



International Conference: Independent Living through Direct Payments

Expertise Centre Independent Living

European Network on Independent Living

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Summarized transcript of the panel discussion 'Direct payments in Belgium, the Netherlands and Sweden'

Moderator: Peter Lambreghts (Expertise Centre Independent Living, Belgium).

Participants: Davy Gaeremynck (Independent Living Institute, Sweden),

Jos Huys (Bol-budiv, Belgium) and

Lies van de Loo (Per Saldo, the Netherlands).



1. Would you mind introducing yourself – who are you, where do you come from? Also, please tell us briefly about your organization.

Davy Gaeremynck (Independent Living Institute, Sweden): I'm Davy Gaeremynck, I'm 35 years old, I'm a personal assistance user and working with the Independent Living Institute, Sweden, for half a year now. My previous working experiences included administration and user support with a private for profit assistance provider and working for Sweden largest user cooperative for five years.

Independent Living Institute (ILI) helps disability organizations within Sweden and Europe in their efforts in establishing an inclusive community for persons with disabilities and spreads the Independent Living philosophy on a grassroots level.

Lies van de Loo (Per Saldo, the Netherlands): I'm working at the communication office of Per Saldo. Per Saldo is an organization of people who have a personal budget. It was established in the Netherlands, in 1995 by people with disabilities themselves. In my personal life I have a personal budget. This budget makes it possible to pay an assistant or to buy a wheelchair or make adjustments at home.

Jos Huys (Bol-budiv, Belgium): I am a 55 year old man, and a lawyer by profession. Due to progressive muscular dystrophy, I have gradually become more dependent on assistance. As I have never intended to get institutionalized, together with Jan-Jan Sabbe and some other young persons with physical disabilities, we started up in December 1987 the Flanders Independent Living movement. After more than 12 years of political struggle, the movement succeeded to get personal assistance in the Flemish legislation.

2. You are a person with a disability in Sweden, the Netherlands or Belgium and you want to organize your own support. How do you start with it?

Davy Gaeremynck (Independent Living Institute, Sweden): Personal Assistance is a legal right in Sweden. The Independent Living Institute provides an online detailed comparison of most assistance providers in Sweden. There are no waiting lists, the aim is to make sure that assistance to users is up and running within three months.

1. The user gets a decision on the right to personal assistance with a certain amount of granted hours;
2. The user gets in contact with a preferred provider and presents a copy of the assistance decision;
3. The provider organizes basic training for the user;
4. After basic training, an agreement between user and provider is signed. A copy is delivered to the decisive authority;
5. The user sends a power of attorney to the decisive organ, enabling them to arrange payments directly with the provider, a copy is delivered to the provider;
6. The provider signs an agreement with the user's municipality for reimbursement of additional cost that arise on sick leave of assistants;
7. The user recruits his assistants and signs a preliminary work contract with the personal assistant, which then gets legalised directly between provider and assistant;
8. On specific occasions, the user can apply for extra hours with the municipality services, a copy of such an agreement is delivered to the provider.



Lies van de Loo(Per Saldo, the Netherlands): This is the short version. Everybody that needs help can choose for the personal budget. It does not matter if you are young or old, or what your disability is. The first step you have to take is to get in contact with the assessment organization (CIST) that is a nationwide organization that makes assessments on how much and what kind of help you need. Then you must choose between help in kind or a personal budget. The assessment organization will send the assessment papers to the health insurance organization. When you need housekeeping help then the municipality will give you your budget. Most of the time the municipalities will assess themselves and sometimes they leave it up to the CIST.

If you need care help the health insurance organization (nation wide) will give you the budget. Then you go and find people who want to work for you. You are obliged to make up an agreement with your care taker. Then you can start. Depending on the size of your budget you have to account for your budget every half year or every year.

When you need a wheelchair of other kind of provision you go to your municipality. Instead of the provision in kind, you can get a budget and buy the provision yourself. This is very new in the Netherlands.

There are no waiting lists at the moment. The whole process from assessment until the beginning of the budget is about 3 months. That is if everything goes as it should go. For many potential budget holders this is a difficult process. Per Saldo is there to help them.

Jos Huys (Bol-budiv, Belgium): I was already used to organize my personal assistance by myself before the personal budget scheme has started up in 1997 on an experimental basis. I had already some assistants, working for me on a voluntary basis, or paid out of my own means.

Nowadays, people with disabilities can meet within peer counseling groups and learn from each other how to organize their lives with personal assistance. Also, associations of budget holders can inform people with disabilities about the existence of a personal budget system and about the way to apply for it.

3. Ok, you have now a budget. How does this budget look like? Do you get cash or a voucher, or do you work with intermediary services? What are you allowed to do with the budget? Is the budget seen as direct financing, in other words: Are you able to control and determine your support? How flexible is the system when it comes to spending your budget and proving your costs?

Davy Gaeremynck (Independent Living Institute, Sweden): The budget is defined in a certain number of granted hours dispensed every month, with 6 month calculation periods. There are no legal regulations limiting what tasks personal assistants are allowed to do.

