



International Conference: Independent Living through Direct Payments

Expertise Centre Independent Living

European Network on Independent Living

4 June 2010, De Zwarte Doos-Gentbrugge

Quality of Life and Personal Assistance Budget (PAB) in Flanders, Belgium by Linde Moonen

I am Linde and I am going to present to you the results of an investigation about quality of life of people using a personal assistance budget (PAB) in Flanders. I will first tell you about the idea behind the investigation and the research question. After that, I will tell you what professor Shalock means by quality of life and I will tell you something more about the research design. Then, of course, we come to discuss the results of the investigation and draw some conclusions.

First, the idea behind this investigation came from the Expertise Center Independent Living. They noticed that research on quality of life is increasing and it would be interesting to study quality of life of people using a PAB in Flanders. The Association University of Ghent does the execution of the investigation. This means that all data were analysed and announced through them. The goal of this investigation was to research quality of life of 84 people using a PAB. We wanted to provide reliable information on those 84 people. We paid special attention to the user's perspective and to experts by experience. I will talk about that later on in this presentation.

The research questions then. First, we asked: who are the budget users in this investigation? What characteristics describe them best? Secondly, we asked ourselves: how would the respondents evaluate their own quality of life? Thirdly, we asked: will people experiencing high support needs



evaluate their own lives differently than people with lower support needs. Fourth, we searched for an explanatory model to explain the differences in quality of life of the respondents of this investigation. In addition, to conclude, we asked the people what they think about their PAB. What aspects do they see as advantages and disadvantages?

First of all, something more about quality of life according to professor Shallock. He says quality of life is a concept and a construct: it is theoretical and it can be measured. The concept of quality of life then. Shallock says that quality of life is multidimensional: it has personal factors, environmental factors and it is influenced by the interaction between both of them. Secondly, quality of life is universal. It has the same components for all people and these components are subjective and objective. In addition, to conclude, self-determination, researchers, the purpose in life and a sense of belonging enhance quality of life. To measure quality of life, professor Shallock uses this model. First, he says there are eight domains: personal development, self-determination, interpersonal relationships, social inclusion, rights, emotional wellbeing, physical wellbeing and material wellbeing. Shallock says that these eight domains of quality of life are summarised by three factors: independence, social participation and wellbeing. Indicators present the domains. These are predispositions and behaviors, which concern quality of life. You can ask people to evaluate indicators for themselves. That we call personal outcomes. In this research, we asked the people about their personal outcomes. We used three instruments or research tools in this study. First, the Personal Outcome Scale or POS, secondly the Support Intensity Scale or SIS, and thirdly we developed a questionnaire for this investigation ourselves.

I will tell you something more about the Personal Outcome Scale. This instrument is used to evaluate quality of life. It allows people to evaluate their lives for themselves. We ask the person: how are you? And we do this using the eight domains of quality of life, by asking six questions for each domain. In that way, we get a score per domain, per factor and a total index of quality of life. Of course, this scale is not a test; it is the interpretation of the people themselves. The POS consists normally of two parts: self-report and direct observation (by which another person answers the questions for the person whose life we want to have evaluated). However, in this investigation, we only used the part self-report, because we thought user's perspective is very important.

Now I will tell you something more about the Support Intensity Scale. This scale is used to assess support needs. We ask the person: which level of support do you need in order to live your life the way you want to. So again, this is a scale using self-report. The SIS questions support in many life domains and we are presented a total index score. To make the SIS more pleasant to answer, we also used the wishes in personal goals interview. This interview is about the same domains as the SIS. The questions are about their present situation, but also about their wishes, dreams and hopes. We also developed an own questionnaire for this investigation. The questionnaire consisted of four parts. In the first part, we asked about changes in quality of life people experienced since they started using a PAB. Again, we asked about the same eight domains of quality of life. We asked about changes in possibilities, in realisation of the domain and in satisfaction of the domain. In the second part of the own questionnaire, we asked about the advantages and disadvantages of the PAB in Flanders. We used previous research concerning direct payments in different countries and we asked the respondents to complete with their own experiences. In the third part, we asked about changes in support: which support did you have before you were using a PAB?

