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Most people who depend on the help of other persons in the activities of daily living such as getting up in the morning, toileting or bathing face very limited lives in residential institutions or parental homes. How must the ideal national policy for personal assistance look that empowers them to live in the community, as equal and fully participating citizens, taking their rightful place in family, neighborhood and society, with work and families of their own? The European Center for Excellence in Personal Assistance (ECEPA) is a project run by people who themselves depend on personal assistance. This model legislation was formulated using their combined personal experience with personal assistance services in eight European countries.

Model National Personal Assistance Policy

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Introduction

Social policy is rarely made by the people whose lives depend on it. For that reason we often see legislation, programs and practices that make people with disabilities more dependent rather than more independent. In most countries, policies or lack of policies drive people who need help of others in the activities of daily living into dependence on their families or exclude them from the life of the community by forcing them to live in segregated residential facilities or to stay in their parental homes beyond the customary age.

The piece of policy suggested here is different, because it is written by individuals who themselves depend on the daily assistance by other persons. The European Center for Excellence in Personal Assistance, ECEPA (www.ecepa.org) consists of eight partner organizations¹ in eight European countries that are run and controlled by persons with disabilities and specialize in the provision of and advocacy for personal assistance services for persons with extensive disabilities. Using our combined personal experience with personal

¹ The partners are Center for Independent Living Mainz, Germany (lead partner); the Independent Living Institute, Sweden; CIL Helsinki, Finland; ULOBA, Norway; CIL Dublin, Ireland; Vienna Assistance Cooperative, Austria; ENIL Italia, Italy; CIL Thessaloniki, Greece and CIL Zurich, Switzerland, as observer.
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assistance policies a list of features was compiled for a policy that is to promote self-determination and full citizenship for persons with extensive disabilities.

The suggested policy is designed to

- establish the right to direct payments of assistance services for as many assistance users as possible,
- enable as many assistance users as possible to exercise the degree of control over their services which they prefer at any given situation in their lives

by

- providing assistance users with purchasing power which, in turn, creates a market for assistance services with a multitude of service providers with different service delivery solutions,
- eliminating monopolies, public or private, in the provision of assistance services.

As a policy document, the text is primarily addressed to lawmakers and those working for changes in personal assistance legislation. Its focus is not on prescribing service delivery solutions but on creating the legal and financial framework that promotes diversity and quality in service provision. As a model policy it may, at best, describe the ideal legislation, not the strategy in getting there. It shows the destination, but not the road map.

Personal Assistance, the Key to Independent Living

The crucial role of personal assistance in the lives of persons with extensive disabilities has been recognized in several international policy documents, for example, the United Nations "Standard Rules on the Equalization of Opportunities for Persons with Disabilities":

Rule 4. Support services

States should ensure the development and supply of support services, including assistive devices for persons with disabilities, to assist them to increase their level of independence in their daily living and to exercise their rights.

1. States should ensure the provision of assistive devices and equipment, personal assistance and interpreter services, according to the needs of persons with disabilities, as important measures to achieve the equalization of opportunities.

6. States should support the development and provision of personal assistance programmes and interpretation services, especially for persons with severe and/or multiple disabilities. Such programmes would increase the level of participation of persons with disabilities in everyday life at home, at work, in school and during leisure-time activities.

7. Personal assistance programmes should be designed in such a way that the persons with disabilities using the programmes have a decisive influence on the way in which the programmes are delivered.²

The present document can be seen as an attempt to aid member states in the implementation of Rule 4 into national legislation.

Definition of Personal Assistance

Persons with extensive disabilities depend on assistance by others in the activities of daily living such as personal hygiene, eating, dressing, household work, assistance outside the home, at work and during leisure time, and, if applicable, in communicating, structuring the day or with similar cognitive or psychosocial support.

"Personal assistance" means that

² The Standard Rules on the Equalization of Opportunities for Persons with Disabilities, Adopted by the United Nations General Assembly, forty-eighth session, resolution 48/96, annex, of 20 December 1993
www.un.org/esa/socdev/enable/dissre00.htm

- funding of services follows the person and not the service provider,
- 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. Their range of options includes the right to custom-design their own services, which requires that the user decides who is to work, with which tasks, at which times, where and how.

