



Direct payments in the care.

Current situation in 8 European countries

February 2009

**Juliska Van Hauwermeiren
Elke Decruynaere**

Expert Centre Independent Living

Kerkstraat 108 - 9050 Gentbrugge
TEL 09 324 38 77 - FAX 09 324 38 79

info@independentliving.be
www.independentliving.be



Index

1. Introduction.....	p.3
2. The Netherlands.....	p.5
3. England.....	p.8
4. Sweden	p.13
5. Germany.....	p.16
6. France.....	p.20
7. Finland.....	p.22
8. Norway.....	p.26
9. Spain.....	p.29
10. Summary	p.32
11. Conclusion.....	p.34
12. Sources.....	p.36

Introduction

Under construction. That would be an appropriate subtitle to the article. Not only to this article but also to the subject we are writing about. Because, as it happens, in all of the countries that we have taken a closer look at people are very busy experimenting with forms of direct payments.

By direct payments we mean that the disabled person be granted a budget which is not considered an income and with which assistance can be paid for.

By the granting of a budget we mean that the beneficiary can dispose of financial means which are granted by the state or social security and which are destined for a determined objective.

Are as a consequence not considered "direct payments" of support needs of disabled persons: allowances of which the disabled person can freely dispose, refunds of (para)medical costs, tax reductions, etc. ...

Are considered "direct payments" of support needs of disabled persons: budgets granted to the disabled person (or the legal representative) to pay for support needs specific to a certain disability (assistance, support equipment, professional advice etc. ...).

Whereas in Spain and Germany we are talking about rather small-scale experiments, in the Netherlands already more than 100 000 people make use of their own personal budget for care. After 13 years of experimenting the policy makers have now committed themselves to giving the personal budget a legal basis.

Also in Belgium (Flanders) people are busy experimenting. In September 2008 Flanders launched the personal budget experiment. The 180 or so participants have almost completed the preliminary phase. Soon they will be granted with their budgets and they will be able to get to work with them.

This makes people think that in Flanders we fall behind. But in other countries the evolution of the Personal Assistance Budget is observed with much attention. 1533 budget holders independently employ their assistants through the PAB. It is our goal to carefully study this practice in the future because we have noticed that this is not been done all too often today.

And so we can say that this article, just like our inquiry, is not yet complete. It's still under construction. It is our goal to be able to point out on the map of Europe in what countries forms of direct payments have been developed and to give a general description of how these countries have modelled them.

This inquiry describes the frameworks of working with direct payments in the Netherlands, England, Sweden, Norway, Spain, France, Germany and Finland. We have based our inquiry on official documents as well as on investigation reports and interviews with local experts. This has enabled us to gather a lot of information in a short period of time. But lots of questions remain and we were tempted to go deeper into specific matters or to describe a more general context like e.g. the social security system of a country. This however was not the purpose of this article

Per country we will outline how many people are concerned, what budgets are worked with, what the possibilities are and also what is the ongoing political and public debate surrounding the subject. We will conclude this article by emphasizing some recurrent main characteristics and some remarkable highlights. We hope to inspire you and pique your curiosity for further inquiry. Because that eventually is the ultimate goal of the Expert Centre Independent Living:

"To become the expert centre par excellence concerning direct payments. The goal is the empowerment of disabled people so that we may lead an independent life."

THE NETHERLANDS

1. General.

On the 1st of January 1996 the Netherlands introduced the PGB (personal budget). In 2006 there were already 100 000 budget holders, representing a total budget amount of more than a billion euro, with 1500 people a month joining the PGB system. In October 2008 **106 000** people made use of the PGB.

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.

In terms of percentage the share of budget holders within the AWBZ was in 2006 3 times the share of the budget going to PGB. 15% of the people in need of care within the AWBZ made use of a PGB but all together these PGBs only accounted for 4% of the AWZB macro budget. The PGB growth keeps pace with the growth of the total care budget.

In the 2005-2007 period 93.4% of the people that had been assessed by the Centrum Indicatiestelling Zorg (care needs assessment centre) chose for for Zorg in Natura (care in kind). On the 1st of January 2008 this amounted to 91%. 6.8% chose a PGB and 2.2% wanted to combine a PGB with care in kind. The demand for a PGB rose by 35% between 2005 and 2007. The total amount of positive decisions concerning the indications for treatment rose by 11% per year in the aforementioned period. Especially people under 65 years opted for a PGB

A researcher points out that it seems as if the PGB was being kept small. Up until now the use of PGB has been restrained by the macro budget which has had an inhibiting effect on the demand for PGB. The request to put aside 10% of the AWBZ budget for the PGB was not met.

2. Target group and possibilities.

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. Even if it only concerns a period of 3 years. 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.

The budget must be spent on care. 7 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. But not

for mediation upon the application for care or upon the justification or management of the care. There is also a small amount which can be freely used.

With WMO this amounts to 250 euro a year. It used to be a percentage but because of budget cuts this rule has been adapted. With AWBZ, since 2008, this amounts to 1.5% of the available net budget per year, with a minimum of 250 euro and a maximum of 1250 euro a year.

The budget holder is personally responsible for the purchasing of good quality care. It's up to the budget holder to define good quality. This means that there are no terms and conditions imposed upon the assistants or the services where care is purchased.

Budget holders can pay family until the second degree and/ or persons living in the same household with the PGB. 21% of the budget holders only purchases care at informal care suppliers. 43% of the budget holders buys its care at informal care suppliers as well as at regular care suppliers. 36% exclusively purchases care at (health)care institutions.

As from 1st of January 2008 the blind and hearing impaired can also obtain a PGB which is limited to the usage of support equipments.

3. Budget setting and budget amount.

A needs assessment is done by the Centrum Indicatiestelling Zorg (care needs assessment centre). For youths this is done by the Bureau Jeugdzorg (youth care bureau). 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.

For certain functions and target groups there exists a **personal contribution**, with WMO as with AWBZ. For care, support, and guidance for kids and youths aged less than 18 years old there exists no personal contribution. Neither is there a personal contribution for adults with regard to temporary accommodation and guidance. 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 personal contribution is deducted from the granted budget; people do not receive a bill for it. The usual care by family members and partner and all care that one can usually get elsewhere is taken into account upon the assessment of needs.

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). 8% of the budget holders uses a third party or the SVB for support by the administration or managing of the budget. The budget is cash money which is deposited on your bank account. The allotted budget is paid in advance. The payments take place depending on the total amount of the budget (from once a year to once a month). In 2007 the terms of payment were as follows: PGB of maximum 2500 euro per year: all at once; PGB between 2 500 and 5 000 euro per year: every half year; PGB between 5 000 and 25 000 euro per year: every quarter of a year; PGB of more than 25 000 euro per year: every month. Before they worked with vouchers but because of practical reasons they have been abandoned.

In 2004 the average yearly PGB was 9 712 euro and in 2006 it was 11 540. those receiving a budget for the first time have a lower budget in comparison to the whole group of budget holders. The average budget in 2007 was **14 486** euro. The price of the PGB had been calculated by taking 75% of the price for care in kind. The thing is, however, that this 75% no

longer corresponds to reality because the PGB budgets are merely indexed for price inflation.

