

EXPERTISE CENTRE
independent living

De- institutionalization in Belgium

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Introduction

People are making Independent Living.
Conferences, laws and politics are their tools.

In Flanders, the northern part of Belgium,
it all started, in 1987, with just a few people.

Adolf Ratzka, tied to his bed by flu, he spoke to us from Sweden,
and we, Jan Sabbe, Luc Demarez, Eddy Denaeyer and myself, we got the message.

Fokus-living was just another form of institutionalization.
No free choice of personal assistants, no self-determination.

We had to claim the money,
and make come true what was unthinkable.

We had no choice. We were young, fulfilled with aspirations.
And severely disabled. With no other future than being care receivers?

Adolf taught us self-respect. We didn't have to accept this perspective.
We are human beings, with equal rights to happiness.

And nobody else than we, ourselves, had the responsibility to claim this right.
Surely, we found allies in our long struggle.

Damien Kinds, Ann Sleenckx, Tony Verelst, and many others joined our group.
Parents and friends gave us support.

Politicians, academics, judges, journalists, and care workers, sympathised.
But we, people with disabilities, had to trace the path, over more than 12 years.

Jan Sabbe, my best friend, who unfortunately passed away this year.
He saw our dream coming true and I am sure he was a happy man.

Nowadays, in Flanders, about 1400 people with physical, sensorial or mental disabilities live in the
community, despite their often severe disabilities, with a PAB (Personal Assistance Budget).

These people, and their family members, colleagues and friends, that is what Independent Living is
about.

1. Belgium, one state, three regions

Belgium is a federal state, consisting of three regions: Flanders (northern part: Dutch-speaking), Brussels (central part: bilingual), and Wallonia (southern part: French-speaking).

By constitutional law, welfare policy is committed to the regions. Therefore, when we speak on assistance schemes for people with disabilities, we have to distinguish between these three regions.

In Flanders, due to a pro-active independent living movement from 1987 on, we succeeded to have a first experiment (involving only 15 people with physical or sensorial impairments) with personal assistance budgets (PAB) in 1997. The PAB-Decree of the Flemish Parliament of 17 July 2000 gave a legal and more structural basis to the PAB-scheme. Today, about 1.400 people with disabilities in Flanders receive a PAB, the main characteristics of which we will summarise in the next chapter.

In Brussels (8 persons with disabilities) and Wallonia (24 persons with disabilities), the first experiments with PAB are currently running. However, there is no well-organised IL-movement in the southern part of Belgium (more translations of the mainly English-spoken information into French would be helpful) that can keep up the necessary pressure upon politicians to really make a change, only a cooperation between different associations of people with disabilities.¹

Our contribution will thus be limited to the situation in Flanders.

¹ For more information, see the website (in French) www.vieautonome.be

2. Main characteristics of the Flemish PAB Scheme

2.1. Eligibility

2.1.1. Disability

Eligibility is granted:

a) On the basis of a person's need of practical assistance by others in all activities of daily living, such as personal hygiene, eating, dressing, doing household work, assistance outside the home, about town or when travelling, at school, work and during leisure time, and, if applicable, in communicating, structuring the day or with similar cognitive or pedagogical support;

b) Regardless of cause or medical diagnosis of one's disability, employment or insurance situation², income or property of the recipient or the recipient's household or family.

2.1.2. Who?

Children are allowed. Their parents (or other legal representatives) act as budget holders.

People who got disabled after the age of 65 are excluded.

Persons who live in residential institutions or equivalent solutions are not eligible under the PAB-scheme. In order to facilitate the transition from residential institutions to living in the community, the policy grants cash benefits for personal assistance up to 3 months (renewable) ahead of the planned move.

On the other hand, budget holders are allowed to make combinations with day-care centres or to spend a part of their budget to collectively organised assistance, also by residential institutions (e.g. for short-term leave).

2.2. No legal entitlement

People with disabilities are only entitled to payments for personal assistance within the limits of the annual budget, established by the Flemish government. For the year 2008, the maximum number of PAB's is fixed upon 1.900³. The real number of actual budget holders is around 1.400 and by the end of 2007 4.260 people with disabilities were registered on the "waiting list" for a PAB.⁴

Because of this wide gap between offer and demand, the Flemish Minister of Welfare has to determine each year by ministerial decree the criteria for granting new PAB's. Priority is given to people with severe disabilities, especially those with fast degenerative diseases.

² However, the amount granted by insurance schemes (such as for labour accidents and for car accidents) to cover assistance needs is deducted from the PAB.

³ Decree of the Flemish Government of 18 July 2008.

