THE USE OF THE DIRECT PAYMENTS SCHEME: 3 YEARS ON

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This presentation is largely based on the findings of Prof. Dr. J. Breda and his colleagues. Under the authority of the VF (Flemish Fund for the Social Integration of Disabled Persons), the team from the University of Antwerp carried out extensive research into the use of the direct payments scheme (PAB) in Flanders.

In addition, the inspectors of the VF combined their findings in a report and I would like to cite a few of their conclusions for your information.

I. ARGUMENTS IN FAVOUR OF THE DIRECT PAYMENTS SCHEME (PAB)

**Freedom of choice for the direct payments user**

In the past, society preferred to put disabled people in institutions. That way, they disappeared off the street, which seemed the best solution to the problem.

As the disability sector developed, more freedom of choice emerged as disabled people or their next-of-kin became able to choose from a wider range of provisions. The arrival of the direct payments scheme opens up a score of new possibilities. Anyone choosing to be cared for in their own environment, or even by the people they are familiar with, chooses to manage their own care. Self-managed care involves the disabled person taking control of the organisation of his own support, choosing his carers and managing his budget. In the case of people with intellectual disabilities, the choices are evidently made by their legal representatives. The direct payments scheme (PABs) can furthermore be used to make pragmatic combinations of familiar informal carers for practical support with functional tasks and external professionals for specific person-centred care tasks.

**Empowerment of the direct payments user**

The user, in particular the adult direct payments (PAB) user, aims to lead an independent life under his own control in order to achieve a more ‘normal existence’.

**Informal care**

On the one hand, people choose to manage their own budget in order to relieve the informal carers in their immediate environment. They deliberately set out to find expert personal carers in order to relieve their family or friends at regular intervals. On the other hand, people may choose to retain their informal carers while paying them more for the support they give. At this moment paying the informal care is one of the most important elements in discussions about personal budgets. There is a purpose to limit the informal care at 40 % of the budget.
Prevention

The original intention of the direct payments scheme (PAB) was to get people out of residential care services and to shift provisions from residential institutions to the home environment. It eventually transpired that the direct payments scheme is of less interest to people already residing in institutions. The scheme actually has a preventative effect: it keeps people away from institutions for longer, or even for ever. The person with a disability will set out to build up his own network to surround himself with care and will only consider an institution if these attempts fail.

Tailor-made care

This principle also constitutes a starting point in the care provisions. Considering the size of various provisions and the limited staff ratio per group, this starting point can not be universally achieved. If someone is allowed to manage their own budget, they will obviously try and manage their care as much as possible to suit them, in the way they prefer it and with the care assistants of their choice.
II. LAUNCH OF THE DIRECT PAYMENTS SCHEME (PAB)

Mid 1997, a pilot project was started in Flanders, working with cash benefits that were paid directly to the person with a disability, following on from initiatives taken in other countries. Fifteen people with a motor disability received a budget of between 10,000 and 29,700 euros.

Later on, both the duration and target group of the pilot project were extended, as it was widened to include people with an intellectual impairment and people with a sensory impairment.

After these pilot projects, a decree was issued laying the legal foundations for the direct payments scheme (PAB). The conditions were set out in December 2000, in an order of the Flemish Executive.

**Target group of the Direct Payments Scheme (PAB)**

Applicants wishing to join the Direct Payments Scheme (PAB) must meet the following requirements:
- Provide proof that he/she can manage in a home environment with reasonable support
- Formulate a proposal regarding the nature and extent of the desired support, including the way in which the support will be organised
- Be prepared to organise the support him/herself.

At the moment, 820 people in Flanders receive direct payments (PAB). In the period between January 2001 and September 2004, 3936 applications were received to join the Direct Payments Scheme. Some 1800 people completed the application procedure. One hundred and fifty people who received direct payments pulled out of the scheme (died, couldn't find an assistant, couldn't manage the budget,…). Some 2600 people are on the waiting list.

The planning of our Minister is an increase with 300 budgets in 2005, 700 in 2006 and another 700 in 2007.