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. Only 10% of the budget holders makes an appeal to such a care mediation bureau. There are also two budget holders associations, named Per Saldo and Naar Keuze. The latter focuses on the target group of parents with intellectually disabled people. Per Saldo is the largest of the two associations. They look after the interests of the budget holders, they have a very often used helpdesk and last but not least they organize education and trainings for budget holders. The CG-Raad (Chronisch Zieken en Gehandicapten-Raad; council for the chronically ill and disabled persons) is the federation of client organizations of disabled persons in general.

The PGB is monitored and analyzed by order of the government. A large inquiry for the evaluation of the PGB new style of the period between 2005 and 2006 was carried out in 2007. In 2008 a follow-up (about the 2007 period) was published.

4. Public and political debate.

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.

The last years the AWBZ budget has risen in conjunction with the share of PGB. Inquiries, however, have shown that the rise of the total budget is not merely attributable to the PGB. One of the causes were e.g. the waiting lists for youth mental health care. The total number of care demands from children with a psychiatric ailment turned out to have gone up strongly. To be able to control the total budget some cuts were made as from the 1st of January 2009 aiming at the reduction of improper use and the clarification of claims as well as stopping the increase of the budget by slowing down in the target group and the kind of support for which one can use the budget.

In the beginning of 2009 a case of fraud showed up in the news. Police investigations revealed the malpractices of some care bureaus. This resulted in a policy recommendation to deal more carefully with the needs (re-)assessment. There was also made a plea in favour of a clearer distinction between different roles. Criticism has been expressed on the fact that some of the bureaus offer care while at the same time managing the budget holder's PGB. They actually pay themselves. As from the 1st of January 2009 the budget holder - or his legal representative - is obliged to sign the justification form for the expenditure of the budget in order to avoid this kind of practices. Prices also need to be in line with the market price and mediation costs upon a budget application can no longer be taken into account. In addition to that a quality mark is created. An inquiry will start in 2009 to bring the PGB onto the same level as the care in kind.

ENGLAND

1. General

There is a national policy framework for direct payments. The execution of which lies within the hands of the local government. Next to that there is also the Independent Living Fund for seriously disabled persons. In 2008 there were already some pilot projects with Individual Budgets which integrated different kinds of budgets.

Direct Payments are budgets granted by local government to disabled people and other people making use of social services. With these budgets they realize their personal support by employing e.g. their own personal assistants or by purchasing 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. There were already different kinds of projects running where disabled people initiated demands for payments instead of institutionalisation (a very well known project was the one in Hampshire-project '81) but since 1997 there is a policy agreement through the 'Community Care (Direct Payments) act'. 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. Whomever 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.

In 2006 the white paper 'Our Health, Our Care, Our Say' was published, which included a commitment to extend the principle of individual budgets to disabled people by making use of different kinds of funding. Direct payments do not only exist in England: they exist in the whole of the UK. 90 % of the direct payments in the UK occurred in England, hence our focus. 6% in Scotland, 2% in Wales and 1% in Northern Ireland. In the 2007-2008 period 67 000 adults and elderly people made use of direct payments. And to that number we may still add the approximately 20 000 people who used the direct payments for the care of disabled children. The last two years the number has doubled. The total of the government's budget for social care was 20.7 billion euro in the 2007-2008 period. More than 1.4 million people make use of social care in England. 452 million euro was spent on direct payments in the 2007-2008 period. In comparison to the 2006-2007 period this was a 28% increase and five times as much as in the 2003-2004 period. But within the framework of the total budget for adults the direct payments account for a mere 2%.

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.

Individual Budgets: in 13 regions there was an experiment with individual budgets. These budgets are more substantial than the direct payments. Direct payments consist of a budget in cash for social care instead of the services in kind. The individual budgets, however, cover for more than the individual social care, as for example access to work, health care and money from the Independent Living Fund. The individual budgets can also consist of a combination of a budget in cash and services in kind. One of the explicit goals was to have more flexibility to set priorities with regard to the use of the budgets on an individual level. The target groups were people making use of the mental health services, physically disabled persons, those with learning difficulties and elderly people. The average cost was 280 pounds a week (15 234 euro/year) against 300 pounds (16 322 euro/ year) for people making use of care as usual.

The conclusions of this experiment were published in October 2008. Users were satisfied because they had gained more control over their lives. There were some differences between the target groups. The budgets were mainly used for personal care, help with house chores, social and educational activities during leisure time; people felt as if they had more control over their daily lives as compared to before. People with learning difficulties or physically disabled people were most satisfied, elderly people were least satisfied. There was not that much difference in price between the common care and the individual budgets, but there was a difference with relation to the target group. The integration of the budgets did not work out as according to plan. The experiment also sparked the debate about the reassignment of budgets and how and for which purpose public means can be spent.

Independent Living Fund: if you need more than 31 hours of support a week or if your budget is over 16 640 pounds a year (18 861 euro) or 320 pounds (363 euro) a week, then you can appeal to the Independent Living Fund on top of the Direct Payments. You have to be aged between 16 and 65 years old, live in the community for more than 6 months and own assets worth less than 22 250 pounds (your partner's assets and the house you're living in excluded). The fund can pay 455 pounds a week on top of the input of the social services and the assessed contribution (this does not concern the 785 pounds a week). Half of the DLA and Severe Disability benefit (tax free benefits from the government for persons that need care) have to be paid to the ILF. As from the beginning of April 2008 priorities were set because of budgetary reasons. The maximum amount is 785 pounds per week. In 2007 there were 15 290 persons or 3.1 budget holders per 10 000 inhabitants benefiting from this system in England. The money is destined only for people perceived as severely impaired and can be spent exclusively on personal assistance as well as on services, but this does not apply to people living in a residential setting.

This fund is being considered a compensation for the local authority to support people living at home but for whom the cost might exceed the cost of the residential care due to the gravity of the disability.

The Independent Living movement has not always been as enthusiastic about the fact that Direct Payments and the Independent Living Fund exist independently of each other because this means that people have to be assessed twice. But now they perceive the fund as a guarantee for sufficiently high budgets for people that have major support needs.

2. Target Group and possibilities 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. 12% would never grant such a request, 65% would in principle give access to an alternative care supplier if asked.

The government does not eagerly pay for informal care. You can not hire your partner or the person you are living together with. Except when granted an exception by the municipality. 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 succes, whilst a quarter thinks it is an important factor.

With the budget one can also purchase support equipment or technical support. This option became available in the previous years.

29% of disabled people receives the equivalent of 31 hours of support per week, 3 out of 4 receive the maximum care package according to the definition of the Department of Health (DH) (more than 10 hours per week). The used categories are: 0-5 hrs., 6-10 hrs., 11-15 hrs., 21-25 hrs., 26-30 hrs., 31+. For elderly people the amount of high care packages is lower than for physically disabled people. A 2004 inquiry into the Oxfordshire practice revealed that elderly people receive an average of 18.79 hours of care, people in mental health receive 3 hours, intellectually disabled people receive 37.40 hours, physically impaired people receive 23.29 hours and finally disabled children receive 3.67 hours on average. A majority of direct payments packages for people with learning disabilities provide high levels of inputs: in England, for instance, 68% and 24% of packages provided over ten and 31 hours per week of care, respectively. The budget is lower for people making use of mental health care. Less than half of the people in that group uses up more than 10 hours per week.

