



FACT SHEET: Personal Assistance

1. What is Personal Assistance?

Some disabled people may require support or personal assistance in everyday activities to enable them to overcome barriers and live with greater independence. This can range from occasional support up to support of 24 hours per day. The activities may include support with personal care, eating, dressing, household work, shopping, assistance at work and during leisure time, as well as in communicating, structuring the day, or similar cognitive or psycho-social support.

Personal assistance is a tool which allows for independent living. It is purchased through earmarked cash allocations for disabled people, the purpose of which is to pay for any assistance needed. Personal assistance should be provided on the basis of an individual needs assessment and depending on the life situation of each individual. The rates allocated for personal assistance to disabled people need to be in line with the current salary rates in each country. Disabled people must have the right to recruit, train and manage their personal assistants with adequate support, if they choose, and should be the ones that choose the employment model which is most suitable to their needs. Personal assistance allocations must cover the salaries of personal assistants and other performance costs, such as all contributions due by the employer, administration costs and peer support for the person who needs assistance.

2. What are the key elements of Personal Assistance?

The right to live independently and to be included in the community is set out in Article 19 of the UN Convention on the Rights of Persons with Disabilities (CRPD). State Parties to the CRPD are obliged to “take effective and appropriate measures” to facilitate the full enjoyment of this right, including by ensuring that disabled people have “access to a range of in-home, residential and other community support, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community”.

Personal assistance, as set out in Article 19, can be distinguished from other types of services by the following characteristics:

- The service user is the customer or the boss. This means that they are able to contract the service of their choice from a variety of providers, or to hire, train, schedule, supervise, and, if necessary, fire their assistants;





- Users have the option to custom-design their own service, which requires that they are able to decide who will work for them, which tasks they will perform, at which times, where and how;
- Users are free to choose their preferred degree of personal control over service delivery according to their needs, capabilities, current life circumstances, preferences and aspirations;
- The funding follows the user, not the provider, and should be set at market level to allow recruitment of assistants on the open labour market, as opposed to among family members;
- For a personal assistance policy to be effective – i.e. to enable disabled people with complex support needs to live in the community with self-determination and full participation, and to phase out residential institutions - it needs to be combined with other policies around independent living (on housing, barrier free environment, transport, education etc.). There should also be provision for peer support, which should be funded through personal assistance allocations, to support disabled people in managing their personal assistants.

The term “personal assistance” must NOT be used for service delivery solutions where housing and assistance with the activities of daily living are provided in one inseparable package.

3. Who is a Personal Assistant?

The personal assistant is an individual contracted by the disabled person to provide them with support in different aspects of daily life – such as personal care, household tasks, assistance at school, university or the workplace, driving, interpretation and so on. These tasks are customised to the individual needs of the user and assigned by the user. The job of a personal assistant does not always require any particular qualifications or previous experience and can be performed by people of different ages and backgrounds. The key requirement is that the prospective personal assistant is considered by the user him/herself as suitable for the job. The major difference between a personal assistant and a carer is that in the case of personal assistance, the service is designed and managed by the service user directly.





4. What is the difference between Home Care and Personal Assistance?

Agency or state (i.e. municipality) directed “home care” services are based on the medical model, whereas consumer-directed personal assistance services are based on the Independent Living model. Personal assistance is not the assistance of nurses, social workers, charities, the church or medical professionals. Personal assistance is controlled and managed by the disabled person, to facilitate their self-determination and independence on their own terms. Anything else, regardless of what it is called, contravenes the aims and philosophy of the original concept developed by the Independent Living movement.

5. Can family members be Personal Assistants?

Paying family members to work as personal assistants is controversial, with a number of arguments for and against. On one hand, many family members are already providing unpaid care, therefore being paid for this work could be considered as justified. Some disabled people also prefer their family member to provide certain support, because they know them well, trust them and feel comfortable with them. On the other hand, employing a family member can result in the loss of control by the service user, as it may be difficult to establish an employer – employee type of relationship. Furthermore, disabled people may feel under pressure to employ their family member as a personal assistant if this option is available, especially if the family member is already providing them with some support and is unemployed (or the household budget needs topping up). Whatever the arrangement, it is important that the key elements of personal assistance – especially the ability to decide by whom, where, when and how the service will be provided – are respected. It is important that disabled people are not required to employ their family member, which may be the case if the funding provided for personal assistance is too low to employ someone on the open labour market.

6. How are Personal Assistants hired and paid?

Although the Independent Living movement has been campaigning for personal assistance since the 1960s, the situation in Europe still varies. Many countries have no personal assistance schemes, or if they do, they are available to a small number of disabled people. In most Western European countries, where personal assistance is more widely available, personal assistants are generally employed by a service provider (i.e. an agency or a municipality). The user determines the work to be done and the hours, and he/she is required to submit timesheets to the service provider in order for the personal assistant to be paid. Another option is through direct payments or personal





budgets, when the service user receives funding directly and becomes the employer. In this case, the user has complete control over the service, but also has responsibilities, including administrative, financial and legal. Direct payments and personal budgets are available in some countries, but not everywhere. Finally, some personal assistance users get organised in co-operatives, which allows them to centralise administrative and other tasks, and still keep full control over the service. Some of the better known user co-operatives in Europe are based in Scandinavia, for example ULOBA in Norway or STIL and JAG in Sweden.

7. Is Personal Assistance suitable for people with learning difficulties¹ or people with mental health issues?

Personal assistance is suitable for people with different impairments, including people with learning difficulties or mental health issues. In the case of a person who cannot fully manage their own personal assistance, the employer's responsibilities can be contracted out to another party. However, the user – in this case a person with learning difficulties or a person with mental health issues – must still remain at the centre of the decision making process. They should be supported in making the necessary decisions, so that the service is based on their own wishes, their person-centred plan and the assessment of their support needs. Several countries, such as Sweden, Norway, Finland and the UK, have experiences in providing personal assistance to all impairment groups. In many other countries, there are still challenges in including people with learning difficulties and people with mental health issues as a target group for personal assistance.

8. Is Personal Assistance more expensive than institutional care?

Institutionalisation of disabled people is considered to be a human rights violation, as it contravenes Article 19 of the CRPD. Therefore, even if some institutions are cheaper than community-based services, disabled people should never be placed in such settings in order to make savings. As a general rule, however, research shows that community-based services are not necessarily more expensive than institutional care, especially when comparison is made based on the quality of service. When comparing different services in the community, including small group homes, personal assistance makes for the best use of resources. This is because hours of support are tailored to each individual. Whereas some people may require 24-hour-support, others will require less. In addition to enabling disabled people to live independently, in their own homes in the

¹ The term 'people with learning difficulties' is based on the social model with disability. It has the same meaning as 'people with intellectual disabilities'.





community, personal assistance generates employment for others and enables disabled people to be active members of society (including by working in the open labour market and paying taxes).

References and further reading:

Ratzka, Adolf (ed). 2004. Model National Personal Assistance Policy. Available at: <http://www.independentliving.org/docs6/ratzka200410a.html#definition>

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European Network on Independent Living: Personal Assistance Tables. Available at: <http://www.enil.eu/policy/personal-assistance-tables/>

European Network on Independent Living: European Survey on Personal Assistance. Available at: <http://www.enil.eu/reports/>

