



## **International Conference: Independent Living through Direct Payments**

**Expertise Centre Independent Living**

**European Network on Independent Living**

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**Asking Linde Moonen and Anja De Greve questions about the research they conducted on Quality of Life and Personal Assistance Budget in Flanders, Belgium**

**Linde Moonen, the researcher:**

OK, if there are any questions, they are very welcome now! Maybe when you ask a question, you can also add to whom the question is directed. To me or to Anja.

**Question - Jamie Bolling from Sweden:**

It's Jamie Bolling talking. Thank you very much for your report on this research. It was very interesting. I'll start with a couple of comments and I'll have a question at the end. It was interesting to see that there were more women, because a lot of researchers have showed that there are more men needing support. I was very glad to hear that there was participation of experts in all different stages, because there is too much research going on where they are just using us as a reference group and not allowing us to be involved at all levels of a research. And I was also glad to hear that there is the right perspective, because that is what our research needs to be about. Because there is

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too often this description of our lives. I can understand the ladies saying: “why do you ask this question about going to the toilet?”. I think we are all a bit tired of hearing that. Somehow there is a paradigm that allows them to ask us questions that they don't ask other people about. We need to get around that paradigm somehow, I'm not sure yet how. We need to be aware of this paradigm, because somehow I feel that the research the governments ask, slows down the process. We are always just trying to justify why we need personal assistance, rather than more looking at how society can change and how we can make these changes, so that it becomes a society where we want to live in. Then the question that I had... There was one comment: “I feel less dependent from support offered by friends and family”. Does this mean that they feel less dependent when they get help from their friends and families or not?

**Answer - Linde Moonen:**

No. Most people noticed that they don't need as much help from their friends and family, because they have a personal assistant now to help them. When they want to, of course.

**Jamie Bolling:**

Thank you, that I misunderstood. I also observed that you describe this research very much from the family perspective. I don't think we talk about the family perspective that much in Sweden. So it was interesting for me as a social anthropologist to hear this dialogue.

**Question - Peter Lambrechts from Belgium:**

Hello, I'm Peter. I have a question for Anja. You explained to us that being a researcher and being a person with a disability as well, was sometimes a disadvantage, because you were too much involved in it. You described that sometimes you had a bad feeling coming back home about somebody else with a disability and the way he or she had to live. Do you think that it is a threat, some kind of a danger, to the accuracy of the research? Or do you think it's a threat to the researcher herself/himself?

**Answer - Anja De Greve, the researcher:**

To the researcher herself/himself. If you are too much involved, you can not find rest when you are at home. You cannot sleep at night.

**Peter Lambrechts:**

Thank you. I wanted to be sure that I understood it in the right way.

**Linde Moonen:**

If I can make a conclusion . There was a lot of discussion in the research about the question: should we use people who are experts by experience in research because of the reliability of the results? We think that in this study it's all about the opinion of the people themselves, so it doesn't really matter who interviews you. We also think it's an advantage that the people interviewing you know what you are talking about. So reliability was not really an issue here.



**Peter Lambrechts:**

Maybe it's an advantage. If I may talk out of personal experience, I will rather explain how I use the toilet to another person in a wheelchair than to someone in a white coat behind a desk.

**Question:**

Did you have the problem that the persons with disabilities don't want to answer or don't want to answer in a correct or moderated way, because they feel over-researched? I'm asking this because I'm definitely over-researched. Last week, I had an interview with all questions about going to the toilet with visual impairment, paying the bill with visual impairment, and so on and on. I think it's hard and I also feel there is already a huge amount of research on topics connected with handicap. I think we should pay attention to which aspect makes sense to make research about. We should be aware that personal assistance is nothing else then support in everyday life. And then we are talking about everyday things, so not about very special things. Or do you have other experiences?

**Answer - Anja De Greve:**

It's right that some people noticed that they have already answered questions like this when they had their budget assessed in the beginning. When personal assistance with direct payments was introduced in our country, the authorities also asked to do research. Some people of the sample are in both investigations. They asked me why they had to answer these questions again. They said: "Ten years ago, I already said that a personal assistance budget was very useful to me. So why are there still doubts about the usefulness of this? That is not the question. The question is: how can you support me to get a good employer and to find the right personal assistants?" So I agree with you that we have to be very careful to ask too much from people with disabilities and to see them as objects of a research.

**Answer - Linde Monen:**

I agree with that, but the problem is of course that all the information is not centralized. You can not ask: what did the people already tell in other research and can we use this data for our research? They will never do that, so we have to ask it again. But I agree that it's sometimes difficult to tell again and again about your household, how many people live there, and so on. In this investigation of course we wanted to listen to the people. We asked them: "how is your life and what do you need?" So I hope there was a little bit of a different perspective. And after that we asked: "how many people live with you and what are their needs?"