Therefore, a policy for “personal assistance”, among other solutions, enables the individual to contract the service of his or her choice from a variety of providers or to hire, train, schedule, supervise, and, if necessary, fire his or her assistants. Simply put, “personal assistance” means the user is customer or boss.³

Children and users with cognitive or psychosocial impairments might need support from third persons with these functions.⁴

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

A country’s personal assistance policy must be combined with a policy for general barrier-free construction in order to phase out residential institutions and to enable people with extensive disabilities to live in the community with self-determination and full participation.

Necessary Features of a Model National Personal Assistance Policy

In the following, features are suggested which are deemed indispensable for a personal assistance policy that is to give people with extensive disabilities acceptable choices of how and where they want to live.

1. Eligibility

Eligibility is granted

- solely on the basis of a person’s need of practical assistance by others in all activities of daily living, such as personal hygiene, eating, dressing, doing household work, assistance outside the home, about town or when traveling, at school, work and during leisure time, and, if applicable, in communicating, structuring the day or with similar cognitive or psychosocial support,
- regardless of cause or medical diagnosis of one’s disability, a person’s age, age at onset of disability, employment or insurance situation,
- regardless of income or property of the recipient or the recipient’s household or family.

Applicants without the cognitive or psychosocial ability to contract service providers or to manage such tasks as recruiting, training, scheduling, supervising assistants, etc. cannot be declared ineligible for cash benefits.

In determining eligibility care is taken to avoid differential treatment of people with certain types of disabilities, of women, old persons, persons of different ethnic origin, religious belief or sexual orientation.

³ Other definitions might require the ability to individually or collectively employ assistants and to recruit, train and supervise them. These criteria reduce the number of people eligible under the policy. In the present definition, the emphasis is on the individual’s freedom to choose among a variety of services which, together, offer a wide range of different degrees of responsibility over day-to-day operations. In this way, more people are covered by the policy and are free to try assistance solutions with varying degrees of user responsibility and, step by step, at their own pace, to develop the skills required to take on more control over their services.

⁴ Citizens who, despite appropriate information, counseling and other support, are unable to select and evaluate services or to employ their assistants themselves can also benefit from the policy provided that they receive the support from third persons such as a legal representative, family member or other person close to them. The costs of such support need to be covered by the policy, if necessary, by higher payments for the average assistance hour.

Persons who live in residential institutions or equivalent solutions are not eligible under the policy. In order to facilitate the transition from residential institutions to living in the community the policy grants cash benefits for personal assistance up to 6 months ahead of the planned move.

Payments are exportable to countries where users cannot receive equivalent payments.

2. No Costs to Users

Assistance users are not required to contribute to the cost of their personal assistance services regardless of their or their families' or households' income or property.⁵

3. Needs Assessment

In needs assessment the amount of personal assistance is determined which enables assistance users, in combination with the use of assistive technology, adaptation of their living and working environment and barrier-free infrastructure planning in the community, to utilize the same options and opportunities which they would have had without their disability.

Need assessment takes into account

- the whole life situation enabling assistance users to fulfill the role they would have had without their disability, in family, neighborhood and society with all resulting privileges and responsibilities including the culturally customary division of work within the family, care of small children, aging parents, household and property,
- need of assistance at the work place, while attending educational institutions from kindergarten through university, during leisure time, outside the home, on travel and abroad,
- all, not only one or several, areas of activity in one's life,
- the need, if applicable, of experienced and specialized assistants,⁶
- the need of third persons for supporting assistance users who, due to a cognitive or psychosocial impairment, need support in dealing with service providers and assistants,⁷
- activities for the maintenance of one's health and well-being such as self-care or physical exercise. Assistants can perform tasks which normally non-disabled persons, after instruction by medical staff if deemed necessary, would carry out by themselves.

In the case of children, the policy covers assistance needs over and above the parental responsibility that would apply in the case of a non-disabled child.

The assessment does not take into account the funding body's financial situation.

