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► Towards Dignity and Autonomy:

A Comprehensive Look at Personal Assistance Policies
for Persons with Disabilities Worldwide

Cover Photo @ENIL: European Network on Independent Living

- ▶ **Towards Dignity and
Autonomy: A Comprehensive
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► 1 Introduction

1.1 Background and objectives

In recent years, there has been an unprecedented interest at global, regional, and national level in care economy. In this context, care policies are usually discussed in terms of their potential to contribute to gender equality or to create decent jobs. However, there is a growing recognition of the importance to incorporate the perspective of those who receive care and support – persons with disabilities and older persons. Thus the 2023 UN resolution on the International Day of Care and Support highlights the importance of developing care and support systems that protect the rights of both those providing and receiving support. It explicitly acknowledges the role of support for enabling persons with disabilities to live independently and be included in the community. This development marks a significant step in aligning care economy discussions with the principles of human rights and independent living.

This research aims to bring a disability perspective to care economy discussions. Focusing on personal assistance services as a key tool for independent living, the research will explore their potential to create decent work. Together with this, it will examine the impact that the design of services has on their ability to promote self-determination, choice, and control of persons with disabilities, in line with the Convention on the Rights of Persons with Disabilities (CRPD).

The report presents the findings from a review of personal assistance policies and practices from across the world and formulates recommendations on how to ensure that personal assistance promote full inclusion and participation of persons with disabilities in community, including by improving the working conditions of assistants.

This research is a product of the cooperation between the International Labour Organisation and the European Network on Independent Living (ENIL).

1.2 Personal assistance and independent living

Personal assistance is the direct, one-on-one support a person with disabilities requires to achieve the same range of self-determination, opportunities, and activities as a nondisabled person. This can include day-to-day activities such as household chores, personal hygiene, working or studying, and childcare; and spontaneous activities such as going to the cinema or visiting friends.

Personal assistance is a key tool for the realisation of the right of persons with disabilities to live independently and be included in the community, set out in Article 19 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD). This right entails providing persons with disabilities with the opportunity to exercise choice and control over their lives and to make all decisions concerning their lives¹.

To enable people with disabilities to live independently and participate in the community personal assistance needs to be organised in a specific way. As outlined in General Comment 5 by the Committee on the Rights of Persons with Disabilities (CRPD Committee), the defining feature of personal assistance, distinguishing it from other support forms, is that it is managed by the person with the disability.

¹ CRPD Committee (2017) General comment No. 5 (2017) on living independently and being included in the community.

This means they control the service's budget and have the choice to either hire assistants directly or contract the service from a provider. In either case, it is crucial that they remain at the centre of the decisions about how the service is organised and provided and by whom, having control over when, where and how the service provision takes place. Children with disabilities may also benefit from personal assistance services, as it may empower them to live independently when they become adults, and it can reduce the perceived burden on families.

Services labelled as “personal assistance” exist in many countries across the world. However, they are often not aligned with the standards set forth in General Comment 5.

Many assistance programs allow for limited control to persons with disabilities over various aspects of their support. As a result, these programs resemble home care services more closely than true personal assistance². This is also evident in some of the countries examined in this study. The inclusion criteria and the rationale for their selection are discussed in the following section.

1.3 Methodology

1.3.1 Inclusion criteria

Recognising that different countries may be in various stages of development of personal assistance services, and aiming to include variety of experiences, the following inclusion criteria informed the selection of programmes.

- The service involves one-to-one relationship, where the person with disability has a say in determining the tasks of the assistant, and where the assistant is paid for their work.
- The service has been provided for at least two years, to allow for accumulation of data and experience.
- It has national or regional coverage.
- It is publicly funded, at least in part.
- The service is not limited to a specific thematic area, such as education or employment.

1.3.2 Initial mapping of personal assistance services

A non-exhaustive mapping of personal assistance services across the world was carried out, based on the inclusion criteria. The primary methodology used was desk review of the relevant literature, including reports and briefs produced by non-governmental organisations (NGOs) and international organisations, state reports submitted to the CRPD Committee, blog posts, news, and academic articles. The items for review were identified by examining the websites of key international disability organisations (e.g., the European Network on Independent Living, the International Disability Alliance, and Zero project), and UN agencies and bodies (e.g., the International Labour Organisation). Basic Google search was also carried out, and for academic articles – a search of key journals (e.g., Disability and Society) and databases (e.g., Science Direct and JStore). The desk research was supplemented by consultations with disability activists from different regions, ENIL staff and Board members.

² On the difference between home care and personal assistance, see Mladenov et al. (2022) Comparison between personal assistance and home care work. Available at: https://enil.eu/wp-content/uploads/2022/06/Comparison-between-PA-and-CW_final_ENIL.docx <https://enil.eu/explainer-difference-between-personal-assistance-and-home-care/>.

1.3.3 Scope of the study

Nine countries were ultimately included in this study. The selection of these countries was informed by the initial mapping of personal assistance services. Diversity was also sought with regard to income group³ and region. However, during the mapping stage no low-income countries, nor countries in Africa and the Arab states, met the inclusion criteria for personal assistance provision. This aligns with other studies indicating minimal or non-existent investment in long-term care and community services in these regions. Similarly, the experience with personal assistance in South America is quite limited. Consequently, the majority of the countries chosen for in-depth review are primarily from Europe and Asia.

	Upper-middle income	High income
Americas	Costa Rica	
Asia and the Pacific	Thailand	Japan, Republic of Korea, Taiwan
Europe and Central Asia	Serbia, Bulgaria	England, Slovenia, Sweden

1.3.4 Study methodology

A further desk review was carried out, focusing on academic publications, policy documents, reports, and data related to the development and provision of services. In addition, online consultations were organised with at least one stakeholder from each country, primarily through Zoom or email exchanges. Most of these consultations involved representatives from organisations for persons with disabilities and researchers. Unfortunately, we were unable to organise consultations with stakeholders from Costa Rica. The study was conducted over the period of October to November 2023.

1.3.5 Limitations

One limitation of the study is the variability in the quality and quantity of information available across different countries, with limited information available for some. One factor for that are language barriers, as the analysis relied primarily on information in English, Spanish and Bulgarian. This issue was, however, partly addressed through country consultations. Furthermore, in many countries, the availability of publicly accessible data and analysis was extremely limited, and the language proficiency was not sufficient to overcome this challenge. Additionally, the study's constrained timeframe, approximately one month, hindered the ability to access more comprehensive information.

Another important limitation of the study is the limited exploration of the diversity in practices and experiences within the countries. This includes variations among municipalities and service delivery models, for example, persons with disabilities directly employing their own assistants, contracting organisation of persons with disabilities, private for-profit companies, or municipal services. Each of these models represents a distinct approach to service delivery, and their diversity was not fully captured in the study.

³ Based on the World Bank's classification of countries into four groups: low, lower-middle, upper-middle, and high-income countries.



► 2 Country overview

2.1 Legal framework

In Europe, personal assistance appeared at the end of the 20th century in Sweden and England. The Swedish Act Concerning Support and Services for Persons with Certain Functional Impairments (abbreviated in Swedish as LSS) was adopted in 1993, and the British Community Care (Direct Payments) Act was adopted in 1996. In Bulgaria and Slovenia, national personal assistance laws were adopted in 2018 and 2019, respectively. In Serbia, the 2011 Social Protection Law for the first time provided for independent living services, including personal assistance. The act was amended in 2012 delegating to municipalities the development and funding of social services.

In Asia, Japan was a pioneer of personal assistance services. The Japanese Services and Supports for Persons with Disabilities Act was adopted in 2005. The service was introduced in Thailand in 2007 under the Persons with Disabilities' Quality of Life Promotion Act B.E. 2550 (2007)⁴. In Taiwan, the concept of personal assistance was incorporated into legislation under the term 'independent living support services' through the 2011 amendments to the Disability Act. The service was introduced in Korea in the same year, with the Act on Support of Activities of Persons with Disabilities.

In Latin America, Costa Rica was the first, and currently the only, country with national personal assistance legislation and publicly funded service. The Law for the Promotion of the Personal Autonomy of Persons with Disabilities, a key provision of which is the right to a personal assistant, was adopted in 2016.

