

The pgb experiment in Flanders

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Introduction

In 2001 the Flemish Parliament ratified a decree concerning the introduction of a personal budget ('persoonsgebonden budget' (PGB)). The goal of this decree was the assignment of an individual budget to disabled people with which they should be able to organize their own assistance. In 2008 an experiment to test this personal budget was launched. The decree of the Flemish Government stated the following: "The goal of the PGB is to increase the control of the supply of care by disabled persons by taking charge of the partial or complete financial responsibility for the assistance which a disabled person can freely choose. This assistance can be all immaterial support and all forms of support and services which may be provided to disabled people aimed at their social integration"¹.

In 1997 an experiment with personal assistance budgets or so called PABs - with which disabled people could employ their own personal assistant(s) - was launched in Flanders. In 2000 a legal framework was created and nowadays 1533 persons dispose of a PAB. The goal of the PGB is to further extend the use of individual budgets. Not only should it be possible to pay for personal assistance but also for the whole array of care forms as provided today by various services. These services are now directly financed by the government on the basis of average amounts per disabled person. The PGB should also be able to offer a personal budget to persons who make use of these services or it should be possible to work with a drawing right².

The experiment aims at the investigation of the way personal budgets might contribute to a demand based support³. From the start the government has emphasized a scientific guidance aimed at a thorough study of the subject. To this end the government made a contract with the Antwerp university (professor Breda) and the Leuven university. In 2008 the then minister of social welfare Van Ackere ordered an expert committee to operationalize this experiment. Also disabled people had a voice in this expert committee.

In this article we will establish an overview of the actual situation concerning the operationalization of the experiment. In a chronological order we will go through the different subsequent stages since the selection of the participants in 2008. We shall always give a brief description of what happened and what the experiences were. In order to be able to provide even more scientifically sustained information we shall have to await the publication and analysis of the data that were gathered by the researchers of the KUL (Katholieke Universiteit Leuven) and the UA (Universiteit Antwerpen) and the research collective of the VAPH ('Vlaams Agentschap voor Personen met een Handicap' =Flemish Agency for Disabled People'). We shall start by giving an explanation about the experiment's target group and its scientific guidance.

¹ Decree of 7 November 2008 as published in the Belgian Official Journal

² The budget holder chooses to make an agreement with the service which stipulates among other things how much will be charged for the supplied assistance instead of receiving the money in his or her own bank account. The agreement also stipulates that the service will then be directly compensated by the VAPH, also for organizational costs.

³ Resolution adopted by the Flemish Parliament on 12 December 2007.

Number of participants declines in the course of the experiment.

200 adult persons recognized as a handicapped person coming from two different regions could take part in this experiment⁴. (Halle-Vilvoorde area and the greater Antwerp area). One condition was that they had to be registered at the Centrale Zorg Registratie (Central Care Registration)⁵ for more than 3 years with an urgent care demand or with a demand for a personal assistance budget. People with a physical handicap as well as people with an intellectual or multiple handicap took part in the experiment. If we take a closer look at the participant's profile, then we may remark that 53% has no intellectual handicap. 47% has either an intellectual or a multiple handicap. 53% of the participants were on the CRZ waiting list, 44% was on a PAB waiting list and 3% on both waiting lists.

Especially intellectually disabled people were registered at the CRZ. The man-woman ratio is approximately 51,1% of men and 48,5% of women. The age group of 18 to 29 years is well represented. The average age and also the median of distribution is at 41 years. There is however a difference according to the handicap. Participants with an intellectual handicap are much younger (36 years on average) compared to persons with a physical handicap (46 years)⁶. Persons that met with the criteria were contacted by letter and telephone to ask whether they wanted to partake in the experiment. There were also two info sessions after which the participants were asked whether they wanted to confirm their participation. Right after the confirmation the preliminary phase started in October and November of 2008. At the end of April 168 participants remained. This means that at that moment 15% of the participants had dropped out of the project. And we have strong suspicions that this number will still increase. There are various reasons to make this assumption.