3. Budget amount and budget setting with Direct Payments.

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 7 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 budget is not taxed but the amount is determined accordingly with the income. There exist national guidelines in which the minimal conditions with regard to personal contributions are stipulated. 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.

There are different tariffs: day tariff, evening tariff, weekend tariff and during holidays. There are also different tariffs according to the target group: elderly people, intellectually disabled, mental health care, physically disabled, people with sensory impairments, disabled children, care takers. The tariffs vary according to the local authority, which determines the latter. The lowest tariff is 8.7 pounds and the highest is 10.55 pounds. The average for all target groups combined was 8.87 pounds. Apart from tariffs per hour there also exist tariffs for one night, one weekend or one week. These tariffs cover employer's expenses such as charges that need to be paid and the necessary insurances.

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.

4. Political and public debate.

There is an ongoing debate about the implementation and expansion of direct payments. Although national government has made a clear choice, practices can still differ depending on where you live. For that reason the Direct Payments system has been called a 'Postcode Lottery'. Even more absurd is the situation where people moved and by doing so lost their budget whilst their care demands remained the same.

According to inquiries success factors were: an effective support plan, training of the personnel working in primary (health) care, support from local authorities, a positive attitude towards personnel, a national legislation, policy and guidelines, accessible information for the people who make use of care and the care takers and last but not least the evolution of the user's and care taker's demands. The local authority also points to the following keys to success: political support, transparent management by the central government, availability of assistants and volunteers.

Furthermore there is the demand for integration of the different budgets and legal agreements. That was at any rate the goal of the Individual Budget pilot projects. The conclusion drawn from these pilot projects was that the integration of different budgets is not self-evident and sometimes even impossible, at least when it is done without a preliminary debate about the reassignment of government budgets. It is to be expected that over the coming years, in England as well as in the whole of the UK, there will be an expansion of the system of direct payments as an alternative to care in kind – and as an alternative to residential care – but at the same time work will be done on the rules concerned. At the beginning of 2009 it was announced that also in health care there would be a budget for patients: 'personal health budgets'.

In answer to the increased macro budget the counties have become more and more strict in their assignment of budgets and social care. The criteria to be taken into consideration are becoming stricter with eligibility criteria in the 'Fair Access to Care' (FACs) model becoming more difficult to meet. Those who already dispose of a budget do not lose it, but those approaching social services for the first time will have less chance than say 3 years ago to obtain a budget compared to an individual with exactly the same level of support needs. This is due to local authorities making the eligibility criteria more stringent in an effort to save costs and target those they deem most in need.

SWEDEN

1. General

Sweden is a pioneer in the field of direct payments. Already in 1987 there were experiments with Personal Assistance taking place. It was started in Stockholm, initiated by STIL, the Stockholm Cooperative for Independent Living.

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.

In the period between 1994 and 2004 the costs for this kind of support rose by 15% a year on average due to an increase in the target group's absolute number and an increase in the average number of hours of need.

2. Target group and possibilities.

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 (see further).

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.

3. Factors that determine your budget

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.

In case that the municipality or yourself make an application at the 'försäkringskassan' then it will be first verified whether you really need more than 20 hours of assistance with your fundamental needs, by means of the aforementioned 'eye of the needle' principle. Once you have passed this first test, you will be allocated a number of hours through LASS and on the basis of your real support needs. Before 1997 the entire support was paid by the 'Försäkringskassan'. As from 1997 'Försäkringskassan' only pays for the hours exceeding the 20 hours of support per week; the rest is paid by the municipality.

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. This fixed amount can be raised by 12% in specific cases, e.g. when a certain expertise is required from an assistant.

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 (compared to 40 hours per week in the beginning). 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 2008 3% of the personal assistance employed their assistants themselves, in 51% of the cases the employer was the municipality, in 11% an assistance user cooperative and in 35% a private organization. There are cooperative societies that primarily focus on intellectually impaired people.

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.

4. Public and political debates

On the whole we can say that Sweden has one of the most advanced legislations with regard to direct payments.

Nevertheless in Sweden as well some problems have cropped up. Given the fact that the number of LASS users as well as the number of allocated hours per user have increased substantially over the last years, the government wants to cut the social insurance's expenses. At the moment a bill intended to contain costs through, among other things, tightened assessment procedures and redefined eligibility criteria is in the making. There is a chance that the bill gets through parliament this fall or next spring but some political observers do not expect this to happen, since 2010 will be an election year. Whether this will happen and what effect this can have on support is yet to be seen.

GERMANY

1. General

The '**Pflegeversicherung**' ('care insurance') that was established in 1994 as an insurance for people with a long term care need can be considered to be a form of direct payment to the extent that money is allocated for the purchasing of care. The amounts however are that low (max. 1668 euro/ month + 446 euro/ year for the highest category) that it is entirely insufficient to purchase the necessary formal care. The budget merely covers half of the cost price of ambulant care (and in cases with a high need this even amounts to less than 10%) and has to be considered rather as a supplement to ambulant care. The expenditure of the budget is bound to no restrictions. This budget should be compared to an informal care bonus rather than a full-fledged budget that serves as an alternative to care in kind. The success of this budget (in 2005 959 546 use just the individual budget, 204 348 use the individual budget in combination with ambulant care in kind as opposed to 660 000 people in residential care, and 173 251 use just ambulant care in kind) is probably explained by the great importance of informal care and a less developed formal care sector in Germany. But it is the increasing demand for residential care that has urged the German government to explore the further possibilities of direct payments.

The foundations for what could eventually become a worthy alternative to care in kind were laid in 2001. *Socialgesetzbuches IX* (§ 17 Abs. 2 SGB IX) makes it possible for people to receive a budget instead of ambulant or residential care. There were different ongoing experiments within this framework as of 2004. 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 (that means nobody will get **more** money) but is rather a new form of payment for old benefits, thus 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.

This system was tested in 8 model regions from October 2004 to June 2007. The inquiry was led by the universities of Tübingen and Dortmund in cooperation with the Pedagogical Polytechnic of Ludwigsburg. A random overview of the results: 847 budgets were granted between 2004 and 2007. The largest group among the budget holders were people with a mental illness (42%), followed by intellectually impaired people. Persons with a physical impairment only account for 19% of the total. 31% of the budget holders suffered from a visual or audiovisual impairment, organic diseases, seizure disorders (e.g. epilepsy) or development disorders, and tendency to develop an impairment. The majority of the budget holders lived in a private home (77%). The rest of the budget holders had ambulant care at home or lived in a residential accommodation, a residential home for elderly people, etc.. The average budget was 1 041 euro per month in the model regions and 860 euro in the other regions. The budget amount varied between 36 and 13 275 euro, but 80% of the budgets were lower than 1 000 euro per month. On the average the time needed to apply for a budget was 5.5 hours and people received their budget within 3 months.

From October 2004 to October 2008 (during the test phase of the **TPB**) the cooperating care insurances experimented with the **Pflegebudget** in 7 different regions. 7 000 people in need of care took part in the experiment. They were not only disabled people but also (and especially) elderly people and chronically ill people. It was remarkable that it was not the government but the care insurances that took the initiative. The experiment was scientifically accompanied. There was a control group of 1 000 people. The results of the inquiry were presented at various symposiums. The people participating in the inquiry received a sum equal to the cost price of the ambulant care in kind and were free to spend it. A case manager did the follow-up of the individual dossiers and there were also experiments with a new kind of needs assessment.