2.2 Drivers for the development of personal assistance

The development of personal assistance services in most countries has been strongly influenced by independent living ideas and the advocacy of persons with disabilities and their organisations. The sharing of experience and cooperation between persons with disabilities has also played a vital role. The pioneering efforts in England and Sweden, driven by local activists and further promoted by the European Network on Independent Living, have been fundamental in facilitating the proliferation of these services across Europe. Similarly, the Japanese independent living movement has played a crucial role in the Asian region, particularly in Taiwan and South Korea, through training and support initiatives for people with disabilities. In addition, activists from Costa Rica have initiated the creation of an Independent Living Network in Latin America to facilitate the exchange of experience and promote the personal assistance model.

Often, the first step to developing personal assistance service were pilot projects, led by organisations of persons with disabilities. The experience from these projects has played a crucial role in shaping the relevant legal frameworks and facilitating the expansion of the services. This was the case, for example, in Taiwan, where New Vitality Independent Living Association's three-year pilot project led to the development of personal assistance legislation.

4 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>.

In Slovenia, it was YHD (Association for the theory and culture of handicap) who piloted the service, in Sweden – the Stockholm Cooperative for Independent Living (STIL), in Serbia – the Centre for Independent Living in Beograd. The outcomes of these projects have been instrumental in providing both the arguments and the experiential basis needed to support the expansion of these services at a national level.

The development of personal assistance services has been supported by arguments from various key perspectives:

- **Disability rights/social inclusion:** Across all countries, personal assistance is universally regarded as a crucial instrument for facilitating the inclusion of persons with disabilities in the community.
- **Welfare state restructuring:** In addition to independent living, the transition towards marketisation of social services has played a significant role in shaping personal assistance policies in countries like Sweden and England.
- **Economic development:** The service's role in job creation has been a prominent argument in countries, such as Slovenia and Bulgaria. This is not only applicable to the employment of personal assistants but also extends to enabling persons with disabilities and their family members to engage in the workforce.
- **Gender equality:** Personal assistance services contribute to gender equality by relieving family members, usually women, of their caregiving responsibilities. This aspect is especially emphasised in Latin American countries, highlighting the role of personal assistance in addressing gender disparities in care work. Assistance services also promote gender equality by enabling women with disabilities to pursue education and employment opportunities.

2.3 Trends in the development of the service

The trends in the development of personal assistance services vary greatly among the countries, influenced by a mix of local and global factors. These include the economic development, political climate, cultural norms, welfare system structures, and overarching challenges like the COVID-19 pandemic and financial crises.

For example, in Slovenia, there has been a 41% increase in the usage of personal assistance service in one year⁵, which is primarily attributed to the lack of alternative community support options. In Korea, the growth in service usage has been more gradual, with an approximately 50% increase over seven years (2015 to 2022). In Sweden, on the other hand, there has been a decline in the number of personal assistance users, driven largely by the government's austerity policy⁶. In Taiwan, the growth and development of personal assistance services have been somewhat restrained in recent years, predominantly due to political and cultural dynamics⁷.

5 ENIL (2022) Independent Living Survey, summary report. Available at: https://enil.eu/wp-content/uploads/2023/04/IL-Survey_Summary-report_Dec2022.docx.

6 Brennan, C., Traustadóttir, R., Anderberg, P. and Rice, J. (2016). 'Are cutbacks to personal assistance violating Sweden's obligations under the UN Convention on the Rights of Persons with Disabilities?', *Laws* 5(2): 1–15.

7 Chou, Y., Chen, B. and Kröger, T. (2023) 'Lost in translation: implementing personal assistance in an East Asian context', *Disability & Society*, 38(4): 587-609.

Country	Number of users of personal assistance	Year
Bulgaria ⁸	49,505	2021
Costa Rica ⁹	N/A	
England ¹⁰	69,000 (approx.)	2022
Japan ¹¹	23,123	2021
Korea, Republic of ¹²	110,658	2022
Serbia ¹³	375	2022
Slovenia ¹⁴	4,000 (approx.)	2022
Sweden ¹⁵	13,380	2022
Taiwan ¹⁶	1,204	2023
Thailand ¹⁷	N/A	

- 8 Agency for Social Assistance (2022) 'Analysis of the implementation of the Personal Assistance Law for the period 01.01.2021 – 31.12.2021'. [in Bulgarian].
- 9 The publicly available data do not differentiate between paid personal assistants and informal carers, providing a combined total for both categories.
- 10 Skills for Care (2023) *Individual employers and the personal assistant workforce*. Available at: www.skillsforcare.org.uk/topics.
- 11 Ministry of Health, Labour and Welfare (2022) *Overview of the 2021 Survey of social welfare facilities*. [in Japanese] Available at: <https://www.mhlw.go.jp/toukei/saikin/hw/fukushi/21/dl/kekka-kihonyou02.pdf>.
- 12 Korea Institute for Health and Social Affairs (2022) *Social security statistics 2022*. [in Korean] Available at: https://www.mohw.go.kr/boardDownload.es?bid=0019&list_no=378314&seq=1.
- 13 Data provided by the Republic Institute for Social Protection.
- 14 An estimate provided by YHD.
- 15 Försäkringskassan (2023) *Social insurance in figures, 2023*. Available at: <https://www.forsakringskassan.se/download/18.73da25b81888fb1e89b97d/1695274193538/social-insurance-in-figures-2023.pdf>.
- 16 Ministry of Health and Welfare of Taiwan. The data concerns only the service administered by the Ministry of Health and Welfare. It does not include personal assistance provided in workplaces and in schools, which are overseen by the Ministry of Employment and Ministry of Education, respectively
- 17 There was no publicly available data for the number of users of personal assistance services.

► 3 Personal assistance models and independent living

A key feature of personal assistance is that it can enable the choice and control of persons with disabilities over their support, which allows them to customise the service according to their needs and preferences, facilitating their participation in community life.

A range of factors have impact on the potential of personal assistance to support the autonomy and community involvement of persons with disabilities. They include, for example, specific funding mechanisms and provision arrangements employed by the countries.

3.1 Funding mechanisms

3.1.1 Cash allocations vs direct provision of services

In some countries, for example Japan, England, and Sweden, personal assistance is organised in the form of direct payments, where the funds for assistance are paid directly to persons with disabilities. This empowers them to either employ assistants themselves or engage a service provider of their choice. Such a system maximises users' control over their support and aligns closely with the recommendations of the CRPD Committee.

In most of the countries, personal assistance is provided only in-kind – by public or private organisations, including NGOs and organisations of persons with disabilities. This funding model often leads to considerable limitations on the autonomy of service users. They may find themselves compelled to accept the arrangements offered by these providers, without having the opportunity to tailor or influence the design of the service to meet their specific needs and preferences.

In Slovenia and Bulgaria, a specific model of personal assistance is observed. While direct payments are not implemented in these countries, there is still an opportunity for service users to recruit their assistants from the open labour market. Here, the role of the service provider, similar to Sweden, is primarily related to providing support with recruitment, where needed, payroll and administration. Although less restrictive than in-kind provision, this model still presents some limitations in terms of complete autonomy and flexibility compared to the direct payment system.

3.1.2 Centralised vs decentralised funding

In some countries, such as Bulgaria, Slovenia, and Taiwan the funding for personal assistance is centralised, while in others, for example, Serbia, England, and Thailand it comes from the budget of the municipalities. In Sweden and Japan, there is a combination of national and local funding. In Sweden, the local authorities cover the costs of the service for people with less than 20 hours of assistance per week, while the state, through the Swedish Social Insurance Agency (Försäkringskassan), funds those with more than 20 hours per week. In Japan, around 50% of the funding for assistance services come from the national government. The remaining half of the cost is split between prefectures and municipalities.

The decentralised approach to funding personal assistance has created significant challenges for persons with disabilities. In Serbia, for example, the service is only available in 26 out of 145 municipalities¹⁸, which severely restricts the access of persons with disabilities to personal assistance and hinders their ability to participate fully in the social, economic, and cultural life of their communities.

Even when personal assistance is provided across the country, like in England, there can be significant variations in funding levels and rules (for example, cost ceilings) leading to inconsistencies in the quality of the service. This also affects the mobility of persons with disabilities who may face challenges in maintaining the same type and level of support when relocating to a different municipality or region, which can be a major barrier to their independence and quality of life.

3.1.3 Coverage of costs

Apart from the salaries of assistants, there are several other costs associated with the provision of the service: employment-related costs (for example, for taxes and national insurance contributions), costs for administration (recruiting assistants, preparing contracts, payroll, training, and support), and additional expenses related to assistants (for example, travel and event ticket costs). Adequate coverage of these costs is vital to ensuring the effectiveness and quality of assistance.