⁴ Annual Report 2007 Flemish Agency for Persons with Disabilities, 23.

2.3. Needs Assessment

Needs assessment takes into account the whole life situation enabling assistance users to fulfil the role they would have had without their disability, in family, neighbourhood and society with all resulting privileges and responsibilities. The assessment includes the need of third persons for supporting assistance users who, due to a cognitive impairment, need support in dealing with service providers and assistants.

In the case of children, the policy covers assistance needs over and above the parental responsibility that would apply in the case of a non-disabled child.

In the case of adults, the assessment does take into account the assistance that family members in each individual case reasonably can deliver.

Assessment is conducted by so-called “multidisciplinary teams” that fill out a questionnaire about one’s possibilities to perform activities of daily living, education, work and other need categories (not in hours of necessary assistance). The questionnaire is submitted to an independent “Commission of experts” that finally attributes the PAB. The decision can be appealed against before the court.

A re-assessment is possible on demand of the user (in case of a substantial increase of his assistance needs, due to health problems or loss of relatives) and also on demand of the funding agency (e.g. in case of lack of use of the annual budget).

2.4. Cash Benefits

Cash benefits are paid by the funding agency directly to assistance users who, in turn, use the funds for purchasing assistance services from one or several service providers of their choice, organizing their services themselves by employing assistants, including family members, or any combination thereof.

The annual budget varies between 8.543 euro and 39.868 euro, according to the degree of assistance needs that have been assessed. The level of payments is annually adjusted to avoid purchasing power losses.

Assistance users are not required to contribute to the cost of their personal assistance services regardless of their or their families’ or households’ income or property. The highest PAB however is still much lower than the average subsidy that is given pro capita to institutional settings for severely disabled persons, and therefore does not allow a full coverage of the real assistance needs, neither to offer competitive wages or working conditions to the assistants.

Cash benefits are paid every three months and in advance.

One and the same regional level state funding agency covers all recipients.

Payments under the policy are not treated as taxable income and do not affect the recipient’s eligibility for other benefits or services.

2.5. Recipients' accountability

The periods for which the funds are to be accounted are 12 months. Within the annual budget period, users can, as they see fit, save assistance hours from month to month in order to build up a buffer for temporary over-consumption, for example, for travel or illness.

95% of the budget is to be spent on wages, including all indirect labour costs such as compensation for unsocial hours and over-time, workers' accident and liability insurance, assistants' social insurance and payroll administration costs. All expenditures must be based upon written contracts with personal assistants or service delivery agencies.

5% of the annual budget can be spent on the costs of accompanying assistants (*e.g.* for meals, entrance tickets, transportation) or other costs (telephone, bank, stamps, etc..)

The part of the budget, for which there is no adequate or well-proven spending, has to be reimbursed to the funding agency.

2.6. Support of budget holders

Three associations of budget holders have been recognised by the Flemish government to give advice to individual budget holders and to defend their collective interests. These associations are funded by annual government subsidies and by individual contributions by the affiliated budget holders.

3. Some recent developments and hot issues

3.1. The Flemish PAB-Scheme corresponds very well with the requirements, set up in the ECEPA-Model⁵, and is very successful. Yet, until today, it does rarely succeed in getting people with disabilities out of institutional settings. It allows mainly people who live at home no longer to depend fully on “volunteer” work of family members and friends and surely has a preventive effect, as has been confirmed by a report of the university of Antwerp in 2004 on the evaluation of three years PAB in Flanders⁶. Actually, when we look at the official figures in the annual report 2007 of the Flemish Agency for people with disabilities, the PAB-scheme represents **only 3,7 % of the annual budget** of the Flemish Agency, while collectively organized assistance takes more than 90 %⁷ and is still expanding, year after year, at a much higher rate than the consumer-controlled alternative of PAB.

3.2. In order to give more freedom of choice to people with disabilities who are not capable to live outside institutions, a new project, the so-called “**person-linked budget**”, will start up from the first of January 2009 on. About 200 people with disabilities will receive for two years, on an experimental basis, a budget to buy assistance with, either by their own personal assistants or by institutions or a combination of both. The specific characteristics of this scheme are currently in discussion, but the aim is clearly to make the institutions more consumer-oriented.

At my personal opinion, I have great doubts about the possibility of institutions to adapt to the individual needs of each person. Already at this moment, the budget holders association independent living (BOL) has to deal with a substantial number of complaints (no replacement of assistants with pregnancy or sickness leave etc..) from budget holders who decided, while not living in a institution, to buy with their PAB a significant part of their assistance from a collective assistance agency.