In the last part, we asked some general characteristics, such as: Out of how many people does your household consist, how many people do you employ, and so on. We used experts by experience in this investigation, or rather; we worked closely together with them. And together we developed a definition: what is an expert by experience? These are people with disabilities or the people by whom they are closely surrounded, who daily deal with living a life with disabilities. So these experts could also be parents, partners, siblings, assistants and so on. Due to this experience, these people have built up a practical, theoretical and thorough expertise. We worked closely with experts by experience during different stages in this investigation. During the research design, the development of the questionnaire, the interviewing, the interpretation and of course the communication of the results. After this presentation, you will meet Anja De Greve, who is one of my colleagues and an expert by experience. She will tell you about her findings of this investigation. We also asked the respondents what they thought about being interviewed by an expert by experience. Most of them answered that it was a positive aspect. They felt better understood by somebody who also has knowledge about the PAB. Furthermore, the personality of the interviewer also played a part. They were seen as enjoyable people who could take care of a lively conversation. Now I will discuss the results of this investigation. We will use again the five research questions. First, we asked: who is the budget user in this investigation? We noticed that there is a lot of variety in people using a PAB, so 'THE' PAB user does not exist. Budgetholders are people from all ages, men and women, from different compositions of families and different levels of incomes. Likewise, 'THE' assistant does not exist either. Assistants are people from all levels of education and all ages, but we noticed that in this investigation, 73 percent of all assistants were women. Secondly, we asked the people how they would evaluate their own life. We will discuss the general profile of people in this investigation and then we will compare this with the profile from other studies. To do this, we used two other studies: the needs of assessment of people with disabilities or chronic illnesses in Ghent and a comparative research between people with intellectual disabilities and people without disabilities in the city of Middelburg (The Netherlands). Here you see the results of the people in this investigation. So first, you see that the general index (the total score) in average was 111. Secondly, we ranged all the eight domains from high to low (from 1 to 8). We noticed that emotional wellbeing had the highest scores, followed by self-determination and rights. Therefore, these three domains scored the highest in average. The domain personal development scored, compared to other domains, the lowest for most people. We used the research sample from the city of Ghent. These are also people with different disabilities or chronic illnesses.

Comparing the different groups, again we notice that personal development over all scored lowest when compared to the other domains. Self-determination scored highest in most cases, followed by rights. There are small differences between groups according to the disability of the people, but in general, the profile or the ranking from one to eight is relatively equal.

Now we compare the three studies, which I mentioned. In the middle column, you see the results of the respondents in this study, on the left, you see the results of the people in the city of Ghent and on the right, you see the results of people without disabilities in the city of Middelburg (The Netherlands). So when we compare the profile or the ranking from one to eight, we see that in general the profile is quite equal for all people. This follows the conclusion of professor Shalock that quality of life is a universal concept. However, when we look at the domain personal development, we see that people without disabilities evaluate this a little bit higher than people with disabilities.



We think it could be interesting to investigate how this is possible and how we could change it. In the third research question, we wondered if people experiencing higher support needs would evaluate their lives differently than people with lower support needs.

In this investigation, we noticed support needs in two different ways. First of all, we knew from all people which category they were in. This category is an indication of the support needs of the person. Secondly, we asked all people to evaluate their own support needs, using the Support Intensity Scale or SIS. When we look at the SIS and quality of life, we noticed that people experiencing a higher support need reported a lower quality of life. When we look at the PAB category, the image is less clear. People from category 2 reported the lowest quality of life and people from category 4 the highest. This is not quite logical. But we also noticed that there could be differences between people, depending on the disability they experience. So we conclude that quality of life is not only influenced by the support one needs. Other factors will also play a role of course.

