**PERSONAL ASSISTANCE CHECKLIST**

Thank you for your willingness to participate in this assessment of personal assistance (PA) schemes in Europe, conducted by the European Network on Independent Living (ENIL). By sharing your expertise, you will help independent living activists in Europe and beyond in their advocacy for better PA services.

The assessment is a pilot and you will be the first to apply the tool. At this stage, we are in contact with potential assessors in several European countries, including Belgium, Bulgaria, Croatia, Italy, Norway, Serbia, Slovenia, Spain, Sweden and the UK. If the assessment tool works, ENIL plans to use it more widely by translating it in different languages and including other countries, eventually covering PA schemes throughout Europe.

The assessment uses a checklist consisting of 61 statements. Each statement describes a specific characteristic of PA that either enables or hinders the choice and control of PA users in their everyday lives. These characteristics were selected after a consultation with ENIL’s members and subscribers of ENIL’s newsletter (for more information see <http://enil.eu/news/what-is-good-personal-assistance-made-of-first-look-at-the-answers/>).

You are invited to choose a PA scheme you know well and to apply the checklist to it. An option has also been provided to make comments, including comments about the checklist itself. You may complete the checklist alone or in consultation with colleagues or peers. You may also disseminate the assessment tool to other people with experience and expertise in the scheme you will be assessing.

Your participation is strictly voluntary and will be kept anonymous. During their processing and dissemination, the results will be thoroughly anonymised and your name will not appear in any reports. Refusal to participate will not incur any disadvantage and you may decide to withdraw your participation at any stage without giving a reason.

The results of the assessment will be disseminated by ENIL thought its website and newsletter. They may also be written up and published in academic reports and journal articles.

The assessment is part of the research project ‘User-Led Personal Assistance in the European Union: A Critical Comparative Analysis’ led by Teodor Mladenov and supervised by Ines Bulic at ENIL (for more details see <http://enil.eu/best-practices/meet-teodor-mladenov-enils-marie-curie-research-fellow/>).

Please return the completed checklist by 10 November 2018 to Teodor at teodor.mladenov@enil.eu. If you have any questions or need further information, please contact Teodor at teodor.mladenov@enil.eu, or Ines at ines.bulic@enil.eu.

*This project has received funding from the European Union’s Horizon 2020 research and innovation programme under the Marie Sklodowska-Curie grant agreement No 747027. This document reflects only the author’s view. The Research Executive Agency of the European Commission is not responsible for any use that may be made of the information it contains.*

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**Informed consent**

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| --- | --- |
|  | **check to confirm** |
| I confirm that I have read and understood the information about the assessment 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 understand that the information I have submitted will be published as a report and I wish to have access to it. |  |
| I agree that the researcher may use the information provided by me for future research, ensuring confidentiality and anonymity. |  |

Please confirm your consent to participate by also signing this form (print name):

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**Before you begin…**

Please select a PA scheme currently provided in your country on local, regional or national level. This could be a scheme you are involved with (as a founder, user or in some other respect), or just a scheme you are familiar with.

**Technical information**

|  |  |
| --- | --- |
| Country |  |
| Name of the PA scheme (in local language and in English) |  |
| Coverage of the PA scheme (local, regional, national, other) |  |
| Source(s) of funding |  |
| Form of funding (public, private, project-based, other) |  |
| The scheme has been provided since… (if known) |  |
| Your name (optional) |  |
| Your organisation (optional) |  |
| Are you using PA provided by the scheme? (Yes/No) |  |
| Are you a member of ENIL? (Yes/No) |  |

**Checklist**

Complete the checklist by considering each statement and indicating with an X whether the statement is TRUE or FALSE when applied to the PA scheme that you are assessing. You may also indicate that the characteristic is inapplicable, that its description is incomprehensible, or that you do not have enough information to answer by choosing NEITHER. However, we strongly encourage you to choose either TRUE or FALSE, even if the characteristic applies only partially to the scheme or you have only partial information. This will enhance the comparability of results across different schemes, making the outcomes more useful for advocacy purposes. You may also make comments at the end of each section to explain your choices, add information, or comment on the items in the checklist.

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| **Characteristics regarding CONTEXT** | **True** | **False** | **Neither** |
| 1. The scheme was introduced as a result of disabled people’s advocacy (‘bottom up’ origin). |  |  |  |
| 2. The scheme is underpinned by the Independent Living philosophy and/or the social model of disability. |  |  |  |
| 3. 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). |  |  |  |
| 4. The provision of personal assistance under the scheme is recognised as a (human, civil, social) right. |  |  |  |
| 5. The scheme is subjected to cuts (e.g., eligibility is tightened, ‘assistance hours’ are reduced, conditionality is introduced, etc.). |  |  |  |
| 6. The scheme deteriorates by incorporating measures that restrict the choice and control of the users. |  |  |  |
| 7. Policy makers and other stakeholders (e.g., the media) misunderstand, misuse or misrepresent the scheme. |  |  |  |
| 8. The evolution of the scheme is monitored by user-led organisations, including Centres for Independent Living. |  |  |  |
| 9. The scheme empowers users (e.g., to be assertive, to work, study, set up user-led organisations, create cooperatives, engage in advocacy, etc.). |  |  |  |
| 10. The scheme ‘frees’ family members from ‘caring’ obligations, enabling them to undertake other activities. |  |  |  |
| 11. The scheme is used as an excuse for cutting expenses for ‘social care’. |  |  |  |
| 12. The scheme has a positive impact on public perceptions of disabled people. |  |  |  |
| Comments and additional information: |

