

International Conference: Independent Living through Direct Payments

Expertise Centre Independent Living

European Network on Independent Living

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“Is working with Direct Payments less expensive?” + “as a consumer on a care market ” by Peter Lambrechts

For the next hour I will bring you a presentation with the double title: “Is working with direct payments less expensive?” and “as a consumer on a care market”

Before I further explain the reasons for this title and this topic, I would like to tell you a little bit more about myself. Not because I like to talk about myself so much, but because of two specific reasons. The first is that when I am listening to a certain speaker, I always like to have a view on the person who is speaking. I am not satisfied when the speaker reveals nothing more than his/her name. The second reason why I like to open with some personal information, and you have to forgive me for this one, is that it gives me the opportunity to show a slide like this ...

This is me and my beautiful wife and my two little princesses in our own garden. I’m very proud of my girls, that’s why I like to show off a bit with this nice picture. I’m 38 years old and grew up in Antwerp as the oldest son in a family with 4 children. I enjoyed an inclusive schooling and education ‘avant la lettre’. I always organized my own support and assistance thanks to my very lucky situation. By lucky situation I mean that I was always surrounded by a strong family that supported me in many

ways, also financially sometimes, and I also have a big network of friends. I 'automatically' did very normal things for an average guy from Antwerp: I studied, made friends, fell in love, bought a car and an apartment. I became father of 2 lovely girls and I was team manager in a call centre for many years. The last few years I started working for organizations for people with a disability. I was becoming more and more active and very busy as a volunteer, so I decided to become professionally involved.

My motivation, what really drives me, is that I witness with my own eyes that in our society many people with a handicap are made unable to achieve these rather normal things for an average guy from Antwerp. To be able to proudly show a picture like this one is for many of us a utopia. To be honest I can only see 2 important factors which explain this difference. One is that my young parents were stubborn enough to raise me by themselves against the doctors' advice to place me in an institution. The second is that I am one of the lucky few in Flanders who are granted a Personal Assistance Budget. That brings us back to the topic.

Is working with direct payments less expensive? Of course, we mean less expensive than care in kind. Let it be clear that we want to compare direct payment schemes with the more classical way to support people with a handicap through a subsidized institute or service. This is not an easy comparison. Since we agree, or at least I assume we agree, that the means to pay for the support of people with a disability are a matter of solidarity and have to come from the social insurance and the welfare budget of our country, we have to make the comparison on that level. We're comparing the costs and the benefits of direct payments with the care in kind on a nationwide level. Maybe in the future, when the impact of Europe on its nation members keeps growing, we'll have to make the comparison on a European level. It comes down to the question what is the less expensive, or most advantageous policy choice a government can make concerning the support of its citizens with a disability. Naturally, this choice depends on certain standards. I can surely find examples of cheaper ways to deal with citizens with a disability if I look at medieval society, totalitarian regimes or third world countries. But those solutions are (luckily) not relevant here.

So why should we compare direct payments with the care in kind from an economical perspective? Is it a good question? Is it a dangerous one? I have heard different opinions on this among people with a disability. Some of them, even some I consider very intelligent or wise, seem to be afraid to even open this discussion. When I ask them for clarification, they usually say that such a question and comparison should be made by the government. That it is not our job. That we should only emphasize the benefits of direct payments for people with a disability on our Quality of Life, on our independence, on our participation in society, on our self-determination and so on. I agree that this is the most important reason to choose for direct payments systems. But aren't we a bit naive to expect from our government to look at it in the same way as we experience it? Traditionally, organizations for people with a handicap always ask for more money from the government. At least, in Belgium that is. And that is correct; we do need more money. But isn't in our own interest that the money we get out of the social insurance is spent in the best and most efficient way?

I believe we can use economical and financial arguments in our plea for direct payments. We can use these arguments to sustain direct payment schemes or to realize a shift towards them. Jan-Jan Sabbe, which some of you might have known, wasn't afraid to say, or even to declare that direct payments are cheaper to society than care in kind. Why was Jan-Jan so convinced about this? I think



the answer is simple - he reflected out of his own point of view and could see what direct payments meant in his life. If I make the comparison between care in kind or direct payments applied to my own situation the answer is clear. Now I'm able to be a full member of our society. I go to work and pay taxes, I'm a consumer like everyone else, I contribute in many ways and will even raise two children who will contribute to our society too. If I was denied an assistance budget, I would have to struggle in the margin or would have to live in an institution. I would be condemned to a poor life for myself that would certainly be expensive to my society.

