

“personal budget”

for people with disability

Analysis Paper

July 2010

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"Personal budget" means that people with disability (and sometimes people with mental health problems) receive a certain amount of money that they can use for paying people and services who assist them in their daily life, going from shopping over accompanying them on public transport to psychotherapeutic sessions etc... The central idea behind the concept is to place the person, who is supported, or given services, at the centre of the process and to give them the power to decide the nature of their own support. In German the term "Persönliches Budget" is used; in French "budget personnel" and in Dutch/Flemish "persoonlijk assistentiebudget". In the UK, the expressions "individual budget" and "direct payments" are widely used.

“Direct payments” are also cash payments paid directly to the disabled person, for them (or an organization / person supporting them) to buy in their own support, rather than have it delivered by a local authority or state agency. A direct payment may form part of a personal budget.

Personal budgets for disabled people can be used to employ family members as personal assistants, if they wish.

In theory there are no limits to the amounts of funding, but in practice funding and amounts of personal assistance that people are entitled to, are linked to the resource that is available from state agencies or local authorities and their thresholds for setting eligibility criteria.

Disabled people are entitled to self-direct either the funding system and/or the organisation of the personal assistance it pays for, if they wish, and are also eligible to tailored support to do so (Peer-support - provided by Centres for Independent Living or ULOs).

In the large majority of EU states, there is no legal framework for the provision of personal budget and this term is visibly unknown and unused like in Bosnia-

Herzegovina, Bulgaria, Cyprus, Czech Republic, Finland, Greece, Ireland, Italy, Kosovo, Latvia, Macedonia, Poland, Romania, Slovenia, Spain and Sweden.

More traditional patterns of help are implemented there, such as the payment of a disability allowance or the provision, either by the State or the local authorities or the municipalities, of support services and / or personal assistants.

But the introduction of personal budgets are/have been forecasted e.g. in Czech Republic and Slovenia.

In several countries, a personal budget is allocated to both people with physical disabilities and people with mental health problems (Austria, France, Netherlands, Sweden, and United Kingdom). Only in Denmark, people with physical disability can obtain a personal budget, whereas people with mental health problems have no eligibility to such an arrangement.

The present epr-paper wants to give an overview on the recent national provisions and implications with regards to the "personal budget" – with a special focus on Germany, using / quoting the recent findings from European research and studies.

Germany

In the EU countries various kinds of systems of direct payments exist. According to the third Government Report on Poverty and Wealth in Germany, the main sources of income for disabled people in Germany are pensions (63%), followed by earnings and salaries (19%) as well as family support (9%)

Germany is one of the nine countries whereby a personal budget is used to fund personal assistance since recently. A quite complex development took place in the field of personal budget.

'Personal Budgets' ('Persönliches Budget') are regarded as a new instrument to support disabled people's self-determination and independent living. The German Personal Budget entitles people with (severe) disabilities to social security benefits in the form of a fixed lump sum of money or vouchers which are to be handed to rehabilitation providers. Until the end of 2007 allocation of the Personal Budget was at the discretion of the rehabilitation provider; from 2008 recipients have been legally entitled to it.

Foundations were laid in the "Sozialgesetzbuch IX (§ 17 Abs. 2 SGB IX)" in 2001, making it possible for people to receive a budget instead of ambulant or residential care. There were different experiments within this framework as of 2004.

Different kinds of "Persönliches Budget" were being implemented in several Länder/regions ("Modellregionen") in Germany. With the *Trägerübergreifendes Persönliches Budget* (TPB) (combined budget) people could apply for a budget of government authorities and agencies, which will be paid as one combined / overall budget (instead of every authority paying only for the domain it is responsible for. This system doesn't introduce any additional grant, but is a new form of payment for old benefits making care more flexible. The goal is to promote integration and rehabilitation. It makes it possible for people to decide for themselves where, when how and from whom to receive support. From a passive care receiver one transforms into someone who actively decides about his care needs: as a purchaser, as a consumer and even as an employer. It is the intention to offer people more chances for self-determination and

to make them sufficiently independent so that they can take up their roles as equal citizens.

Since the 1st of January 2008 everybody can benefit from the 'Trägerübergreifendes Persönliches Budget' (personal budget) as an alternative to care in kind. This budget is granted to disabled people who need assistance of different bodies for rehabilitation, support with living, support with working, etc. So this budget "survived" the model phase and is now a regular service and the main budgeting system in Germany. This budget is an *enforceable right*.

Whilst in theory the disabled person has control over the use of these hours, in practice the municipality often decides how support and services are provided. In Germany, the principles of independent living and user control seem to be quite high-profile, and disabled people themselves (and their organisations) have had an impact in campaigning for independent living and changing laws. The evidence is in the number of Centres for Independent Living (now one per state), and the new right to a personal budget (2008). The articulation of the principles of user-control (e.g. what makes a personal assistance service) is faultless.

The budget amount is determined on the basis of the *assistance plan*. Although the budget amount should in principle equal the cost of similar care in kind, local authorities have different practices (meaning exact figures are not available).

Research in Germany concludes that granted budgets do not cover the costs of personal assistance, especially for those with higher needs (Bundesvereinigung Lebenshilfe für Menschen mit geistiger Behinderung e.V., 2008) and that because of a 'best value' approach, some people have been forced into institutional care.

