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Insider Perspective Quality of Life by Anja De Greve

I am Anja De Greve, a budget user since 2002 and a researcher at the High School University of Brussels. Because of these two personal characteristics, I was very interested in working together with Linde to help to interview people with disabilities. For me as a researcher it was very interesting to learn how to work with the SIS and the POS, the instruments that we used in the interview. I know these instruments from the research group at the University, but I have never used them in practice with people with disabilities. I also had the occasion to meet other people with disabilities and to broaden my network.

What are the advantages of an insider perspective for a research in general and specifically for the research on quality of life? First, there is the natural knowledge from the field of research. I am a budget user myself, so I know the difficulties and the possibilities of such a situation. I also know some people that are involved with independent living and that is useful for professional networking. If I need some information as a researcher, I can ask the people in my network. In this interview, I could more easily ask the right questions. For example, in the POS there was a question about whether people have the control over their own keys in their own home. To people who are living alone and who are very able to organize their life, which was very clear from the story they told me, I could directly say: "I know that you have control over your home key, but are there some moments that you want to go outside and it's not possible because you don't have assistance?" Some people

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said that it happened sometimes and others said it was not the case. Therefore, I could adapt the questions to the specific situation of the person I interviewed. Another thing that I did was translating professional knowledge into the everyday language and vice versa. In the interview, we used some terminology, which was not clear for the people with disabilities. Then I gave them some translation/explanation. For example, in some questions there was a possibility to answer that people did not know. Next to this, there was a code 99 and some respondents asked me why it was the code 99. As a researcher, I could explain to them that the code 99 is used in standard for "I don't know"; to be sure that there are enough numbers free before 99 to have enough possibilities to answer. So for these questions it was an advantage that I was a researcher too.

However, there are also some threats when you are a researcher as well as a person with a disability. There is a danger of too much personal commitment. Sometimes when I came back home from the interviews, I thought: "This person has not an easy life", but on the other hand, I was very happy with my own life. So there are always two sides of this. Furthermore, as a person with a disability working in an environment where there are not many people with disabilities, you can feel frustrated when your colleagues' visions conflict with your own insider perspective. People with disabilities must hear some things that hurt a bit. When I just started as a researcher, people asked me what kind of work I would choose in a normal environment, i.e. a specialized environment. I said that they would never encounter persons with disabilities who answered they want to work in a specialized environment. The right question has to be: which adaptations do you need to be able to work in an inclusive environment? It takes some time to explain this to colleagues, but now we know each other personally and it is easier.

In the interviews I did for this investigation, the respondents sometimes were a bit frustrated. They said to me: "Why are you asking me all those questions?" A mother told me: "My only problem is that I'm looking for the right assistants for my son. No questions will help me with this problem. You would better help me to find the right person to assist my son." In addition, she said: "Why are you asking me what kind of help my son needs to go to the toilet? You are not asking the same question to my neighbors. And if you did so, they would be very scandalized about such a question." So sometimes, the people I interviewed did not appreciate these questions. And people got the feeling that they have to answer questions like this repeatedly.

Those were the most important things that I had to say. Thank you!