In most countries, employment-related costs are usually included in the funding for the service. There are, however, exceptions, such as in some Serbian municipalities where employer's taxes and national insurance contributions are not covered. This practice can adversely affect the working conditions of assistants, subsequently impacting the quality of the service.

Administrative costs associated with the provision of the service are covered in most countries, although the level of financing, and the funding models vary. In England, for instance, people employing their own assistants often use payroll companies to manage contracts, salary calculations, and contributions payments. Local authorities cover the cost of these services, which are not deducted from the personal assistance budgets. A different approach is adopted in Sweden and Slovenia where the state's per-hour payment for assistance includes both administrative and additional costs. This system grants providers the flexibility to determine how to allocate funds between salaries and various additional costs. This allows for more choice and control of persons with disabilities who are able to choose among different providers, based on the conditions they offer.

The insufficient funding allocated for administrative costs can lead to adverse outcomes. For example, in Bulgaria, while the legal framework permits private organisations to act as service providers, the limited allocations for administrative expenses have effectively barred their involvement and resulted in services being exclusively provided by municipalities. This has restricted the choices available to users, denying them the opportunity to select from a variety of providers or to switch their provider if they are dissatisfied with the service received.

Many of the countries provide coverage for certain additional expenses, such as transportation costs incurred by assistants while providing the service, although often with restrictions. In Taiwan, for example, such costs are reimbursed, subject to per-instance and monthly limit, and the requirement that each trip starts and ends at the same point. However, in countries such as Bulgaria, these costs are not covered, and in England, coverage varies by municipality.

¹⁸ Data for 2022, provided by the Republic Institute for Social Protection.

The transportation costs for assistants to and from the job are typically not considered part of these additional expenses and are usually not reimbursed. This, coupled with the generally low salaries of assistants, can negatively impact recruitment, particularly in rural and remote areas with limited public transport, and for situations where assistants work split hours. To address recruitment issues, some countries have implemented measures to mitigate the financial burden of commuting expenses on assistants. For example, Korea offers additional payments to cover long-distance travel and travel to areas not well-served by public transport. However, these payments are subject to daily visit limitations and two fixed rate categories based on distance (less or more than 10 km). Taiwan has adopted a different approach, offering a higher hourly rate for assistants in remote areas. Slovenia, on the other hand, has implemented a more universal solution, providing all assistants with a fixed extra payment with their salary to cover commuting expenses.

3.1.4 Cost ceilings

Many of the countries have implemented cost ceilings, which limit the number of hours people with disabilities can use. These ceilings vary widely both between and within the countries. For example, in Bulgaria the ceiling ranges from only 15 hours per month for some groups of persons with disabilities, up to 168 hours for others.

The practice of setting maximum limits on assistance hours restricts the ability of persons with disabilities to fully meet their support needs. This limitation poses a significant barrier to achieving independence and social inclusion. When the allocated assistance hours are insufficient, persons with disabilities may need to rely on additional informal support, which can significantly hinder their autonomy. This reliance also places undue burdens on family members, particularly women, who are more likely to assume caregiving responsibilities, affecting their opportunities for personal and professional development. Persons with disabilities without access to such informal support, might find themselves compelled to living in an institution, which further isolates and excludes them from society and contradicts to the principles of the CRPD¹⁹. They might also be unable to adequately meet basic needs related to food and drink, and personal care²⁰.

There are also countries where personal assistance has been organised without formal cost ceilings. For example, England, Slovenia, and Sweden base the allocation of personal assistance hours on the needs of each person with disabilities, as determined through an individualised needs assessment. This allows users to receive the necessary level of assistance to meet their support requirements, enabling them to participate fully in society.

3.1.5 Co-payment

In some countries, there is a requirement for users of personal assistance services to contribute financially to their support. An example of this can be seen in Taiwan, where the provision of assistance is subject to means testing. Individuals whose earnings exceed a specified threshold are obligated to cover 30% of the cost of their assistance.

This approach can pose significant financial challenges for persons with disabilities, particularly affecting those with higher support needs.

19 CRPD Committee (2022) Guidelines on deinstitutionalisation, including in emergencies. Available at: https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD/C/5.

20 曾玉婷 (2023) 'A first case! A person with disabilities wins a lawsuit against the government for manpower issues. Severely disabled individual, Yu Jie, says: "I only wish not to be soaked in urine at night' [in Chinese], *Right Plus*. Available at: <https://rightplus.org/2023/03/20/independent-3/>.

It risks undermining the accessibility and affordability of personal assistance, which are fundamental to enabling independent living and participation of persons with disabilities in society. Much like the limitations imposed by cost ceilings, the obligation of co-funding can lead to institutionalisation and/or reliance on family care.

3.2 Assessment and provision of personal assistance services

3.2.1 Assessment of needs of assistance

In Japan, Korea and Taiwan, the assessment of personal assistance needs is integrated into a comprehensive care and support evaluation that considers the person's medical conditions, psychosocial needs, daily living skills, and environmental factors. This evaluation informs the creation of care services plan, detailing the types of services needed, their goals, and timelines, including required personal assistance hours. Other countries, such as Bulgaria, Slovenia, and Sweden, employ a more distinct personal assistance assessment process, focusing primarily on determining the number of assistance hours required.

Peer support is crucial in many countries' assessment processes. For example, in Taiwan, it is formally part of the assessment, with a peer, who is also a disabled person employed by the local authority, guiding and supporting the development of an Independent Living Plan. In This plan is then reviewed by the service provider contracted with the local authority to administer the service.

The need for assistance is typically determined using task lists, covering various daily living activities, for example, related to personal care, household chores, education, work, and social activities. However, there are differences among the countries in how these task lists are utilised. In Sweden, the time needed for each activity is estimated and then totalled to determine the monthly amount of assistance hours. In Japan, while the time for specific tasks is taken into consideration, the focus is more on the individual's overall needs rather than just the sum of time and tasks.

The time and tasks approach to assessment has several shortcomings. Quantifying and allocating specific times for specific tasks may not allow for the time and flexibility needed to respond to the person's changing needs and meet their unique requirements²¹. Moreover, the narrow focus on tasks and time can result in underestimating the actual hours of assistance required. Additionally, the rigid scheduling of brief time slots for specific activities can negatively impact the recruitment of assistants, especially when combined with poor working conditions²².

3.2.2 Service design

General Comment 5, emphasises that a key element of personal assistance is the user's ability to design their service, including decisions about who provides the assistance, as well as where, when, and how it is provided.

However, there is considerable variation among countries in terms of the degree of control users have over these aspects. Many countries have imposed various restrictions. For example, in countries like Thailand and Taiwan, the recruitment of assistants is typically carried out by the provider. The users are not able to choose their assistants who are 'assigned' to them by the provider.

21 Consultations, Sweden.

22 Think Local Act Personal (2022) The forgotten workforce: recruiting and retaining personal assistants.

Many countries restrict the provision of assistance to standard office hours, leaving users unsupported outside these times. In Bulgaria, the use of the service is often confined to the user's municipality. Persons with disabilities are thus unable to use assistance while traveling, whether for work or leisure, even within the country.

Such restrictions transform what is intended to be a personalised assistance service into a service resembling traditional home care. More importantly, they drastically limit the opportunities of persons with disabilities to engage in employment and participate in the social and cultural life of their communities.

3.2.3 Providers

Significant variations often exist in how personal assistance services are organised, even among different types of providers within the same country.

Some providers may impose additional constraints on the flexibility of the service even where such restrictions are not mandated by national policies. There are also cases where providers or assistants exert control over the daily activities of the users, such as when to take a shower or go out or determine when assistants will take their holidays. Such issues exist across the countries, including those that have adopted direct payment systems like Sweden and England.

There are also providers that align closely with the philosophy and principles of independent living and the CRPD, thus offering more flexibility and autonomy to persons with disabilities in managing their support. A notable example here are the Centres for Independent Living.