All people that are frequently or to a considerable extent in need of care because of physical, psychological or mental illness or disability during their daily activities or for a period of at least 6 months belong to *the target group*. This includes also children and elderly people.

The budget is based on an *agreement between the budget holder and the government authorities*. One of the government authorities is from then on the contact person and coordinator with regard to the budget. Budget holders only have one contact person, even when they receive money from different authorities. For an application people can contact all kinds of authorities: care insurance, pension insurance, youth service, social service, integration bureau, employment agencies and the regional service bureaus. Within 2 weeks you should get an answer of all the concerned authorities. After that there is an interview about your concrete support needs. Finally you will reach an agreement about your support. In the agreement is stipulated which benefits and compensations you can benefit from with your budget. The service that you initially contacted will then give you an agreement containing all the details concerning your budget.

Which services can be "bought" with the budget?

Services supporting the integration and participation in community life: assistance at the workplace, transport, nursing, leisure time activities, living costs in the framework of assisted living, therapy costs, support equipment, etc., services provided by the health

insurance and care insurance, but only when needed regularly and on a supplementary basis.

The budget provides also for: services of the integration bureau such as trainings and other services, services for the prevention of impairments with adults and support of children with an impairment.

General practitioner costs can not be paid with the budget.

The budgets of the Persönliches Budget should actually cover all assessed needs.

No maximum limit has been defined. The budget is determined by the assessment. The disabled person needs to establish a plan which includes the number of hours of support, the type of support and how he wants to realize the support. If this plan is accepted then you will receive a budget according to your needs and in accordance with the responsibilities of the concerned authorities and within the legal boundaries as set by the latter. That means especially that if the budget includes benefits from the social welfare (which local governments are responsible for), the government will decide the level of benefit you'll receive. The vast majority of budget (and assistance) users are dependent on social welfare as a consequence of how the German care legislation works.

As a budget user you are quite free to choose how the budget will be spent. If you make use of a care provider then the care provider will calculate the cost price of its service. If you make use of a personal assistant then the government will determine the budget you will receive to this end. This may vary depending on the place you live and is sometimes limited to 4 Euro as hourly income after taxes for the assistants. If you want a higher budget because you need a skilled assistant then you can state your grounds for obtaining a higher tariff.

The procedure by which you account for your budget expenditure depends on the place you live. Some local authorities have very strict procedures; some authorities give more leeway for the management of your budget.

The budget is paid out on a monthly basis. The applicant can also opt for the government to pay directly to the care provider. Local authorities provide help with the management of the budget but this has been met with criticism because of the fact that the authority's help is bound to certain conditions.

In Germany, e.g. the "Lebenshilfe" offers counseling for disabled people and their families on how to operate a personal budget. This service is accessible to people with learning disabilities. In addition, budget counselors are being trained by other organisations and may work either as employees of a ULO, or operate on a freelance basis and be costed into an individual's personal budget.

See also: <http://www.bmas.de/portal/45142/>, http://www.einfach-teilhabe.de/cln_164/DE/StdS/Home/stds_node.html, http://www.bmas.de/portal/18894/fragen_und_antworten_zum_persoelichen_bu_dget_01.html, <http://www.pb-lebenshilfe.de/>, <http://www.budget.paritaet.org/>, http://www.familienratgeber.de/recht/persoeliches_budget.php, <http://www.budget-tour.de/>

OTHER EUROPEAN COUNTRIES

The practice for “personal budgets” varies greatly by country. There are also huge differences in terms of variations in the limits that are applied to the resources allocated. The majority of member states appear to have developed mainstream policy where there are clear statements supporting options for independent living including direct payment schemes (Estonia, Netherlands, Iceland, Slovakia, Ireland, United Kingdom – see below, Spain and Norway). Some countries have developed individual pieces of legislation which articulate specific aspects of support for independent living, such as the right to personal assistance (Finland, Sweden, Denmark, Poland, Italy, Spain) and to personal budgets (Germany, Netherlands, United Kingdom).

Austria

Disabled people are expected to use their benefits to fund personal assistance if they want/need it. In Austria, ‘long term care benefit’ is the main source of finance for personal assistance and can be taken as a direct payment. Theoretically it can be used to buy in support, but in reality the universality of this approach is hampered by a lack of personal assistance schemes and services in many areas of Austria.

The amount of the benefit is often too low to purchase sufficient personal assistance for effective independent living. Disabled people are expected to pay some or all of the costs of this support, using their benefits or other financial means, depending on their financial circumstances.

In Austria, there is a well-established group of three Centers for Independent Living which are developing good local practice in supporting and implementing personal assistance. However, Federal and Provincial laws, and the paradigm of the medical model of disability, do not fully support these developments.

According to the Bundes-Pflegegeldgesetz -BGB), a personal budget can be allocated to people with disabilities, including mentally and psychologically handicapped people. To get the money, the person who needs care should be first examined by a doctor working for independent agencies appointed by the care insurers. There are 7 categories of medical assessment and the amount paid is a lump sum depending on the care needed; the assessment is based on units of help. The person who gets the money is free to use it and hire a personal assistant.

Belgium

Belgium is experimenting on personal budgets. A Personal Assistance Budget (Persoonlijk Assistentie Budget - PAB) was introduced in the Flanders region in 1990. People suffering from a "disability" ("any major long-term restriction of a person's ability to integrate into society as a result") who prefer to live at home can apply for a personal assistance budget, provided that: he/she apply before reaching the age of 65 and he/she lives and resides in Belgium. This budget can enable them to employ a home helper. It consists in cash benefits, paid by the Vlaams Agentschap voor Personen met een Handicap).

