



International Conference: Independent Living through Direct Payments

Expertise Centre Independent Living

European Network on Independent Living

4 June 2010, De Zwarte Doos-Gentbrugge

Conclusions and acknowledgments by Viviane Sorée

Dear colleagues,

I'm tired but satisfied and proud. During those two days we listened and debated intensively. We've got to know each other a little bit more. We are equal, we inspire each other and we reinforce each other.

Yesterday I opened the international conference, today I'm closing it. My final task is to summarize your expectations about the future goals of the Independent Living Movement and the Expertise Centre Independent Living. I thank Jamie Bolling, Elke Decruynaere and Patrick Vandelanotte for borrowing their notes.

Challenges for the Independent Living Movement

There must be a mindset change. The person with a disability is the one in the centre. S/he is the expert and knows best what his/hers needs are. So nobody else can measure and say what kind of personal assistance and how many of it you need. You are the expert.

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It is not about having just enough personal assistance to merely keep your head above the water, it is about full participation in all the domains of life.

Challenges

- To reach more organizations and more (younger) people by spreading the word. In turn they will spread the word.
- To give information to institutions with influence to close them (de-institutionalization!).
- To fight for the UN Convention and a EU Directive for Independent Living including the right to personal assistance through direct payments, with one clear definition (see ECEPA), otherwise everybody will have his/her own definition. It should be in the constitution as a law. Concerning the UN Convention: elaborate shadow reports about the implementation.
- A European standard for personal assistance – A HIGH standard?
- To gain and disseminate knowledge about how to start with lobby work towards the politicians, administrations.
- To fight for the freedom of choice of your assistance without imposed qualifications, where you live and what you do. FULL PARTICPATION IS THE STANDARD.
- Choice of living space (accessible housing), technical aids (a personal budget), portability of assistance (EU Directive of free movement of goods and services) are the keystones of Independent Living.
- A national system of personal assistance is very important.
- A national Centre of Independent Living is important.
- To organize training for young people (e.g. a summer camps) so that they become acquainted with the spirit of the movement and well-informed.

Challenges for the Expertise Centre Independent Living

- The center itself has a goal of becoming an international center for research on Independent Living issues.
- Research on disability issues should be carried out through Disabilities Studies with disabled people as partners through all phases of the research process.



- Studying economical aspects of direct payments, such as return on investment (more active and healthier people and families), budget provision and strengthening the consumer healthcare market.
- Giving training to people with disabilities, organizations, service providers that want to undertake in 'healthcare market'. We will organize seminars, publish in journals, invest in smart communication.
- Gaining expertise in writing policy proposals for direct payments.
- The Expertise Centre Independent Living is 'officially' recognized as a centre of expertise.
- To continue to gain and disseminate (practical) knowledge of innovations in care
- To initiate research and create spin-offs.
- Focus will be also increasingly shifted to a European cooperation (e.g. Building a European Network).
- Gathering and disseminating the evidence-based practices on IL.
- Studying proper work conditions for personal assistants.

Pitfalls

- If the government does not move.
- Often the lack of awareness by the authorities and politicians. That's why the organizations of people with disabilities have to lobby for political participation ("nothing about us without us").
- If our 'needs' can be used for 'profits', this can turn against us. The systems of direct payments can't be exploited for profit, this is socially unjustifiable.
- Gradually, the new generation of people with disabilities don't live in institutions. Compared to the pioneers, who revolted against a life in institutions, the younger generation is often content with their situation and lack a big motivation.

This was the overview of the challenges facing the movement and the Expertise Center. This list is not absolute and can be completed.

You don't have to wait to elaborate ideas etc. until we see each other again. Contact us with your questions, proposals, comments now!

THANKS!

I want to thank you all for the cooperation and in particular I want to thank all the members of the Expertise Centre Independent Living and budget holders organization BOL-BUDIV for their efforts. Without them, this conference wouldn't have been possible.

I wish you all a safe return and I hope we see each other again!