Centres for Independent Living and personal assistance user cooperatives

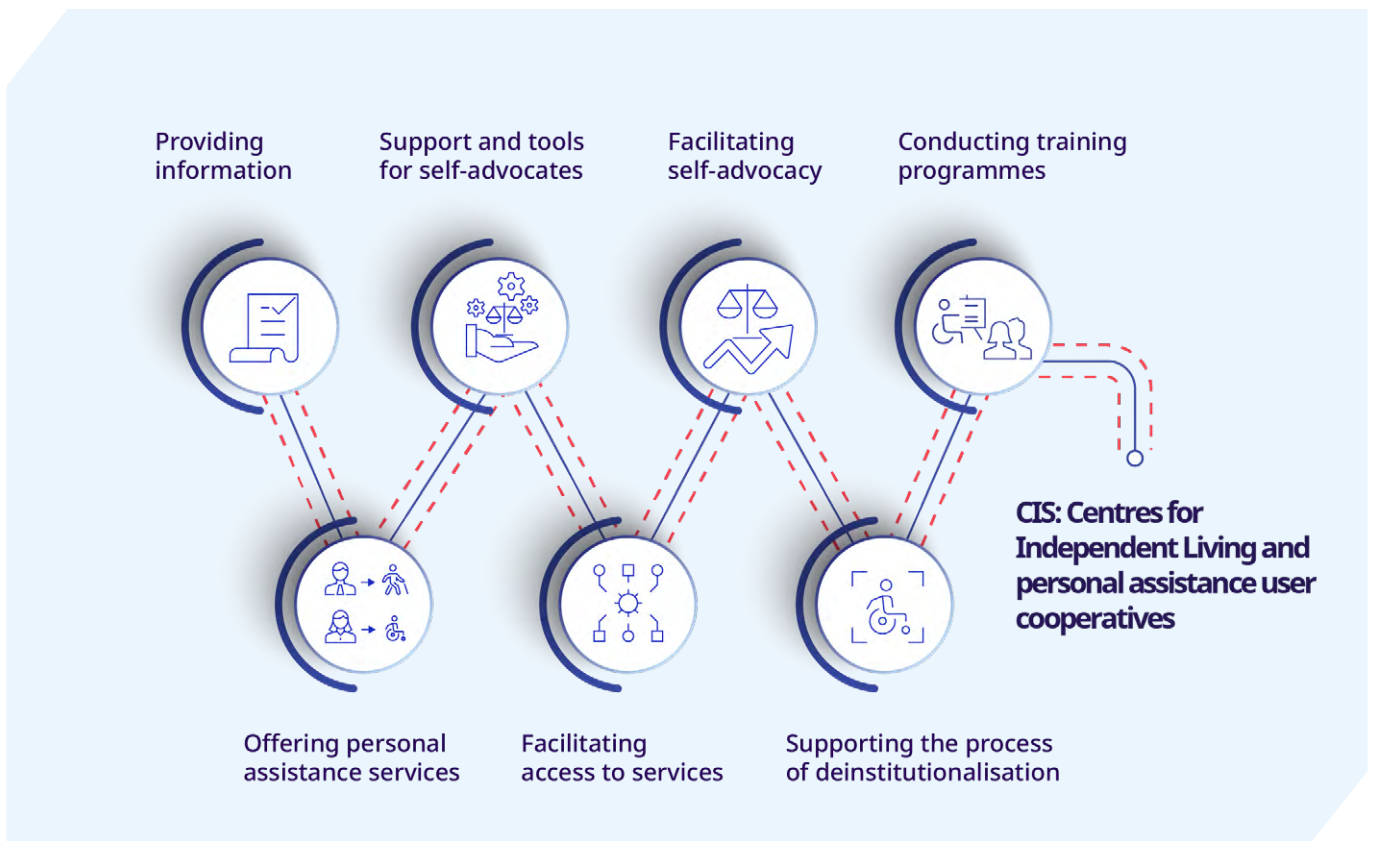
The Centres for Independent Living (CILs) are organisations run and controlled by persons with disabilities, dedicated to promoting independence and inclusion of persons with disabilities through service provision and policy advocacy. Common services and activities offered by CILs include:

- Providing information on a range of disability-related issues.
- Offering peer support and tools for self-advocates.
- Facilitating self-advocacy, empowering persons with disabilities to speak up for themselves, and providing individual advocacy.
- Conducting training programmes, for example, to build independent living skills,
- Offering personal assistance services.
- Providing assistance with housing, assistive devices, etc., and facilitating access to education, employment, health services, and a decent income.
- Advocating for and supporting the process of deinstitutionalisation, which involves transition from institutional care to community-based services.

The first CILs originated in the United States during the 1960s and have since spread globally, including to Africa, Asia, Europe, and South America. While the term ‘CIL’ is widely used, similar organisations may have different names in various countries. They may also vary in their focus areas (like services and advocacy), the services they offer, and their funding models, reflecting regional and national differences.

In most countries the Centres for Independent Living have been instrumental for the introduction and development of personal assistance. They are also actively involved in the provision of the service, where the legal framework permits, and where adequate resources are allocated to allow private organisations to participate. This is the case, for example, in Costa Rica, England, Japan, Serbia, Slovenia, South Korea, Sweden, and Taiwan. A specific type of CIL, which has developed in Sweden²³ are personal assistance user cooperatives.

CILs’ core values are rooted in personal autonomy and self-determination, the empowerment of persons with disabilities to exercise choice and control over their support and, by extension, their lives. As providers, they typically aim to ensure that users can choose who works for them, define the tasks to be performed, and determine when, where, and how these tasks are carried out. CIL enables users to have the control they prefer over their support and empowers them to shape their support in a way that best suits their individual needs and preferences.



²³ Similar cooperatives have also developed in Norway. However, Norway was not included in this specific study.

Working conditions of personal assistants

3.3 Profile of personal assistants

In most countries there is limited publicly available information about personal assistants. The table below shows the number of assistants in the countries for which information was obtained.

Country	Number of personal assistants	Year
Bulgaria ²⁴	54,552	2021
Costa Rica ²⁵	29,836	2018
England ²⁶	130,000 (approx.)	2022/2023
Japan ²⁷	23,280	2021
Korea, Republic of ²⁸	103,378	2022
Serbia ²⁹	317	2022
Slovenia ³⁰	8,000 (approx.)	2023
Sweden ³¹	66,049	2022
Taiwan ³²	692	2023
Thailand ³³	1246	2022

The data about the profile of assistants from England, Slovenia and Sweden show that a significant majority of assistants (92% - 96%) are under 64 years of age. The profession is predominantly female, with about 70% in Serbia and Sweden, 75% in Taiwan, and even higher in England at around 82%. This gender distribution is consistent with broader trends in caregiving and personal assistance roles, which are often female-dominated.

A considerable proportion of personal assistants in Sweden were born outside the country (around 30% in 2021). In England, around 20% of the employees in the broader care sector are non-British, but only 5% among personal assistants. The lower proportion of non-British personal assistants as compared to the broader care sector might be influenced by the effects of Brexit. The occupation of 'personal assistant,' unlike 'care worker,' is not listed under the eligible occupations for the 'Skilled Workers' route in the new points-based immigration system, thus limiting the access of non-British workers to personal assistant roles. In Taiwan, migrant workers are not allowed to work as personal assistants ³⁴.

²⁴ Agency for Social Assistance, 'Analysis'.

²⁵ Instituto Nacional de Estadística y Censos (2018) *Encuesta Nacional sobre Discapacidad, 2018*.

²⁶ Skills for Care, *Individual employers*.

²⁷ Ministry of Health, Labour and Welfare, *Overview*. The figure shows the full time equivalent.

²⁸ Korea Institute for Health and Social Affairs, *Social security statistics*.

²⁹ Data provided by the Republic Institute for Social Protection.

³⁰ Figure provided during consultations, not verified.

³¹ Statistics Sweden. (2022). Employees 16–64 years at national level by occupation (4-digit SSK 2012), region of birth and sex, years 2019-2021. Available at: https://www.statistikdatabasen.scb.se/pxweb/en/ssd/START__AM__AM0208__AM0208E/YREG50N/.

³² Ministry of Health and Welfare. The data concerns only the service administered by the Ministry of Health and Welfare.

³³ Department of Empowerment of Persons with Disabilities (2022) *Situation of people and children with disabilities*.

³⁴ Ministry of Health and Welfare (2015), Regulation for Personal Care Services for Persons with Disabilities.

3.4 Working conditions of assistants

3.4.1 Rights and protections at work

Personal assistants are typically engaged either as employees through employment contracts, or as self-employed with service contracts. The structure of these working relationships depends on the laws and common practices within each country. For example, in Bulgaria and Slovenia, the legal framework stipulates that personal assistants must have employment contracts. In Sweden and England, both options are available, however, it is not common for personal assistants to choose to work as self-employed and the large majority are with permanent contracts³⁵. In Serbia, on the other hand, while the legal framework also allows for employment and service contracts, around half of the assistants are engaged under service contracts³⁶. This trend is primarily due to the lack of funding for insurances and other employment-related costs associated with formal employment contracts, which forces organisations administering the service to use service contracts.