Disabled people are entitled to self-direct either the funding system and / or the organisation of the personal assistance it pays for, if they wish, and are also eligible to tailored support to do so (Peer-support - provided by Centres for Independent Living or ULOs).

In Belgium, whilst some institutions remain, de-institutionalization has developed in each region of the country. This is alongside enlightened services providing personal assistance, and the use of personal budgets.

The access in Belgium is fairly mechanistic, in that a set number of personal budgets for personal assistance are agreed each year in certain localities.

In Belgium, new systems of providing budgets to individuals with disabilities are being developed. Clear procedures exist with regard to the provision of assistive devices, which are procured through close collaboration between multi-disciplinary teams and disabled people.

The recent emergence of individual budgets will allow people more choice than the 'package' system that is more common with the existing personal assistance budget, when it is available.

Bulgaria

Disabled people receive personal assistance as a service, in terms of an allocation of hours, rather than as a budget, or a cash payment. Family members can be employed as personal assistants under this system.

In Bulgaria, the 2008 de-institutionalization through Provision of Community Services to Risk Groups programme funded by the EU PHARE mechanism has yet to make any quantitative difference to the number of people living in institutional settings. There seem to be only a few support options for community living that exist and there is no clear evidence of choice or control for disabled people.

Czech Republic

Many disabled people are still living in institutions. National policies do not appear to be explicit or directive enough to bring about change and effective de-institutionalization. There is no evidence of the involvement of the disabled people's movement neither in policy making or service provision, nor of the existence of personal assistance or other support for independent living.

Denmark

Denmark supports the use of direct payments or personal budgets makes it possible for the disabled people to employ family members as personal assistants, if they wish.

In Denmark, there is no peer-support (support which is provided by Centres for Independent Living or ULOs).

Estonia

Disabled people receive personal assistance as a service, in terms of an allocation of hours, rather than as a budget, or a cash payment.

There is no clear data to see whether or not disabled people can employ family members as personal assistants. In Estonia it appears there are no limits on the level of resource that may be provided (up to 24 hours per day, 7 days per week).

There is a personal assistance scheme in Estonia, which is run by the state. There is very little obvious involvement of disabled people in general, and community support is not well developed. There is virtually no support for family carers, the expectation being that they will support disabled people at home.

Finland

Since 1987 Personal Assistance is inscribed in the law. In September 2009 a new law is to integrate the existing "Service and Assistance for the Disabled Act" and the "Act on Special Care for Intellectually Disabled People" into one new law.

Personal Assistance is a municipal competence. There exist many different practices according to the regional level. According to the new law a municipality can under no pretext refuse to provide a Personal Assistance service to anybody (when this person meets the legal requirements).

At the moment about 5 000 persons make use of Personal Assistance. Who eventually can and who can not receive Personal Assistance is to a great extent determined by the municipality, although there exist some general guidelines:

With the introduction of the new agreement also intellectually disabled persons will have a right to Personal Assistance. It is however still mandatory that the person concerned can to a certain extent explain what he or she wants or needs.

There is no minimum or maximum age limit. It must be well clear that you have not acquired their disability as a result of old age.

Finland is in quite an anomalous situation, as it still has institutions for people with intellectual disabilities on the one hand, yet has legislated for personal assistance on the other.

In Finland you can freely choose your assistant. But there is a general problem finding (suitable) assistants. At the moment it is not really clear whether it is possible to engage informal care providers as well. The new law on the other hand states that family members can not be personal assistants, except for certain extraordinary situations.

A social worker has to carry out an individual inquiry and assess whether the disabled person requires Personal Assistance. The new law stipulates that when it comes to your job, studies or support with daily activities, you receive the number of hours that you think you need. Concerning hobbies, for social life there exists a 10 hours limit per month which will be raised to 30 hours per month as from 2011.

The municipality pays out the wages directly to the assistant or the municipality gives money to the disabled person who in turn then pays his assistants with it.

The new law provides two more possibilities: 1. the municipality gives a voucher to the disabled person with which he or she can purchase assistance at a service / 2. the municipality organizes the assistance, through its own service or by purchasing a service, or through a contractual collaboration with other municipalities.

You can only use your budget for paying salaries, insurances, health care, paid annual leave of the Assistant, and, to a lesser extent, transportation costs. The control of your

budget expenditure is very strict. There are no prescribed minimum or maximum limits. The highest budgets can amount to 9 000 Euro per month. The average budget is approximately 2 000 Euro per month. It is possible to receive support at night: some people receive support 7 days per week and 24 hours round the clock. The payment mode, whether paid out in advance or as a reimbursement, varies according to the municipality.

France

France uses personal budgets (or a direct cash payment to the disabled person themselves, or the organisation managing the support) to fund personal assistance and supports the use of direct payments or personal budgets for disabled people to employ family members as personal assistants, if they wish.

Disabled people are entitled to self-direct either the funding system and / or the organisation of the personal assistance it pays for, if they wish, and are also eligible to tailored support to do so (Peer-support - provided by Centres for Independent Living or ULOs). In France there are still large numbers of people in institutions, but significant legislation is in place to improve quality of life for disabled people.