**Bente Skansgård from Norway:**

I'm Bente from ENIL in Norway. I just want to say that I agree with the people. My Austrian colleague says that there is a lot of interest if there is something new. In Norway, I think there was a research institute that wrote some 20 reports on personal assistance, because it wanted something new. But we got more and more aggressive with the institute, because they are not disabled people and they are not really on our side. They are just observers, we don't need them. And then I had a question for



Linde about quality of life of the respondents. On the PowerPoint it says: “observed minimum” and “observed maximum”. Have you observed the people? It sounds like that.

**Answer - Linde Moonen:**

No, it's about the elder people. We noticed the highest score on this domain and we called it the “observed maximum”. From the 84 people the lowest score on personal development we noticed or observed was 6, that's the absolute minimum it could be. The highest score could be 18, but the highest we noticed was 17. In each domain you can score between 6 and 18.

**Question – Bente Skansgård :**

But how is a score of 34 then possible?

**Answer - Linde Moonen:**

34 is a factor about two domains. It could be between 12 and 36. The other two domains are social participation and well-being. The score there can be between 18 and 54. So it's not an observation, because all the people answered for themselves.

**Viviane Sorée from Belgium:**

I want to say three things. Firstly, it's very interesting to see that personal development has a very low score. And did you ask what the reasons for this are? I think we already know some reasons: the education, the employment because these are important factors of personal development.

Then, I don't agree with the fact that because you have a disability, you are less reliable as an investigator. Every investigator has his own ideas, his free judgment. You only have to be honest about it. That we call intersubjectivity. The third thing: it's a very important result or fact that the amount of years you are working with the PAB has an influence on your quality of life. This means that people have to learn to work with the PAB.

**Question from Austria:**

One other question regarding the investigation. You said, thanks to personal assistance, people have the opportunity to live more independently, away from home and friends. Did you have the opportunity to talk about the fact that people with a disability could have the opportunity to employ, to give work to their friends? In Austria, there are a lot of people who investigate their friends, because they say: my friend helped me without payment, he knows me well, so I don't have to explain each step he or she should take. Did you have experience or comments?

**Answer - Linde Moonen:**

We asked the people: “what was your relationship with your assistants before you employed them?” Then we noticed that half of the people who were employed were not known by the person before and the other half were known, so they were family, friends, neighbors, and so on. We also noticed that the unpaid support that the people use now has changed. Before, they used more support from



parents or partners and now it has changed to other people in their network. That was quite interesting to notice. There is a lot to say and I had only 40 minutes, so there is a lot of information still left in the report.

**Question:**

You have made a report about your investigation, with all the details. Do you have a short version that we can read or could you send it out or something?

**Answer - Linde Moonen:**

There will be a definite report, but it's not ready yet. It will also be translated. You will find it on the website of the Expertise Center Independent Living.

**Jamie Bolling:**

I have something I think we could talk about as a group. Talking about this expert experience and being involved in this research. I know there is a debate between disability studies and disability research and how much we, people with disability, should be involved. Right now, there is a project in Sweden, which is looking for criteria for expert experience. I'm not sure what these criteria are going to be in the end. But once they are developed, it would be interesting if we, from the Independent Living Movement, would look at them to see if we agree with them or not. Can we make them better? Could we have criteria for expert experience to be able to be? It's just a question. If you guys think the way I think. Something that again the Expertise Center could have maybe a network of people working on, making it up-to-date, making sure that we see that there is more and more research done in this way.

**Linde Moonen:**

This question was posed to the whole group, I guess. I will show you the definition we composed together with the experts of this investigation. Maybe that can help you. We didn't really put together criteria. We just said: "if you have an experience in living with a disability, you are an expert". That's what we thought. I don't know if anybody agrees or disagrees. Should there be more in this definition?

**Dominiek Porreye from Belgium (translated from Dutch to English by Linde):**

He is Dominiek and we have worked together as researchers in this investigation. He says that all researchers and all people who want to be researchers need some training and education on how to do so.

**Martine from Belgium:**

My name is Martine. I'm working at GRIP as a freelancer. We had a publication on this matter. How people with experience can contribute in government studies and so on. We came to the conclusion that not every person can do it, but if you get instructions on what the specific goal of the research is, and if you are ready for it, then you can do it. But not every person can contribute to every field.



Some people can only go to speak to schools, to universities, in front of a public. Others, like Anja, can contribute to such investigation. Not everyone is suited for that. Everyone has his own specialty, but not everyone has experience in all fields. You have to know your talents and use them.

