalization, democracy, self-representation, cross disability and self-determination.

[enil.eu](https://enil.eu)

### Contact details

International Labour Organization  
Route des Morillons 4  
CH-1211 Geneva 22  
Switzerland

T: +41 22 799 7239  
E: [@ilo.org](mailto:@ilo.org)