Direct payments in France are regulated by two laws. The so called "PHC" is a form of direct payments for disabled persons, "APA" concentrates on elderly people. PCH stands for 'la Prestation de Compensation du Handicap'.

With the PCH the needs of the disabled person shall be charted on different levels, through an individual plan, called 'plan de compensation'. The different kinds of support needed over the coming years are clearly defined:

- support by personnel, a sort of Personal Assistance,
- support equipment, permanent and anticipated expenses,
- the necessary adaptations to transport or housing,
- guide dogs, etc. ...

At the end of 2007 there were 146 000 PHC and ACTP (old system) users, which represents an increase of 5.5% in comparison to 2006. Of this group still 118 000 people are ACTP users. At the end of June 2007 some 17 700 persons benefited from a Prestation de Compensation, at the end of December 2007 there were already 28 600 of them.

There are three criteria with which a person has to comply in order to benefit from the PCH:

1. A disability criterion: The person has to experience one 'absolute' difficulty with the performance of one essential activity (i.e. the person cannot perform the activity all by himself) or experience grave difficulties with the performance of two essential activities (i.e. it is difficult for the person to perform these activities on his own). There is always a comparison with a person of the same age. The person has to have suffered from the difficulties over a period of minimum one year. Also intellectually impaired people fall into this category.

2. An age criterion: minimum 20 years and maximum 65 years old, apart from exceptions. A residence criterion: The person has to be a legal resident of France.
3. The granting rules of the special benefit are the same for the physically handicapped persons and for people with mental health problems. The applicant must have a certain level of incapacity (80%) and be 20 years old at least. The budget consists in cash benefits (monthly income), managed by local authorities.

Informal care takers can be hired as an assistant but those receive substantially lower wages than other care providers. A so called 'aide familiale' does not receive a salary but rather some sort of compensation. This form of support accounts for 69% of the remunerated hours for 'aide humaine'.

A person that has submitted an eligible request at the Maison Départementale des Personnes Handicapées (MDPH) will be contacted by a multidisciplinary team. This team will establish the 'plan de compensation'. In the plan the 'aide humaine' is expressed in hours. It is not clear to us to what extent the disabled person has a say in this process.

The personal income is not taken into account for the establishment of the 'plan de compensation' and the decision to allot. Personal income is however taken into account in one other way. Tariffs for support are at 100% if your personal income is less than 259.88 Euro per year. If your income is higher then the tariffs are at 80%.

Once the number of hours are determined you have to decide in which way you want to organize your assistance: You may be your own employer or you can outsource your role as an employer. Depending on how you want to organize your assistance you will benefit from a different tariff:

- If the disabled person personally hires someone: 11.57 Euro per hour.
- Use of the 'service mandataire': 12.73 Euro per hour.
- 'Service prestataire': 17.19 Euro per hour.
- An 'aidant familial' is remunerated at 3.36 Euro per hour.
- The limit is fixed at 837.98 Euro per month per care worker.
- If a family member has to entirely or partially put an end to his professional activities then the remuneration is 5.03 Euro per hour.

The average amount for PCH per person was 1 150 euro per month in 2007. This figure does not exclusively refer to the 'Aide humaine' but it concerns the whole of PCH. The PCH -at the end of 2007- was used by 28 600 disabled people. Again there is an age limit of 64 years. The budget amount depends on your income. In practice the budget is mainly used to pay for informal care.

Greece

In Greece, there has been some progress in developing options for community living, like supported housing and sheltered flats, for people with mental health problems or an intellectual disability; there has been little progress in this respect for people with physical impairments. Some community support exists, but it is much undeveloped.

Ireland

Disabled people receive personal assistance as a service, in terms of an allocation of hours, rather than as a budget, or a cash payment.

There is no data available to see whether or not disabled people can employ family members as personal assistants.

Disabled people are entitled to self-direct aspects of the organisation of their personal assistance, if they wish, and are also eligible to tailored peer-support from Centres for Independent Living or ULOs to do so.

Religious and charitable organisations have played a leading role in service provision in Ireland, and there are still a large proportion of disabled people who live in institutions or residential provision. Although some of the rhetoric of independent living is starting to appear in policy, there is a recognition that this is not matched by practice

Iceland

Disabled people are expected to use their benefits to fund personal assistance if they want / need it. They may apply for 'home support services and social support' and they are expected to pay some or all of the costs of this support, using their benefits or other financial means, depending on their financial circumstances.

Although Iceland has only three small institutions, community living is still institutionalised to a great extent and the concept of independent living is not fully developed or even understood despite policy exhortations.

Italy

Disabled people receive personal assistance as a service, in terms of an allocation of hours, rather than as a budget, or a cash payment. It is not clear, whether or not disabled people can employ family members as personal assistants.

Disabled people are entitled to self-direct aspects of the organisation of their personal assistance, if they wish, and are also eligible to tailored peer-support from Centres for Independent Living or ULOs to do so.

But: in Italy there is great variation between different regions, with some attempts to put the principles of independent living into action. Personal assistance seems to be accepted as an idea for disabled people with physical impairments, but not those with intellectual disabilities or with mental health needs. Where personal assistance exists it tends to be provided by associations and by municipalities, with very varied progress towards the involvement of disabled people and user control.

Latvia

In Latvia, progress towards independent community living has been very slow, in large part due to its financial crisis. The country is in the early stages of developing 'halfway houses' and group homes, but there are no specific strategies or policies around independent living in place.