To conclude there was an experiment with the **Integriertesbudget**. This was a combination of the **Trägerübergreifendes Persönliches Budget** and the **Pflegebudget**. Again it were the care insurances that took the initiative. The Rheinland-Pfalz federal state did an experiment with this budget in two regions. The experiment took place from the 1st of January 2005 to the 30th of April of the same year and there were 15 participants. Meanwhile this experiment has come to an end.

As from the 1st of January 2008 every person in Germany is entitled to a **Trägerübergreifendes Persönliches Budget**. So this budget “survived” the model phase and is now a regular service. As it is the main budgeting system in Germany, we refer to it as **Persönliches Budget** (personal budget) from now on.

This budget is an enforceable right. Meanwhile there is a pending case in which a disabled person wants to enforce the right to a budget as an alternative to an institute.

2. Target group and possibilities of the Persönliches Budget.

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. At this moment an estimated number of only 3 500 people make use of the Persönliches Budget, but this number is still growing.

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. These authorities can find out for what kind of assistance you may apply. They contact all other relevant authorities. 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. This agreement is reevaluated and adapted to the current situation every two years.

In many cases it is the local authority that acts as a contact person. The implementation of the budget lies with them and not with the national government.

To which services can one appeal 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. General practitioner costs can not be paid with the budget. 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.

3. Budget Amount and budget setting with the Persönliches Budget

In 2004 a hypothetical inquiry into the possible cost of the Persönliches Budget in comparison to the existing care in kind was carried out. It revealed that in the future a higher quality of care combined with a cost reduction could be assured due to the fact that the Persönliches Budget would diminish the popularity of residential facilities.

Budgets in the Pflegeversicherung account for 50% in the applicable cost price of care (meaning people get only half of the amount that care providers can receive)– and only a small part of the real costs of care is applicable, anyway. The budgets of the Persönliches Budget are generally higher and 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), then the budget is means tested¹. However, unfortunately 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, in money and never in vouchers. 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.

¹ **Means testing** is the process the government uses to decide the level of benefits someone receives.

4. Political and public debate.

It was the pressure on the social security and more specifically the rise of the overall budget of the Pflegeversicherung that made the authorities decide to choose in favor of a full-fledged system of direct payments. It is only as from the 1st of January 2008 that everyone can make an appeal to it. In June 2008 it turned out that the system was still something very theoretical to many people. Also in former experiments it was at this point that everything went wrong. It was also found out that the target group as well as the care providers and the professionals in the potential 'central contact points' were not well informed about the possibilities. That's most probably the reason why the government now puts a lot effort into a major publicity campaign about the possibilities of this new measure. The evolution of the Persönliches Budget surely deserves our further attention.

FRANCE

1. General

Two laws regulate direct payments in France. The so called "PHC" is a form of direct payments for disabled persons, "APA" concentrates on elderly people. In this report we will only be talking about PCH.

PCH means 'la Prestation de Compensation du Handicap' and is inscribed in the law of 11 February 2005 called 'Loi pour égalité des droits et des chances, la participation et la citoyenneté des personnes handicapées'. This law has entered into force as from the 1st of January 2006. The PCH has taken the place of the former 'Allocation Compensation Tierce Personne' or ACTP. Those who still receive the ACTP can choose to carry on with it or can opt for the PCH.

The idea of PCH is that the needs of the disabled person are 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:

- Les aides humaines: support by personnel, a sort of Personal Assistance.
- Les aides techniques, spécifiques ou exceptionnelles: support equipment, permanent and anticipated expenses.
- L'aménagement du logement and l'aménagement du véhicule: the necessary adaptations to transport or housing
- Les aides animalières: guide dogs, etc. ...

In this report we will mainly focus on the explanation of the 'aide humaine'

At the end of 2007 there were 146 000 PHC and ACTP users, which represents an increase of 5.5% in comparison to 2006. Of this group still 118 000 people are ACTP users.

The number of PCH users has increased drastically in a short period of time. 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.

2. Target group and possibilities?

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

- 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.
- 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.

With aide humaine you may in principle purchase the following.

- Assistance with personal care: (hygiene-eating ...), moving around inside and outside the house and participation in social life (leisure time), as well as accompaniment in case the person suffers from an intellectual, cognitive or physical disability.
- Permanent supervision to avoid persons being exposed to a threat of their integrity or safety.
- Additional costs linked to professional activities.

If you wish you may hire informal care takers 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'.

In some cases a family member can receive a salary: on the condition that the family member is not retired, gives up entirely or partially his professional activities and is not family in the first degree.

3. Budget setting and budget amount.

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 must then establish the 'plan de compensation'. If so desired by the disabled person or the multidisciplinary team, the latter can meet with the disabled person or take a look at the disabled person's home environment. The established plan treats the 5 sections of PCH. 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. Certain tariffs are determined for each section of PCH: for 'aide humaine' it concerns a compensation per hour, but also for technical support equipments tariffs are determined. These tariffs for support are at 100% if your personal income is less than 24 259.88 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:

- You pay the (different) employees (family members included) yourself
- You compensate an 'aidant familial' with, but you do not pay a real salary
- You make use of a 'service mandataire'. This 'service mandataire' searches for employees and exclusively performs administrative tasks but you remain yourself the employer.

You can also outsource your role as an employer and pay a 'service prestataire d'aide à domicile'. This is an organization which engages employees and places them at the disposal of private individuals to assist them at their homes.

Some statistics: 69% of the remunerated hours within the framework of the 'aide humaine' go to 'aide familiale'. Only 15% of the remunerated hours go to assistants who are directly employed. 10% of the hours go to the 'services prestataires', 5% to the 'services mandataires'.

Depending on how you want to organize your assistance you will benefit from a different tariff:

- If the disabled person personally hires someone the tariff is 11.57 euro per hour.
- If you make use of the 'service mandataire' the price is fixed at 12.73 euro per hour.
- For a 'service prestataire' this is 17.19 euro per hour.
- If you appeal to an 'aidant familial' then this person usually is remunerated at 3.36 euro per hour.
The limit is fixed at 837.98 euro per month per care worker. In some circumstances this amount can be increased by 20%.
- 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.

Just to have an idea: 88% of persons with a PCH receive 'aide humaine', 4% receives support with technical equipments, 10% receives support for housing adjustments or transportation adjustments, and 16% receives support for specific or exceptional expenses.

The eventual amount is paid out or deposited every month over a maximum period of 10 years and is audited by the 'Conseil Général'.

After 10 years a new request for PCH has to be submitted.

4. Public and political debates.

Unlike the inquiries into other countries there have been no contacts with any direct payments experts in France.

Consequently it is hard to describe what are the ongoing public and political debates.

FINLAND

1. General

In 1979 for the first time a person received Personal Assistance in Finland. In 1987 Personal Assistance was inscribed in the law as 'Personal Assistance System'. At the moment about 5 000 persons make use of Personal Assistance.