**Scope of use**

Personal care assistants can be called on for help and/or support with
- housework
- activities of daily living (ADL)
- journeys
- ADL-assistance at school or at work
- daily activities inside and outside the home
- pedagogic support
- specialised child care (max. 4 hrs/week)
The budget must not be used for:
- the purchase of technical aids
- medical and paramedical treatment
- education and didactical support which overlaps with provisions available from the education system.
- support which overlaps with the Pathway to work service
- debt counselling

The PAB must not be combined with a provision or foster family already subsidised by the VF either. However, combinations with day centres for adults or non school attending children are permitted to some extent. A maximum of 5% can be spent on indirect costs, e.g. train tickets or cinema tickets for the assistant, etc. Budgets currently vary between approximately 7,500 euros and 34,700 euros. Sixty percent of budgets amount to 25,000 euros or more.

**Lessons learned from the pilot projects**

In general, the direct payments scheme (PAB) leads to a comprehensive reorganisation of the care provisions. On average, the personal care assistants provide
- 40 hours of care per week for people with motor impairments
- 23 hours of care for people with an intellectual impairment
- 9 hours of care for people with a sensory impairment

The personal care assistants tend to take over hours of care from the informal circuit (informal care).

On the other hand, the scheme brought three less positive results for the government:
- the intention to withdraw direct payments users from institutions failed. Only 6% moved away from a residential setting.
- the system is very expensive because it partially pays for services which were formerly offered in kind
- the rights of personal care assistants are not always safeguarded.
- It is difficult to control the quality of the delivered care

**Findings from research conducted by Prof. Breda after 3 years of the Direct Payments Scheme (PBA)**

The profile of the typical direct payments user is as follows:
- approximately an equal proportion of men and women
- 25% minors and 75% adults, half of which are aged between 22 and 50
- 58% have a motor impairment, 20% have a single or multiple intellectual impairment; the remainder consists of people with other disabilities (autism, cognitive impairment due to non-hereditary brain damage, etc)
- the group with an intellectual impairment is dominant among the minors
- the group with a physical impairment is dominant among the adults
- 25% of the users live alone; these are the largest group without a paid informal carer
- 60% have a regular daily activity outside the house: 35% attend school or go to work, 11% attend a day centre or a provision for non-school attending children and 14% have another regular activity outside the house
- on average, a direct payments user contracts personal assistance 37 hours a week
- the tasks for which assistance is sought are mainly support with making journeys outside the house, recreational activities and daily household chores

The profile of the personal care assistant:
- more personal assistants from outside the natural support network among minors
- in 48% of cases, the paid informal carer is one of the parents
- in 26% of cases, it is the partner
- 81% are women
- personal assistants from outside the natural support network tend to be under 40, informal carers over 40 years old
- no great differences in the educational attainment of informal carers and personal assistants outside the natural support network; personal assistants of young people with a disability tend to have a higher educational attainment
- 39% combine their personal care work with another job
- 74% of informal carers and 62% of personal assistants outside the natural support network improve their financial position

Adults more often use several assistants due to:
- their care involving different clusters of tasks
- the continuity in the care provision
- the assistants opting to work part-time

On average, a personal assistant performs 17 hours a week: a paid informal carer works on average 26 hours a week while personal assistants from outside natural support networks take on average 14 hours a week for their account.

Income of the personal assistant:
- on average, 1,108 euros per month
- 50% of personal assistants earn a maximum of 1,000 euros
- the average salary of the personal assistant from outside natural support networks lies below the salary earned by informal carers, particularly by informal carers who are living with the user.