An important reason is the budget amount. In some cases this is lower than the cost price that is actually charged for assistance in kind to which they already make an appeal or the PAB category for which they were assessed. Other reasons why people abandoned the experiment: their care demand has been taken care of, they have changed their mind or their situation has changed. In December e.g. a potential budget holder who stayed in an RVT⁷ (Rust en Verzorgingstehuis) awaiting appropriate assistance passed away. But there were also participants that dropped out because of the vagueness of the experiment and confusing communication. People were expected to take part in the experiment without knowing beforehand what the possibilities would be. Lots of questions remained unanswered during the info sessions because of the fact that relevant decisions had not been made yet at that moment in time. This uncertainty combined with the great efforts that were asked of the participants (in the first phase they were interviewed intensively for at least 3 times) was discouraging to many participants.

⁴ Decree of 7 November 2008 as published in the Belgian Official Journal.

⁵ In 2009 a total of more than 15 000 people with an urgent care need are registered.

⁶ Gevers, Hans., *Beschrijvende overzicht experimentele groep*, Universiteit Antwerpen, Onderzoeksgroep Welzijn en Verzorgingsstaat, 19 mei 2009.

⁷ A home for the elderly is destined for the nursing of elderly people in need of care

9 months before the arrival of the first budgets.

The participants who dropped out of the experiment will be interviewed with regard to their motivations. These data are not yet available. At the end of April 2009 all the participants finally received a letter with the results of their assessments and the budget they were granted. Again there were two info sessions. Only as from the middle of June 2009 the budgets will be paid out. The experiment will already have been running for over 9 months before even the first participant will receive his own budget. The exact duration of a pregnancy indeed, which is actually quite sad given the fact that the experiment ends 31 December 2010, which means that already a quarter of the experiment's time will have passed.

Quality of the scientific guidance

The experiment was preceded by a preliminary investigation into Personal Budgetting in Germany, the Netherlands and England.⁸ An interesting first exploration but without any useful recommendations as a result. The research was carried out in a too superficial way. For the scientific guidance the VAPH collaborated with the research group 'social welfare and welfare state' of the Antwerp university . At the beginning, in the course and at the end of the experiment, students of the Antwerp university were to visit all the participants at their home to try to find out about their situation and their experiences by means of a questionnaire. The same questionnaires were used with a comparable test group. The difficulty was to establish accessible questionnaires that could also be used to interview intellectually disabled persons and to find suitable interviewers who could empathize with the interviewed persons. The reactions received by Bol-Budiv from certain participants imply that this has not always been the case.

In the course of the experiment the scientific basis of the experiment has been regularly used as an argument to restrict the target group to 200 adults coming from 2 well defined regions. Now that it has become clear that at least 15% of the participants has dropped out this raises some questions. Is it possible to carry out a representative investigation with only 168 people in the target group? And is it still worthwhile holding on to the strict limitations with regard to age and region?

The researchers were also faced with many difficulties. Professor Bea Maes and researcher Kristien Hermans of the Leuven University were responsible for the preparation and evaluation of the phase of question clarification. They have developed a web application to implement the support plan online while it was not clear which was the exact purpose of these support plans. During the preparatory phase this repeatedly changed, which was confusing for the people responsible for the question clarification.

⁸ Breda, J., Gevers, H, Van Landeghem, C., *het persoonsgebonden budget in Nederland, Engeland en Duitsland*, in opdracht van het VAPH, mei 2008.

The preliminary phase

1. Question clarification and the establishment of the support plan.

All participants had to make an agreement with a question clarification service. Question clarification is the examination and clarification of the desires and the there from resulting assistance needs of the person and his environment with regard to the various aspects of life⁹. 36 different services and organizations have reported themselves as a question clarification service. 17 of those did eventually start working as one. Seven ambulatory services (domestic assistance or assisted living with recognition of accompaniment) worked with 83 persons. The maximum number of clients was 42 and the minimum 1 per service. Two multidisciplinary teams attached to a health insurance organization have made agreements with 17 participants. One service took care of 6 people, another one took care of 11 people. The 5 existing customer organizations supported altogether 48 persons with their question clarification. The maximum here was 18 and the minimum 3. Finally also 3 services were created for this specific purpose – e.g. to provide accompaniment or question clarification. Those three accounted for 11 agreements. One service worked with 1 client, the maximum here was 7¹⁰.

