

PERSONAL ASSISTANCE INVENTORY

This inventory is part of the project ‘User-Led Personal Assistance in the European Union’ that looks at personal assistance for disabled people from the perspective of assistance users. The project is conducted by Teodor Mladenov, a Marie Curie Individual Fellow at the European Network on Independent Living.

At this stage, the research does not seek to assess any actually existing personal assistance schemes but to elaborate the means to do so.

Assistance users, their organisations and allies are kindly invited to help with the development and evaluation of a number of statements about personal assistance included in this inventory. These statements will then be used to develop a questionnaire to assess the impact of actually existing personal assistance schemes on disabled people’s choice and control in everyday life. This would enable assistance users in Europe and beyond to monitor the quality of personal assistance and to advocate for policy changes.

Participation in this research is strictly voluntary and will be kept anonymous. Refusal to participate will not incur any disadvantage and you may decide to withdraw your participation at any stage without giving a reason. The full inventory can be reviewed in approximately 20 minutes.

The results of the research will be disseminated through the website of the European Network on Independent Living (enil.eu). If you prefer to complete the inventory on paper or have questions, please contact the researcher Teodor Mladenov at teodor.mladenov@enil.eu or his supervisor Ines Bulic at ines.bulic@enil.eu.

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Consent Form

I confirm that I have read and understood the information about the research ‘User-Led Personal Assistance in the European Union’ provided by the researcher.

I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.

I understand that confidentiality and anonymity will be maintained and it will not be possible to identify me in any future publications.

I agree that the researcher may use the information provided by me for future research, ensuring confidentiality and anonymity.

I understand that the information I have submitted will be published as a report and I wish to have access to it.

Please, confirm your consent to participate by signing this form:

Category 1: Context

Below, you will find an inventory of statements that could be used to assess a personal assistance scheme. The statements are organised in five categories: Context, Funding, Needs Assessment, Provision, and Working Conditions.

Please, evaluate each statement on a scale from -3 to +3, where:

- -3 means that what is described HINDERS users' choice and control to maximum extent;
- 0 means that what is described NEITHER HINDERS NOR ENABLES user's choice and control, or that it is irrelevant;
- +3 means that what is described ENABLES users' choice and control to maximum extent.

Note that the point is not to assess an actually existing personal assistance scheme but to evaluate the potential impact of what is described by each statement on choice and control in principle. At the end of each category, you can add comments and suggestions for changes.

Subcategories	Statements	-3	-2	-1	0	+1	+2	+3
Advocacy	The scheme was introduced on the initiative of professionals and/or policy-makers ('top-down' origin).							
	The scheme was introduced as a result of disabled people's advocacy ('bottom up' origin).							
	The development of the scheme was enabled by international exchanges and cooperation.							
Principles	The scheme is underpinned by the Independent Living philosophy and/or the social model of disability.							
	The scheme is underpinned by national and/or international human rights concepts and instruments (e.g., the UN Convention on the Rights of Persons with Disabilities).							
	The scheme promotes the creation of markets of assistance services where service providers compete to attract customers.							
	The scheme is developed as part of a wider strategy to cope with unemployment and/or overcome 'welfare dependency'.							
Legislation	The provision of personal assistance under the scheme is recognised as a (human, civil, social) right.							
	The scheme is codified in regional or local legislation (regulations, ordinances, etc.).							
	The scheme is codified in a separate national law.							
	The scheme is included as one item ('service') within a more general legislation.							
	The scheme is delivered as a pilot project.							
Evolution	The scheme is expanding (e.g., new categories of users become eligible, the number of 'assistance hours' per user increases, etc.).							