Things however are changing. 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. This new law will bring about all sorts of changes. In what follows we will try to describe the current situation and the stipulations of the new law.

Personal Assistance is a municipal competence. This implies that there exist many different practices according to the regional level.

So far there were even municipalities where you could not make use of Personal Assistance. Some municipalities were not in favor of Personal Assistance and preferred to offer other services. According to current legislation there are no legal grounds for the enforceability of a budget. This will change with the new law. A municipality can under no pretext refuse to provide a Personal Assistance service to anybody. At least when this person meets the legal requirements for benefiting from this service.

2. Target Group and possibilities.

The 1987 law states the following: "A disabled person shall be fully or partially compensated for the costs made to hire a personal assistant and this in accordance with his support needs resulting from his illness-disability ..."

The new description is as follows: "Severely disabled persons who need support on a regular basis with their daily activities at home or outside their house are entitled to Personal Assistance."

Notice that according to the new law you are 'entitled to' (you can claim the right to) 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:

In the actual legislation for intellectually disabled persons for example there was no mention of the possibility to make use of Personal Assistance. Although some individuals do make use of it their support so far has been regulated by a different legislation.

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.

In Finland you can freely choose your assistant and no conditions are imposed by the authorities. There is however a general problem finding (suitable) assistants. Because of the low salary the job of personal assistant is not quite the most popular job and it is not that easy finding and keeping personnel.

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.

3. Budget setting and budget amount

The disabled person with a support need is supposed to contact a social worker. Subsequently the social worker has to carry out an individual inquiry and assess whether the disabled person requires Personal Assistance. The assessment is carried out on the basis of the number of hours of support required. Disabled persons have already pointed out that social workers are not always capable of charting all the needs. The quality of the inquiry also varies according to the municipality.

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, social life there exists a 10 hours limit per month which will be raised to 30 hours per month as from 2011.

Concerning the employership there exist two possibilities according to the current agreement:

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.

Apart from the already existing possibilities the new law will provide two more possibilities:

- The municipality gives a voucher to the disabled person with which he or she can purchase assistance at a service.
- The municipality organizes the assistance, through its own service or by purchasing a service, or through a contractual collaboration with other municipalities.

The idea is that persons who do not want to be or can not be an employer, e.g. intellectually disabled people, may be able to also receive Personal Assistance.

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, every euro has to be accounted for and you can only spend the budget on the previously determined articles and services.

There are no prescribed minimum or maximum limits. The highest budgets 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.

4. Public and political debate.

When you take a look at the measures in the new law, you will notice that they try to solve the problems encountered in the old legislation. Personal Assistance will become a right, the target group is expanded to include intellectually impaired people and the rules concerning employership have been simplified, not in the least to give access to Personal Assistance for intellectually disabled persons.

In relation to this last point it must be remarked that training and support of employees as well as employers is a delicate point in Finland. At the moment this is happening all too little. Given that in the near future intellectually impaired people can also receive assistance, extra support is needed. The new law wants to provide for this: persons that are not able to manage their own finances can apply to 'Guardianship Services'. There are also different kinds of new (sometimes private) organizations springing up which in the future will be able to accompany intellectually impaired people with the organization of their Personal Assistance.

For now it is still too early to speculate about the influence of this new legislation on the lives of disabled people. It will nevertheless be worth the while to keep an eye on the new developments in Finland.

NORWAY

1. General

Norway has introduced direct payments in a somewhat later stage than its neighbor Sweden. The first initiatives were taken in 1991 with the establishment of the cooperative society ULOBA.

In 1991 Personal Assistance was inscribed as a test program. It was the first time municipalities received money for organizing Personal Assistance.

As from 2000 Personal Assistance has been officially inscribed in the 'Social Services Act'. Personal Assistance is a municipal competence.

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.

How quick your request is approved depends on the reliability and relevance of the request. Requests for ailments such as CFS require a longer period before their approved. There is no waiting list, and municipalities can not turn down a request because of a shortage of financial means.

2. Target group and possibilities

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. Although the possibility already exist for three years, apparently only 4% of the users of Personal assistance are intellectually impaired people. The great majority of people making use of Personal Assistance have a physical impairment and approximately 10% are people with a sensory impairment or brain damage.

One of the reasons for the underrepresentation of intellectually disabled people may be the fact that it is a municipality's representative who decides whether a disabled person is capable of receiving 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.

3. Budget setting and budget amount.

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 (so far the only cooperative society in Norway), 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.

At the moment the municipality is the employer in 65% of all cases, the cooperative society ULOBA takes a share of 25%, and only in 9% of cases the person is his or her own employer. If you are your own employer you receive your budget in cash. If the municipality is the employer then the municipality pays your assistant a salary. If you work with a cooperative society then it is the ULOBA which receives the money with which they pay the assistants, plus all other employer responsibilities.

The municipality decides who the employer will be. Nevertheless this choice can have a great impact on very different levels:

- Whether the costs cover for your expenses.
 - If the employer is ULOBA then they will do everything to make your budget sufficient enough to cover for your expenses.
 - If the employer is the municipality or the disabled person himself, then you will have to fight and plead for every (extra) money that you spend.
- the control you have over the organization of your support:
 - Disabled persons who work with ULOBA look for their own assistants, train them, establish their working hours and they control them. They decide for themselves where and when they receive assistance.
 - If the municipality is the employer then disabled persons are less involved in the organization of their assistance and consequently they have less control over the content of their support. In many cases the municipalities even decides who shall give assistance to which person and when and where.
 - 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.
 - If the employer is the municipality the payments are effectuated by the municipality and consequently you are not held accountable for your budget expenditure. You do still have to motivate the reasons for your assistance.
 - If you are your own employer you have to account for all your expenses to the municipality.
 - If ULOBA is your employer they report to the disabled person every month and every three months to the municipality.
- Finding personal assistants:

- Municipalities encounter some problems finding personnel.
- Disabled persons in ULOBA have less trouble finding personnel.

The following organizations give assistance with the employership:

ULOBA provides training and private organizations can help you managing your budget.

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.

43% of the users gets 16-38 hours of support per week. 26% gets less than 16 hours per week and 28% gets more than 38 hours of support 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.

4. Public and political debate

In 2007 the Ministry of Health and Care discussed a new proposal titled ‘Green Paper’ in which two reforms are recommended:

- The individual should be able to decide for himself who is to become his or her employer. The idea is actually to evolve towards a system of direct payments, where the money would directly go to the disabled person. The budget would be granted according to the number of hours of support needed. With this budget the person can choose whether he or she works via a third party (which is more expensive), whether he or she becomes their own employer and how much he or she pays the assistants.
- Personal Assistance would become an individual right for people with extensive disabilities (who need more than 20 hours per week). Critics say that this could well lead to more persons that are eligible for Personal Assistance but that their number of hours would diminish. And a decrease in the number of hours would lead to a lower level of self-determination.

It might be interesting to keep an eye on how things will evolve in the future.

SPAIN

1. General

At the end of 2006 the Spanish national Parliament voted a new bill called **LEPA** (Ley de promoción de la autonomía personal y atención a las personas en situación de dependencia) 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.

A further elaboration of the bill has to take place on a national level and in consultation with the different regions in Spain.

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.

2. Public and political debate

At first sight this is a first step into the right direction. There are, however, some remarks to be made:

- 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.