You are free to choose your assistance provider or employ the assistants yourself. Every month you provide a bill with the amount of Personal Assistance hours consumed two months earlier, possibly with the assistant's time reports as proof.

Lies van de Loo(Per Saldo, the Netherlands): Since 2007 we have two kinds of personal budget. One for care and one for housekeeping. Before that time there was one budget for all. This means that if you have a budget for housekeeping you cannot use it for care and vice versa. During the assessment process the size of the budget is determined. A small part of the budget is free to spend so you don't

have to justify that. The rest you have to justify how you have spent your budget every half year or every year.

Jos Huys (Bol-budiv, Belgium): Flemish budget holders receive a yearly cash budget and are free to choose their own personal assistants or to “buy” them at the service providers. They can use personal assistance for support with activities of daily living, at work or in school, for household chores or when travelling around. They have to account for all the expenditures.

4. You are of course very busy with direct financing in your countries. Can you give us some interesting figures and facts, such as height of the budget? Do you know the macro budget for care in your country? What is the percentage of care in kind? Since when do direct payments in your country exist? How does it evolve? Do you have other interesting facts and figures?

Davy Gaeremynck (Independent Living Institute, Sweden): The Government sets a standard amount for the assistance allowance each year, for 2010 it is 252 SEK per hour, approximately 23,8 EURO (exchange rate according to xe.com at 2010-03-01). Försäkringskassan [Social Insurance Agency], after consulting Sveriges Kommuner och Landsting, SKL [Swedish Association of Local Authorities and Regions], propose a standard amount to the Government before 1 March each year. The Government then makes a decision based on this and other economic calculations. 87% of the standard amount is considered to cover cost for salaries, employers’ fees etc. This shall at large follow the expected wage development for the coming year. The remaining 13% is to cover assistance costs (entrance fees, travel tickets, lodging), training (courses in lifting, respirator use, fire prevention, lectures), administration fees (costs the provider has for offices, administrative staff, insurances), work environment tools (gloves, soap, coffee). This part of the allowance shall at large follow the raise in the consumer price index. The economic situation in the national budget could also be taken into account.

Försäkringskassan [Social Insurance Agency] can, based on special reasons, grant a higher level of assistance allowance. However, the absolute maximum is a raise of the standard amount with 12%, i.e. 282 SEK per hour, approximately 28,9 EURO (exchange rate according to xe.com at 2010-03-01). Special reasons for raised allowance can be need for assistants with specific training, need for assistant working as a supervisor coordinating the assistance and providing support for the other assistants. Another reason could be a disproportionately large part of assistance hours during unsociable hours.

In January 2010 there were 15 799 people with personal assistance allowance from social insurance. These had an average of 110.7 hours of assistance per week, 47% were female and 53% were male. The women had an average of 109.3 hours of assistance per week, while the men had 111, 8 hours of assistance per week. Of these had 47.5% had their assistance in the municipalities, 38.9% hired an assistance company, 10.7% support a cooperative and approximately 2.8% were employers of their own assistants.

In addition there are about 3400 people (Dec. 2009) who have personal assistance under LSS granted by municipalities. However, there are no statistics on their choice of support providers. Of these 3400 people with personal assistance according to LSS about 41 % had an average need of less than 20 hours per week, and the rest had more than 20 hours per week.

Lies van de Loo(Per Saldo, the Netherlands): There are 118.000 care budget holders, with a total budget of 2.13 billion Euro . At this moment, 18 percent of the people entitled to care choose for a

4

personal budget. The total amount spent in care is about 22 billion Euro. The total of housekeeping budget is not known because municipalities are very slow with giving figures. We know that with the start of the budget for housekeeping in 2007 there were 30.000 people with only a housekeeping budget, moved to the municipality. The care budget has grown 10% in 2009.

Jos Huys (Bol-budiv, Belgium): In 1997, we started up on a experimental basis, with 15 budget holders, all people with physical or sensorial impairments. Today, we have 1,750 budget holders in Flanders, children and adult people with all kinds of functional impairments.

Annual PAB-budgets vary between 8.845,34 and 41.278,24 Euro, according to the support needs of the budget holder. Assistance users are not required to contribute to the cost of their personal assistance services regardless of their or their families' or households' income. The PAB-scheme however represents only 5% of the total expenditure of the Flemish Agency for Persons with Disabilities.

5. To which services do you have to go to or can you appeal to when working with your personal budget in your country? What role do the organizations for budget holders take up? Are there other services or means that play a supporting role when it comes to managing the administration, finding and hiring assistants or purchasing support?

Davy Gaeremynck (Independent Living Institute, Sweden): In order from passive to active assistance users: Users who let their municipality take care of the services – Users hiring a cooperative/private for profit organizations – Users employing the assistants themselves

Pros and cons of municipalities: Pros are that everything gets organised for the user, no effort needed in recruiting, scheduling or reporting, have replacement pools. Cons are less control who is helping you, if the schedule fits your lifestyle, and no control of economic means.

