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This project is funded by the European Union.

## Towards Independent Living of Persons with Disabilities in Turkey

### Personal assistance model

#### 1. Introduction

This document aims to provide a framework for the realisation of a pilot personal assistance project in Turkey. It sets the key principles and mechanisms on which the pilot project should be based in order to be in line with the UN Convention on the Rights of Persons with Disabilities (CRPD).

Due to the innovative for the Turkish context nature of personal assistance, the realisation of a pilot project is an important first step towards the introduction of a comprehensive personal assistance service. Based on the experience from the pilot, the relevant policy and legal framework for the provision of the service at national level can be developed.

The pilot project will support the realisation of the right of people with disabilities to live independently and be included in the community by facilitating the development of a range of support options in the community and reducing the need for people with disabilities to leave their homes to access care and support.

The pilot project is expected to directly benefit the following groups:

- people with disabilities who will be supported to live independently in their homes and participate in the life of the community, including by engaging in education and employment;
- families and/or carers of people with disabilities who will be able to start or go back to paid work, if they wish so;
- personal assistants, as the project will create new workplaces and refugees can be encouraged and additionally supported to apply for personal assistants.

The proposal was drafted by people with disabilities and organisations of people with disabilities from Turkey in consultation with the European Network on Independent Living (ENIL) and the Association of Women with Disabilities (ENG-KAD). It was prepared within the framework of the project Personal Assistance as a Key Tool for Independent Living and Social Inclusion of People with Disabilities (PAKT), implemented jointly by ENIL and ENG-KAD in 2021-2022. The work on the model was informed by the CRPD and General Comment No5 of the Committee on the Rights of Persons with Disabilities<sup>1</sup> and drew on ENIL's Personal Assistance Checklist<sup>2</sup>.

#### 2. Personal assistance and the right of persons with disabilities to live independently

The right to independent living is guaranteed by Article 19 of the United Nations Convention on the Rights of Persons with Disabilities, to which Turkey has been a party since 2009. Art. 19 recognizes 'the right of all persons with disabilities to live in the community with choices

<sup>1</sup> General comment No. 5 (2017) on living independently and being included in the community, available at: <https://documents-dds-ny.un.org/doc/UNDOC/GEN/G17/328/87/PDF/G1732887.pdf?OpenElement>.

<sup>2</sup> Mladenov, T., Pokern, I., Bulic Cojocariu, I. (2019) PA Checklist: A Tool for Assessing Personal Assistance Schemes, available at: [https://enil.eu/wp-content/uploads/2022/03/Mladenov\\_Pokern\\_Bulic-PA\\_Checklist.pdf](https://enil.eu/wp-content/uploads/2022/03/Mladenov_Pokern_Bulic-PA_Checklist.pdf).



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equal to others' and requires that the states take measures 'to facilitate full enjoyment by people with disabilities of this right and their full inclusion and participation in the community'. It goes on to emphasise that these measures should ensure that 'persons with disabilities have access to a range of in-home, residential and other community support services, **including personal assistance** [emphasis added] necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community'.

Acknowledging the existence of different models of personal assistance, General Comment No5 of the Committee on the Rights of Persons with Disabilities emphasises that to support the independence and full participation of persons with disabilities, the service needs to be organised in a specific way. It highlights that the person with disability should be at the centre of the decisions about the service and should be able to choose their preferred degree of personal control over service delivery. It also points out that the person using the service should be able to recruit, train and supervise their assistants and should not be required to 'share' assistants with others (for example, when the assistant is required to support more than one person).

### 3. Personal Assistance and the Turkish context

In the last decade, Turkey has made steps to align its legislation and policies with the requirements of the CRPD and move from a largely medical to a more social and human rights understanding of disability which see people with disabilities as holders of rights rather than objects of charity and medical interventions. An important next step would be to transform existing practices, including by developing independent living services such as personal assistance. While currently there is a range of services available to persons with disabilities and their families, they offer limited support for independent living. Except for home care support, there is no services like personal assistance service that is shaped according to the needs of persons with disabilities and can be used outside the home.

The introduction of personal assistance will directly address the concerns raised by the CRPD Committee in its Concluding observations on the Initial Report of Republic of Turkey about the 'absence of measures aimed at obtaining personal assistance'. It will also support the realisation of Turkey's priorities related to independent living and inclusion, set out in the recently adopted strategic document Barrier-free 2030 vision.

### 4. The personal assistance pilot project

#### 4.1. Training of project staff

Traditional attitudes towards persons with disabilities as objects of care could be a major barrier for the development of a personal assistance service based on choice and control of persons with disabilities. Therefore, it is essential to ensure that the project team involved in the administration of the service has a good understanding of disability rights.

- Before the start of the project, the project staff should take part in an interactive training/discussion on independent living and the social model of disability. The training should consider staff's prior knowledge and experience in the area.
- Further training and support should be provided to the staff throughout the project with a special focus on the needs assessment process and how to provide support to persons with disabilities respecting their autonomy and choice.



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- It is essential that people with disabilities with experience of living independently and/or using personal assistance are actively involved in the design and delivery of the trainings and support for staff. Initially, these could be people with experience from outside the project, for example, people who have used their own resources to hire assistants, and later – project participants.

#### 4.2. Needs assessment

The amount of assistance needed by each person should be established through an individual needs assessment showing the individual needs of assistance in number of hours per month.