For these services they received 540 euro from the government for every person with whom they had an agreement concerning the question clarification. The services that made an agreement with the budget holders had a brief training¹¹ about the vision, the goals and the indicators for a sound question clarification, but were free to choose their operating methods. It is still not clear in which way the question clarification took place (frequency, by means of home calls, duration of the interview, method ...), what the quality and the content of the support plans are and whether there exists a correlation with the kind of service (e.g. domestic assistance service attached to a service, the possibility that those exclusively refer to their own care offer).

Given the comments of the inspection services of the Department of Finances¹² with regard to the fact that health insurance organizations play a part in the question clarification as well as the assessment it might be interesting to investigate how the different question clarification services have gone about and whether the results vary according to the question clarification service's position. This is one of the research questions of professor Bea Maes concerning the evaluation of the question clarification. The final product of this phase had to be the support plan. The VAPH has drawn up a list containing all domains of life and the possible means of assistance. A web application was developed where the question clarification services had to indicate to which service the budget holder wanted to make an appeal, for which period of time and their motivation. This list was available as from the month of March. At the moment the submitted support plans are being analyzed. In the foreseeable future professor Bea Maes will present the extensive conclusions of the

⁹ Maes, B, Vraagverduidelijking en ondersteuningsplanning in het kader van het PGB experiment, december 2008.

¹⁰ Data of professor Bea Maes which were presented at a presentation on the 3d of June 2009 at a seminar about Independent Client Support in Hasselt.

¹¹ A training by professor Bea Maes's collaborators (KUL)

¹² " The Financial Inspection Department is of the opinion that the question clarification and the establishment of the support plan on the one hand and the assessment on the other hand should best be carried out by two separate organizations and not by one and the same." Preparatory document of the expert committee PGB, by VAPH 30 September 2008.

research. A first remark with regard to the format of the support plan is that multiple choice questions were often focused on the existing care offer. One had to choose between 'regular services', 'personal assistance', 'informal care' and 'VAPH services'. This has probably limited the ability to think out of the box with regard to the existing services and it was also not clear what was the actual meaning of it.

The experience of Bol-Budiv, which acted as a question clarification service for 21 budget holders, is that a minimum of 5 interviews of 2 to 3 hours time each were necessary to establish the assistance needs as defined by the people that need assistance. The late availability of the web application but also the vagueness of the support plan were perceived as problematic. The same went for the questionnaires which contained many open questions or which, on the other hand, took the existing care offer as a starting point.

Reports issued by the question clarification services show that there was only one contact moment for 25 of the clients. The maximum number of contact moments was 11 but this turned out to be an exception. Overall there were 45 clients who had 3 contact moments. There is great satisfaction about the question clarification. 76,7% of the clients is satisfied with the question clarification service's approach, an even number of clients is satisfied with the way the question clarification took place and 72,9% indicates being satisfied with the drawn up support plan.¹³ Until we can compare between the different services however, the question remains what value these kind of satisfaction surveys.¹⁴

A number that came as a real surprise to us is the mere 55% of participants to the experiment that disposes of his or her own electronic or written version of the support plan, although this support plan was supposed to serve as an auxiliary tool for the participants themselves.¹⁵ The sharing of information was by the way one of the process indicators for a successful question clarification.

The expert committee intensely debated the role of the support plan, the VAPH regarded the plan as an action plan to be followed and which could be used for budget setting and which should be corrected each time a different organization of assistance was desired. The support plan was to be judged with regard to its inclusive character. This means that the assistance which could be retrieved at regular services was not to be compensated through the PGB. This means that assistance that could be retrieved at regular services was not compensated through PGB. The proposition was however not accepted because of the fact that the practice of the support plans varied strongly and because the intention was after all to let budget holders freely decide about their expenditure and because the proposition would lead to a situation where there would be two different budget calculations and where you would have the risk of VAPH assigning the lowest budget or judging about the legitimacy of a given care demand. This proposition was as a consequence not accepted after a negative advice from the researchers and after a meeting with the Minister of social welfare at the beginning of February 2009. The conclusion was that the support plan is a personal tool for the client in order to be able to help with making choices with regard to the expenditure of the budget.

¹³ Data of professor Bea Maes which were presented at a presentation on the 3d of June 2009 at a seminar about Independent Client Support in Hasselt.