This is no easy task for the regions neither:

- National government only pays for a part of the assistance and hence the community has to look for additional means elsewhere
- Moreover every region has to decide how to implement this form of direct payments.

Consequently 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.

3. A few experiments in detail:

There are many experiments and pilot projects going on in Spain. The first experiment started in Guipuzcoa, in the Bask region, followed by Madrid and Barcelona. There is also an experiment running in the region of Galicia, but developments are not so positive. Although there are other experiments, we will limit ourselves to the three experiments with the best results. It is noteworthy to see that in all three experiments a cooperative society is involved (or will be involved in the near future), just as in the Scandinavian example.

Guipuzcoa, Bask region:

The project started out as the first pilot project in Spain in 2004 and is still running today. The initiative was taken by the provincial authority of Guipuzcoa, an autonomous province within the Bask region. The purpose of the experiment was to try out the Personal Assistance system.

The number of participants has risen from 3 all in the beginning to 60 today. There are various requirements to be fulfilled before someone can register for the program:

- The person has to be an inhabitant of the autonomous province Guipuzcoa in the Bask region.
- Only physically impaired people can apply and they have to be able to organize their support independently.
- The person must have a house at their disposal.
- The person has to establish a feasible plan which demonstrates how he or she wants to fulfill his or her personal needs so that he or she can have a minimum quality of life and which also contains an estimation of the costs.
- The person has to be able to rely on a minimum personal network of people.

If you want to apply for Personal Assistance you must establish a plan yourself, in which you indicate what kind of support you need. Then the province has to approve the plan, although they may e.g. decide to allot a smaller amount. The province subsequently pays the disabled person a certain amount per month with which the person can organize his assistance independently. This amount can not be higher than the costs for residential care. This comes down to an amount between 2 500 and 2 900 euro per month.

Until now no support has been provided for the employership. At this moment everybody organizes the employership by himself. But there is an OVI, 'Oficina de Vida Independiente', in the making, modeled after the Norwegian ULOBA, on which the Barcelona and Madrid OVI's are equally based.

This OVI will perform as a supporting network for the users of Personal Assistance and wants to take care of the employership. The establishment of the OVI will also lead to a first time unification of the different users. In that way they are better equipped to pressure the administration to carry on with the program so that it may eventually lead to a permanent arrangement.

Madrid:

The project started in July 2006 and initially the idea was that it would run until 2008, but it is still running today. It all started when "La Consejeria de familia y asuntos sociales" of the Madrid region contacted "AYSPAM Madrid" to think about a pilot project. They decided to establish an "Oficina de Vida Independiente" (OVI) which had to take charge of the management of the pilot project.

At the moment 35 people with a severe physical impairment take part in the experiment. They have to be of age and must live in the Madrid region.

The project has been organized differently than that in the bask region. It is the cooperative society OVI that receives money from the Madrid region. With this money OVI pays the assistants for the 35 participants in the project. The participants can nevertheless decide

who the assistant will be and when and how the assistance is to occur. The services provided by OVI are free of charge. The participants actively take part in the development of OVI, although in a lesser extent than in Barcelona as it is the AYSAM Madrid who administer the program. They also control whether OVI pays the salaries on time and correctly.

Individual persons can receive up to 16 hours of support by an assistant per day. There is a budget for the entire experiment of 2 921 829 euro, spread out over 3 years (2006-2008).

Barcelona:

The project started on the 15th of November 2006. Initially it was to run over a period of 1 year. Anyhow, it is still running and will not end before April 2009. At that moment the experiment should evolve towards a permanent arrangement based on the new 2006 bill (LEPA), which stipulates that the local administration has to give Personal Assistance to whomever applies for it. However, it is yet to be seen whether this will happen in reality.

The pilot project is a cooperation agreement between "Institut Municipal de Persones amb Discapacitat" (IMD) of the city of Barcelona and the cooperative society OVI of Barcelona. OVI manages the project and receives money from the IMD to this end. So it is the city of Barcelona that pays the costs.

9 persons with a severe physical impairment take part in the experiment. The OVI is managed and run by these 9 participants and is set up as a cooperative society. The participants decide entirely independently when, where and by whom the assistance is given.

The participants receive support for the hours they deem necessary, and there is no set limit. The most number of hours received by one person is 89 hours per week, the least number is 22 hours per week. An average of 11.25 euro per hour of assistance is charged. The participants in the experiment receive 2 465 euro per month on average. When the pilot project started in 2006, there was a 264 337 euro budget for one year. Eventually there was a budget of 532 480 euro, spread out over two years (15 November 2006 until 31 December 2008).

SUMMARY

Sweden is and has always been a pioneer. In 1987 the Swedes started with Personal Assistance and meanwhile this has become an enforceable right. 19 000 Swedes work with a budget. Only those having acquired a disability before the age of 65 can make a claim to it. The average annual budget is 90 000 euro for people who use more than 20 hours of assistance per week. The municipalities play an important role. The budget expenditure is bound to no specific criteria. Only 3% of the budget holders is his own employer, in 52% the employer was the municipality, 11% of the users worked with a cooperative society and 35% with a private organisation. Over the last years the number of users has increased significantly. At the moment the government is preparing a cost-cutting measure aimed at the reduction of the budgets.

There are 5 000 people today in **Finland** who make use of Personal Assistance. This has already been inscribed in the law since 1987. Also in Finland the implementation of the law is a municipal competence, which means that there exist many regional differences. A new law which makes it possible to legally enforce the budget is expected for 2009. Under this new law intellectually disabled persons will also be able to apply for Personal Assistance. Another novelty in this new law is the possibility to work with vouchers or to purchase assistance at the municipality so that you do not have to be your own employer. The actual budget expenditure audit is quite strict. The average budget is 2 000 euro per month, the highest amounts are more or less 9 000 euro per month. The new law wants to take into account the concerns of those people for whom it is not self-evident to be their own employer.

Norway has started somewhat later than Sweden. After 6 years of experimenting Personal Assistance was inscribed in the law in 2000. Initially intellectually disabled people were excluded but that changed in 2005. Nevertheless this group of people only accounts for 4% of the users actively working with a budget today. 3 500 people in Norway work with a personal assistant. The municipalities implement the law and decide who is eligible and who is not. They may also act as an employer. The budget holder himself can also be his own employer. A third possibility is to work with a cooperative society. The amount of the budget and the range of possibilities it offers as well as the way in which you have to account for the budget, depend on who your employer is. But you do not get to choose who is to be your employer, that choice is up to the municipality. The average number of hours is 36 hours per week. There is a maximum income—dependent personal contribution. Two changes are in the pipeline: freedom to choose your employer and the budget as an individual right. It is feared, however, that those changes will require a limitation of the budget amount.

The largest group of people working with a personal budget is situated in **the Netherlands**. Probably this is attributable to the fact that the budget is not limited to people applying for the budget before a certain age but is on the other hand available to all elderly people and chronically ill people. The personal budget nevertheless remains a personal choice and although the number of users is on the rise, only 10% of all people that are eligible for care choose the PGB. With this budget people can employ assistants or purchase care or other services. The average budget was 14 486 euro in 2007. As from the 1st of January 2007 the 'domestic care-segment' was transferred from the PGB to the municipalities. The amount of the budgets is determined at 75% of the cost price of care in kind. People can get help with the management and administration of their budget from the 'Sociale Verzekerings Bank' and budget holders associations. A small minority completely outsources the management

and administration to care mediation bureaus. The evolution of care and more specifically the PGB is in the spotlights because of the growing number of care demanders and the rise of the budget. Also some cases of fraud have led to a political debate and adjustments.