But at least, institutions will no longer be financed on the basis of the number of “beds” they fill up, but by their clients, whose person-linked budget is established on an assessment of their individual needs. However, it’s not at all clear yet that a real freedom of choice will be granted, as some decision makers propose to attribute higher budgets for people with disabilities who opt for an institutional setting! And another threat could come from new conditions of use of the person-linked budget (only with “registered” and “qualified” service deliverers etc.) which could affect the PAB-scheme later on.

3.3. Another interesting development is the growing success of circles of “personal future planning”, so-called “own experience planning” workshops, and other informal support groups which help people with disabilities to **create a social network** around them. Indeed, nobody can live in the community without relatives, colleagues and friends. A lot of people with disabilities, due to poor or segregated living conditions, only dispose of a very restricted number of people who support their personal life plan. A parent who dies, a spouse who leaves the house, or even the one good friend who leaves town, can result in a catastrophic scenario.

⁵ Ratzka, Adolf (ed.). 2004-10. "Model National Personal Assistance Policy." A project of the European Centre for Excellence in Personal Assistance (ECEPA). Internet publication URL: www.independentliving.org/docs6/razka200410a.html

⁶ J. Breda, *Drie jaar later: evaluatie van het PAB-gebruik. Eindrapport*, Universiteit Antwerpen, Departement sociologie, april 2004, 250.

⁷ Annual Report 2007 Flemish Agency for Persons with Disabilities 2007, 64.

That's why we have to create, on a structural basis, a group of people who are emotionally involved in our well-being. They are not paid for their time, but can be initiated and followed up by a professional "coach". Several programs have been set up in the past three years, of which the one that is recognized by the Flemish Agency for people with disabilities alone had already 226 "plans" running in 2007⁸. While it has become clear that a support network is essential in realizing a personal life plan, there is no legal status yet for the actions (such as negotiating with assistance agencies) performed by the members of the support group.

3.4. Not all recent developments are in favor of empowering care receiving people. On the contrary, the established collective assistance providers try by all means to increase their quasi monopolistic share in the fastest growing sector of our economy: care for people. One of the latest illustrations of their efforts was the so-called "**Decree on care of 18 July 2008**" that has been voted by the Flemish Parliament and will get legal force, as soon as the Flemish Government takes the regulations to implement it.

This decree⁹ makes every act (except on a voluntary basis) of assistance in activities of daily living, such as eating, bathing and dressing up, punishable by penal provision, unless the act is performed by a qualified and registered assistant or by an assistant who works only for one single user. The personnel however of the collective assistance agencies, recognized and subsidized by the Flemish Government, are legally presumed to fulfill the qualification criteria and don't have to be registered. All the other assistants are outlawed!

Due to amendments to the original proposition, and after a fierce debate in the "Welfare Commission" of the Flemish Parliament, the personal assistants in the PAB-scheme have been excluded from the field of application of the decree. However, the Flemish Minister of Welfare has announced a new initiative towards these personal assistants before the end of this year.

3.5. Flanders has not become the paradise on earth for people with disabilities. The majority of them still depend fully either on "voluntary" care by their relatives or/and the professional care organized by institutions. But a significant number of actual budget holders are ready to defend their life as a free citizen, that has been made possible by the direct payment scheme of PAB.

Moreover, Flanders has acquired a lot of expert knowledge on direct payments and can play a key role in making a bridge between the Anglo-Saxon world and the rest of Europe. From the first of January 2009 on, the so-called "**expert centre on direct payments**", a spin-off of the budget holders association Independent Living, will open its website with a lot of links to all European centres of excellence in the field of direct payments. We hope for the support from all of you!

⁸ Annual report 2007 of the Personal Future Planning Project, 20.

⁹ Decree 18 July 2008 concerning care and assistance delivery; *Official Publications of the Belgian State*, 29 August 2008.

Conclusions

Of course, direct payments are not the only issue on the way to an inclusive society. Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments, which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others¹⁰. Therefore, a society that embraces different potentials of all people in education, work, public and private life will diminish considerably the pressure on the welfare system.

But let us not indulge in a false illusion. Even a society without barriers and with real equal chances, including reasonable accommodations for people with disabilities, will still be obliged to take care for people with disabilities. How to build up the necessary solidarity to provide care, without limiting the free options of life of the care receivers, will remain a debate for the coming decennia.

Equal rights, direct payments, personal assistance, these are just tools for a better world, a society where disability is no longer a ticket for exclusion. Has Flanders understood the message? Yes, the counter attacks are heavier than ever before; but we will not surrender until we die, with dignity and self respect.

¹⁰ Art. 1 UN Convention 13 December 2006 on the Rights of Persons with Disabilities