The nature of contract has implications for benefits, and workers' rights. Employment contracts ensure that assistants are covered by the countries' employment legislation and entitle them to the same employment rights and protections as all other workers. This includes, for example, paid holiday and sick leave, pension contributions, regulations concerning working hours, dismissal procedures, minimum wage, and other employment-related rights. While each country has its own employment legislation, European Union (EU) member states – Bulgaria, Sweden, and Slovenia – have harmonised their legislation with EU directives, ensuring a common baseline of workers' rights and protections.

Personal assistants engaged via service contracts have fewer statutory protections and benefits. Depending on the country, they may not be entitled to receive sick leave or maternity leave payments, unemployment benefits, and they may be required to arrange and potentially finance their own cover during periods of absence. The practice of utilising service contracts with less favourable terms has broader repercussions. For example, in Serbia, the widespread use of service contracts has led to a high turnover rate among assistants³⁷. This has a negative impact on persons with disabilities using assistants, as it affects the continuity and quality of the service.

A third type of contract on which personal assistants can be hired is the so called zero-hours contracts. These contracts entitle assistants to a limited range of employment rights, for example, statutory annual leave and minimum wage, and do not provide protection against unfair dismissal or a right to redundancy payment. Zero-hours contracts are prohibited or not used in most countries; however, they are common in England where a fifth of personal assistants (20%) and a third of care workers in the independent care sector (35%)³⁸ are engaged through such agreements. In addition, in England, the eligibility for some statutory benefits such sick pay is tied to earnings thresholds³⁹, which could disadvantage many personal assistants who work limited hours. To qualify for these benefits, assistants need to work at least approximately 12 hours a week (with an average pay of 10.50 per hour⁴⁰). However, as of 2023, nearly 60% of them worked fewer than 15.9 hours.

³⁵ Skills for Care, *Individual employers*.

³⁶ Data provided by the Republic Institute for Social Protection.

³⁷ Interview Serbia.

³⁸ Skills for care, *Individual employers*.

³⁹ For 2023/24 the threshold is 123 per week on average, before tax

⁴⁰ Skills for care, *Individual employers*.

3.4.2 Salaries

The limited information obtained about personal assistants' salaries present a complex picture, characterised by low or declining wages. For example, in Thailand, the salaries of assistants are described as insufficient to cover living costs⁴¹. In Taiwan, they are lower than those of workers in similar sectors, such as home care workers.

In Europe, the salaries of personal assistants are generally comparable to those of workers in similar occupations, such as care workers (England) or nurses in residential institutions for persons with disabilities (Slovenia, Serbia). However, in recent years, the real income of assistants has declined due to wages not keeping pace with inflation, which has been particularly high in the period following the Covid-19 pandemic. In Slovenia, for example, the hourly rate for personal assistants has remained unchanged since the introduction of the service in 2019. In Bulgaria, personal assistants' salaries are calculated as a percentage over the minimum wage (1.4% above the minimum wage). Despite a nearly 10% increase in the minimum wage in 2022, inflation soared to approximately 17%, leading to a real time decrease in personal assistants' earning. In Sweden and England, the salaries of assistants have also not kept up with the inflation. A participant from England noted that while in the past the payment provided by their local authorities was sufficient to compensate personal assistants above the minimum wage level, due to the limited adjustment of these payments to inflation, they can now only offer minimum wage.

The real terms reduction of assistants' salaries is also felt outside Europe. For example, in Japan, it has led to diminishing wage gap with other professions, perceived as less demanding, such as supermarket workers. This has made the assistant's job less appealing, leading to difficulties in recruiting assistants.

3.4.3 Stability and security at work

Although the social care and health systems of some countries, such as England and Sweden rely strongly on migrant labour, the situation of migrant workers, including personal assistants, is often more precarious compared to domestic workers. Migrants are at an increased risk of job loss and income insecurity due to uncertainty related to their work permit, which is often granted for a certain period of time, after which people need to re-apply if they want to continue working. Anti-immigration policies have exacerbated this uncertainty and imposed additional burdens on migrant workers. In Sweden, for instance, the new Labour Immigration Law adopted in 2023 significantly raised the earnings threshold that immigrant workers must meet to qualify for a work permit. Furthermore, this heightened earnings requirement is retroactively applied, affecting periods prior to the law's enactment as well as those subsequent to it. The law is expected to result in numerous personal assistants losing their legal right to work in Sweden. This will disrupt the lives and livelihoods of the migrant workers affected and will also impact persons with disabilities who will lose their assistants. Given the share of migrants among personal assistants, the restrictive regulations will make it more difficult for persons with disabilities to find assistants. Similarly, after Brexit and the introduction of strict immigration restrictions in the United Kingdom, the number of vacant posts in the adult social care in England increased by 52%⁴².

The job and income insecurity are a significant challenge for assistants employed on zero-hours contracts. The absence of guaranteed minimum working hours results in unpredictable monthly income, making financial planning difficult. In addition, zero-hours contracts allow employers to dismiss workers without a notice period, which further exacerbates job insecurity.

⁴¹ Suksanguan, 'Addressing social workers shortages'

⁴² Skills for Care (2023) The state of the adult social care sector and workforce in England.

3.4.4 Visibility and recognition of personal assistance profession

The public image of the personal assistance profession poses challenges in many of the countries. There is a general lack of awareness about the role personal assistants play in helping persons with disabilities transition from passive recipients to active agents of political and economic change. For instance, in England, the role of personal assistants is not widely known or understood, even among social care professionals who often view assistants as unskilled care workers⁴³. Similar problem exists in Slovenia where personal assistants are less valued than similar jobs in the health and social care sector. In Japan and Thailand, the profession is perceived as particularly difficult and challenging. In addition, in Sweden, the profession's image has recently been further compromised due to incidents of fake news and negative media coverage.

The lack of recognition and the negative public image of personal assistance profession can make it less attractive. This can contribute to workforce shortages as potential candidates are deterred from pursuing careers in this field.

3.4.5 Workforce shortages

The inadequate working conditions of personal assistants have contributed to workforce shortages in most countries. The single most important factor, highlighted by all consulted, is the low or unattractive wages of assistants. The lack of visibility and recognition of the personal assistance profession is also crucial, and in Serbia, the significant job insecurity poses further challenge.

It should be noted that some of the countries, such as Bulgaria, England, Japan, Slovenia, and Sweden experience shortages of labour in various fields, not just personal assistance, due to aging population and emigration. At the same time, restrictive immigration policies, for example in Sweden and England, have prevented migrants from filling the workforce gaps. In Slovenia, the small size of the labour market was also identified as a challenge, while the decline in the unemployment rate has been a contributing factor in Sweden.

The workforce shortages indirectly impact persons with disabilities, making it more difficult to recruit assistants. This not only hinders their independence but can have serious implications for their physical and psychological health and wellbeing⁴⁴.

3.4.6 Job satisfaction

Despite the difficulties experienced by persons with disabilities in recruiting personal assistants, the turnover rate is low in comparison with similar occupations, which suggests higher job satisfaction of assistants. For example, in England the turnover rate of personal assistants is nearly 50% lower than that of care workers⁴⁵. Consultations in Japan and Slovenia also indicated that assistants tend to maintain long-term employment.

43 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>.

44 Think Local Act Personal, *The forgotten workforce: recruiting and retaining personal assistants*.

45 Skills for care, *Individual employers*.

► 4 Training and support

The access to training and support is important both for persons with disabilities and for their assistants. It may enable persons with disabilities to recruit and manage their assistants effectively, improve working conditions of assistants, which will also have an impact on the quality of support.

4.1 Training and support for users

The availability of training and support for users is key for enabling some people with disabilities to exercise choice and control over their support. In countries like England, Japan, Serbia, Slovenia, and Sweden, assistance users have access to trainings on a wide range of relevant topics, including recruiting assistants, conducting job interviews, managing work and time, managing relationships, conflict resolution, reporting, and legislation. However, the availability of training and the specific topics may vary between municipalities and providers and may differ with regard to how well it takes into account the needs and preferences of persons with disabilities.