¹⁴ Adolf Ratzka at a lecture at the seminar about Independent Client Support on the 3d of June 2009 in Hasselt.

¹⁵ Data of professor Bea Maes which were presented at a presentation on the 3d of June 2009 at a seminar about Independent Client Support in Hasselt.

2. The assessment

A new assessment tool was tested in the course of the experiment. The participants were assessed by 10 mdt's¹⁶ who received a training to this end. The new tool exists of different scales, including the SIS¹⁷, the Barthel scale, the Van De Boer scale which all measure the level of self-help ... the goal is to measure the level of care needs in an objective way. To this end all domains of life are taken into consideration. In comparison with the existing assessment tool which is currently used with PAB, the new assessment tool provides a more accurate estimation of the need of accompaniment. After a series of test assessments the assessment tool was corrected in such a way that there exist 2 versions now: one for physically disabled people and one for intellectually disabled people. This is because not all questions of the SIS scale seemed as relevant to the VAPH¹⁸. Recent research has also revealed that experience with- and training for working with the SIS scale are determining factors with regard to the reliability of the results¹⁹.

The new assessment tool has already been criticized. Some results imply that the assistance needs of physically disabled people are underestimated. So it definitely needs to be established whether the new assessment tool is an improvement as compared to the tool currently used for the PAB assessment. It is thought to be an improvement because it enables to distinguish better between the different kinds of accompaniment that are required. In reality it seems that there are many 'difficult cases' that need to be discussed. All these cases have been discussed for a second time by an assessment committee which adapted the scores if the parameters did not correspond with the real care needs. This committee however had no idea whatsoever about the budgets that corresponded with the various parameters.

Which were those parameters? The number of hours and the type of assistance required were expressed in parameters which then corresponded with a budget. P stands for the permanence and B for accompaniment on different levels: daily living, daytime scheduling, and a supplementary assistance with daily living during weekend time.

There are also different gradations in P and B. On top of that there is also the parameter N which is only assigned when somebody needs assistance at night. Also for that parameter you have gradations. The higher the gradation, the more/ intensive assistance is required²⁰. Every parameter is linked to a value which can be converted into a budget. Individual cases and reactions received by Bol-Budiv imply that the assignment of these parameters (e.g.: someone needs assistance during night time) was carried out differently according to the mdt. This probably also explains the correction that was carried out by the assessment committee.

¹⁶ Multidisciplinary teams

¹⁷ The Support Intensity Scale measures the assistance needs for all domains of life and was originally developed for people with an intellectual disability.

¹⁸ Flemish Agency for Disabled People, the government administration competent for the execution of the policy concerned.

¹⁹ Thompson, R.J., Tassé, M.J., McLaughlin, A. C., *Interrater Reliability of the Supports Intensity Scale*, American Journal on Mental Retardation, volume 113 nr 3, may 2008, p. 231-237.

²⁰ N1= During the night time personnel is on stand-by, upon a call assistance can be supplied within an hour. Assistance is supplied sporadically (not every night); value = 2,2006. N4 = During night time the personnel is physically present. There is a constant supervision and assistance is supplied on a regular basis during the night, depending on the needs; value = 8,4094

The results of the assessment were not discussed with the assessed budget holder. The mdt's passed on their results to the VAPH.

The VAPH then discussed these results in the assessment committee which altered the parameters in some of the cases. The committee then gave feedback to the mdt's of which only 4 responded to these corrections. An analysis of the way in which the assessments were carried out, the results, the discussion in the committee and possible adaptations has not yet been carried out and is scheduled to take place at the end of June.

3. The budget calculation

It was not the real cost price of assistance that was calculated but the cost price of the kind of permanence/ accompaniment as it is organized today in the public services which are recognized by the VAPH. The calculation of this real cost price was then based on the prices that were calculated within the framework of the gradation of care and on the average seniority in the sector, to be able to establish a fixed amount²¹. These are the budgets that are linked to given values.²² This means that there is no one on one accompaniment and that for the calculation of the budgets it is the actual and not the ideal number of care personnel which was taken into account.²³

This choice was inspired by financial reasons. The Minister and the VAPH did not want to assign budgets that were not in accordance with the actual financial means of today. Moreover the minister strictly holds on to the given budget of 4 million euro. Although this may seem logical from the administrative point of view, it might jeopardize the experiment. After all this budget amount was established after political negotiations in February 2008 when it was not yet clear how many participants there would be for the experiment. The amount setting was more or less an educational guess. In March and April 2009 simulations were supposed to take place to make sure that this budget would not be exceeded. Rather than taking the assistance needs of the budget holders as a starting point, decisions were made on the basis of the simulations. The eventual maximum budget that was allotted was 3 867 973.55 euro²⁴ (the 15% overhead for all the participants included).