Assessment is conducted in the form of a dialog⁸ between the individual assistance user aided, if desired by the individual, by person(s) of his or her choice⁸ and a representative of the funding agency. Individuals who work for or are associated with service providers do not carry out assessments.⁹

⁵ Items 1 and 2 reduce disincentives to gainful employment, promote users' social and geographical mobility, decrease dependence on the family's financial situation and priorities, on charity organizations and volunteers or, where applicable, on the municipality's financial situation and priorities.

⁶ The need of specialized training of assistants may affect the average hourly cost of a person's assistance.

⁷ This need is expressed in additional hours of assistance.

⁸ Peer support has proven to be effective in informing, training, supporting and advocating for assistance users.

⁹ Their interests may conflict with assistance users' interests.

The need of personal assistance is expressed in the average number of assistance hours per month that a person needs and not in terms of one of several need categories.¹⁰

In assessing needs care is taken to avoid differential treatment of people with certain types of disabilities, of women, old persons, persons of different ethnic origin, religious belief or sexual orientation.

Assistance needs, in terms of the average number of hours per month, are reassessed periodically, at intervals of two years or more or at any time when requested by the assistance user due to changing needs, for example, changes in one's impairment, vocational career, the transition from parental home or residential institution to living in the community, the birth of one's child, etc.

4. Appeal Procedure

During the assessment process assistance users are informed about their rights to appeal assessments. The appeal procedure is clear and straightforward, inexpensive to the assistance user, and includes several instances including courts of law.

In all contacts with the funding agency's staff regarding needs assessment, appeals or other administrative issues assistance users can utilize the counsel and support of third persons of their choice, in particular, other personal assistance users.

5. Cash Benefits, not Services in Kind

The policy stipulates cash benefits¹¹ that are paid by the funding agency directly to assistance users who, in turn, use the funds for

- purchasing assistance services from one or several service providers of their choice
- organizing their services themselves by employing assistants or
- any combination thereof.

Recipients must be free to purchase services from public or private, for-profit or not-for-profit service providers and/or to employ their assistants themselves, including family members.¹²

Cash benefits are paid monthly and in advance. Payments consist of the average number of assessed hours per month multiplied by the estimated cost of the average assistance hour. The amount per hour is either the same for all assistance users or varies from user to user depending on the user's need of specialized assistants and other related expenses.¹³

¹⁰ Many assistance users prefer workers to get paid by the hour. Thus, there is a direct link between their needs and the number of hours their assistants work.

¹¹ "Cash benefits" and "Direct Payments" are used interchangeably throughout the document. The terms are to connote payments from the financing agency directly to assistance users to be used for personal assistance services.

¹² Cash payments create a market with competing providers and turn users into customers who have a choice and can demand quality. Direct Payments are indispensable for users' self-determination. Services in kind reduce users' choices, in particular, if they are provided by monopolistic service providers which often tie users to certain buildings and other limited geographical areas.

Services in kind do not permit users to take responsibility for cost-efficient solutions. Cash benefits, on the other hand, enable individuals to custom design assistance solutions in accordance with their needs and preferences and give them an incentive to get the best services for their budgets.

¹³ In one proven solution (Swedish Personal Assistance Act of 1994, see www.independentliving.org/docs3/englss.html) the amount per assistance hour paid to users is a flat rate that is determined by the national government each autumn for the entire following calendar year. The flat rate is the same for all recipients, regardless of geographic location, disability, service provider, etc. and is to cover all direct and indirect expenses of personal assistance as enumerated in point 9 - unless a recipient applies for a higher rate and is able to show evidence for his or her higher assistance expenditures per average hour. Recipients of the flat rate have to verify only the number of hours they consumed by presenting evidence in the form of signed timesheets for each assistant who worked during a given month.

6. Payments' Amount

The monthly amounts are to cover the average costs of the recipient's personal assistance as enumerated under point 9.

The amount granted per average assistance hour is based solely on assistance needs and not on the service providers' identity. Thus, persons employing their own assistants receive the same amount per average assistance hour that providers would charge for assistance services.¹⁴

7. One Central Funding Source

One and the same national level state funding agency covers all recipients and all their activities.¹⁵

Each recipient has no more than one agency to deal with. In case several sources contribute, one of them is the guarantor for the other sources.

8. Payments for Personal Assistance as Legal Entitlement

Recipients are legally entitled to payments for personal assistance irrespective of the funding body's financial situation.¹⁶

Payments under the policy are not treated as taxable income and do not affect the recipient's eligibility for other benefits or services.