(this is also a discussion in Flanders because sometimes a
mother earns a salary like someone who went to the university while she is only doing assistance in daily living activities)

Motivation of the Direct Payments (PAB) User

- to organise better personal support and to avoid admission to a residential institution (74%)
- to choose individual support and to increase their independence (72%)
- to implement their own choices (66%)
- to spend time in a meaningful way and in an inclusive environment (64%)
- to relieve informal carers

Motivation for recruiting a paid informal carer:
- shortage of other assistants
- interim solution in the first three months after the application
- no stranger in the home, a relationship of trust
- using up the remaining budget for a specific calendar year
- flexibility of the care provision

Motivation to recruit personal care assistants from outside natural support networks
- no natural support network, or they are not available or capable (particularly the case for adult disabled people)
- preference for new professional care assistants (particularly the case for minor disabled people)

Motivation of the personal assistant

For paid informal carers:
- provide the best care for the person with a disability
- continue existing care arrangements
- a duty of care

for personal care assistants from outside the natural support network:
- paid work
- an interesting job
- a complementary job
- a job involving a one-to-one relationship

Reasons to discontinue the contract of a personal assistant:
- the contract was only a temporary solution
- the assistant was insufficiently qualified
- tension between the assistant and the disabled person or his environment
- change in personal circumstances

EVALUATION OF THE DIRECT PAYMENTS SCHEME (PAB)

Implications for the user

80% of the named direct payments users make their own decisions.

Their role is more involved than simply organising the care. The direct payments user must decide what support he wishes to receive, who he wants to receive it from and when. Users often devolve the payroll-management to an employers’ social-accounting secretariat.

The task of being budget manager and employer is often experienced as irritating, difficult and complex. It requires the direct payments user to be well-organised and punctual, as well as able to understand and apply legal texts.

A certain level of educational attainment is clearly required in order to function as a direct payments user. Forty-four percent of direct payments users hold a certificate of upper secondary school and 36% of them have followed higher education.

A direct payments user is also better off with leadership skills in order to deal appropriately with his personal care assistants. The research showed that many direct payments users adopt quite a rigid attitude as ‘the boss’.

Some organisational skill does not go amiss. After all, direct payments users need to draw up a time schedule, often for several assistants. Managing the resources requires some organisation, too, and the hours worked need to be calculated and paid.

Sixty-five percent of the direct payments users are satisfied with the budget allocated. In the case of a paid informal carer, the budget is even more adequate than when all the support needs to be organised with assistants from outside the natural support network. Thirty-five percent claim that they are unable to put all their preferences into practice based on the budget allocated (including some of the people who currently receive the highest payments).

Fifty-five percent of current users want to combine the direct payments scheme full-time or part-time with services in residential institutions. A very clear demand exists for combining the direct payments scheme (PAB) with respite care and home-based professional intervention. The ceiling of 5% for indirect costs also causes some resentment.
The users pronounce themselves largely satisfied with the care and living arrangements but less so with the administrative burden.

Conclusion: the direct payments scheme (PAB) allows great freedom of choice but it requires considerable knowledge, skills, assertiveness and energy.

Implications for the assistants

The research demonstrates that
- assistants carry out varied work with demonstrable results
- the direct payments users takes the wishes and needs of the assistants into account
- the job often entails important responsibilities

The work offers less scope for development, creativity and learning, particularly among adults.
Personal assistants don’t tend to have a great deal of autonomy over how they carry out their work.
This is in line with the intention of the direct payments scheme (PAB), which is to give the decision-making authority to the user.

In general, a personal assistant puts in 17 hours a week.
As far as the pay is concerned, the average hourly rate for assistants is 13 euros for informal carers and 10 euros for assistants from outside the natural support network. The assistants are more likely to receive an employment contract for an indefinite period when caring for adults, but for minors, the assistants tend to be recruited on a temporary or free-lance basis. Approximately 1 in 5 of all assistants are dissatisfied with the pay they receive.

Assistants have few opportunities to receive training. Furthermore, they have little chance to exchange knowledge and experience with their colleagues due to the one-to-one relationship with the client.

Direct payments users and personal assistants are more likely to have a positive relationship in the case of minors: 78% compared to 57% of adults. Then again, assistants enter into the private realm of the person with a disability and the mutual relationship is often so intense that the borderline between employer-employee and friendship fades and at times even disappears.

Implications for care services and for the government
The outflow from care services due to the direct payments scheme (PAB) proved to be minimal. Instead, the system tends to work in a preventive way. Although one hour of the direct payments scheme is cheaper for the government than one hour of formal care, the fact that little substitution of the formal circuit takes place means that the government needs to commit more resources.