If we were to consider the 'Pflegegeld' in **Germany** as a form of direct payments then we would have to conclude that Germany has the highest number of budget holders. The budget amount, however, makes us think otherwise. Rather than a budget to pay for assistants or services, this is a compensation for informal care. Nonetheless there have been experiments with higher individual budgets. It is only as from the 1st of January 2008 that everybody can benefit from the 'Persönliches Budget' as an alternative to care in kind. Data about the number of users, budget amount and the way the budget may be used, are not yet at our disposal.

About the situation in **England** lots of research material has already been published. In 2006 an extensive inquiry into Direct Payments in the UK was carried out. For also in Scotland, Northern Ireland and Wales people with a care need can opt for financial support with which they may purchase care independently. In any case that is how it is written in the law. But also here the local authorities play an important role. They are responsible, not only for the assessment, but also for the payment of and the contacts with the care providers. 19 000 people make use of Direct Payments. Also elderly people can claim Direct Payments. For intellectually disabled people there exists the possibility of Indirect Payments. But not everybody is eligible to the latter, especially people in mental health care. Those who need more than 31 hours of support per week can make a request at the Independent Living Fund. More recently 13 pilot projects came to an end in which it was tried to integrate both budgets – supplemented with other compensations – into 1 budget. We presume that in the years to come the Direct payments will evolve towards Individual Budgets for disabled people.

In **France** it was the PCH (Plan de Compensation du handicap) that drew our attention. At the end of 2007 28 600 disabled people made use of this arrangement. Again there is an age limit of 64 years. The budget amount depends on your income. The average budget was 1150 euro per month. In practice the budget is mainly used to pay for informal care.

In **Spain** there is a new law since 2006, called LEPA, that has provided a framework for Personal Assistance on the national level. The assistance under LEPA is, however, rather limited: it only concerns severely disabled people, there is no mention of support during leisure time and users are supposed to pay an income-dependent contribution. Moreover the maximum amount has been fixed at about 800 euro per month.

It is up to the regions to put into practice the new law and that is no easy task. On the one hand they are supposed to find the financial means and on the other hand they have to find out how they want to implement this direct payments system. The result is that everywhere in the country experiments are springing up. Those are all small scale experiments (60 participants in Guipuzcoa in the Bask region, 9 in Barcelona and 35 in Madrid) that mostly work with a cooperative society, inspired by the Norwegian model. Ultimately these experiments should lead to a general legislation and a permanent arrangement. It is yet to be seen how and how quickly this will happen.

CONCLUSION

We have come to the conclusion that in each of the 8 countries that we have taken a close look at, there exists some sort of a system of direct payments.

In the Netherlands, England, Finland, Sweden, and Norway this is even a current practice. In Sweden it is a legally enforceable right already for some time, in Germany this is the case since recently and in Finland legal anchorage is being considered as well. Spain started experimenting only recently.

A remarkable conclusion is that a great deal of responsibility lies with the municipality. The municipality receives the applications, decides whether someone is eligible for support, and determines the budget amount. In The Netherlands and Germany this partly so, in Spain and France most work is done on a regional level ('comunidades autónomas' or 'Départements').

In the Scandinavian countries and Finland they even take it one step further. There the municipality can manage your budget or employ your personal assistant. In England there exists an intermediary form in which the municipality does pay out the budget, but it does not organize the support. It makes contracts with care providers to that end.

Also new players entered the market. In England it was the explicit goal of the government to come to a more hybrid care offer which involves new private and market oriented care providers. Also in Sweden there are private companies active on the market.

It is very interesting also to take a look at the Independent Living Centres in England or the cooperative societies in Sweden and Norway. In those centres and cooperative societies disabled people unite, and collectively organize their budgets and their support. So it is collective care, but controlled by and for the people. This model is copied in Spain, where in most of the experiments the Personal Assistance is organized through similar cooperative societies.

A recurrent issue is budget holders using the budget partly to pay for care in kind. There are exceptions though: in Norway and before long in Finland you may employ a family member only in very exceptional cases. In other countries the money appears to be going mostly to care in kind. There are various reasons for that. Often people intently choose to do so. People prefer it when they receive support from somebody they know. But the budget can also serve as an argument. Very low budgets may well be sufficient to compensate an informal care provider for foregone wages, but they are not high enough to purchase professional support.

The macro budget can also be an argument in favour of direct payments. In Germany this was the ultimate argument which convinced the government to provide the right to a full-fledged individual budget for all disabled people as from the 1st of January 2008. In the Netherlands on the other hand, the government decided to cut costs with regard to the personal budget (PGB). Research, however, revealed that it was not the PGB which caused a rise of the budget but that it were rather the increased support needs which were responsible. Not only is there a pressure on the budget because of the ageing population, there is also an increasing care demand amongst children and adolescents. The increase of demand in this target group has also been observed in Flanders.

We do not yet know what the result of this will be. It will be one of the main topics for discussion in the political debate about the long-term planning for the disabled person's sector.

The Expertise Centre Independent Living would like to plead for creative and innovative solutions to the problems we are challenged with today. Direct Payments could well prove to be the lever for the simultaneous realization of several goals: custom-tailored care and the chance to lead an independent life.

SOURCES

THE NETHERLANDS

Scientific sources:

- [Ramakers, Clarie e.a., Persoonsgebonden budget nieuwe stijl 2007 Vervolgonderzoek, Nijmegen, 2008.](#)
- [Ramakers Clarie, e.a., Evaluatie persoonsgebonden budget nieuwe stijl 2005-2006 Eindrapport, 2007.](#)

Government reports:

- Website van het Ministerie van Volksgezondheid, Welzijn en Sport: <http://www.minvws.nl/dossiers/awbz/feiten-en-cijfers/>
- [PGB in perspectief](#), Kamerstuk, 9 november 2007.

Literature study:

- [Price WaterhouseCoopers, Analyse biedt inzicht in instroom in de pgb-regeling voor jeugd-ggz, Analyse van de instroom in de pgb-regeling via Bureau Jeugdzorg, 27 mei 2008.](#)
- [CIZ, PGB in ontwikkeling, 2008.](#), 13 juni 2008.
- Oostrik, Frans, *Als je het mij vraag, waarom mensen kiezen voor zelfbeschikking in de zorg*, , proefschrift, Amsterdam, 2008.

