



International Conference: Independent Living through Direct Payments

Expertise Centre Independent Living

European Network on Independent Living

3 june 2010 De Zwarte Doos–Gentbrugge

What is the Expertise Centre Independent Living by Chris Robbroeckx

History

At the end of 2007, **Adolf Ratzka** (Independent Living Institute, Sweden) and Jan-Jan Sabbe (budget holders association BOL-BUDIV, Belgium) came to the conclusion that there exist interesting practices of personal assistance in different countries. The problem is however that we do not learn from our mutual experiences. That is how the idea originates to found an expertise centre independent living.

Jan-Jan Sabbe thinks big and dreams of an Independent Living Centre where people can share experiences and find information, expertise, individual services, lobbying services. His dream comes true. At his own risk he engages an employee who looks into the possibilities for grants. Somewhat later he calls in the budget holders association BOL-BUDIV which presents a project for an expertise centre and starts lobbying.

1



When Jan-Jan unexpectedly passes away, BOL-BUDIV decides to let its employee finish the work. In July 2008 the Flemish government and the European Fund for Regional Development each give a grant of € 209.580 to this new initiative. The planning is further elaborated, an additional employee is recruited and later on that year the Expertise Centre Independent Living gradually evolves into a partnership.

What is the expertise centre independent living – mission statement:

The Expertise Centre Independent Living was launched in February 2009. The centre gathers knowledge about direct payments for the support of disabled people. Direct payments are a powerful tool in that sense that people can dispose of an own budget which enables them to control the care instead of depending on it. Our mission is to become the expertise centre ‘par excellence’ concerning direct payments. Our goal is the empowerment of disabled people so that they may lead an independent life.

The Expertise Centre is a cooperation which is now supported not only by the budget holders association BOL-BUDIV but also by other Flemish organizations like: GRIP, VFG, Focus op Emancipatie and Onze Nieuwe Toekomst. Academics cooperate as counselors in this Expertise Centre. The Expertise Centre is subsidized by the European Fund for Regional Development and the Flemish Minister of Economy for a two-year period.

We carry out research on PAB (‘personal assistance budget’) and PGB (‘personalized budget’). We closely monitor the evolutions in Flanders. But we also have been looking beyond our own region. We gather expertise about good practices abroad through a network of experts.

All this knowledge is used for political lobbying and is also made public. We disseminate the results of our work via our website, research reports and a newsletter.

The newsletter and website are not only available in Dutch but also in English and partly in French. The idea is to go international. That is why we are closely cooperating with the European Network on Independent Living ENIL, with the Independent Living Institute in Sweden, with Per Saldo (budget holders association in the Netherlands) and why we are actively participating in international conferences (25 years of Independent Living in Sweden, Freedom Drive in Strasbourg, Day of PGB in the Netherlands).

Common vision

- Our focus group consists of all disabled people.
- The centre is mainly led and controlled by disabled people or persons who are directly concerned. This also goes for the personnel and the executive committee.
- We acknowledge the importance of peer counseling, by which we mean the expertise gathered through daily living with a handicap.
- We promote the concept of peer counseling: a mutual exchange of information and advice between disabled people who find or have found themselves in the same situation.
- We fight discrimination of disabled people.

Most importantly - we promote working with direct payments. This means:

- The budget is personalized and is destined for the disabled person (or his/her representative). The disabled person is thus the budget holder. The subsidies no longer go directly to the care providers.
- Disabled people can freely determine the amount of control they exercise over their own assistance; assistance which corresponds with their needs, abilities, actual living conditions, preferences and desires.
- This freedom of choice also includes the right of the disabled person to determine the content of the assistance all by him/herself. The budget holder decides who is to work as an assistant, for which assignments, at what time and where and how the assistance is to take place.

What have we been doing over the past two years?

In June our first project period is coming to an end. Today we present you the results of 2 years hard work!

What we did:

- We wrote a first report entitled "Direct payments in care. Actual situation in 8 European countries" which was published in February 2008. It contained an overview of the way direct payments are organized in the Netherlands, Germany, Sweden, the United Kingdom, Spain, France, Norway and Finland. This report was presented in September 2009 in Strasbourg.
- After that we made info sheets about Ireland, Italy, Slovenia, Switzerland and Wallonia with the help of several experts of direct payments in these countries.
- We focused on how direct payments are organized in the Netherlands, with the help of the Dutch budget holders organization 'Per Saldo'.
- The Independent Living Institute made a profound analysis about the practices of personal assistance in Sweden for the Expertise Centre Independent Living.
- We made several reports about the personal budget experiment in Flanders.
- We did research about market forces in the support of disabled persons.
- Together with the University of Ghent we researched the quality of life of people using personal assistance.

A lot of the information will be discussed today, but you can also find these reports on our website.

What can you expect from us in the future?

Through the last years we have been focusing on research. The next two years, we want to focus on the following issues:

- Economical aspects of direct payments;
- Disseminating the knowledge towards the Flemish audience through trainings, info meetings, publications in Flemish media;

3



- Creating a user cooperative in Flanders;
- Lobby work in Flanders;
- Gradually we want to focus on an international working, European networking and dissemination of the information towards European organizations. After those two years we want to become an internationally oriented expertise centre.

In a brief summary - the Expertise Centre Independent Living would like to become an international expertise center on direct payments and the situation of disabled persons in different countries. By doing so, we believe we will be supporting people with a disability in their rights for freedom of choice and for a dignified and independent life!

