EVERY EURO COUNTS

Arguments in favour of efficiency in the disabled care.

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Peter Lambreghts

Expertise Centre Independent Living

Kerkstraat 108 – 9050 Gentbrugge
TEL 09 324 38 77 – FAX 09 324 38 79
info@onafhankelijkleven.be
www.onafhankelijkleven.be

INCREASING CARE DEMAND

The care demand is on the rise. This has been thoroughly documented[1]. By the way, this conclusion does not only apply to care or support of disabled people. Other sectors as well, for instance youth care[2], child day care or elderly care, are faced with an increasing demand. This is not a typical Flemish or Belgian phenomenon. In the Netherlands e.g. there has been an increase by 30% [3] of the number of clients in the disabled care between 2002 and 2007. Also our neighbouring countries are engaged in the debate about the measures that need to be taken with regard to this ever increasing pressure on our modern welfare state.

One of the main reasons for this increase is a population which is on average getting older and older. However, this ageing is an indicator for a future continuous increase of the care demands, but it does not offer an explanation for the recent increase. Only as from 2011 will the baby-boom generation start to leave the labour market and will we experience the full effect of the ageing population. The care demand will further increase because there will be more elderly people and at the same time they will live longer. As a consequence, the period during which care is needed shall be longer. This problem is sometimes referred to as the 'double ageing process'.

Although demographic data such as an increasing birth rate, ageing of the population and an exponential increase of the average lifetime of disabled people play a role, there are also other factors which have an influence.

An important reason for the increasing number of care demands are developments in the medical field. Many ailments and disorders which in earlier days would have lead to the decease of people, can now be fought successfully. Even in cases of very premature births or serious car accidents, nowadays doctors manage to save more and more lives. It goes without saying that, as a result of this, there are also more 'survivors' who need much care and support. Furthermore there are better diagnostics for certain chronic diseases and disabilities such as autism spectrum disorders, which makes for an ever growing group of people who are entitled to care.

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[1] Vlaams Agentschap voor Personen met een Handicap (04.12.2009) *Zesmaandelijks rapport over vraag en aanbod personen met een handicap / persbericht*. Consulted on 26.02.2010, at http://www.vaph.be/vlafo/view/nl/3724063-Zesmaandelijks+rapport+over+vraag+en+aanbod+personen+met+een+handicap.html

[2] Cuyt F. en Rombouts T. On behalf of the Vlaams Welzijnsverbond (2008) *3% jaarlijkse groei nodig om de kloof in de jeugdzorg te dichten, persbericht*

[3] van der Kwartel Drs. A.J.J. i.o.v. VGN – Vereniging Gehandicaptenzorg Nederland (maart 2009) *Brancherapport gehandicaptenzorg 2008*

Finally there are sociological factors. Informal care is subjected to an increasing pressure in our rapidly changing society.

Smaller families and a higher workforce participation, especially among women, lead to a situation where people need to look more often for care and support outside the family. Waiting lists in other welfare sectors like the mental health care, elderly care, youth care and even social housing increase the pressure on the disabled care sector.

Our expanding and rapidly changing society causes a significant increase of the number of care demands. This increase will continue in the decades to come. The most radical effects of ageing have not manifested themselves yet. Also the considerable increase of the number of pupils in special education will cause the number of care demands to rise in the coming future. Within educational type 1, where children are being prepared for activities in a day care centre or prepared for a life in a home for the non-working, we have noticed an increase[4] by more than 33% between 2002 and 2007.

GROWING BUDGET ?

Not only the care demand has risen over the last years. Also the government budget for disabled care has increased.

For the period 2004-2009 this amounts to a rise of the operating funds of 295 million Euro in 5 years or an increase of 36%. In other words, this comes down to an average budget rise of 59 million Euro. These budgets are used for maintaining the currently existing capacity as well as for the expansion of the care. This budget rise however didn't seem to keep pace with the number of care demands, and as a consequence, the waiting lists have continued to grow.

In order to respond to the current care demands which haven't been fulfilled, a lot of extra money is required. If on top of that we are to make up for the growing number of care needs in the future, there shall need for more amounts of money. This has been calculated by the Vlaams Agentschap voor Personen met een Handicap (Flemish agency for disabled people; VAPH) in its Multi-annual analysis[5].

[4] Vlaams ministerie van onderwijs en vorming (2010) *Onderwijsstatistieken van de Vlaamse overheid*, consulted on 26.12.2010, at http://www.ond.vlaanderen.be/onderwijsstatistieken/

[5] Vlaams Agentschap voor Personen met een Handicap (2009) *Meerjarenanalyse: Een achteruit- en vooruitblik op de zorgbehoeften van Personen met een Handicap*, p. 76 - 83

It was calculated how much money would be needed for different possible scenarios. In order to merely maintain the currently existing capacity, an increase of the total budget by 165.25 million Euro would be necessary. If we take into account the growth factors, then hypothetically a 2.5 % budget increase, i.e. 387.94 million Euro should be required. Moreover, if we want to recover lost ground and eliminate the shortages, then the estimated budget rise for the 2010-2014 period would be 655.71 million Euro.

From the point of view of disabled people such investments are absolutely necessary and shortages really need to be eliminated. In turn, the government cannot limit itself to merely consolidating the shortages in the care sector, because this would not be in keeping with the self-imposed care objectives accessibility, quality and affordability. Time and time again the then responsible politicians have urged themselves to find the necessary budgets and they have repeatedly promised to eliminate the waiting lists. But in the long run this has proved to be easier said than done. The care need turned out to be growing much faster than expected and despite all the extra money, there never seemed to be enough.