The direct payments scheme (PAB) entails complementary expenditure for the government, involving individual payments on top of collective provisions. The long-term viability and financial feasibility of the system is therefore called into question. After all, the direct payments scheme (PAB) generates additional demand which affects the financial manageability.

Residential provisions will need to change the way they operate only when the extended direct payments scheme (PGB) will be fully in place. At that point, they will need to develop a flexible range of services at a transparent, fair tariff.

**Support**

It has quickly become obvious that the direct payments scheme (PAB) involves a considerable set of extra tasks for the direct payments user. The administrative burden arising from being an employer should not be underestimated. A direct payments user needs many skills to cope with it all.

For that reason, a strong need for support has arisen. On the one hand, people need general information. On the other hand, they have specific needs for support in connection with the administrative process, the search for assistants, to remain abreast of changes in regulations, etc.

Firstly, there are associations of direct payments users. These are currently still subsidized, contrary to the original regulations. Their objective is to give advance information and to support users in their employer’s role.

Furthermore, there are care counsellors attached to professional home care services with a fairly similar mission to the associations of direct payments users.

In addition, the users can call on the employers’ social accounting secretariat which looks after payroll administration.

Finally, channels exist to help with finding assistants. However, it remains a segment of the labour market which is insufficiently known and trusted. This is partly due to the lack of an adequate workers’ statute for assistants.
Advantages and disadvantages

ADVANTAGES:

- the scheme reinforces user-led service provision
- more autonomy for the person with a disability
- a means of empowering the person with a disability, tailor-made care
- already allows far-reaching diversity as a result of the client’s freedom of choice
- promotes inclusion and opportunities for personal development
- a direct payments (PAB) user can fluently combine various circuits: both informal and formal care provision, in order to address the issue of mobility, among other problems.
- defers or avoids going into residential care
- more inclusion

DISADVANTAGES

- The search for suitable personal assistants is often cumbersome
- The budget is perceived as insufficient to meet all requirements
- The administrative burden requires the budget holder to have multiple skills
- A tightly regulated system with a complex control system
- Working conditions for personal care assistants have not yet been finalised and are repeatedly breached
- Tensions between the direct payments scheme (PAB) and other social and tax regulations
- A hugely expensive system which will eventually become prohibitive
- Cannot be sufficiently combined with other (residential) care provisions
- Dubious distinction between employer-employee relationship and friendship
- Doubts about the quality of the delivered care
- No statute for the assistant yet
- Some people cannot manage their budget; they have to pay the money back but they have spent the money on other things than care → social disasters
- How can you define ‘capable’?
III. THE EXTENDED DIRECT PAYMENTS SCHEME (PGB)

The extended direct payments scheme (PGB) aims to provide equal treatment and financing for equal needs and requirements, regardless of where the care is provided and of the type of carers used.

**Increasing the range of options**

The decree on the extended direct payments scheme (PGB) aimed to widen the scope of the direct payments scheme. In practice, a system is conceived allowing people with a disability to use their personal budgets to buy technical aids, to appoint personal assistants or to buy care from a recognised care service. This should make it easier for the direct payments user to organise his support and to find personal care assistants. If the possibility exists to stay in a residential institution part-time, combined with support in the home environment, more tailor-made care can be provided for the person with a disability. To this effect, the care provisions can be expected to become more flexible and to change the mentality into person centered care.

**Better developed structures**

Also based on the findings from the direct payments scheme (PAB), awareness grew that clients considering becoming a direct payments user need more support and guidance. This already matters from the information-gathering stage onwards. Many direct payments scheme (PAB) users don’t realise what they will be faced with when they apply to join the direct payments scheme. For that reason, a well structured application procedure is essential (and not only for the direct payments users). It is important to build up a full picture of the person in question, of his skills and shortcomings. The assessment will be used to judge the capacity of the direct payments user and the best way to meet his support needs. In addition, direct payments users need structures to help them manage the scheme and to fulfil the administrative responsibilities of an employer.