In some of the countries with still dominant medical model of disability (for example, Bulgaria, Serbia, and Slovenia), the importance of trainings on social model of disability was underlined during the consultations. Such trainings can address the self-perception of many people with disabilities as passive recipients of care and empower them to direct their support.

A specific type of support, offered by many centres for independent living, is peer support. It is provided by other users of personal assistance and may cover various aspects of their experience as users, for example, assessment, recruitment of assistants, assigning tasks, being assertive, etc. Peer support is crucial for the functioning of personal assistance services ⁴⁶.

4.2 Personal assistants' qualification and training

4.2.1 Compulsory vs voluntary training

In many countries, it is compulsory for assistants to receive training before or within a certain period after they start work. Trainings usually cover topics, such as independent living, obligations and rights of assistants, communication skills, lifting, and rolling a wheelchair. In some countries, for example Japan, Korea, Taiwan, and Thailand ⁴⁷, the training also includes field work, while in Costa Rica, a simulation room is used where people with disabilities and their assistants interact ⁴⁸.

Trainings can be designed and delivered by organisations providing assistance services or by training and accreditation institutions. For example, in Serbia the National Institute for Social Protection offers accredited professional training programme for personal assistants.

⁴⁶ Ratzka, A. (2004) 'Model National Personal Assistance Policy'. Available at: <https://www.independentliving.org/docs6/razka200410a.html>

⁴⁷ Department of Empowerment of Persons with Disabilities, *Situation of people and children with disabilities*.

⁴⁸ Flier, D. (2022) Cómo trabajan las personas con discapacidad para gestionar los apoyos que les permiten vivir con autonomía, *Redaccion*, 2 February 2022. Available at: <https://www.infobae.com/america/soluciones/2022/01/25/como-trabajan-las-personas-con-discapacidad-para-gestionar-los-apoyos-que-les-permiten-vivir-con-autonomia/>

Depending on the municipality, assistants are required to pass the programme before they are employed or up to four months after they start work. In Japan, and Slovenia, training can be provided by NGOs, including DPOs, and private companies.

In other countries, such as Bulgaria, England and Sweden, there is no formal qualification or mandatory training requirement for assistants at national level (although some providers may choose to introduce such). This allows persons with disabilities to train their assistant according to their own needs and preferences, which aligns with the principle of choice and control, promoted by the CRPD (General Comment 5). This may also involve on-the-job training, where a new assistant works alongside a more experienced one. In Slovenia, although assistants' training is mandatory, it can be provided by users as well as service providers.

Key insights from recent research in England further support this model. The findings suggests that formal qualification does not necessarily lead to better employment and retention rates. Instead, focusing on personal qualities and behaviour attracts staff who not only performs better but has lower sickness rates, and greater levels of success in developing the skills needed in their roles⁴⁹. It is also worth noting that preliminary qualification or experience can sometimes be perceived as an obstacle by users, requiring them to 'untrain' assistants in order to adapt to their specific requirements⁵⁰.

The lack of compulsory training requirement in some of the countries does not deprive personal assistants of access to training. In both England and Sweden, assistants can take part in a range of trainings, if agreed with the user. Similar to the situation with users' trainings, the availability of trainings for assistants may vary across municipalities and providers.

4.2.2 Training arrangements and funding model

The funding models significantly influence both the ease of access to training and the available training options. The Swedish model is particularly illustrative of how funding and provider policies can impact the training and development of personal assistants.

In Sweden, where the money for administrative costs is included in the hourly assistance rate, the user has available a training budget, which they can decide how best to use for training purposes. Assistants can participate in trainings provided by the organisation administering the service, or by other organisations, if the specific training topic is not offered and the cost first with the allocated budget.

However, there are variations among providers in terms of the size of this training budget and the rules for its use. In STIL, the Stockholm Cooperative for Independent Living, persons with disabilities are encouraged to conduct annual individual meetings with their assistants. These meetings serve two primary purposes: evaluating the assistant's work performance and identifying any specific training needs or interests they may have. If the assistants do not have specific training needs related to the provision of the service, and if the budget permits, the user may authorise the assistant to attend training on a topic of their interest. This could range from courses in psychotherapy or languages to human rights education, etc.

This flexible approach to training, underpinned by a user-directed budget, offers several advantages. On the one hand, it allows users to have a say in the training and development of their assistants, ensuring that training is relevant and tailored to their specific needs.

⁴⁹ Skills for care, *Individual employers*.

⁵⁰ Consultation, Sweden.

On the other, it allows assistants to develop their competences, which enhances their job satisfaction and results in better-quality support.

4.3 Prevention of abuse and harassment and ensuring safe working relationships

Addressing the issue of harassment and abuse in the context of personal assistant services is a critical aspect of ensuring a safe and respectful working environment for both assistants and users. Various measures are implemented to tackle this issue, and their quality and coverage can vary significantly across different countries and service providers. Some useful strategies include, information and training, follow up meetings, and support arrangements.

4.3.1 Information and training

Trainings and information aim to raise the awareness and equip both users and assistants with the knowledge and skills necessary to identify, prevent, and respond to such situations. They make it clear that harassment and abuse are not tolerated and that there are mechanisms in place to deal with such issues effectively. The topics covered in such trainings might include:

- Understanding the forms that abuse and violence can take, including physical, emotional, financial, and sexual abuse.
- Recognising the signs of violence and abuse as key to preventing escalation and ensuring prompt intervention.
- Effective communication skills, setting clear boundaries, understanding rights and responsibilities and other strategies that could potentially preventing situations that could escalate into harassment or abuse.
- Support services, including what support is available and how it can be accessed if there are problems in the relationship or if incidents occur. This may include contact details for support services, legal advice, and emergency contacts.
- Response strategy, or practical guidance on what to do if abuse or violence is suspected or observed.

Typically, these trainings are offered as an introduction, before the start of the service, with additional ongoing training opportunities available. Their formats can be diverse, including face-to-face sessions, real-time online courses, such as those conducted via Zoom, self-guided online courses, and a combination of all. Each training format has its advantages and can be chosen based on the specific needs and preferences of the users and assistants. The availability of a range of training options will make possible to accommodate different learning styles and accessibility needs.

4.3.2 Follow-up

Service providers might also conduct regular follow-ups with users and assistants. The participants, the frequency and the format of these follow-ups may vary. In Bulgaria, where personal assistant services are decentralised, there is a legal requirement for municipalities to conduct meetings with users at least twice a year. These meetings allow for a direct assessment of user satisfaction and an opportunity to address any concerns or adjustments in the service. STIL, in Sweden, maintains regular contact with users through calls and, where necessary, face-to-face meetings. In addition, they organise meetings with assistants once a year to discuss working conditions.

These regular contacts serve as a proactive measure to ensure the safety and well-being of both users and assistants. They provide a safe and confidential environment for users and assistants to voice their concerns. In addition, they allow for timely intervention and resolution of any issues which could range from interpersonal conflicts to harassment and abuse. They can also ensure that appropriate support and intervention measures are promptly put in place.

4.3.3 Support arrangements

Both users and assistants can turn to the organisations administering the service for advice and support in case of problems or incidents. The presence of a designated contact person may facilitate this process as it may make it easier for users and assistants to speak openly about sensitive issues. Having multiple user-friendly channels for reporting and seeking support, such as online forms, email, voice messages or direct messaging service, ensures that diverse needs and preferences are accommodated. Various support arrangements might exist for out of office hours, for example, a 24/7 hotline maintained by the provider or another relevant institution.

4.3.4 Other measures

In addition to these general measures that apply to both users and assistants, there are specific approaches tailored to address the unique needs and situations of each group.

Criminal record check of personal assistants

Conducting criminal record checks on potential assistants is a frequent practice, typically done by the organisation administering the service. These checks aim to ensure the safety of users by verifying that the assistants do not have a history of criminal behaviour that could pose a risk. This requirement can be either compulsory or voluntary, depending on the country's regulations and the policies of the service provider.

Personal assistants' registers

In some countries, compulsory registration of assistants is adopted as a measure to ensure the quality of service and prevent abuse⁵¹. This often involves specific requirements that assistants must fulfil, such as participating in certain trainings and passing criminal record checks. It thus serves as a form of accreditation, potentially providing reassurance to users that their assistants meet certain standards set by the regulating bodies.

This type of registration is controversial, as it removes the control employers have over choosing and their assistants. In addition, the effectiveness of registration systems for preventing abuse is also questionable. No evidence has been found of more cases of suspected abuse in people employing personal assistants compared to those using in-kind services⁵².