The assigned budgets vary between 4 818 and 48 176 euro. For a number of participants this estimated amount is higher than what they would get through PAB and the CRZ and for some this is less.

For on top of the budget for the actual costs there is also a budget for overhead costs or infrastructure costs. These are all the costs that are not directly made to finance the assistance itself, in other words all the costs other than the personnel's salary. This overhead budget however is only assigned if the PGB is used to purchase assistance at a service. When a budget holder chooses to use his entire or a part of his budget to pay for assistance

²¹ Studie Zorggradatie, Bart Sabbe, Catherine Molleman 2008. Studied the number of personnel per module and its costs. The personnel was categorized in accordance with their qualifications (accompanying, logistical, licensed, ...) and the personnel equivalent was then converted in an average cost price based on average seniority. In the PGB experiment the medical and paramedical costs were not taken into account for the budget calculation.

²² The values are mentioned in the annex.

²³ There was a demonstration of the care sector on 8 May to protest against the freeze on recruitment which had led to a subnormal capacity usage of 20%.

²⁴ Source: the VAPH table with the assigned budgets, 3d June 2009.

provided by a service, then this budget is increased by 15%. This additional amount can only be spent on overhead costs and this has to be clearly mentioned on the service's invoice. Despite the plea of different budget holders associations it is not possible for people engaging assistants themselves to be compensated for any overhead costs. Nevertheless Bol-Budiv has calculated that the mere legal obligations²⁵ lead to an overhead cost of 6,5% and that this cost could amount to 12,5%²⁶. The VAPH was opposed to the principle of the assignment of a compensation for overhead cost for personal assistance. As a compromise the budgets for the hiring of personal assistants will be increased by 2%. these budgets will not yet be taken into account for the budget assignment in April because at the moment it is still not yet clear how people will use their budgets. The assignment of percentages on top of the 'basic budget' in accordance with the budget expenditure will start only in the course of 2009. It is regretful that by doing so there will be distinguished between those who take on the organization of their assistance themselves and those who (partly) purchase their assistance at services. The latter will be assigned a higher budget whilst the first category will dispose of an insufficient budget to be able to cover for the overhead expenses.

Budget holders can choose for themselves whether they want to work with a cash budget or with a drawing right. This choice has in turn no effect on the budget amount. Services may demand to make use of a drawing right. Whether those services will often or always demand this is yet to be established by the experiment. The budget amount largely depends on the amount of care needed (with the exception of the overhead costs). The assigned P, B and N values determine the type of budget one will receive. As a result low budgets raise questions about the assessment. Where did it go wrong? Upon the assessment or upon the budget calculation? Several budget holders report to Bol-Budiv that their PGB is lower than the PAB budget category. So the question arises whether the values that are linked to the P, B and N parameters are realistic ones? Or are people being assessed in a wrong way?

The experiment based itself on the actual financing of the collectively organized assistance. The means were then distributed on the basis of the amount of care needed. It is obvious that these budgets cannot cover for a 24 hour one on one accompaniment. But at least people are given the possibility to dispose of the same budget as when they would make use of the existing care offer. With a little creativity and the use of informal care it just might be possible to organize the assistance necessary. Today however it is clear that the budget is insufficient for several participants to purchase the collective care to which they could automatically appeal in the existing system. This is to say at the prices that the services charge for this collective assistance. And this also might prove to be problematic, because the question remains how these services calculate their budgets. Logically speaking they should calculate their prices using the same parameters as were used during the gradation of care exercise which formed the basis for the budget calculation.