**New way of financing the care provisions**

Residential institutions must devise a detailed set of tariffs calculated on the basis of services rendered, specifically to adjust to direct payments users. In addition, detailed tariffs are important to establish the total budget for a direct payments scheme per person. The breakdown of charges will also serve to calculate how to finance the system taking account of the relevant level of care, both for residential customers and for extended
direct payments (PGB) users. A detailed analysis of the charges will help to build up a more transparent funding system.

In practical terms, the funding would entail that the direct payments user enters into a contract with a care service, on the basis of which a price is agreed for the care package the user wishes to buy. The price may vary from one service to another, since the experience of the staff, the scale of the service, additional investments made in the accommodation facilities, etc. all play a role in determining the price.

Also important in the new system of financing the institutions is the distinction between care-costs, which are subsidised, and the living costs, that are paid by the client.

IV. RECOMMENDATIONS AT THE LAUNCH OF THE EXTENDED DIRECT PAYMENTS SCHEME (PGB)

Opening up the option of the extended direct payments scheme (PBG) has several unmistakable advantages. However, it should also be made clear that the system cannot be applied on a large scale or by just anyone.

It is therefore important to clearly demarcate the target group. People with a motor impairment and sufficient organisational skills mostly manage to take control of their own support system. In that case, the budget holder is usually the actual person with a disability, taking decisions for himself. In other cases, we notice that the person with a disability is often not the budget holder and that decisions therefore need to be made by someone else than the client. This already deviates to a larger extent from the original objective of self-management and empowerment.

In view of the complexity encountered with regulations, employer-related obligations and organisation, it is advisable to restrict the scope at first. As more mix-and-match options become available, the (financial) management will also become more complex. On the one hand, it will lead to more rules, on the other hand, the system will become less transparent and less manageable. It is very important for the user that the system won’t become too wrapped up in red tape, making it much more time-consuming to manage. It is also advisable to examine in advance which existing regulations will also apply to extended direct payments users, both from a social and tax point of view. It would be best to bring the regulations in line with each other, to avoid the user being penalised in the long run.
As time progresses – and as soon as the ambulant and (semi)residential sector has been able to reorganise itself in the context of the extended direct payments scheme (PBG) – the system could be broadened to allow more wide-ranging combinations.

With a view to **financial manageability**, the impact of paid informal care should be carefully thought through. It has already emerged as additional expenditure because it involves a new target group. Allowing care within the familiar context certainly provides benefits. However, it deserves careful reflection whether some budgets can reasonably be entirely allocated to informal care. Maybe some restriction could be incorporated in the scheme, without completely abolishing it. In Flanders informal care is now limited until 40 % of the budget. Also the level of the pay is limited.

On the other hand, we must dare to address the question as to whether we would be prepared to go as far as allowing the cost of extended direct payments schemes (PGB) to exceed the cost of the most expensive place in institutions. One-to-one relationships are beneficial, but they are unfeasible for long-term care and for a wider target group. It is a fact that the wishes are endless but the budget is not. You have to define the highest budget to keep it manageable.

**Information and support** for the budget holder are also crucial in order to avoid any misunderstandings. Help with finding personal care assistants and with employer-related tasks are also crucial. In my opinion, this should be managed by organisations other than the Government. These organisations would ask a fee on the budget holder, payable from the budget. Furthermore, mainstream bodies should be able to assist the budget holder. After all, the system is aimed at integration, implying it should involve setting up as few separate circuits as possible.

Another recommendation is to have **a good, objective and independent assessment**, based on a multi-disciplinary method with the advices of a doctor, a psychologist, a social worker, ...An assessment has also to be based on the activities someone is doing (and not on the things he can’t do anymore.) After that you need to define the total need of care so you can find out what kind of activities can be done by the family of relatives (without paying for it), what kind of care can be delivered by the regular sector and finally what can be done by the disability sector.

At the finish the person himself can make his choice: an institution, a personal budget or a combination.

The organisation of personal budgets needs also a good control-system: not to complex but just enough to conclude that the money is used in a correct way. At the end personal budgets in Flanders are paid with money of the whole society.

Last but not least, for me it stays important that in every system you keep the possibility for everyone to make their own choices.