ENGLAND

Scientific sources:

- ESRC End of Award Report (RES-000-23-0263) Disabled People and Direct Payments: a UK Cooperative Study. August 2006.
- [Ibsen: the national evaluation of the Individuel Budgets pilot programme, October 2008](#)

Government reports:

- [Personal Social Services Expenditure and Unit Costs England, 2007-08](#), the Information Center of the National Health Service, februari 2009.
- <http://www.individualbudgets.csip.org.uk/>
- <http://www.ilf.org.uk>
- http://www.ilf.org.uk/reports/statistics/user_profile_analysis_september_2008/index.html rapport sept 2008
- Report about the obstacles for the use of Direct Payments, 2004. http://www.csci.org.uk/PDF/direct_payments.pdf
- Website Commission for Social Care Inspection: <http://www.csci.org.uk/>
- The Community Care, Services for Carers and Children's Services (Direct Payments) (England) [Regulations 2003](#).
- Direct Payments Guidance Community Care, Services for Carers and Children's Services (Direct Payments) [Guidance, England 2003](#).

Consumer organizations:

- <http://www.independentliving.org/25years2008evans#speech>
- Correspondence with Debbie Jolly, researcher and Regional Delegate for ENIL.
- Correspondence with Philip Mason, HCIL.

SWEDEN

Cooperative society for Persons with Personal Assistance:

- www.easpd.eu/LinkClick.aspx?fileticket=SOJipRNCOiM%3D&tabid=3529 –
- http://www.uni-siegen.de/zpe/veranstaltungen/fruehere/europkonferenz3/forum_a_cecilia_blanck.pdf
- Blanck Cecilia, Scherman Agneta, Sellin Kerstin, Ten years with Personal Assistance. The Jag Association. Stockholm 2006.
- Correspondence with Adolf Ratzka of Independent Living Institute

Scientific sources:

- Ole Peter Askheim, Personal Assistance in Sweden and Norway: From Divergence to Convergence? Scandinavian Journal of Disability Research. Vol. 10, N.3, pp 179-190, 2008.
- Grassman, Eva Jeppsson, Whitaker, Anna and Larsson, Annika Taghizadeh (2008). 'Family as Failure? The Role of Informal Help-Givers to Disabled People in Sweden'. Scandinavian Journal of Disability Research. pp 1-16, 29 July 2008.
- Lewin, Barbro, Westlin, Lina and Lewin, Leif (2008). 'Needs and ambitions in Swedish Disability Care'. Scandinavian Journal of Disability Research. pp 237-257, 01 January 2008.
- Boeykens Julie, Scriptie ingediend tot het behalen van de graad van licentiaat in de pedagogische wetenschappen, optie orthopedagogie. Persoonlijk assistentiebudget: een vergelijking van deze zorgvorm in Vlaanderen en in Zweden. Academiejaar 2006-2007.

Literature study

- Literatuuronderzoek door Marja Pijl in opdracht van VWS. Zelf zorg inkopen: hoe gaat dat in het buitenland Persoonsgebonden budgetten in Zweden. 8 juni 2007. <http://www.minvws.nl/rapporten/lz/2007/zelf-zorg-inkopen-hoe-gaat-dat-in-het-buitenland.asp>

GERMANY

Literature study:

- [Sömmer Esther, Het persoonsgebonden budget in Duitsland, Brussel, 2008.](#)
- [Breda, J., Gevers, H, Van Landeghem C., Het persoonsgebonden budget in Nederland, Engeland en Duitsland., uitgevoerd in opdracht van het Vlaams Agentschap voor Personen met een Handicap, 2008.](#)

Government sources:

- <http://www.pflegebudget.de/>
- http://www.bmas.de/coremedia/generator/9266/persoenliches_budget.html
- <http://www.budget.paritaet.org/>

FRANCE

Government sources:

- Drees, Etudes et Résultats. L'allocation personnalisée d'autonomie et la prestation de compensation du handicap, 05-08. <http://www.sante.gouv.fr/drees/etude-resultat/er-pdf/er637.pdf>
- Drees, Etudes et Résultats. Les prestations de protection sociale en 2007, 10-08.

<http://www.sante.gouv.fr/drees/etude-resultat/er-pdf/er665.pdf>

Service providers

- Prestation de Compensation de Handicap Adulte Ladrome, Maison Départementale des personnes handicapées. Parc De Lautagne. 42 C Avenue des Langories B.P. 145 Valence., 05-2008.
- La prestation de Compensation de Handicap, Place Handicap. Maison Départementale des personnes handicapées de la Seine Saint-Denis.
- <http://www.aurelie-services.com/p1-article17-service-prestataire-service-mandataire.php>

Other:

- <http://information.handicap.fr>
 - Literatuuronderzoek door Marja Pijl in opdracht van VWS. Zelf zorg inkopen: hoe gaat dat in het buitenland. Persoonsgebonden budgetten in Frankrijk. 8-06-07. <http://www.minvws.nl/rapporten/lz/2007/zelf-zorg-inkopen-hoe-gaat-dat-in-het-buitenland.asp>

FINLAND

Consumer organizations:

- Urhonen Amu, Treshold Association Finland. Personal Assistant System in Finland. Riga, 19-08-08. http://www.apeirons.lv/down/PA/riika_19.8.08.pdf
- <http://www.kynnys.fi/kynnys/english.html>
- Independent Living: Challenge for disability policy. <http://pre20031103.stm.fi/english/pao/publicat/paocontents14.htm>
- <http://www.om.fi/en/Etusivu/Julkaisut/Esitteet/Holhoustoimenpalvelut>
Guardianship Services
- <http://www.kynnys.fi/content/view/434/437/>
- Correspondence with lawyer Terhi Toikkanen , Threshold association.
- Correspondence with Jarmo Tiri, president of consumer organization Hetta

Government:

- Minister Risikko, The right of people with disabilities to personal assistance is a human rights issue. 08-10-08. <http://www.stm.fi/Resource.phx/publishing/documents/16598/index.htm>
- Government Report on Disability Policy 2006 <http://www.stm.fi/Resource.phx/publishing/documents/7545/index.htm>

NORWAY

Cooperative society for Persons with PersonalAssistance:

- <http://www.uloba.no>
- Correspondence with Bente Skansgård of the cooperative society ULOBA.

Scientific sources:

- Ole Peter Askheim, Personal Assistance in Sweden and Norway: From Divergence to Convergence? Scandinavian Journal of Disability Research. Vol. 10, N.3, 179-190, 2008.
- Ole Petter Askheim, Lillehammer University: Personal assistance service in Norway, 19

August2008,http://www.apeirons.lv/down/PA/1_PA_service_in_Norway_OlePetterAskheim.pdf

SPAIN

Independent Living Organization:

- http://www.minusval2000.com/relaciones/vidaIndependiente/asistencia_personal_vida_independiente_y_promocion/index.html
- http://www.minusval2000.com/relaciones/vidaIndependiente/pdf/primera_oficina_vida_independiente.pdf
- http://www.minusval2000.com/relaciones/vidaIndependiente/programa_vi_comunidad_madrid_cermi_.html

Other Internet sources:

- <http://www.imsersomayores.csic.es/landing-pages/ley-autonomia-personal.html>
- <http://blogs.nortecastilla.es/apimf89/2006/8/24/-por-esto-me-gusta-lepa->

Laws:

- Ley 39/2006 de 14 de diciembre, de Promoción de la Autonomía Personal y Atención a las personas en situación de dependencia.

Communication with peer counselors:

- Correspondence with Nuria Gomez, coordinator of OVI Barcelona
- Correspondence with met sir Kiko Fernández of VIGALICIA
- Correspondence with Eva Santos, Personal Assistance user in Guipuzcoa.