In this experiment the granting of a budget has become a rather technical matter given the fact that the parameters are linked with fixed values in order to result in a given budget. This turns the budget assignment into a mere administrative task. That is the reason why no

²⁵ Insurance for industrial accidents, management costs of the administrative help service, registration costs for the personal assistant's adherence to the external service for prevention and safety at work, compensation for transport to and from work.

²⁶ Expenses made by the assistant, office equipment for the budget holder, shipping costs, telephone bills, advertising costs, central for disabled persons, compensation for voluntary work, extra costs for taxi, training costs for the personal assistants, enrolment at the local employment office, the care consultant's fee, registration costs for the budget holder's association.

expert committee is at work as is the case with PAB. It is still unclear however where budget holders can turn to with questions about their assessment or the assigned budget. Since it concerns an experiment which will end at the end of 2010, there is no possibility to start an appeal procedure. A reassessment and a recalculation of the budget can only be asked when the situation of the person changes.

As a consequence it is very important that the assessment and the budget calculation take place in a correct way. It is only then that we can find out whether the values assigned to the parameters are adequate. In the case where the budgets are lowered in an artificial way upon the assessment or by the assessment committee it becomes very difficult to determine whether the values linked to the parameters are indeed adequate.

Right of access to information dishonored

In the course of the preliminary phase the participants in the PGB experiment have been interviewed at least 3 times about sometimes very personal matters. There was the assessment, the questionnaire of the researchers of the Antwerp university and finally the question clarification process. But strangely enough they have barely been informed about the result of all these interviews. As we have mentioned earlier on in this article almost half of the participants do not dispose of their own support plan. When it comes to the assessment matters are even worse. A minority of the participants disposes of their personal assessment report. Only after insisting for a long time some individual persons managed to obtain it.

Freedom of expenditure

The level of freedom within the experiment is the same as with the Personal Assistance Budget. One can freely choose when and what kind of assistance one needs. It is yet to be seen whether the conditions required to realize this are present in reality. As with PAB all real expenditures need to be accounted for by means of invoices and pay cheques. Every quarter of the year a bill of costs needs to be submitted. The budget holders inform the VAPH about the amount of the budget they have already spent. What is left over after one year is reclaimed by the VAPH. Probably there will be used advance payments on a quarterly basis, the amount of which (maximum 4 times a quarter of the annual budget) will be determined by the budget holder himself.

A quarterly monitoring will take place within the framework of the research aspect of the experiment. This means that budget holders will report on how they have used their budgets. There will be guidelines for the budget holders as well as for the care providers about what is and what is not possible with the budget during the experiment. An important rule e.g. is that the budget cannot be used for paying for housing- and living costs and paramedical costs. The rules for the budget holders²⁷ are to a large extent based on the actual guidelines that apply for the Personal Assistance Budget. The guidelines for care providers/ license-holders are new²⁸ and put an emphasis on the elements that need to be present in the agreement with the budget holders, the taking of evidence with regard to the VAPH and also what should and what should not be taken into account for the PGB.

²⁷ <http://www.vaph.be/vlafo/download/nl/3140428/bestand>

²⁸ <http://www.vaph.be/vlafo/download/nl/3140428/bestand>

Various players

Next to the recognized VAPH care providers²⁹ it is also possible to purchase care at other organizations. This was in any case the intention. But for now this is being limited to the care providers recognized by the VAPH because only those care providers have been informed and to the date of 4 June 2009 there was still no form available with which those other care providers could apply for a license.

It is possible to make an appeal to regular services³⁰ that are already being subsidized by another authority for their supply of for example services to households, but the patient should only pay the patient contribution and not the total cost price. Due to the heavy workload of these services it is very probable however that they will not always be able to help the budget holders or work at patient contribution's tariff. Meanwhile professor Bea Maes indicates that the analysis of the support plans shows that there exist many obstacles for disabled people which makes that they cannot make use of these services.³¹

On top of that new players in the field can in principle make license agreements with the VAPH. The proposition to impose all currently applicable conditions for recognition, was not accepted because this would mean that the PGB experiment would exclude new players in the field such as the Thomashuizen from the Netherlands. As an alternative the VAPH shall include some essential conditions in the contract requirements for the agreements between budget holders and care providers. Those are conditions concerning transparency, joint decision making and quality. Choosing not to work with general conditions but with actual guarantees laid down in contracts, makes it theoretically more possible that new initiatives will get a chance as well.