**Nadia Hadad from Belgium:**

My name is Nadia. I definitely agree with Jamie Bolling. We should protect ourselves from people who think they are experts. They go and speak about us, as if they knew all of us. There must definitely be criteria and I think we must select them. Not everybody can go and speak for all kinds of disabled people thinking they are the experts. We had the same problem with foreign people at the beginning of the 80s, I think. If you just had another color or if you just looked different, others thought you were an expert speaking about foreign people. They even brought people from Asia to speak for people from Africa. There was a really big mess in all that kind of research. We should not let them make the same mistakes. So if somebody is named as an expert and is going to speak about disability, let him or her please at least have some certain criteria. Let him be able to represent us, to speak in a good way for us and not against us.

**Jamie Bolling:**

I just also want to say that I think it was interesting to see that we went into the focus of the experts. And I was thinking also broader as well. I agree with what Nadia said. We do need to think about this. The researcher has to be a researcher. I agree with that of course. You are a researcher when you have done your profession as a researcher. But then there is the involvement of the disability movement and the people with disabilities. I think I'm quite tired of just being a sort of a member of a reference group. There is this wanting to be there, to decide about the research from the beginning to the end, from A to Z, to being involved. So I'm thinking of criteria not as much as the individual expert; the person who's a researcher, such as Anja. But I'm also thinking of the criteria of how we want research to be done on ourselves. How do we want to be involved in the organizations with our experts, at all the different levels and as many people that are disabled? With research we hope that there will be more and more and can be involved more and more. Right now, there's a limitation because schooling hasn't been accessible, so we don't have as many people at those levels as we should have.

**Question - Lies van de Loo from the Netherlands:**

I am Lies from Holland. I was wondering: is there in your research a question about the fact that if you have a personal assistance budget, it's easier for you to find jobs or work? Is there a relationship between those things?

**Answer - Linde Moonen:**

We didn't really investigate the relationship, but asked people if they worked and what kind of work they did. We noticed that there weren't so many people doing paid jobs, not as much as we would expect. There were about 20 percent of the people that volunteered. But of course it's not always the same. When you don't get paid for your work, many people estimate it lower. "It's not a job, it's only voluntary work", they told us. So we did asked about it, but we didn't investigate the relationship as such.

**Answer - Anja De Greve:**

I could add to this that in my sample of 9 people, there was a person who was busy writing a book. And it was not a little book, but a book of 600 pages. It was already in the final stage and it will be published this month. So when we come to the question of work-related activities, this person told me that he didn't work and I was saying to him: "Some time ago, you were telling me about your writing activities and you will sell the book in professional book stores. Don't you think that is some kind of a professional activity when you do this sort of work?", "But I'm not paid for it", he answered. I can agree with the comment of Linde. When people are not paid for it, they don't consider such an activity as work, even when it has more of the characteristics of a professional activity than of voluntary work. So I think there's also some work for society to value other activities than activities you are paid for in a traditional manner.

**Question - Peter Lambreghts:**

I have one more question. Now that you have investigated the quality of life of people using the PAB (the Flemish personal assistance budget), do you plan on making a comparison of the results with research results on people who have, for instance, used care in kind?

**Answer - Linde Moonen:**

I think it would be very interesting to make a direct comparison between people using a personal assistance budget and people with other forms of support. But then we need groups that are comparable - put people with the same age, sex and disability and so on in one group with a PAB and compare that with the same people in the other group without a PAB. That's quite difficult to find and I don't think it would feel the same for the people in the investigation. They will really be a test group. It would be interesting, but I don't think it would be so nice to be investigated.

**Peter Lambreghts:**

It might be quite confronting, but the results would be very interesting to use, perhaps for lobbying for more direct payments. Although, now I'm making conclusions before the research.

**Linde Moonen:**

I think it would be more interesting to do it on a personal level. When you start with your PAB, you can measure: "how is my life now?" After 5 years for example, you can do it again and then notice: "how did my life change when using the PAB?" Then you are less of a member of an experiment, but more a person using the budget.

**Question Viviane Sorée:**

Linde, would it be interesting to do such investigation in different countries?

**Answer - Linde Moonen:**

I think it would be interesting, but like I noticed before: the quality of life is the same for all people living in different countries. It has the same components. But it would be interesting to notice the

impact of the different cultures and social and political systems. And like Viviane said, the environment is also very important of course.

I think investigation on a European level wouldn't be that useful, neither possible. We need to have a comparable level of how political systems work there. For example, in Germany and Austria we have the same federal structure, but not the same way of direct financing or care financing. So a comparison on a European level? Maybe in 300 years, OK, but not in the next 3 to 50 years, I suppose.