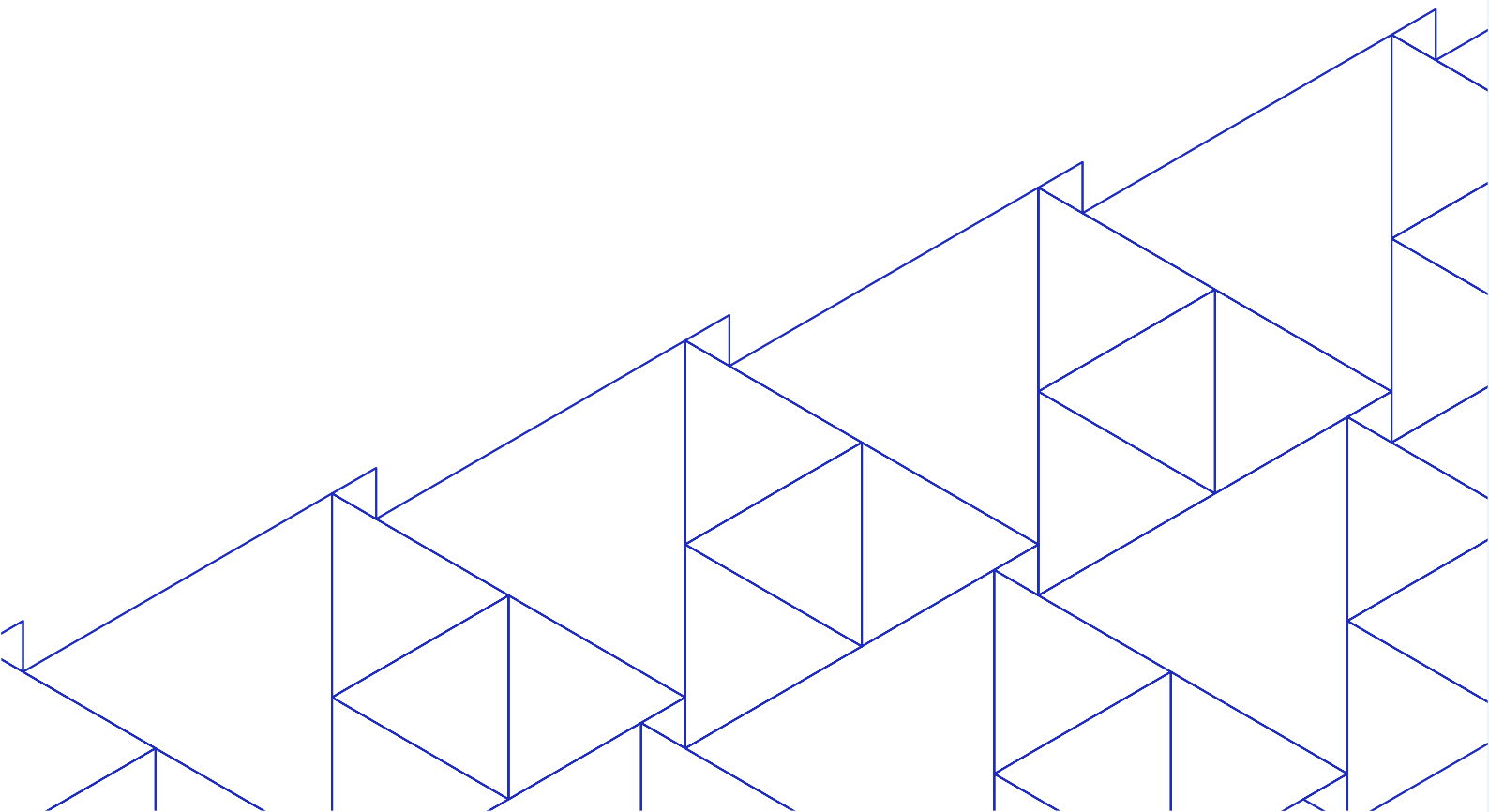
⁵¹ These compulsory accreditation-type registers should be distinguished from personal assistants' registers maintained by organisations to facilitate the recruitment of assistants.

⁵² Cairncross, L. and Crick, A. (2014) *Research on abuse and violence against the social care workforce: focus on personal assistants*, Leeds: Skills for care. Available at: <https://ipc.brookes.ac.uk/files/publications/Research-on-abuse-and-violence-PAs-301014-FINAL.pdf>; Ismail et al. (2017) 'Do Personal Budgets Increase the Risk of Abuse? Evidence from English National Data', *International Social Policy* 46(2): 291-311.

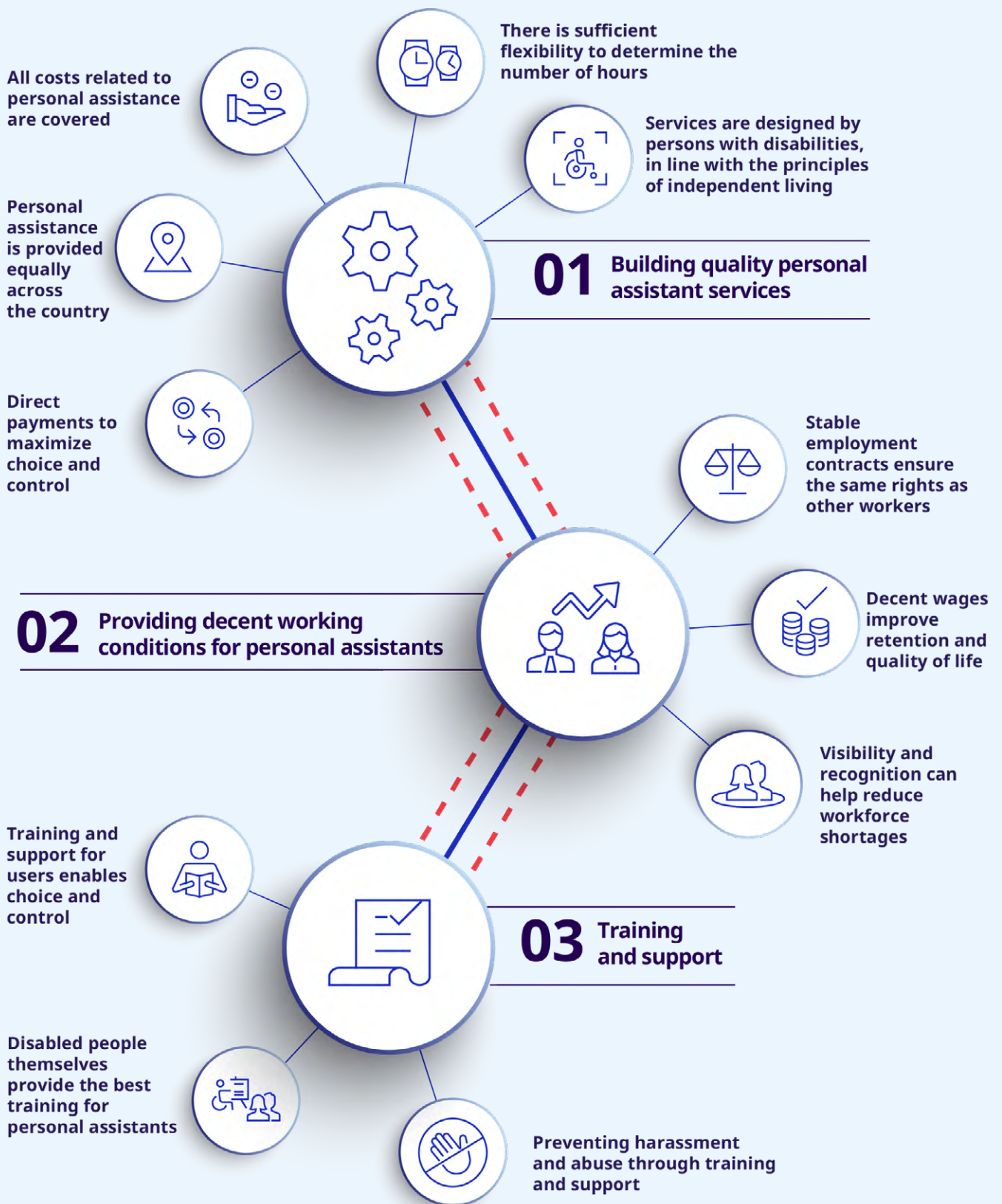
Beyond criminal checks and registration, other measures are crucial for ensuring high-quality support and preventing abuse. These include recruitment based on personal qualities and compatibility, provision of training and information, support services, and adequate reporting mechanisms.