We can use these kinds of arguments because we, as budget holders, are the living proof that direct payments are more advantageous to society than care in kind. We can testify from our own experience. We and our families are the real experts on living with a disability. Therefore, we must get recognition. Our experience and opinion on this should be heard and taken into account. Until now, too often persons without a disability or without first-hand experience made their opinion stand above ours. We also have to deal with the problem that argumentation out of our experience as a disabled person can always be set aside as just one personal experience. Often we hear that what we claim can be true for us in person, but not for all people with a disability. Doesn't it sound familiar to you - somebody saying something like: yes, working with direct payments may be good for you, an exceptional strong person, but this isn't possible for the most people with a handicap, they're simply too weak for it.

Quality of Life arguments alone are also not enough to win a debate most of the times. Actually, they should be. But the simple truth is that this concept is not known or not known enough by policy makers. I don't think that with proving the positive effect of direct payments on the Quality of Life alone we will change the general opinion or realize a policy shift. It's certainly very valuable, but probably not enough on its own.

Saying or proving that direct payments are cheaper to society than care in kind is a winning argument in a debate. Our personal experience as disabled people or our quality of life, are - bluntly said - only a real matter for people with a disability themselves. But an efficient use of government money is a real matter for everyone. This is something everyone is sensitive about, especially in times of economical crisis. If it is true, and if we can prove that it is cheaper supporting us with a personal budget instead of spending money on care in kind, we will make this policy shift happen. At least, that is how I see it.

Our goal with the Expertise Centre Independent Living is to empower and emancipate people with disabilities and we see direct payments as a key element. Gaining full control over your own support and assistance is essential for independent living. If we can use financial arguments in favor of direct payments, we certainly have a strong argument against any opposition. But we must know what we are talking about! Comparing direct payments with care in kind is not easy at all, because the outcome is very different. If you narrow the comparison down to the effect on the macro budget for care and support of people with a disability, it is not an honest or correct comparison. Although even then there might be a clear efficiency profit. If we take into account the effect on a whole subgroup of the population of having access to a personal budget, which makes it possible to live a fuller, more active and more productive life, the potential profit, and benefits for society are immense. We have to find ways to bring the repay to society on all levels into scope and into account.



The Expertise Centre Independent Living is very aware of this, that is why I got the task to look at the policy on the support of people with a handicap in Flanders from an economical and financial perspective. I had the time and means for literature study, to go and speak with economists and to build up knowledge and insight on this 'economical approach'. It struck me that there were very few economists to be found who really did some research on the organization of the support of people with a handicap. I found health and welfare economists, but they usually specialize in things like hospital efficiency, support of the elderly or the effect of generic medicines, to give a few examples. They did show a lot of interest in the subject, and most of them were shocked to learn how inefficient the support for people with a disability in Flanders is organized.

So a first very clear and surprising finding is the enormous gap between economics and financial science and the world of people with a handicap, disability studies, and so on. In fact, in Flanders that is, people who are highly regarded as experts in the field of policy on persons with disabilities, make statements on the cost effectiveness of direct payment systems. But their statements are arbitrary and not based on any economical theory or knowledge. They often believe or fear that Direct Payment schemes are expensive and uncontrollable. Here we are confronted with the lack of research, especially economical research on this topic. That is why we need to initiate research and bring in the expertise required. We need to narrow the gap between two worlds, as illustrated on the slide.

An excellent opportunity to make a position statement on this topic in Flanders occurred about a year ago. In the run-up to the 2009 Flemish elections, market forces became also in our region an important topic in the debate concerning the waiting lists in the disability care. In those debates it became clear to us that, just like it is the case in the international polemic regarding this subject, terms such as market forces, privatization and commercialization are not always used in an unambiguous way and moreover carry a certain ideological load.

So the first thing we did in our economical analysis was getting the terminology clear. We wanted to look with an open mind at the situation, free of political preferences or ideological prejudices.

This article: "Market forces in the support of disabled persons: Position statement" was published in January 2010 and you can download it on our website. I'm not going to present this article in detail here. Some of you might have already read it. Some parts, for some of you, will perhaps focus too much on the Flemish situation. I'll bring the aspects which are internationally relevant.

On an international level, the affordability and efficiency of public services in the public health care sector is under discussion. Sometimes the end of the 'modern welfare state' is even mentioned. The aging population and more recently the economic crisis have only sped up the demand for efficiency and suitability. Discussions about a receding state and the implementation of market forces in the public health care have an impact throughout Europe. What I learned very quickly while studying and reading on this topic is that, whenever someone makes a general statement pro or contra market forces, their goal is not to find the best solution for a problem or that they generally don't really know what they're talking about. It's usually politicians who tend to do that. For every different public service you need to analyze how it is organized in that specific country or region. On the basis of that analysis you carefully consider if it needs more government control or more mechanisms of



the market. And also which kind of market forces we need to apply or how exact and how far the government control needs to be in effect.