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| **Characteristics regarding FUNDING** | **True** | **False** | **Neither** |
| 13. The scheme is funded by the state, out of the state budget (centralised funding). |  |  |  |
| 14. The scheme is available on the national level (i.e., every eligible citizen or resident of the country has access to the scheme). |  |  |  |
| 15. The users of the scheme (can choose to) receive direct payments or personal budgets instead of services in kind. |  |  |  |
| 16. The scheme covers additional employment costs such as employer’s contributions, payroll work and other administrative costs. |  |  |  |
| 17. The scheme covers additional costs for the assistants such as tickets for events, travel, accommodation and food. |  |  |  |
| Comments and additional information: |

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| **Characteristics regarding NEEDS ASSESSMENT** | **True** | **False** | **Neither** |
| 18. The needs assessment is led by the user, possibly aided by peers. |  |  |  |
| 19. The training of the assessors includes modules on the Independent Living philosophy and/or the social model of disability. |  |  |  |
| 20. The training of the assessors includes modules on relationship management (e.g., conflicts, communication, confidentiality, emotions, etc.). |  |  |  |
| 21. The scheme is limited by a ‘cost ceiling’ and users whose support costs more are directed towards traditional services (e.g., residential institutions). |  |  |  |
| 22. The scheme is provided irrespective of age. |  |  |  |
| 23. The scheme is provided irrespective of individual or family income. |  |  |  |
| 24. The scheme is provided irrespective of family (including marital) situation. |  |  |  |
| 25. The scheme is provided irrespective of insurance status. |  |  |  |
| 26. The assessment covers the needs for assistance in all areas of life, including family, intimacy, education, employment, leisure, etc.  |  |  |  |
| 27. The assessment procedure is straightforward and transparent. |  |  |  |
| 28. The assessment is repeated upon the request of the user. |  |  |  |
| 29. The users of the scheme have the opportunity to appeal the outcome of their assessments. |  |  |  |
| 30. The appeal procedure is straightforward, transparent and does not entail additional expenses for the user. |  |  |  |
| Comments and additional information: |

| **Characteristics regarding PROVISION** | **True** | **False** | **Neither** |
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| 31. The users can employ and manage their personal assistants themselves. |  |  |  |
| 32. The quality of provision is monitored and assessed by the users and/or users’ organisations, including Centres for Independent Living. |  |  |  |
| 33. The users can keep their assistance when moving to another region or local authority within the country. |  |  |  |
| 34. The users can choose their personal assistants. |  |  |  |
| 35. The assistants are appointed by the provider, without the involvement of the user. |  |  |  |
| 36. The users can dismiss their personal assistants. |  |  |  |
| 37. Under the scheme, assistants work fixed hours (e.g., from 9:00 AM till 5:00 PM). |  |  |  |
| 38. Under the scheme, the user determines the times when assistance will be provided, including during nights, weekends, holidays, etc. |  |  |  |
| 39. The users of the scheme can save and transfer ‘assistance hours’. |  |  |  |
| 40. Assistance tasks are determined by the user, without restrictions. |  |  |  |
| 41. Assistants are not allowed to perform tasks related to health care (even after delegation or approval by medical professionals). |  |  |  |
| 42. Under the scheme, assistance is bound to a location (for example, it is provided only at the user’s home). |  |  |  |
| 43. The users of the scheme have access to peer support, i.e., support provided by users of personal assistance. |  |  |  |
| 44. Peer support for the users is organised by user-led organisations, including Centres for Independent Living. |  |  |  |
| 45. The users have access to training on using personal assistance. |  |  |  |
| 46. The training of the users is provided by other assistance users. |  |  |  |
| 47. The training of the users includes modules on recruitment and management of personal assistants. |  |  |  |
| 48. The training of the users includes modules on the Independent Living philosophy and/or the social model of disability. |  |  |  |
| 49. The training of the users includes modules on relationships management (e.g., conflicts, communication, confidentiality, emotions, etc.). |  |  |  |
| Comments and additional information: |

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| **Characteristics regarding WORKING CONDITIONS** | **True** | **False** | **Neither** |
| 50. The wages of the assistants are protected by minimum wage regulations.  |  |  |  |
| 51. The assistants are entitled to benefits such as social security and paid leave (annual, sick and parental). |  |  |  |
| 52. The assistants are protected by health and safety provisions. |  |  |  |
| 53. The assistants are protected by anti-discrimination provisions. |  |  |  |
| 54. The requirements about the qualifications of the assistants are formulated by the users (rather than by the scheme, the provider, etc.). |  |  |  |
| 55. The work of the assistants is considered valuable by the wider society. |  |  |  |
| 56. Personal assistance is recognised as a profession by the wider society. |  |  |  |
| 57. The assistants have access to training on providing personal assistance. |  |  |  |
| 58. The training of the assistants is provided by assistance users. |  |  |  |
| 59. The training of the assistants includes modules on the Independent Living philosophy and/or the social model of disability. |  |  |  |
| 60. The training of the assistants includes modules on relationships management (e.g., conflicts, communication, confidentiality, emotions, etc.). |  |  |  |
| 61. The training of the assistants includes modules on health and safety. |  |  |  |
| Comments and additional information: |

**Thank you for sharing your expertise!**