Subcategories	Statements	-3	-2	-1	0	+1	+2	+3
	The scheme is subjected to cuts (e.g., eligibility is tightened, ‘assistance hours’ are reduced, conditionality is introduced, etc.).							
	The scheme deteriorates by incorporating measures that restrict the choice and control of the users.							
	Policy makers and other stakeholders (e.g., the media) misunderstand, misuse or misrepresent the scheme.							
	The evolution of the scheme is monitored by user-led organisations, including Centres for Independent Living.							
Impact	The scheme supports deinstitutionalisation in the country.							
	The scheme empowers users (e.g., to be assertive, to work, study, set up user-led organisations, create cooperatives, engage in advocacy, etc.).							
	The scheme ‘frees’ family members from ‘caring’ obligations, enabling them to undertake other activities.							
	The scheme reduces the demand for other services (e.g., hospital care, day care, home care, etc.).							
	The scheme is used as an excuse for cutting expenses for ‘social care’.							
	The scheme has a positive impact on public perceptions of disabled people.							
	The scheme influences the provision of services in other sectors (e.g., personal budgets are gradually introduced in healthcare, education, etc.).							
	There are studies on the impact of the scheme, including studies on its cost or cost-effectiveness.							
You can add comments here, including suggestions for additional statements or other changes:								

Category 2: Funding

Please, evaluate each statement on a scale from -3 to +3, where:

- -3 means that what is described HINDERS users' choice and control to maximum extent;
- 0 means that what is described NEITHER HINDERS NOR ENABLES user's choice and control, or that it is irrelevant;
- +3 means that what is described ENABLES users' choice and control to maximum extent.

Subcategories	Statements	-3	-2	-1	0	+1	+2	+3
Source	The scheme is funded by the state, out of the state budget (centralised funding).							
	The scheme is funded by regional or local authorities, out of regional or local budgets (decentralised funding).							
	The scheme is funded by civil society actors (e.g., foreign donors, private funders, charities, etc.).							
	The scheme is funded through social insurance.							
	The scheme is funded through general taxation.							
	The scheme is funded on a project basis.							
Coverage	The scheme is available on the local level (i.e., only the residents of a specific municipality or region have access to the scheme).							
	The scheme is available on the national level (i.e., every eligible citizen or resident of the country has access to the scheme).							
	Disabled people living in rural areas have access to the scheme.							
Form	The users of the scheme (can choose to) receive direct payments or personal budgets instead of services in kind.							
	Personal assistance under the scheme is provided in kind.							
Adequacy	The scheme covers additional employment costs such as employer's contributions, payroll work and other administrative costs.							
	The scheme covers additional costs for the assistants such as tickets for events, travel, accommodation and food.							
	The scheme covers additional training costs such as personal assistance training for the users and assistants.							
	The scheme covers additional costs for improving the working environment of the assistants.							
	The scheme covers additional costs for specialised assistance or specialised training of assistants.							
	The scheme covers additional costs for support with decision-making of users with limited 'mental capacity' (e.g., children or persons with intellectual impairments).							

Subcategories	Statements	-3	-2	-1	0	+1	+2	+3
	The users of the scheme are required to contribute financially to the service.							
	Receiving assistance under the scheme restricts the users' eligibility for other benefits and/or services.							

You can add comments here, including suggestions for additional statements or other changes:

Category 3: Needs assessment

Please, evaluate each statement on a scale from -3 to +3, where:

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- +3 means that what is described ENABLES users' choice and control to maximum extent.

Subcategories	Statements	-3	-2	-1	0	+1	+2	+3
Agency	The needs assessment is led by the user, possibly aided by peers.							
	The needs assessment is led by professionals (e.g., medical professionals, social workers, psychologists, etc.).							
	The agency that provides the funding for the scheme conducts the assessment as well.							
Training of the assessors	The assessors are trained by personal assistance users.							
	The assessors are trained by professionals (e.g., medical professionals, social workers, psychologists, etc.).							
	The training of the assessors includes modules on the Independent Living philosophy and/or the social model of disability.							
	The training of the assessors includes modules on relationship management (e.g., conflicts, communication, confidentiality, emotions, etc.).							
Eligibility	The training of the assessors includes modules on the specific needs of people with different types of impairments.							
	The scheme requires medical certification of the applicant as a prerequisite for applying.							
	The scheme is provided irrespective of the type of impairment.							
	The scheme is provided irrespective of the degree of impairment.							
	The scheme is limited by a 'cost ceiling' and users whose support costs more are directed towards traditional services (e.g., residential institutions).							
	The scheme is provided irrespective of age.							
	The scheme is provided irrespective of individual or family income.							
	The scheme is provided irrespective of family (including marital) situation.							
	The scheme is provided irrespective of the level of social activity, including the user's involvement in paid work and/or education and/or volunteering.							
	The scheme is provided irrespective of insurance status.							
	The scheme is provided irrespective of citizenship status (e.g., it is available to 'residents' or 'migrants' as well).							