9. Full Coverage of all Costs Associated with Employing Personal Assistance

The payments cover all¹⁷ costs of employing assistants such as

- competitive wages, all indirect labor costs such as compensation for unsocial hours and over-time, workers' accident and liability insurance, assistants' social insurance including sick leave, pension plan, vacation pay, maternity leave,
- the costs of accompanying assistants around town (e.g. for meals, entrance tickets, transportation) or when traveling (e.g. for airfare, hotel room, meals),

¹⁴ The same hourly rate irrespective of the service provider's identity is indispensable, if users are to freely move between providers and different forms of organizational solutions including employing one's own assistants.

¹⁵ One central funding source promotes users' geographical and social mobility and liberates them from local governments' finances and priorities. A funding source in the form of a state authority frees recipients from dependence on charities and their fundraising methods. This improves the image of disabled people in society.

Dividing financial responsibility for assistance among several funders increases users' administrative work and vulnerability in case of disputes among funders, reduces users' control over their assistance and daily lives, and drains their energies. One national level funding source, as opposed to several ones, guarantees politicians and taxpayers a high measure of transparency.

¹⁶ Legal entitlement reduces dependence on fluctuations in the funding body's economic situation, enables users and families to plan for the future, promotes de-institutionalization and encourages assistance users' and their household members' (re-)entry into the labor market.

¹⁷ If payments do not fully cover service providers' administrative costs, assistance users are forced to employ their assistants themselves, assume the resulting legal responsibility at their personal risk and perform the administrative work themselves. Users who are unable to do so are limited to services from charitable organizations or public service providers, if any, that are able to subsidize the difference between their actual costs and what recipients of cash benefits can afford to pay. Without the ability to pay competitive wages assistance users are not able to attract and keep competent workers and are forced to employ grey or black labor without contract or any social insurance benefits. In this way, assistance users are further marginalized by operating outside the law and made dependent on other people's charity. Under these conditions it is impossible to build a sound image around personal assistance as a profession.

- payroll administration and other administrative costs,
- training and support of assistance users and assistants, if deemed necessary by the user,¹⁸
- purchase of equipment, supplies and services which facilitate the assistants' work and are necessary to maintain a safe and healthy working environment,¹⁹
- compensation for the employer's risk in, among other things, labor disputes.

The monthly cash benefits are of such an amount that they enable the individual recipient to build up and maintain a budget that, over the course of one year, covers all the above items.

10. Constant Purchasing Power of Payments

The level of payments is annually adjusted to avoid purchasing power losses.²⁰

11. Recipients' accountability

Recipients periodically account for use of funds.²¹

The periods for which the funds are to be accounted are 12 months or longer. Within the budget for this period, users can, as they see fit, save assistance hours from month to month in order to build up a buffer for temporary over-consumption, for example, for travel or illness.

A distinction has to be made between accounting for the *number of assistance hours* consumed during the 12 months period and the *average cost per hour* during this period. Recipients who receive a flat rate per assistance hour need only present invoices from their service providers or time sheets signed by their assistants to verify their consumption of assistance hours. On the other hand, recipients who are granted a rate higher than the flat rate need to show proof of their cash expenditures.¹³

12. Monitoring, Evaluation and Adaptation

Any piece of legislation needs to be continually monitored, periodically evaluated and adapted to changing circumstances. In the case of personal assistance policy, organizations of persons with disabilities need to participate in the process. In particular, the expertise of individuals who themselves in their daily lives depend on personal assistance services need to be recognized and decisively involved.

¹⁸ For such training and support assistance users are free to contract services of their choice. Peer support has proven to be effective in informing, training, supporting and advocating for assistance users.

¹⁹ This is the employer's legal responsibility in a number of countries.

²⁰ An appropriate method might be the automatic annual or, if necessary, more frequent adjustment of the flat rate by the labor cost index for service industries.

²¹ In countries with cash payments for personal assistance without accountability, assistance needs are, typically, not fully covered by the cash benefits, since politicians and civil servants seem to assume that users will hire gray or black labor who work for less than competitive wages, without contracts or social insurance.