

EXPERTISE CENTRE
independent living

Direct payments systems in support of persons with disabilities in Europe

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1. What is it all about?

Within a system of direct payments public means are granted to persons in the form of individual budgets.

Systems of direct payments may be used within the framework of various types of support. Today we will be talking about the support of disabled persons, regardless whether they be young or old, woman or man, and regardless of the nature (physical, psychiatric, sensorial or mental) of their disabilities. Moreover we will limit ourselves to direct payments for the support by means of assistance.

Direct payment systems for the support of disabled persons are based on the fundamental principles of solidarity, justice, efficiency and accountability.

Solidarity

In a civilized society we have to acknowledge the fact that the risk of becoming dependent on someone else's assistance is not something that the disabled person himself or his or her close relatives can take upon themselves alone. Each and every one of us runs the risk to be confronted sooner or later with his own disabilities or those of his close relatives. It is thus out of a well-considered self-interest that society agrees to allot a certain share of the public means to the support of disabled persons.

Justice

These collective means then must be redistributed according to the assistance needs of each individual disabled person and not with regard to random criteria such as the type of facility of which he or she makes use, or the disabled person's personal income or the income of his family members.

Efficiency

The use of these collective means must also be controlled by the user, given the fact that he or she is the best placed person to determine how those means can be used for his or her support.

Accountability

The budget holder has to account for his budget expenditure. This is the inevitable reverse side of the freedom to choose.

For a more elaborate description of the standards of direct payment schemes, we refer to Ratzka, Adolf (ed.). 2004-10. "Model National Personal Assistance Policy." A project of the European Center for Excellence in Personal Assistance (ECEPA). www.independentliving.org

2. Research results

Obviously no existing system of direct payments is perfect, but we have surely observed a strong increase of systems for the support of disabled persons that try to combine these fundamental principles of solidarity, justice, efficiency and accountability.

With the Expertise Centre Independent Living, which was launched in February this year, we have given an overview of the existing systems of direct payments which comply with the above mentioned criteria in eight European countries. I would like to present the results of this research in the form of two tables.

In table 1 we take a closer look at the admission criteria for the system of direct payments for personal assistance, how many persons make use of those in each country and whether people are legally entitled to be supported for their assistance needs in the form of an individual budget.

In table 2 we focus on the amount of the personal budgets granted and on what the budget holders can use those budgets for.

2.1. Who can claim direct payments for one's assistance needs?

As you can see the Netherlands and England are the countries with the highest number of budget holders. In those two countries, already since 2001, people have been able to choose between care in kind and the payment of a budget with regard to various forms of assistance.

Still we have to put these figures into perspective. For both countries elderly people who only ask for domestic help are also included in these high numbers. In addition the Netherlands grant many personal budgets to people with psychiatric disabilities.

According to a report of the British National Health service the expenditures for direct payments for adults have risen by 28% in 2007/2008 in comparison with the previous year and yet they only accounted for a mere 2% of the total cost of social care in England. In the Netherlands as well, 90% of assistance to disabled persons still consists of care in kind.

Also the Scandinavian countries have a relatively high number of budget holders (taken into account their smaller populations), and especially Sweden. In Sweden there has been reported a decline of admissions into residential facilities as a result of the granting of individual budgets, first among young disabled people and more recently also among adult disabled persons.

Even though in Sweden and more recently in Finland the right to assistance through a personal budget has been made legally enforceable, the criteria for eligibility in those countries are often more selective: Sweden excludes disabled people who have acquired their disability after the age of 65. Norway as well as Finland count but a few intellectually disabled persons amongst their budget holders. Since 2005 Norwegian legislation has dropped the legal obligation to act as manager for one's own assistance, and as from this year new Finnish legislation provides new possibilities to purchase assistance via organizations that may tender for a contract with local authorities which then offers a wider range of opportunities for people with learning disabilities.

In December 2007 already 28 600 people in France switched to the new system of "Plan de compensation du handicap", which also provides the possibility of personal assistance. About 88% of people receiving PCH, make an appeal to the so called 'Aide Humaine', a form of personal assistance. Most of this 'aide humaine' however is carried out by informal caretakers.