Secondly, we noticed that the budget category of people in this investigation did not correspond with the support they told us they need. Comparing with the support needed according to the SIS of course. You see that some people seem to get a budget, which is too high according to their support needs, and others receive a budget, which seems too low for their support needs. Therefore, we advise the government to look at this. We also investigated the factors, which could explain the differences in quality of life for the respondents in this investigation. First, we investigated the impact of respondent characteristics such as age, sex, the support one needs or the disability one experiences. Secondly, we investigated the impact of environmental characteristics such as the regular contact with friends, the number of hours of support one receives, and so on. Thirdly, we combined respondent and environmental characteristics. The combination of these two led to this model. On the right, we see the valuables, which were not significant, which means that they could not explain the differences in quality of life for the people in this investigation. These valuables are: number of hours of paid assistance, having a multiple disability, and the level of support you need. On the left, we see the valuables, which were significant in explaining the differences in quality of life. We see that the number of hours of unpaid support is significant, as well as having regular contact with friends and the numbers of years you use a PAB. These three valuables could explain 55 percent of the differences in quality of life of the people in this investigation. How should we interpret this model? First, we noticed that people having regular contacts with their friends, reported a higher quality of life. Secondly, people who have been using their PAB for a longer period experienced a higher quality of life. Thirdly, people who have to rely on unpaid support to a higher degree reported a lower quality of life. How could we explain this? We already noticed a discrepancy between the budget you receive and the support you need. People seem to compensate this discrepancy by using more unpaid support, but when you have to use unpaid support, you can feel less independent. To conclude this model, we noticed that, considering environmental characteristics, the respondent characteristics no longer seem significant. This is important, because environmental characteristics can change. You can have an impact on your own quality of life when changing these characteristics.

To conclude, we asked about the advantages and disadvantages of the PAB in Flanders. Most people agreed upon the phrase: I have received support from someone I trust, trust a person who respects



me. Most people found the PAB to be more cost efficient and they felt less dependent from the support offered by friends and family. Most people did not agree with the phrase that their health has been improved since they started using a PAB. When asking about the advantages for the family, most people told us that their family can let go off them when there is a personal assistant, and that there is more time for family life. When we talked about disadvantages of the PAB, most people told us that the administration could be a burden and that the rules concerning the PAB in Flanders sometimes are too strict. They also noticed that the budget is not always high enough to provide in good working conditions for the assistants, like social welfare and sick leave, for example. The people did not agree with the phrases that there would be not enough money to accomplish hopes and dreams or that the boundaries in the relationships with the assistants would not be clear.

When asked about disadvantages for the family, most people noticed that there are no disadvantages for the family. The burden of the support has been elevated and the family is not more isolated than before. We asked the respondents to complete some phrases we found in research. 64 percent of them mentioned additional personal advantages, which are mostly linked to their own situation. This makes clear to us that a PAB can be used in many different ways. When we asked about the advantages for the family, there is more correspondance in the answers given. 24 percent of the people noticed that their family had more time for themselves and 12 percent noticed that the roles within the family normalized again. When using a PAB you can be mother and daughter again, brother and sister, husband and wife... As the most important disadvantage, most people noticed that privacy could decline when you hire an assistant. For example, an assistant can witness a fight between you and your brother. We discussed this point together with the experts of experience and noticed that being an employer is not always easy. You have to learn to watch over your own and your family's boundaries. We noticed that budget users could learn much from each other when it comes to be an employer. We also asked the persons about remaining needs. 14 percent of them mentioned that transport is not always flexible in use and 12 percent mentioned that it would be nice to pay medical costs also with your PAB.

To end, I will again walk through the five research questions and answer them with a short conclusion. The first question was: who are the budget users? We noticed that THE budget user and THE assistant do not exist. Secondly, how would the people evaluate their own lives? We concluded that the average score for most of the respondents is 111. The emotional wellbeing scored highest, personal development scored lowest. Comparing with different research samples, we noticed that the profiles in general are quite similar. Then we looked at the differences in people according to their support needs and we noticed that at first sight differences between people experiencing a high and a lower support need existed. Those with a high support need reported a lower quality of life, but we also have to consider other factors. We looked at these factors in the explanatory model and noticed that when we consider environmental characteristics, the importance of respondent characteristics seem to disappear. To conclude, the last question: we asked the people about the advantages and disadvantages of the PAB. We concluded that most people were very positive about their PAB, but positive does not equal perfect, so respondents made some critical remarks which could improve the PAB.