Lithuania

In Lithuania, families still act as the primary source of support for disabled people, while most resources are put into institutional care. There are laws that should make independent living possible, but they are incompatible with each other and this causes

huge difficulties. On the positive side, disabled people are involved in some active NGOs which are the main instigators of change.

Netherlands

The Netherlands use personal budgets to fund personal assistance. It was estimated that the cost of financing personal budgets has risen from 1.1 billion Euro in 2006, to 1.5 billion in 2007 (Gezondheidsorg balans, 2008).

According to the Exceptional Medical Expenses Act and the Provisions Act for Disabled and Elderly People, people suffering from disability, a chronic illness, psychiatric problems or age related impairments can receive a sum of money to buy various kinds of help and support. The personal situation is taken into consideration to decide whether PGB (personal budget) is given or other assistance means (modification of the home for instance). To apply for a PGB, people must contact the Needs Assessment Body (Centrum Indicatiestelling Zorg – CIZ) of their place of residence.

As from the 1st of January 2007 the home care function of the PGB was transferred from the AWBZ (Algemene Wet en Bijzondere Ziektekosten; general law and specific medical expenses) to the WMO (Wet Maatschappelijke Ondersteuning; law concerning social support). This means that the municipalities are made responsible for the provision of home care, but also for support equipments such as wheelchairs, transportation facilities or housing adjustments. The municipalities can freely decide on the regulations to be made and the facilities to be provided.

There is no minimum nor maximum age limit. The agreement also applies to children and elderly people. All who have been indicated for treatment can opt for a PGB (personal budget). Also intellectually disabled people or people with mental problems can make use of a PGB. People can choose between care in kind or a PGB or they can combine both.

In the Netherlands, the idea of independent living seems only to apply to people with physical or sensory impairments. For these groups there are much medicalised access system (i.e. they have to have a professional assessment, and have very little power over their own assessment). If eligible, you can get a personal budget and decide how to spend it for yourself. There are a vast range of services and service providers, but people with intellectual disabilities and mental health needs mostly live in institutionalised settings. These may be houses in ordinary communities, but they are often owned and organised by service providers. On the positive side it appears that people in these homes may be able to choose to have a personal budget and choose their own support workers.

The budget must be spent on care. Seven functions of care are taken into consideration: home care, personal care, nursing, supportive guidance, active guidance and temporary accommodation. The needs assessment is not strictly confining but you will still have to justify your choice for one of these functions. Three out of four of the budget holders says they have paid for care in accordance with the needs assessment.

A care agreement has to be submitted. You may also use the budget for mediation when organizing the care. There is also a small amount which can be freely used.

The budget holder is personally responsible for the purchasing of good quality care. It's up to the budget holder to define good quality. Budget holders can pay family until the second degree and/ or persons living in the same household with the PGB.

A needs assessment is done by the Centrum Indicatiestelling Zorg (care needs assessment centre). The necessary number of hours per function is determined. There is a different kind of agreement for work and for education. This makes it all the more complicated. That is why an integrated participation budget is requested.

The amount of the contribution depends on the family income. The average personal contribution was 9 000 to 10 000 Euro in the period between 2005 and 2006.

The budget goes to the budget holder or his legal representative. You can also opt for a third party managing your budget. Administrative matters can be taken care of by the Sociale Verzekerings Bank (social insurance bank).

The Sociale Verzekeringsbank (social insurance bank) can help you with your duties as an employer. You can also completely outsource the control or mediation to a bureau.

9 out of 10 budget holders is satisfied or very satisfied with the PGB. A minus point is the administrative burden due to the complicated set of rules.

Norway

Norway has achieved almost all of the markers towards independent living outlined above. There are no institutions for disabled people. There is a well established system of support in the community, based on access to generic social services for anyone who needs them. Mostly disabled people live in their own homes with support. However, personal assistance is provided by on an hours based rather than a cash/personal budget based system. It is not clear, whether or not disabled people can employ family members as personal assistants.

In 2005 there was an important amendment of the law. Before that date the disabled person had to be able to "act as a manager with regard to his or her assistance". As a result intellectually disabled persons and children were excluded. This demand had been left out in the new law.

Approximately 3 500 persons organize their assistance by making use of personal assistants.

Personal assistance is not an individually enforceable right. On the other hand municipalities are obliged to provide Personal Assistance, next to other kinds of social services. But it is a municipal body that finally decides which service is most suitable for the person.

Personal Assistance is in principle not limited to a certain category of disabilities. It is the municipality which decides whether you're eligible for Personal Assistance. And there exist a lot of differences between the different municipalities.

Age can not be a defining criterion and as from 2005 also intellectually disabled people and disabled children can receive Personal Assistance.

Personal Assistance do not have to meet certain requirements. In exceptional cases one may hire family members as assistants, if permission to do so has been granted by the municipality.

The calculation of the budget happens on the basis of your individual support need. It goes as follows: When you need Personal Assistance, you make a request to the municipality for a certain number of hours of support and you motivate the request. In principle the support concerns all aspects of your life, although you should be able to motivate your request for a particular kind of support. If wished so people can ask for help from the cooperative society with the drafting of the request.

Eventually the municipal authority decides whether your request can be approved.

Subsequently your support need is expressed in a number of hours of support.