That's what we did concerning the support of disabled persons in Flanders before making our position statement. Before I show the next slide, let me do a small experiment. I'm going to ask you all a few small questions: who is proponent of market forces in the support of disabled persons? Who is in favor of market forces in our care and support? Please raise your hands. Now, who is in favor of direct payments in the support of people with a disability? Please raise your hands. Are there people here who raised their hand in favor of direct payments but who didn't raise their hand, who are against market forces in the organization of our support? Yes ... please raise your hand?

Well, in fact if you are in favor of direct payments that automatically implies that you are pro the use of market forces in the support of disabled people. Direct payments are indisputably a form of demand financing, which is a way to apply a certain market force mechanism, namely demand steering. When reading on economics and the application of free market mechanisms in public services to make them work better and cheaper, it struck me that one of the mechanisms described was called demand steering. I did hear that concept many times before. Every professional in the care and support of persons with a handicap in Flanders agrees that demand steering is the way to go. They all want to deliver demand steered, or at least demand oriented support, at least that's what they say. Every politician or policy maker dealing with these topics in Flanders will agree without a doubt that we should leave supply driven support and realize a demand steered care and support. I wonder, and even doubt that they realize this kind of statement in fact means that they are in favor of a complete shift to direct payments. Because it is a simple fact that in economical theories a demand steered support implies that we give the demand side, being people in need of support, the means to steer the suppliers. Those means being a budget, and the freedom and possibility to maximize this budget in a market. From an economical point of view this is very clear, but for people busy or working in the sector of disability care, this is often a completely new insight. And the little experiment just showed us that this is also true for people with a disability themselves, that it is a new insight for us as well.

It is somewhat confronting for Flemish professionals in the support of people with a disability and even more for the policy makers if they are made clear that the only demand steered possibility in Flanders is the PAB, the Personal Assistance Budget. The PAB is kept small by our government. There are only 1,830 persons who are granted a PAB, more than 35,000 persons get care in kind. About 24,500 of them get their support and care by residing in an institution or staying in a day care centre. About 10,500 persons receive subsidized support at their own home. It is important to understand that support is not a right in Belgium or Flanders. You have the right to ask for support and to get an assessment to see if you are entitled to it. If you are entitled to it, you get a positive decision. Only this decision doesn't give you any support in any way, it only says that you are now on a waiting list. There are about 19.000 persons on the waiting list for the different forms of care in kind and over 5,300 persons waiting for a PAB. Our system works with a closed macro budget for support of people with a handicap. It is the government that plans and controls all of this. Annually they decide how many new recognitions they allow for each form of care in kind and for the PAB. The share of demand steered support possibilities is kept very small in Flanders.



It's very clear that we have a serious problem with waiting lists in Flanders. Several ministers of welfare, who are responsible for this, successively promised to solve the waiting lists. They managed to increase their macro budget, they created more support, but they didn't change their approach to the problem and the waiting lists kept on growing. Our latest minister tells us that he doesn't want to make false promises and he is not going to make the waiting lists disappear. He gives in. Can we call this government failure? Modern states like ours put themselves certain goals regarding care and support that they have to guarantee for those who need it. Generally these goals are summarized in 3 words: accessibility, quality and affordability. To me it's clear that we don't reach these goals. If accessibility was guaranteed, we wouldn't have these structural waiting lists. If demand steered support is so marginal in Flanders, we can certainly put question marks behind the aspect of quality. If this system was affordable, then why do we deny support for all those people in need on the waiting list? It is clear this is a case of government failure and the classical answer to such a problem is the application of market forces. This doesn't mean we have to leave everything over to the so-called free market. Blind belief in market forces has led in certain cases to serious problems too. As well as government failure there also exists market failure. What we, with the Expertise Centre Independent Living, propose is a regulated support market with direct payments as a solution for the situation in Flanders. Remind yourself what I've said a few slides ago. That it's never intelligent to be in favour or against market forces without careful consideration and analysis of the specific situation.

A most helpful source that I encountered, studying on this topic, was from a specialist on government policy from the Netherlands, called Delroy Blokland. You can see in the article I wrote that his assessment tool and decision tree are very useful tools on deciding how to apply market forces. In fact he names the PGB (direct payments scheme in the Netherlands) as an example of a successful application of the market force demand steering.