- The assessment should look at person's basic needs (for example, related to washing, and feeding) but should also cover all areas of one's life, for example, education, work, leisure, and family.
- The assessment should be carried out by the person with disability with support from the project team.
- The assessment should be carried out at the beginning of the project and could be repeated upon the request of the user, for example, to reflect a change in individual circumstances.
- The assessment process should be transparent, and users should have an opportunity to appeal the outcome of the assessment, i.e., the amount of assistance provided.
- Support, including peer support, should be provided to people with disabilities to prepare for the assessment. They will receive information about the process and guidance on how to assess their needs of assistance.
- The number of assistance hours allocated should be based on individual needs. There will not be an upper limit on the number of hours.

#### 4.3. Personal assistance budget

Based on amount of assistance required by each person, a personal assistance budget should be allocated to each person with disabilities participating in the pilot.

- The personal assistance budget should be used to cover the following costs:
  - personal assistants' salaries, including tax and insurance contributions
  - costs for the administration of the service (e.g. preparing contracts, accounting)
  - costs for training and other support to be provided to people using the service and assistants.
- There can be other costs related to personal assistance, for example, for public transport or entry tickets to events or venues of PAs accompanying people with disabilities. These costs should also be covered by the project, to ensure there are no barriers for people with disabilities to use PA in all areas of life. After the pilot, the need to cover such costs could be partially alleviated by extending the scope of existing in Turkey state policies for provision of free or discounted services for people with disabilities to include personal assistance when accompanying people with disabilities. This could include, for example, free entrance for PAs to museums and archaeological sites, free travel for PAs accompanying people with disabilities ('fully dependent individuals'), free entrance to state theatres, discounted movie tickets.
- A sound monitoring and reporting system should be established, in line with the existing in Turkey regulations and practices, to ensure the money is used for personal assistance service. For example, monthly timesheets will be completed, and regular financial reports



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will be submitted. If money is transferred directly to a person with disabilities (direct payment) to organise their service, special measures should be taken to ensure that it is not used by the family members to cover other, unrelated to assistance costs.

#### 4.4. Administration of the service

During the pilot, the service can be organised through a service provider managing the personal assistance budget on behalf of the user.

- Even though the provider will be administering the service, the person with disability should be the one deciding how the service is organised and delivered. This means that they should instruct the providers about whom, how, when, where and in what way the service is delivered. Assistants should not be appointed by the provider without the involvement of the user who should also be able to decide whether to replace or dismiss their personal assistants.
- The provider should ideally be an organisation familiar with independent living principles and practices. Still, training should be organised for staff involved in the administration of the service (see 4.1.).
- A direct payment approach could also be tested, where funds are provided directly to the person with disability. They will then be responsible for all administrative tasks, including preparing contracts with assistants, making payments for salaries, taxes and insurances, bookkeeping, reporting, etc.

#### 4.5. Key parameters of the service

- Assistance should be available 24/7, if needed.
- The times when assistance service is provided should be determined by the user, according to their needs and can include evenings, weekends and holidays.
- Each person could have more than one assistant, based on their needs.
- The unspent assistance hours can be accumulated and transferred to another month.
- Assistance services can be provided in different locations, based on the needs of the users. For example, at home, in school, at the workplace, outside, etc.
- The specific tasks of the assistants are determined by the users, based on their needs and in line with the relevant legal framework.

#### 4.6. Training and support for people with disabilities using assistance services

- Persons with disabilities should have access to the support they need when recruiting and managing their assistants. This could include, for example, support with preparing and disseminating an announcement, carrying out interviews with PA candidates, conflict management, etc. The opportunities offered by information and communication technologies could also be utilised. For example, to support the recruitment process, a platform/site could be set up to link PA candidates and users. Online tools could also be used to facilitate the exchange of information and support between people using the service. Online training materials, including videos and written materials could also be prepared.
- To ensure that users have a good understanding of their rights and their role and responsibilities in managing their assistants, they should have access to a training on independent living and the social model of disability. Variety of trainings on relevant to disability and personal assistance topics should also be made available.



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- Users should also have access to peer support, that is, support provided by other personal assistance users.

#### 4.7. Personal Assistant's training and working conditions

- The requirements for the qualification of assistants should be set by the users, not by the project.
- Given the limited awareness about disability rights and the dominant medical model of disability, it is recommended that assistants too receive information and/or training on independent living and the key principles of personal assistance. Additional training opportunities can be provided for those assistants who wish to make use of them; they should not be made compulsory.
- Assistants' wages will be protected by wage regulations, set in the relevant labour laws.
- Assistants have rights such as social security and paid leave (annual leave, sick leave and maternity leave). Assistants working outside regular working hours will be entitled to overtime wages.

#### 4.8. Pilot project parameters

##### 4.8.1. Duration and location

The proposed duration of the pilot is 2 to 3 years, which will allow to develop systems and practices for the provision of the service and to test the service with different groups of persons with disabilities, including children and people with intellectual and psychosocial impairments.

##### 4.8.2. Participants

The pilot project will start with a group of adults with physical and sensory impairments, which after the first year could be expanded to cover people with intellectual and psychosocial disabilities and children with disabilities. In the case of children, personal assistance will aim to cover the needs from assistance over and above the parental responsibility that would apply in the case of a non-disabled child. It can be particularly useful to support children's participation in educational and social life.

##### 4.8.3. Monitoring and evaluation

A monitoring and evaluation framework will be developed at the beginning of the project. The framework will guide the collection of information in variety of areas, such as the impact of the service on people with disabilities, their families and carers, the experience of people using the service, the level of awareness about PA and the attitudes towards personal assistants, etc. This will allow to gain evidence about the effectiveness of the service and will inform the development of national policies and practices.