In Norway the employer of a Personal Assistant can be the cooperative society ULOBA, as well as the municipalities or the disabled person him or herself. Unlike Sweden there are only a few private companies on the Norwegian Personal Assistance market.

The municipality decides who the employer will be. Nevertheless this choice can have a great impact on very different levels. If you are your own employer then you can determine the organization of your support independently. But you still have to be able to account for all the expenses made with the budget. And you have to fight to be able to pay for all your expenses. The control of your budget expenditure: the money that is not used has to be refunded to the municipality.

In theory the municipalities should provide training for disabled people to learn how to manage Personal Assistance. According to users this happens too little.

Intellectually disabled persons can benefit from a special arrangement. They usually receive more assistance than physically impaired people because they need additional support.

There is not a minimum or maximum salary, one may receive support 24 hours round the clock assistance. The average number of hours of support is 36 hours per week.

Your personal income or the income of the people you are living with has no influence on your budget, although it does have an influence on your "income dependent contribution".

This personal contribution must be paid for assistance with domestic assistance, not for assistance with personal hygiene. This personal contribution is very limited and takes into account your personal income. There is, for every municipality, a fixed maximum limit to the personal contribution.

Poland

In Poland, there are few opportunities for disabled people to live independently. Some NGO's try and address these gaps, but there are no significant proposals for policies or strategies to support people to live in the community rather than in institutions.

Portugal

Disabled people receive personal assistance as a service, in terms of an allocation of hours, rather than as a budget, or a cash payment. It is not clear, whether or not disabled people can employ family members as personal assistants.

There limits on the level of resource that may be provided: personal assistance is only available for disabled employees.

Portugal is at an early stage of developing an independent living project that will include personal assistance.

Although there is an awareness of the need for autonomy and independent living, there is still a long way to go in securing this for disabled people. NGOs are said to have 'made a huge effort to promote independent living and integration in local communities'.

Romania

Disabled people receive personal assistance as a service, in terms of an allocation of hours, rather than as a budget, or a cash payment. Family members can be employed as personal assistants under this system.

Steps towards supporting disabled people to live in their own homes have yet to be taken to any great extent. There is no move to close down existing institution and support for community living is not well developed.

In Romania there are a significant number of disabled people within large residential institutions, in particular for people with intellectual disabilities.

Community services are still at an early stage of development. Essential services do not exist, especially for those people who become disabled at an adult age.

Slovakia

In Slovakia, two new policies have set out entitlements to direct payments and personal assistance. There are also measures from social services to support community based care and recent guidance aims to focus support at community/home level. But, there is still a reliance on institutional care and insufficient safeguards for people with intellectual disabilities not to be placed in residential units. There is also some evidence of retrograde developments in moves to building more institutions and investment in upgrading existing ones.

Slovakia uses personal budgets (or a direct cash payment to the disabled person themselves, or the organisation managing the support) to fund personal assistance.

The use of direct payments or personal budgets for disabled people to employ family members as personal assistants is only permitted in exceptional circumstances.

In Slovakia, there is an upper limit of 7,300 hours of personal assistance per person per year. There is no peer-support (support which is provided by Centres for Independent Living or ULOs) available.

Spain

Major policy changes in Spain have occurred in recent years. These provide choices for disabled people to live independently in their own homes and in the community. However, only some groups of disabled people (still few in number) are playing a role in promoting independent living. Services with a more inclusive approach, such as personal assistance services, are insufficient in terms of the financial support available.

At the end of 2006 the Spanish national Parliament voted a new bill called LEPA which provides for the possibility of direct payments. This bill determines the general policy with regard to persons who find themselves in a dependent position, which includes disabled persons.

LEPA makes it possible for people who fall into the highest category of dependency (also elderly people) to receive a financial compensation for the hiring of assistants. Those assistants have to be able to give assistance with respect to everyday activities with which the disabled person has difficulties. The assistants should also improve the access of the disabled persons to education and work.

The greatest responsibility however lies with the regions. They will have to be able to offer the possibility of direct payments in the future. There are all sorts of experiments going on everywhere in Spain.

At first sight this is a first step into the right direction. There are, however, some obstacles:

- There is no mention of support during leisure time and in social life
- It merely concerns severely impaired persons
- Users have to pay a part of the expenses by themselves, depending on their income
- The maximum support is fixed at approximately 800 euro per month.

Much will depend on the efforts of the different regions and whether this will be a long term process or not. Most probably also here there will occur regional differences with regard to the direct payments policy.

Sweden

Sweden supports the use of direct payments or personal budgets for disabled people to employ family members as personal assistants, if they wish. Disabled people are entitled to self-direct either the funding system and / or the organisation of the personal assistance it pays for, if they wish, and are also eligible to tailored support to do so (Peer-support - provided by Centres for Independent Living or ULOs).

The data from Sweden shows an increase in overall spending on housing adaptations but the cost per grant has slightly decreased. Alongside evidence that the cost of

personal assistance is less than that of local government's home help services, it would suggest that this form of support has some benefits in terms of cost in Sweden.

Sweden stands out in its progress towards enabling disabled people to be fully included in the communities of their choice and its independent living movement is internationally renowned. There are no institutions in Denmark and the vast majority of all disabled people live independently in the community, supported via individual budgets. Legislation supports the right to live in the community, a right which can only be denied if people are deemed dangerous to themselves or to others. Only a small proportion of disabled people live in 'residences', though this number may be increasing as fewer independent options appear to be available, particularly for people with intellectual disabilities. Residences, in the form of sheltered housing schemes, appear also to be growing larger and more 'institutional' in form. This is a worrying trend.

