



International Conference: Independent Living through Direct Payments

Expertise Centre Independent Living

European Network on Independent Living

3 June 2010, De Zwarte Doos-Gentbrugge

Workshops: “How does direct payment work in your country?”

Concept: *There are 4 questions per subject. We ask every nationality present to answer the questions. After all the questions are answered, we ask the participants to pick the country they would prefer to live in. We also ask them to motivate their choice.*

I. Legal base and enforceability of the support

Moderator: Koenraad Depauw

Report: Juliska Van Hauwermeiren

Questions:

1. Is there a system of Direct Payments in your country? How many people choose it? Are there people who don't choose direct payments and instead opt for service in kind, and why? Can you pay e.g. residential or homecare services with your budget?



2. Are Direct Payments (or Personal Assistance) a right? Is this right enforceable? If so, in which way (through court)? If not, are there initiatives to make this right enforceable in the future? Can you share experiences and give advice to other countries?
3. Who is entitled to Direct Payments? All people with a disability? Older people, children, people with learning disabilities, people with psychiatric impairments etc. What do you think of it?
4. How long do you wait between applying for support and receiving the support? Are there waiting lists and how do you deal with those?

II. Development of the Independent Living Movement in your country.

Moderator: Nadia Hadad

Report: Elke Decruynaere

Questions:

1. Is there an Independent Living Movement in your country? When did it start and how does it work today?
2. How did this movement contribute to an Independent Living through Direct Payments? Did this movement contribute to Independent Living in other ways?
3. What are the three main challenges for the future of the movement?
4. How can we deal with these challenges nationally and internationally?

III. Support in working with direct payments.

Moderator: Cor Van Damme

Report: Linde Moonen

Questions:

1. Is there a service (choice of services?) that gives support during working with direct payments? If so, how? Support only with the administration or also trainings for the employer? Is it possible to buy assistance/services/care there?
2. Is this support necessary/sufficient?
3. What is the relation between movement and services? Can you combine those?
4. Does the same service provider play a role in support-training of personal assistants? If so, how?



Conclusions of 3 workshops discussing “how does it work in your country?”

Peter Lambreghts: Introduction

Now we are going to make conclusions on the three workshops that took place this afternoon. I'm handing the microphone to the reporters of the workgroups.

Juliska Van Hauwermeiren: Legal basis and enforceability of support

I will give you the report of the first workshop on the legal basis and the forcibility of support. We were with people from Ireland, Sweden, Norway, Germany, The Netherlands, Austria and Belgium (Flanders, Brussels). We first asked if they have a system of direct payments in their country and how many people make use of it.

We started with Ireland. They said there is not really a system of direct payments. There is a sort of personal assistance, but it is provided through organizations and not many people are using it. In Norway there is personal assistance, about 5,000 people are using that. In Sweden there is personal assistance and also direct payments, there are 90,000 users. In Flanders there are 1,800 people using personal assistance. In Germany there are 10,000 and in the Netherlands about 100,000 people using it. In Austria there are also direct payments, but the number of people working with those is very small and the system is not well organized.

There was also a question about whether you could buy residential services with direct payments. Actually we had a kind of discussion whether it should be possible to buy residential services with a personal budget. Some people in our group said "No". Somebody said there had been a survey where they asked a lot of questions to people in residential services. Ninety-two percent of them said they were not happy there. Other people of the group said you need to have the choice yourself. If you want to buy the residential services with your budget, then it should be possible. There were two different opinions on this.

The second question was about the enforceability of direct payments in your country. In Sweden it's an enforceable right. In Norway also. In Germany it is an enforceable right, but the height of the budget and what you can do with it is arranged locally. In the Netherlands there is no enforceable right. Then we asked who is entitled to personal assistance? In Norway all people could use it. In Sweden also, although there are some exclusions, like deaf or blind people. In Flanders, people can use personal assistance, but there are also exclusions. In Germany everybody can use personal assistance.



Elke Decruynaere: Development of the Independent Living movement in your country

We had people from Belgium, Sweden, Norway, Germany and Ireland in our group. In all those countries there is an Independent Living Movement. The movement mostly started at the end of the eighties and at the beginning of the nineties and succeeded in lobbying for direct payments and personal assistance. Only in Ireland there are no direct payments.

Participants from each country gave a brief overview of the development of the Independent Living movement. Afterwards, we tried to draw conclusions from everyone's experiences and observations and formulate main challenges the Independent Living movement faces.

The main challenges are:

- There should be a change in view. The person with a disability is the one in the centre. S/he is the expert and knows best what his/her needs are. Nobody else can measure and say what kind of assistance you need and when; you know it best.
- Spreading the word, trying to get more people interested in the movement, especially young people! (Nowadays young people are satisfied, they don't fight, they don't feel like starting a revolution; they don't see a sense in doing so. A new revolution is needed);
- A EU directive with a definite, clear, single definition of personal assistance and direct payments. It should be in the constitution as a law;
- Fighting for the UN Convention;
- Fighting for the freedom of choice of your assistance, of choice of living space, technical help, portability of assistance;
- Fighting for full participation in the society – "It is not about enough assistance to survive, it is about full participation";
- Informing people with a disability and their representatives;
- Informing institutions about personal assistance and encouraging them into a change;
- National lobbying and national CIL are important;
- More research into economical aspects of direct payments – "We cost money but also save money!"



Linde Moonen: Support in working with direct payments

There are many differences between the supporting services in different countries. E.g. in Norway we have supporting services completely steered by experts by experience, people with a disability. In France these services are still in an early stage of development. In Germany, support in working with direct payments is an actual right.

Then we asked the people in the workshop if they considered this kind of support necessary and if it was sufficient. Most of them agreed on this being a matter of personal choice. Everyone has to decide for him/herself if they need this support, but there have to be enough possibilities to use this kind of support when needed. The government should provide these supporting services with the means to offer their services to the users for free.

We looked into the relation between movement and services. According to most of the people in the workshop being a movement and providing supporting services can be combined. As a movement, it is important to be aware of what is happening in the field and to stay connected with practice. Of course, there is a certain risk. Since you're a movement and a service, you need to divide your energy and find a right balance.

Finally, we asked ourselves if the training of the assistant can or must be done by the supporting service. Some of us thought that as a budget holder you must train your assistant yourself, but that it can be necessary or useful that first the budget holder is trained to do so. In this way the supporting service can empower the budget holder. The assistant can be trained to adapt the attitude that always leaves the person with a disability to be the central figure. The service that trains the assistants and the one that trains the budget holders shouldn't be the same, since you need very different capacities for each of them.