Support of the budgetholder

Budget holders receive 50 euro on top of their budget to enable them to join a budget holder's association. These associations not only defend the interests of the budget holders, they also organize trainings for their members and they supply individual services with regard to the drafting of contracts, negotiating, administration, etc. ... Concerning the collective care offer the budget holders associations are being directly financed by the government with 150 euro per member and this comes on top of the aforementioned 50 euro. To this end every budget holder receives 12 vouchers to the value of 150 euro. If that is not sufficient then the PGB budget may also be used to this end.

The fact that all services that have previously presented themselves as candidates for question clarification are eligible to this constitutes a problem. This as a consequence also includes services which at the same time operate as care providers or operate in a similar

²⁹ "The VAPH recognizes and subsidizes services and infrastructures that take care of of the accompaniment and reception of disabled persons. These services may obtain an additional license at the VAPH for offering assistance within the framework of a PGB experiment." Source: PGB guidelines.

³⁰ Regular services are organizations to which every person may appeal in principle. It concerns services recognized and subsidized by the Flemish Community and that ask for a contribution which usually depends on the income. Examples: home care services, attendance services, ... Source: PGB guidelines

³¹ Presentation on the 3d June 2009 at a seminar about Independent Client Support in Hasselt.

way. And what to think of the situation were a budget holder gets assistance with his negotiations by a colleague of the care provider with whom he is negotiating? Or those services that claim all the vouchers at once? From the experience of care mediation bureaus and the PGB in the Netherlands we know that the disabled people's control over their care suffers from such conflicts of interest and may even lead to corruption.

Conclusion

The operationalization of the PGB experiment has not worked out the way we intended it to. Some of the conditions have been met such as the direct link between the assessment and the budget amount. This is important given the fact that only the assistance needs can form the basis of a just scale of apportionment for the limited budget and because of the fact that the whole idea of the experiment is a more demand based care. But many questions still need answering. The most important being the double role of several players during the preliminary phase and in the course of the ensuing phase, the application of the new assessment tool, the low budgets, the discrimination with regard to overhead costs and last but not least the outright violation of the right to access to information with regard to the question clarification (!) and the assessment.

Above all we think that it is important that the PGB decree - dating already back to 2001 - will be implemented. The experiment also represents a positive step forward for all the people who were already waiting more than 3 years on any kind of care. It is however expected that a great number of participants will still drop out. The question arises then whether the target group should be extended or not, whether the regions taken into consideration for the experiment should be enlarged or whether the budgets need to be reexamined. We already dispose of some facts that point into that direction. We hope that the provisional evaluation carried out by researchers at the Antwerp university will be able to provide a decisive answer. In the mean time the Expert Centre Independent Living wants to provide a proper provisional overview of the actual situation for all the disabled people, people who are directly involved in the matter, policy makers and researchers – in Flanders and elsewhere – who observe these evolutions with great attention.

The Expertise Centre shall further closely monitor the experiment and more specifically we will do research on the effects of those choices that we do not approve of as well as on the evolutions which worry us.

ANNEX

Budgets that were linked to the different parameters in the budget calculations.

These are annual budgets and are expressed in euro.

Overnight assistance	
0	/
1	1.559,88
2	1.977,32
3	3.036,70
4	5.960,93

Regular assistance			
0	/	/	/
1	239,9819	/	/
2	479,9639	Pdb1	1813,5778
3	2039,846	Pdb1	1813,5778
4	3860,194	Pdb2	2536,6989
5	5790,291	Pdb2	2536,6989
6	8628,669	Pdb2	2536,6989
7	15440,78	Pdb3	5073,3977

P

Intensity of accompaniment			
1	4818,905	/	/
2	6746,467	Bdb0	2371,867
3	7096,257	Bdb1	3399,675
4	7888,274	Bdb2	5293,071
5	10403,83	Bdb3	7720,472
6	16933,89	Bdb4	11435,04

B

Supplementary scheduling		daily
/	/	
Adbd1	699,38	
Adbd2	1.292,96	
Adbd3	2.335,58	
Adbd4	2.958,40	
Adbd5	5.605,39	