The number of budget holders in Germany is expected to rise steeply, especially since January 2008 and after some successful experiments the choice for a Persönliches Budget has been laid down in Book IX of

the German 'Sozial Gesetzbuch'. This budget is granted to disabled people who need assistance of different bodies for rehabilitation, support with living, support with working, etc.

Other European countries have launched experiments with smaller numbers of budget holders. In our report we have already highlighted Spain as an example. Also the two-weekly ENIL newsletter has brought us this year some exciting news about starting budget holders and campaigns in favor of the introduction of personal assistance schemes in Serbia, Latvia and other countries.

2.2. How can budget holders make use of their individual budget?

The essence of the debate concerning direct payments is not so much about quantity as it is about quality. Do budget holders have a real alternative for institutionalized care?

It is rather common that obstacles are laid down for a really honest choice between on the one hand the care in kind and on the other hand the assistance in the form of direct payments: in the Netherlands e.g. persons receive a budget which is only 75% of what he or she would be receiving in the form of care in kind; in France the budget amount is to a great extent determined on the basis of the form of assistance for which a person has opted in the "Plan de Compensation" (going from 3.36 euro per hour for a family member to 17.90 euro for an external service), etc.

The decisive criteria that make direct payments a real alternative to institutional care however are the amount of the budget and the degree of self determination to use the budget.

Are the budgets sufficiently high to offer people with extensive disabilities the possibility to organize their own assistance?

This most certainly is the case in the Scandinavian countries, but also in the Netherlands. Amongst the Dutch budget holders there are many elderly people who only receive a budget for domestic help, which accounts for the fact that the average amount of the yearly budget looks rather small. More important still is the fact that the maximum budget, when needing assistance on several levels (nursing, housekeeping, daily activities, etc.), rises above 75 000 euro per year.

In Germany 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, we have remarked that local authorities have different practices, so that we do not dispose of any exact figures.

As a result of the very low individual budgets in France and Spain persons with extensive disabilities have to rely upon informal care when they do not opt for institutionalized care.

The fact that the determination of the budget in England is strongly dependent on the income of the budget holder is problematic because it strongly discourages the employment of disabled persons. In the Netherlands and Norway the personal contributions for the budget holder's assistance costs are less problematic since these are only required for the assistance with domestic activities and are being limited to a maximum.

To what extent can the budget holder personally control his or her assistance?

The efficiency of a system of direct payments is largely determined by the budget holder's expenditure freedom. In table 2 we can see that budget holders in most countries can act as employers of their assistants or work with a cooperative society to this end, and they may as well purchase assistance at care providers. In most cases these services are provided by municipal bodies or other nonprofit organizations, but in Sweden, the Netherlands and England also commercial enterprises have an important role to play in the assistance of budget holders.

In Norway the municipal services grant the budget and the same service also decides whether one may be one's own employer or with whom one should purchase the assistance. This rather arbitrary restriction of the budget holder's expenditure freedom will probably be undone by a new bill. In Finland the new legislation has extended the expenditure possibilities to include vouchers which the budget holders may use for services which are no longer being provided exclusively by the municipal social services.

We do recognize an almost general tendency towards offering sufficient alternatives to guarantee the freedom of choice of an assistance provider. On the other hand there exists a lot of ambiguity about the possibility to pay for family members with the budget. In the Netherlands this is fully admitted, in Sweden as well in practice, albeit through an intermediary organization which acts as employer for the family member. In England this is rarely allowed by the local authorities who grant the budgets. As long as the new law has not been adopted, this also is the case in Norway. The new Finnish bill on the other hand has restricted the arbitrary practices of the local authorities and has determined the exact conditions with which budget holders have to comply before they can pay family members with their budget.

More results?

For the full report, we refer to J. Van Hauwermeiren en E.Decruynaere, "Direct payments in the care. current situation in 8 European countries", www-en.onafhankelikleven.be, February 2009.

3. Some conclusions and challenges for the future

These were just some of the results of a pioneer study which has been carried out by the Flemish Expertise Centre on Independent Living and which will be followed up by a more thorough analysis of the systems of direct payments in the Netherlands and Sweden, as these countries often serve as models for Flanders. But we also want to keep an eye on the new developments in other European countries. We have a network of experts in direct payments who keep us posted and which allows us to publish new information sheets on our website. The tendency towards more self control of disabled people on their own assistance is unmistakably present throughout Europe.