Subcategories	Statements	-3	-2	-1	0	+1	+2	+3
	People living in residential institutions have access to the scheme.							
Procedure	The assessment covers the needs for assistance in all areas of life, including family, intimacy, education, employment, leisure, etc.							
	The assessment procedure is straightforward and transparent.							
	The assessment is conducted in the form of an open-ended interview or dialogue.							
	The assessment is conducted in the form of a structured interview, using lists of pre-defined activities and/or needs.							
	The assessment is conducted in the form of a questionnaire filled in by the user.							
	The assessment is repeated over a fixed period (e.g., every year or every two years).							
	The assessment is repeated upon the request of the user.							
Outcome	The applicants are ranked through a point-based system and only those beyond a certain cut-off line receive assistance.							
	The outcome of the needs assessment is expressed in hours of assistance needed by the user per unit of time (week, month, etc.).							
	The outcome of the needs assessment is expressed in needs categories or desired outcomes (e.g., dressing, cooking, shopping, socialising, studying, etc.).							
	The users of the scheme have the opportunity to appeal the outcome of their assessments.							
	The appeal procedure is straightforward, transparent and does not entail additional expenses for the user.							

You can add comments here, including suggestions for additional statements or other changes:

Category 4: Provision

Please, evaluate each statement on a scale from -3 to +3, where:

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- +3 means that what is described ENABLES users' choice and control to maximum extent.

Subcategories	Statements	-3	-2	-1	0	+1	+2	+3
Providers	The users can employ and manage their personal assistants themselves.							
	The users can choose among a variety of providers (e.g., the municipality, user cooperatives, non-profit or for-profit organisations, etc.).							
	It is easy to change providers.							
	The providers are subjected to licencing/accreditation/certification by an independent body.							
	The quality of provision is monitored and assessed by an independent body.							
	The quality of provision is monitored and assessed by the users and/or users' organisations, including Centres for Independent Living.							
Portability	The users can keep their assistance when moving to another region or local authority within the country.							
	The users can keep their assistance when moving to another country.							
Recruitment	The users can choose their personal assistants.							
	The assistants are appointed by the provider, without the involvement of the user.							
	It is relatively easy to recruit personal assistants (e.g., because assistance wages are attractive, the availability of assistants exceeds the demand, etc.).							
	A user can have more than one assistant, but the number of assistants per user is limited.							
	A user can have unlimited number of assistants, depending on individual needs.							
	The users can dismiss their personal assistants.							
Timing	Under the scheme, assistants work fixed hours (e.g., from 9:00 AM till 5:00 PM).							
	Under the scheme, the user determines the times when assistance will be provided, including during nights, weekends, holidays, etc.							
	The number of 'assistance hours' per user is limited.							
	The number of 'assistance hours' per user is unlimited and depends solely on individual needs.							
	The users of the scheme can save and transfer 'assistance hours'.							
Tasks	Assistance tasks are determined by the user, without restrictions.							
	Assistants are not allowed to perform tasks related to health care (even after delegation or approval by medical professionals).							