Specific arrangements for personal assistants

Specific arrangements can be made for assistants who work with people who are known to be of higher risk to be abusive. These measures are designed to protect the safety and well-being of the assistants while ensuring that the users receive the support they need. Some of these arrangements might include assistants working in pairs, ensuring that they are not alone in potentially challenging situations, and the provision of additional training and support.



Infographic: the 3 main areas of intervention to improve the quality and working conditions of personal assistants



► 5 Conclusions and recommendations

Personal assistance services are increasingly gaining recognition and expanding globally, which highlights their important place in modern care and support strategies. Their value is twofold: they strengthen the care economy through job creation and play a key role in facilitating the inclusion and active participation of persons with disabilities in society.

Investments in the growth and improvement of personal assistance service thus directly contribute to a more inclusive and equitable society, while simultaneously bolstering the economy. This represents a progressive move towards a care and support model that values both the economic contribution of caregivers and the autonomy and dignity of care receivers.

The policy and practice recommendations presented in this section are aimed at enhancing the development of personal assistance services. They are guided by two core objectives: the principles of self-determination and independent living for persons with disabilities and ensuring the provision of decent working conditions for personal assistants.



Developing services based on independent living principles.



Ensuring decent working conditions for personal assistants.



Cross-cutting issues.

5.1 Developing services based on independent living principles

In order to fulfil its potential as a tool for inclusion of persons with disabilities, the service need to be user-centred rather than provider-centred. This means, allowing users to determine how their assistance is organised and delivered and by who.

The following suggestions aim to support the development of funding and provision models based on independent living principles.

- **Self-Directed funding:** Funding models should allow persons with disabilities to manage their budgets for personal assistance services and make decisions regarding the hiring, management, and evaluation of their personal assistants. Providing control over the budget allows for greater flexibility and personalisation of services.
- **National funding:** Providing all or a portion of the funding nationally could help alleviate the disparity and maintain the quality of the service across different regions.
- **Coverage of all assistance-related costs:** Inclusive funding models should be adopted that encompass all essential expenses related to the provision of the service (for example, payroll, transportation, training, and support). This is key for enhancing the quality of personal assistance services and the working conditions for assistants.
- **Dynamic funding model:** As an alternative to fixed cost ceilings, a dynamic funding model should be implemented. This model would consider the varying degrees of assistance required by different persons with disabilities, adjusting the allocated funds based on individual needs assessments.
- **24/7 availability:** Personal assistance services should be made available on a 24/7 basis to adequately meet the needs of persons with disabilities. Continuous availability is essential to ensure that individuals have access to necessary support at all times, thereby enhancing their safety, independence, and quality of life.
- **Training and support, including from peers:** It is important to ensure that persons with disabilities have access to training and support on recruiting and managing personal assistants, understanding their rights and responsibilities, managing conflicts, etc. Including peer support as a core component of these programs is crucial, as it allows persons with disabilities to learn from others who have firsthand experience in using personal assistance.
- **User-determined qualification of assistants:** The decisions about the profile and qualification of assistants should be made by users rather than service providers, which will ensure that the assistants chosen are best suited to meet the individual needs and preferences. It is recommended to promote recruitment strategies that emphasise personal qualities, attitudes, and behaviours over formal qualifications alone.
- **Assessing quality through impact on user rights:** The quality of assistance schemes should be evaluated based on their overall impact on persons with disabilities. This involves examining whether the services provided effectively enable persons with disabilities to access education, employment, leisure, political participation, etc.

Choice and control of users and decent working conditions

It is important to stress that the emphasis on user control and flexibility of assistance service, for example, with regard to working hours, can coexist harmoniously with the commitment to ensuring good working conditions for assistants. For example, to allow the service to be available 24/7 without compromising the working conditions of assistants, higher wages can be paid for work outside the usual office hours. The balance between choice and control of users and working conditions of assistants is essential for a well-functioning personal assistance system that respects the needs of both users and assistants.

Choice and control and funding cuts

The emphasis on choice and control of persons with disabilities should not be used as an argument for cuts in public funding for the service. For example, the demand of many persons with disabilities to train their assistants themselves should not lead to reducing funds for training and support, which are often not sufficient.

5.2 Ensuring decent working conditions for personal assistants

The working conditions of personal assistants are not only critical for the assistants themselves but also significantly impact the quality of support received by persons with disabilities. Ensuring fair and decent working conditions is key to providing high-quality, reliable assistance.

In addition, the improvement of these working conditions carries an important gender dimension. Given that a substantial majority of personal assistants are women, as suggested by available data, enhancing their working conditions is intrinsically linked to promoting gender equality.

- **Adequate pay rates:** It is strongly recommended that personal assistant wages are regularly reviewed and adjusted to reflect the prevailing economic conditions and cost-of-living increases. Adequate compensation not only ensure that personal assistants are fairly compensated but can also help address the workforce challenges in the sector. It is also key for elevating the status of personal assistance profession within the broader care economy.
- **Support, including from peers:** Personal assistants should also have access to support network, including from peers. It should be designed to assist personal assistants in navigating legal and administrative issues, as well as in managing various challenges such as conflicts, stress, and other work-related problems.
- **Access to training and development, which is user-controlled:** Personal assistants need to have access to training and skills development. It is essential that the users of the service have the authority to guide and decide on the training their assistants undergo and could chose to train them themselves. The opportunities for career advancement and skill enhancement can in turn, lead to improved service quality.

Improving the working conditions of personal assistance should maintain sufficient flexibility for users in terms of hours, location, etc., while providing adequate safeguards for both parties.

5.3 Cross-cutting issues

- **Statistics and data collection:** Improving the collection and availability of information and statistics related to personal assistance is essential. This should include disaggregated information about the implementation of the service, such as number and profile of assistants and users, the impact of the service, and the challenges faced by persons with disabilities in accessing and using the service.
- **Understanding of independent living values and principles:** It is important to promote a thorough understanding and implementation of independent living values and principles in personal assistance services, avoiding confusion and ensuring support aligns with these values.
- **Visibility and image of personal assistance profession:** Improving the visibility and recognition of the role of personal assistance within the care economy is important for promoting interest in the job. Media campaigns and awareness-raising activities can be instrumental in portraying personal assistance in a positive light, as a rewarding profession with a long-lasting effect on the lives and rights of persons with disabilities. It is also important to highlight the economic benefits of personal assistance as a service that enables persons with disabilities to access and remain in employment and education and to contribute to the broader economy.
- **Research:** Further research on personal assistance can enhance understanding of the service's development and impact in various contexts. This could include examining models of personal assistance provision in regions and income groups not covered in this report (for example, by looking at pilot projects). Other potential research areas include:
 - practices for managing assistants and supporting their wellbeing,
 - strategies to address recruitment challenges,
 - barriers and facilitators for the development of assistance services, including cultural and societal attitudes,
 - the service's role and challenges in crisis and emergencies.
- broader economic benefits provided by personal assistance. This involves understanding the economic value of persons with disabilities living independently with the support they require, and the impact of personal assistance on closing the disability employment gap.

A related but distinct research area concerns CILs and their unique roles in providing support and creating jobs. Current research is limited, often focusing on early development with little on present operations, especially outside the United States, the United Kingdom, and Japan. Future research on CILs could cover several key aspects:

- Mapping the development of CILs globally, offering insights into their diverse types, roles and significance in different contexts, their growth and the challenges they face.
- Exploring the range of services offered by CILs, comparing their service delivery models across different regions, and analysing how social, political, cultural, and financial factors influence these models.
- Examining what distinguishes these organisations from other service providers, and how these specific characteristics impacts service delivery.
- Identifying best practices and innovative approaches within CILs and user cooperatives.
- Investigating employment opportunities and conditions in these organisations, focusing on the inclusion of women and persons with disabilities.
- Exploring the challenges and strategies for ensuring long-term sustainability of CILs.
- Examining the role of technology in service provision.
- Assessing the community and social impact of CILs, particularly in terms of changing perceptions and attitudes towards disability.



▶ **Contact:**

**ILO Global Business and
Disability Network**

Route des Morillons 4
CH-1211 Genève 22 Suisse
T : +41 22 799 61 11
ilo.org

Telephone: +41 22 799 7273
Email: businessanddisability@ilo.org
Website: businessanddisability.org

ENIL European Network on Independent Living
Website: enil.eu