On the next slide we see a visual representation of the idea of a regulated support market. What do we mean by that? We have 3 different parties on this market. We have the suppliers of the support, who are now mostly the people still working in the traditional institutions. But also there we see development, we see more and more people in the institutions who try to work in a more person-centered ways. I'm not going to say that it's demand-steered, but it can be called demand-oriented in a number of cases. So, maybe we should try to make partnerships and go into dialogue with them in order to find balance in this support market. We also see in Flanders there is a growing attention for what they call clarification of needs/demands. This is a new concept that actually helps a lot in order to have people with a disability consciously reflecting on their life. What are my goals? What do I want and how will I manage to get there? The way to reach these goals also gets more and more attention; it's what they call 'trajectory support'. So, we see a shift also with the people working in the traditional setting. They learn about new paradigms and views on disability. We often used to see them as enemies, but perhaps we can find allies there.

Then there is the next corner on the figure here, people with a disability themselves. A regulated support market means that we are the ones in control, that we actually steer the support. This means that we can do it, that we are able to, and also that we are the ones that should do it and who are responsible. According to the Independent Living philosophy this seems perfectly normal, but it is still a revolutionary idea that people with a disability are responsible and capable of controlling their own support. For this we have to get into dialogue with the suppliers of support. But we also have to



make true what we say. We can claim to be capable to steer our support, but we also have to actually do it!

The third corner of this regulated support market is the government. This being the policy makers, but also the administration who has to execute the policy. In Flanders this administration is still a very strong barrier against a real shift towards direct payments. In a regulated support market the government has to let go of its absolute control. The government should play another, more facilitating role. They should give us all the information we need to organize our support in the best way, so that the possibilities and its consequences are transparent. We also need them to guard the right balance in the support market and adjust it when necessary. If we allow commercial players on this market, we need them to live up to certain standards and to follow some rules. This is where the government has to play an important role, as a regulator in an open dialogue.

This brings us to the second part of the title of this presentation: “As a consumer on care market”. If we compare the role of a person with a handicap who receives care in kind or who works with a personal budget we can certainly see direct payment systems as an upgrade. Instead of the passive, helpless person in need, we become a consumer on a care/support market, it’s certainly an upgrade. With direct payment schemes we even become more than a client; we become employers.

We have to ask ourselves: “Are we ready for it?”. We certainly see a lot people with a handicap who are ready for it. But are we all ready for it, as a group? Are all people with a disability ready to take up that role and what do we have to do to make sure all people with a disability are ready for it? How can we reinforce ourselves as a group? Do budget holders take a special part in this, are they a kind of pioneers? We can see in Flanders that people with a PAB have to find out a lot of things by themselves, that they have to find solutions for difficulties by themselves. They are creative and pave the road for other people with a disability. Those 1,800 people with a PAB in Flanders had to learn how to find assistants, how to deal with the administration and the consequences of becoming an employer and so on. Luckily there are budget holders organizations like BOL-BUDIV to offer some support and to help with a lot of these matters.

If we reach this policy shift and can create this care market, how do we deal with commercialization? How do we prevent that it becomes a market which is too free? Do we want money from the social security to be used only to make profit? If not, how do we control and prevent it? We have to think about that and find strategies and tools to limit the profit or the excesses. We have to make sure the profits are reinvested in better support of people with a disability. If this market situation becomes a reality we, as people with a handicap and our organizations, need to be ready to play an active role in this market. Should we already prepare and set up the constructions to be able to act in this support market? I think it’s important that we start our own cooperatives or firms for social entrepreneurship, that we anticipate. If not, we can expect big commercial players trying to manipulate the market, limiting our freedom of choice and to take the place that should belong to us. What do we expect from our government in this new situation? Do we only want them to give us a budget and that’s it? It’s important that we make this clear, that we think about this and list it up. We have to make sure that we are heard.

So, there are a lot of considerations and questions to discuss and to contemplate on. It brings us to the next question, “do we need more research?”. We really need a big scientific research project



which answers this question – are direct payments less expensive than care in kind? The research also needs to listen to the indications and knowledge people with a disability can distill out of peer counseling as experience-experts. We can also use knowledge out of disability studies and see that concepts like Quality of Life and the shift towards an inclusive society and the support paradigm are taken into account. But we certainly need to include economical specialists on different areas, sociologists, experts on public administration and public policy, maybe even lawyers or political economists. A research which is strongly scientifically based and multidisciplinary like this one will take easily 4 or 5 years by a broad team of specialists and will cost a lot of money. If we want this to be an international study, all of it even becomes more complex and more expensive. On the other hand, a strong report which answers in favour of direct payments on an international level is even more valuable.