Subcategories	Statements	-3	-2	-1	0	+1	+2	+3
	There is a pre-defined list of tasks that the assistants can do.							
	Under the scheme, assistance is bound to a location (for example, it is provided only at the user's home).							
	There are contingency arrangements for providing support in the case the assistant(s) become unavailable.							
	The users of the scheme must account for their use of assistance, for example, by providing invoices and/or filling in time sheets.							
Support	The users of the scheme have access to peer support, i.e., support provided by users of personal assistance.							
	Peer support for the users is organised by user-led organisations, including Centres for Independent Living.							
	The users have access to training on using personal assistance.							
	The training of the users is provided by other assistance users.							
	The training of the users is provided by professionals (e.g., medical professionals, social workers, psychologists, etc.).							
	The training of the users includes modules on recruitment and management of personal assistants.							
	The training of the users includes modules on the Independent Living philosophy and/or the social model of disability.							
	The training of the users includes modules on relationships management (e.g., conflicts, communication, confidentiality, emotions, etc.).							
	Users with limited 'mental capacity' (e.g., children or persons with intellectual impairments) have access to support with decision-making.							
You can add comments here, including suggestions for additional statements or other changes:								

Category 5: Working conditions

Please, evaluate each statement on a scale from -3 to +3, where:

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- +3 means that what is described ENABLES users' choice and control to maximum extent.

Subcategories	Statements	-3	-2	-1	0	+1	+2	+3
Remuneration	The wages of the assistants are competitive in comparison with similar occupations.							
	The wages of the assistants are protected by minimum wage regulations.							
	The assistants receive additional pay for exceptional working hours (e.g., overtime, during nights, weekends, holidays).							
Protection	The assistants are entitled to benefits such as social security and paid leave (annual, sick and parental).							
	The assistants are protected by health and safety provisions.							
	The assistants are protected by reasonable accommodation provisions.							
	The assistants are protected by anti-discrimination provisions.							
	The assistants are protected in the case of death of the user.							
Profile	The assistants have the opportunity to join a relevant trade union.							
	The requirements about the qualifications of the assistants are formulated by the users (rather than by the scheme, the provider, etc.).							
	Assistants have experience with providing formal 'care' (e.g., in a hospital, a day care centre, a residential institution, etc.).							
	Assistants are predominantly women.							
	Assistants are predominantly migrants.							
	Assistants are predominantly young people.							
	Assistants are predominantly family members of the users.							
Status	The scheme does not allow for family members to be recruited as personal assistants.							
	The work of the assistants is considered valuable by the wider society.							
	Personal assistance is recognised as a profession by the wider society.							
	Assistants are regarded by the users in instrumental terms, for example, as 'arms and legs' or 'staff'.							
	Assistants are regarded by the users in dialogical terms, for example, as 'colleagues'.							
	Assistants are regarded by the users in emotive terms, for example, as 'friends' or 'part of the family'.							

Subcategories	Statements	-3	-2	-1	0	+1	+2	+3
Support	The assistants employed under the scheme have access to peer support, i.e., support provided by other personal assistants.							
	The assistants have access to training on providing personal assistance.							
	The training of the assistants is provided by professionals (e.g., medical professionals, social workers, psychologists, etc.).							
	The training of the assistants is provided by assistance users.							
	The training of the assistants includes modules on the Independent Living philosophy and/or the social model of disability.							
	The training of the assistants includes modules on relationships management (e.g., conflicts, communication, confidentiality, emotions, etc.).							
	The training of the assistants includes modules on the specific needs of people with different types of impairments.							
	The training of the assistants includes modules on health and safety.							
<p>You can add comments here, including suggestions for additional statements or other changes:</p>								

Additional information

What is your name? (optional)

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What is your country of residence? (optional)

.....

Are you a personal assistance user?

- Yes
- No
- Prefer not to say

Are you affiliated with an organisation active in the disability field?

- Yes
- No
- Prefer not to say

If you are affiliated with a disability organisation, is your organisation led and controlled by personal assistance users?

- Yes
- No
- Prefer not to say

If you are affiliated with a disability organisation, what is the name of your organisation? (optional)

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What is your email address? (optional)

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Thank you for your responses!