Sweden is a pioneer in the field of direct payments. Already in 1987 there were experiments with Personal Assistance taking place. The actual legislation dates back to 1994 and regulates Personal Assistance through two laws.

On the one hand there is the so called LSS («Lag om Stöd och Service till vissa funktionshindrade »). LSS regulates some ten services for disabled persons on the municipal level. One of these services is Personal Assistance for people who need less than 20 hours of assistance per week for basic needs. Municipalities can opt to either supply services in kind or give direct payments to the individual for the purchase of services.

On the other hand there is the law LASS (« Lag om assistansersättning ») that applies to persons who need more than 20 hours of personal assistance a week for basic needs. Under LASS recipients get direct payments from the national social security system (« försäkringskassa »).

For the moment there are some 19 000 persons who receive Personal Assistance. 15 000 of those are LASS users and 4000 are LSS users.

Disabled people, including persons with cognitive or psychiatric disabilities, are eligible for personal assistance regardless of diagnosis. Personal Assistance is a legal entitlement.

There is no minimum age limit, only a maximum age limit. Persons that have not applied for Personal Assistance before the age of 65 can afterwards no longer benefit from it. Those who were entitled before their 65th birthday continue to be so also after that date.

Entitlement to LASS is based on a need for personal assistance of more than 20 hours per week, as assessed by Försäkringskassa, for such basic activities of daily living as getting dressed, personal hygiene, toileting, taking meals and communicating (in the case of non-verbal persons). Persons who meet the criteria for 20 hrs/week of assistance for these basic needs are also eligible to receive an additional number of hrs for other activities such as assistance with household, shopping, cleaning, preparing meals, practical assistance with raising small children, at work and study, leisure time, on travel within and outside the country.

Recipients of direct payments for personal assistance are free to purchase services from any service provider - the municipality, a private for-profit company, a personal assistance user cooperative - or employ their assistants. Most service providers allow the customer to freely choose their personal assistants, decide where, when and with what they are to work. You may hire family members as personal assistant on the condition that you are not the employer.

A shortage of assistants does not exist in principle, although it is mentioned that the municipalities, that also provides assistance, sometimes has a hard time finding personal assistants. This is due to the fact that the wages are not too high.

In principle it works as follows: the municipality has to examine your need for assistance or support and express those needs into a number of hours of support per week. This happens upon a home call. If the municipality estimates that you need more than 20 hours of assistance per week, than you are referred to the 'försäkringskassan'. You can also make an application for support yourself.

If you need less than 20 hours of support per week you will fall under LSS, that is: the municipal authority. The further practical organization of your assistance (by means of a budget or by means of service) depends on the municipality. The municipality pays for the assistance.

Once your number of hours to which you are entitled have been established, these numbers are multiplied with a flat rate per hour (for 2009 about 25 Euro and annually adjusted by the government to reflect inflation). The result of which is the amount of the budget you will receive.

There is no minimum or maximum budget. At the moment the average number of hours for LASS users is more than 100 hours per week. In 2005 the annual average budget of LASS users was approximately 90 000 Euro. Your budget amount is recalculated every two years.

With the budget that you receive you pay wages, social security benefits, administration, training of assistants and expenses, etc.. You are free to determine how you spend and manage the budget.

You can choose whether you want to become employer or whether you want to outsource that to the municipality, a cooperative society or a private organization.

In principle you have the control over your assistance: you decide who works for you, when and where. It is mentioned that you have more control when you are your own employer or when you buy your services from private organizations or cooperative societies than from the municipality. Recipients have to account for the use of the direct payments, after each 6 month period, either by showing receipts of payment for the purchase of services from service providers or, when employing one's assistants directly, by giving proof of all expenses. Amounts left after the 6 month period have to be resubmitted.

The size of recipients' budgets depends solely on their need of personal assistance and not on their or their families' or household members' income or property. The budget is not considered as taxable income and does not affect one's eligibility of other benefits.

See also: Direct payments in Sweden, October 2009,

<http://www.independentliving.be/upload/EOL/Publicaties/Engels/def%20artikel%20Zweden%20Eng%20def.pdf>

United Kingdom

The United Kingdom supports the use of direct payments or personal budgets for disabled people to employ family members as personal assistants, if they wish. In theory there are no limits to the amounts of funding, but in practice funding and amounts of personal assistance that people are entitled to, are linked to the resource that is available from state agencies or local authorities and their thresholds for setting eligibility criteria.

There has been significant movement towards policy support for independent living in recent years. The policy framework in the United Kingdom provides a range of support to allow the majority of disabled people choices to live in the community, although there are concerns about the denial of choices to some.

The policy framework in the United Kingdom provides a range of support to allow the majority of disabled people choices to live in the community rather than in institutions. In terms of national strategy, Improving the Life Chances of Disabled People (PMSU 2005) provided a 20 year vision for the inclusion of disabled people by 2025. The 2008 Independent Living Strategy is then a key reference point (based on a major review in 2006).

As part of social care reforms, the government document Putting People First moved towards the 'personalisation' of support - including commitments towards greater individual choice and control (<http://www.dh.gov.uk/en/SocialCare/Socialcarereform/Personalisation/index.htm>).