For the Expertise Centre Independent Living initiating research like this is a real challenge and objective. Finding the right partners and funding for research like this is not easy. If we want to lift this to an international level we need to find more international partners and funders. The research the Expertise Centre already carried out on the different use of direct payments schemes throughout Europe and the international contacts we have with organizations like ENIL and others, makes us a valuable partner for research like this. In fact we could convince our governments, on a national, but also on a European level that it is their role and responsibility to invest in research like this. It surely strengthens their policy or shows them the way in which their policy on people with a disability should be steered. The consequence is of course that we lose partial or complete control over the research then and that we cannot guarantee that the right scope is held on, on all levels.

I'm going to end this presentation by reading an excerpt of a text written by Dr. Adolf Ratzka. We hoped Adolf could be here with us during this conference but unfortunately he couldn't make it. So to make up for that I will read you - to my opinion – one of his most inspiring speeches, titled: "Independent Living for people with disabilities: from patient to citizen and customer". It's a part of his keynote speech at a conference in Barcelona in 2007 in commemoration of the 25th anniversary of The Spanish Law for Persons with Disabilities.

You can find the whole text on the Expertise Centre website, in publications.

The part I will read is relevant to the topic of this presentation. So ... I'm reading you Adolf's words now:

"Breaking the culture of dependency: cash payments instead of services in kind

Most countries pay more money for keeping someone in an institution than for enabling that person to live in the community. For example, the recent Spanish Ley de la dependencia pays € 2,500 a month to an institution per person but only € 780 to an individual for contracting personal assistance services in the community. Could one explanation be that charities running institutions can afford to spend more money than their inmates for lobbying?

The Independent Living Movement aims to replace state support in the form of services in kind by state support in the form of cash payments. In such a solution, cash payments enable users to buy services in the market from the providers of their choice and to custom-design their personal assistance according to their individual needs and personal preferences (that is the reason why call them "personal" assistance services).

Payments are based on needs in terms of the number of assistance hours and not on the type of service provider that delivers the services. Thus, the same amount of money per hour of service is paid to the recipients of the cash payments regardless of whether their service provider is public or private, for profit or not for profit, whether recipients join personal assistance cooperatives or employ their assistants themselves.

Breaking the culture of dependency: demand-driven instead of supply-driven services

In Sweden, we have had such a system of cash payments since 1994. There is now a market consisting of about 14,000 assistance users, 300 local governments and some 450 private entities that provide services, with altogether 70,000 personal assistants. The market is driven by the demand from assistance users. Providers compete with each other for customers using service quality as a weapon.

Before the reform, the local government's budget determined how many hours of assistance were to be allocated among how many assistance users. Users had no choice as to which persons would work for them, when, with what tasks and how. It was a supply driven service, the local government was the only provider and quality of services was not even mentioned. Service users were forced into a passive, powerless role with no responsibilities.

Today, recipients of the cash payments are entrusted to make decisions in their own best interests in selecting the services that best fit their needs. Persons with cognitive or psychiatric disabilities are supported in their consumer role by relatives or friends. In fact, a large assistance user cooperative consists exclusively of persons with multiple disabilities including learning disabilities. They run and control the organization and direct their personal assistants with the help of their legal representatives. Before the reform, we used to be called "the weakest of the weak". Now we are customers and employers. It's been a real revolution!

Breaking the culture of dependency: de-regulation promotes competition and quality

In most countries, assistance with the tasks of daily living cannot be called a "market", since the number of sellers of services is restricted to a regional monopolist or oligopolists and consumers are not free to choose. The numbers of assistance hours a given provider produces is determined by the budget and not by the customers who prefer one provider over another on the basis of service quality. No matter how poor the quality, providers will be assured that all assistance hours produced within the budget are used up - assistance users simply have no choice.

A similar situation existed earlier in Europe's telephone market. Regional or national monopolies effectively blocked technological changes, productivity gains or quality improvements. The accelerating innovations for telephony users within the last decade are not due to technological advances but to the European Commission's de-regulation of the telephony market. Without the abolition of national monopolies consumers would not have been free to choose among a multitude of new service providers who compete for customers by employing the latest technology for better quality services at lower prices.

I would like the Commission and national governments to also de-regulate services for persons with disabilities. Tax money spent on today's monopoly or oligopoly providers for assistive technology or assistance would yield far greater efficiency and user satisfaction, if it was paid out in the form of cash payments to users. Only then we would have a demand driven market with its advantages.



A democratic society is based on the principle of citizens' freedom of choice as voters. A modern interpretation of democracy would extend this freedom of choice from the voting process to the market of goods and services. In most areas of life our society trusts in its citizens' ability to make decisions in their own best interest. It is time that disabled people too are recognized as full citizens with full freedom of choice not only on election day but also as customers in the market place. "

We end with these wise words from Adolf.

Thank you all for listening.