A first and very important challenge is to provide a solid legal basis to the freedom of choice with regard to personal assistance as an alternative to collectively organized assistance. Already more than 2 000 persons from all European countries have signed the PA Law Campaign petition on the ENIL website. This petition calls for the implementation in national legislation of art. 19 of the United Nations Convention on the Rights of People with Disabilities. This petition will be submitted to the European Parliament in Strasbourg by our friends of the "Freedom Drive".

Along with this political struggle we – the Expertise Centre – want to carry on studying and learning lessons from what has already been realized or is in full development in Europe. Today is a great occasion for me to express our thanks to the experts all over Europe who filled out our questionnaire and continue to feed us with news on the ongoing struggle in their countries for self-determination. Direct payments turn out to be the tool par excellence for persons with a great need of assistance to be able to live an independent life with the same chances to lead a qualitative life as their peer group members of the same age who have no disability. They guarantee the user that he may appeal to reliable and qualitative assistance when it comes to his or her vital needs and that he or she may purchase this assistance on a diverse market.

Table 1: for whom?	Target group	Number of budget holders	Enforceable right?
1. Germany P.B.	Everyone who needs assistance. Many persons with psychiatric disabilities.	3.500 (June 2008)	Yes. German Social Lawbook, Book IX § 17. Since 1 January 2008
2. The Netherlands P.G.B.	Also elderly people and children. Also psychiatric disabilities.	106.000 (October 2008)	Freedom of choice, when a budget only 75% of the cost price of a collective service
3. France PCH	65 year = Age limit, (also a DF agreement for the elderly)	28.600 (Dec. 2007, strongly increasing)	?
4. Spain LEPA	Only for extensive assistance need. Also elderly.	60 in Bask region, 9 in Barcelona and 35 in Madrid	
5. Sweden LASS	LSS for assistance need < 20h./ week LASS for assistance need > 20h/ week. Not for handicaps which occurred after 65 year	LASS:16.000	Yes
6. England DP	All those eligible for "social care". Supplements for severely disabled people (> 15 and <65 year) via ILF	67.000 + 20.000 children ILF: 15.290 (2007)	Right to freedom of choice (cash or care) since 2001
7. Norway	Few people with an intellectual disability (only as from 2005)	3.500	No (municipality decides whether PMH is able to 'manage' his or her budget), unless when recent bill?
8. Finland PAS	Serious disabilities. Up until today few people with intellectual disabilities	5.000	Yes. New bill. Previously just optional for municipalities

Table 2 For what?	Average budget	Maximum budget	Personal contribution	Spending possibilities
1. Germany PB	No figures Combination budget	Determined with regard to assistance plan		Purchasing or act as one's own employer. Various possible combinations. Cash, vouchers for nursing care
2. The Netherlands PGB	14 486 euro (2007)	Combinations Exceptionally > 70 000 euro	Yes (for domestic help, not for accompaniment)	Cash: Purchasing or act as one's own employer. Combinations are possible. Also family members
3. France PCH	13.800 euro (also auxiliary tools)	MDT draws up "Plan de compensation" with number of hours of "aide humaine"	Yes	Mainly informal care
4. Spain LEPA		9 600 euro	Yes	Experiments rather along the same lines as Scandinavian cooperative societies
5. Sweden LASS	90 000 euro (2005)	Necessary hours x 25€ per hour	No	Cash: Purchasing (at the municipality, profit or nonprofit) or act as one's own employer. Combinations are possible. Also family members, through an intermediary
6. England DP		44 181 euro (ILF)	Yes (very definite)	Varies strongly according to the municipality (in general no family members are allowed)
7. Norway	36 hour /week	No exact figures, but very high(up until 24 hours assistance per day)	Limited personal contribution for domestic help	Own employer, cooperative society ULOBA or municipality, but local authority decides. Exceptionally family members (on condition that there is a an agreement with the local authority)
8. Finland PAS	24 000 euro	108 000 euro		Cash or payment by the municipality Family members: under certain conditions