Pros and cons of cooperatives: Pros are considerable control over your staff, schedules and means. Influence over policies and activities within the cooperative, you often get legal help. Cons are a lot of effort from the user to get the assistants well organised and a balanced economic situation, often no replacement pool available.

Pros and cons of private for profit organisations: Pros are that they offer different levels of service and responsibilities, and are often able to meet your demands. Their aim for profit guarantees that you have a balanced economic situation. You often get legal help. Cons are: their aim for profit could limit possibility to vary and use of your means. No influence over business decisions in the company.

Pros and cons when hiring your own assistants: Pros: maximum over your assistance, you get assistance during hospital stays, and assistance allowance are paid after your death. Less strict legal arrangements to consider when organising the work of your assistants. Cons are that you cannot save funds over your six month calculation period. The user can't employ people that share the same household. Since you have the total responsibility you have to follow all changes in legislations, taxes, trade union agreements.

Lies van de Loo(Per Saldo, the Netherlands): If you need help with managing your budget you can call Per Saldo. You only have to pay your membership fee. When you need more help there are many agencies who want to help you. Many of them do good work and do the paperwork for you and help you to find workers. But there are also agencies that take advantage of the budget holder. They

organize everything so you become dependent on them again. Also there are homecare agencies that cannot get a contract with the municipality and force their customers to get a personal budget. We are very much against that because we think that you must consciously choose for a personal budget. The budget gives you the possibility to take charge of your own life. Also there are agencies that defraud with the budget they get from the budget holders. Per Saldo is working on a quality mark so people can separate the wheat from chaff.

Jos Huys (Bol-budiv, Belgium): The main supporters of the budget holder are his or her nearest of kin. People who love us and live with us know very well what our needs are and how they can be supported by personal assistants. Moreover, our loved ones, our colleagues at work and even our assistants are all affected themselves by the way our lives and our personalities are, or are not, developing well due to the way assistance is delivered.

6. Is the budget system generally accepted in your country, or is it regularly under the fire? What is the position of the care institutions, the trade unions, the political parties and the government administration? What is lying under fire and how do you respond to that?

Davy Gaeremynck (Independent Living Institute, Sweden): There is no obvious opposition from politics or trade unions any more, there was a big trend to de-institutionalize in the 1980's. The trade unions also defend the working conditions of their members-the assistants.

We notice budget moderation with the uniformed assessment "instrument", calculation of every assistance need in minutes and exclusion of inactive working time. Disability organizations opposed to this indiscrete questionnaire because of lack of sense of reality.

Lies van de Loo (Per Saldo, the Netherlands): Politicians are critical because some cases of fraud. They want more rules on what you can do with your budget. We are against that. We think that you must educate the budget holders on how to handle their budget. We also think that there must be rules for agencies about their services, not for budget holders. A quality mark will help budget holders.

There is also a discussion about the quality of care that budget holders buy. We say that the budget holder must determine the quality and no one else. But this is a very difficult discussion because in the Netherlands many people have a personal budget because they cannot be helped by the regular institutions and organizations and so they only can get the help they need by organizing it themselves through a personal budget. We therefore believe it is important that people can also get the help of institutions. We think it is important that people consciously choose a personal budget. This is only possible if you can also receive the help you need from an institution.

Further there is the problem of the size of the budget. The maximum budget now is 300 Euro per day. Living in an institution costs 150 Euro per day. So some politicians say that the budget must not be higher than living in an institution so the maximum budget must be reduced to 150 Euro per day.

Living the way you want to is now becoming a financial discussion and not your own decision. Of course we are not happy with that at all.

Jos Huys (Bol-budiv, Belgium): Not all recent developments are in favor of empowering care receiving people. On the contrary, the established collective assistance providers try by all means to

increase their quasi monopolistic share in the fastest growing sector of our economy: care for people.

One of the latest illustrations of their efforts was the so-called “Decree on care of 18 July 2008”. This decree makes every act (except on a voluntary basis) of assistance in activities of daily living, such as eating, bathing and dressing up, punishable by penal provision, unless the act is performed by a qualified and registered assistant or by an assistant who works only for one single user. The personnel however of the collective assistance agencies, recognized and subsidized by the Flemish Government, are legally presumed to fulfill the qualification criteria and don’t have to be registered. All the other assistants are outlawed!

Due to amendments to the original proposition, and after a fierce debate in the “Welfare Commission” of the Flemish Parliament, the personal assistants in the PAB-scheme have been excluded from the field of application of the decree.

However, the Flemish Minister of Welfare has announced a new initiative, the so-called “white book on reform of care”. The original version of this “white book” announced the end of the Flemish PAB-scheme and provided a transition period. Due to protests from organizations of people with disabilities, the proposals have been amended. In the actual version of the “white book” the Flemish PAB-scheme will be limited to “people who are able to run their own budget”, which means that children and people with intellectual disabilities will be excluded.

By way of conclusion: Flanders has not become the paradise on earth for people with disabilities. The majority of them still depend fully either on “voluntary” care by their relatives or/and the professional care organized by institutions. But a significant number of actual budget holders are ready to defend their life as a free citizen, that has been made possible by the direct payment scheme of PAB.