Some of the key elements (of relevance to this report) include: a greater emphasis on self-assessment of need; person-centered planning and self-directed support; increasing the numbers of people using Direct Payments; and, 'personal budgets for everyone eligible for publicly funded adult social care so that there is a clear, upfront allocation of funding to enable people to make informed choices about how best to meet their needs'.

In the United Kingdom, eligibility to direct payment and individual budgets (to pay for personal assistance) is based on individual assessment, but this is underpinned by set thresholds for eligibility, which can change in response to what level of resource is available.

Local authorities also have a duty to set thresholds for eligibility: to determine the level at which they can afford to meet needs. They do not have to meet needs which are below the threshold ('unmet need') but generally they do have to meet those that are above the threshold. The threshold may be moved according to the level of resources, and people who have been eligible may become ineligible if resources become tighter, as has been the case in the United Kingdom in recent years. Therefore there are no absolute categories for eligibility to services.

The national government policy focuses on an enlargement of this system within the general framework of the individualised care or 'putting people first' policy. It claims to make disabled people the co producers of the welfare policy.

In England it has been the 2001 Health and Social Care Act which made it possible for local authorities to grant budgets to those who could make an appeal to social care and were able to finance that social care with a personal budget.

As from April 2003 every local authority is obliged to grant a budget to people in need of care – if wanted by the latter – instead of direct care. Whoever applies for social care will be asked whether they want it through direct payments or in kind. However, they must meet the eligibility criteria of their local authority and cash must be available in the authority budget.

Due to the fact that that local authorities (counties) play an important role there are differences on the level of execution. Different factors are at play there. The authority's political colour as well as the pressure exercised by the disabled persons movement are determining factors. Especially conservative authorities are convinced by the cost-effectiveness argument. Labour authorities on the other hand dislike the talk about market forces and privatisations. Support of budgetholders by disabled people themselves or organizations of disabled people (peer support), has been noted as a success factor in the organization of direct payments.

Disabled people can be budget holder as from the age of 16. Parents that are responsible for their disabled child can also apply for a budget. Also caretakers working for disabled people can make use of a budget to support themselves, e.g. with regard to tasks like domestic chores or training. Also elderly people (since 2 000), intellectually disabled people, people with mental health needs, people who are revalidating, people in a rehabilitation process (for a short period of time that is) and people with a sensory disability can make an appeal to the direct payments.

Physically disabled people and people with a sensory disability constitute the largest group on average. The smallest group is the group of people with mental health needs. They are often not considered suitable. Nowadays 19 000 people make use of Direct Payments.

The settlement also applies to those with learning disabilities. But in that case it is the parents that manage the budget because they are still responsible for their child or the money is managed by a third party. The last years the possibilities to support people with their budget management have increased. People can also make an appeal to a 'circle of friends' for their budget management. That is a network of family members or other people closely related to the budget holder.

One can use the money for home care: cleaning, doing the shopping, social services or personal assistance with eating, going to the toilet, personal hygiene, Medical care and nursing are not covered by this arrangement. The local authority decrees what one can and cannot do with the budget. A care plan is established for each individual person. Direct Payments are essentially meant for people living at home and consequently not for residential facilities, except for a short period of time. When working with a care supplier it is much recommended that you work with a care supplier

with which local authority is already collaborating. There is the possibility to apply to an alternative care supplier but it is not always appreciated.

The government does not eagerly pay for informal care. You can not hire your partner or the person you are living together with. Apart from that one can engage whomever one wants to engage. The government does not set out any criteria or conditions with regard to qualifications of personal assistants. A standard 'criminality check' however may take place. The government advises the employer to screen the future employee for a possible police record. Many disabled people engage someone they know.

In some areas it is difficult to find suitable personnel, but not everywhere. It may prove to be more difficult in rural areas or areas with an older population. Another factor is the presence of major employers in the region. The jobs are not always that attractive due to the limited number of working hours or the short evening visits. Almost a third of the English local authorities points to the availability of personnel wanting to work as a personal assistant as the key factor of success, whilst a quarter thinks it is an important factor.

The social worker of the local authority carries out an assessment. This assessment determines the budget amount and what social services one may make use of. The budget is set in accordance with the number of hours of support that you are entitled to. There are different categories, varying from 0 to 31+ hours of support per week. The support needs are assessed on a broad level, but eventually it is only the support one would be receiving from the local authority's social services that is taken into account. The personal contribution is calculated over the household's total income. People owning less than 12 750 pounds in assets do not have to pay in principle. People owning between 12 750 and 21 000 pounds in assets have to pay a personal contribution for the care costs and those owning more than 21 000 pounds in assets have to pay for the care costs all by themselves until their assets have diminished to 21 000 pounds (2006 numbers). The house's value is not taken into account for the calculation of the asset's worth.

The amount is deposited in cash money on an account. The payment mode depends on the local authority. The budget can only be used for the support for which one has been assessed. One has to declare beforehand what the budget will be used for and exceptions have to be justified.

The budgets differ according to the local authority. They work with different tariffs. Some local authorities also provide a starters budget, for example to pay for an advertisement. The payment is done in advance and in variable sums. The payment is deposited in a separate account and a report about the incoming money and outgoing expenses should be submitted. As a justification the agreements with the care providers should be presented.

List of references and useful Links

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