Meanwhile we find ourselves in the midst of a worldwide economic crisis. Our politicians tell us we will need to tighten our belt and that everyone shall have to economize. For the time being there are no cuts in the budget for the support of disabled people. On the other hand, no budget has been provided for the long-term evolutions to come. At least, that is, if we continue on the same path. So other options are being investigated.

The VAPH for instance wants to reduce its target group in order to decrease the number of entitled persons. VAPH's mission shall also be reassessed in order to include less tasks. Certain responsibilities shall be left to regular services and other sectors. But all that offers no solutions for the real support needs of individual persons and families; it's merely moving the problem around. Where do we find a solution then? We absolutely need to think about real reforms.

EFFICIENCY PROFITS

According to us, with a supply-oriented organization of the support of disabled people, as is the case today in Flanders, it has to be possible to have substantial efficiency profits. This has been confirmed throughout several discussions with experts in the matter. It does however imply a willingness to change things drastically in the disabled care sector. The change towards a regulated support market based on demand-steering through the maximum implementation of direct

payments, as is recommended by the Expertise Centre Independent Living[6], does not only meet the modern-day needs, but at the same time allows us to do more, with the same budget.

In the Netherlands direct payments, and more specifically the personal budget (PGB; *persoonsgebonden budget*), are getting more and more widely accepted and have taken their position next to the older system of subsidized care in kind, which makes it possible to compare the two systems.

A pilot study[7] carried out by Zorg Consult Nederland and assigned by the budget holders association Per Saldo, has revealed that the PGB's efficiency profits amounts to 12% when compared to care in kind.

The researchers selected 15 persons with a PGB with different care profiles and examined in detail how these persons used their budget. Furthermore, they asked for bids from 2 or 3 regular care providers for each person. In that way they were able to make a cost comparison which proved that with a PGB it is possible to buy more care for less money.

Moreover, the PGB holder is more satisfied with his or her care and it increases his or her quality of life. The biggest plus points were the control over one's own life, less alternating care providers with whom one can have a closer bond and a greater flexibility.

Surely more research on a bigger scale needs to be carried out in order to be confirm these results more in detail, but still this pilot study provides a clear indication. It shows that the economic theory about controlled market forces and the logic of profit maximization in a quasi market based on demand-steering prove to be right. This Dutch study reveals that, compared to care in kind, a PGB allows for people to purchase support 12% less expensive. People using a PGB are also more satisfied with their support and they achieve a higher quality of life with it.

And why is this? Because the required flexibility, which is so important to people, is very easy to realize with the PGB.

This has also been demonstrated in Sweden where direct payments as a means of support have been an option for disabled people since 1994. In a response to the assumption that providing 'group housing' for seriously disabled people would be

[6] Lambreghts P. / Expertisecentrum Onafhankelijk Leven. (januari 2010) *Marktwerking in de ondersteuning van personen met een handicap: standpunt*

[7] Kaaij R. en Huijsman R. (april 2009) *PGB als strategische pijler van zorgaanbieders*, article in ZM magazine, p. 4 - 9

cheaper than the financing of personal assistance, JAG – a cooperative society of Swedish budget holders – carried out a comparative study[8].

Personnel costs in a number of group housings were recalculated into the costs of the number of hours of personal assistance to which each individual resident would have been entitled in the direct payments system. The government expenses on a municipal level which cover for a substantial part of the overhead costs as well as the construction costs of such housings, where not even taken into account. Neither was taken into account the fact that a personal assistant can provide one-on-one availability to the seriously disabled person, so that flexibility can stay at the same level.

The study unambiguously revealed that care in kind provided through small-scale group housings was in most cases (in four of the five group housings investigated) costing more to society than personal assistance and on top of that it proved to be less flexible.

People increasingly choose to stay at their own house as long as possible and at the same time fewer people make an appeal to residential care facilities. The providing of alternatives or investigating the best ways to make use of care in kind, are possibilities which nowadays are not fully exploited. Research into organization-related costs of VAPH facilities already indicated 20% overhead costs.

The Expertise Centre is pleading in favour of a comparative study comparing the real cost price of the care for disabled persons as it is organized today in Flanders and the cost price of care organized by people who are creatively using a PAB.

CUTTING THE KNOT

“2010 is an important year”, says Jo Vandeurzen (CD&V; political party), the Flemish minister of Well-being in the magazine Handblad[9] (issued by VAPH). Furthermore he says that he is still learning, but he is determined to bring continuity and transparency.

[8] Blanck C., Scherman A. & Sellin K. on behalf of the cooperative society JAG (januari 2006) *The price of freedom of choice, self-determination and integrity. A cost analysis of different forms of support and service to people with extensive functional impairments.*

[9] Vlaams Agentschap voor Personen met een Handicap (December 2009) *‘Het is nu het moment’ – Minister Vandeurzen over het gehandicaptenbeleid van de volgende jaren.* VAPH magazine Handblad #40, p. 4 - 5

The last years there have been a lot of new evolutions in the disabled care sector and the minister would like to continue the disabled people's policy into this new direction. In order to speed up reforms, crucial decisions shall have to be made this year, still according to the minister.

The minister announces important reforms. In any case these reforms should lead to a more effective policy, given the fact that care needs are ever increasing and that we find ourselves in the midst of an economic crisis. The disabled care sector shall need to do more with the same financial means. Hopefully there will be money for dealing with the shortages, but with the current economic reality we can call ourselves lucky if we only manage to avoid budget cuts. The announced reforms are welcomed by the Expertise Centre rather as an opportunity to start the long-expected care reforms than as an underhand way to cut budgets.

Efficiency benefits can non longer be a taboo notion. In these times of scarcity, more than ever it should be a moral duty to manage public funds in the most sensible way possible. As disabled people we obviously would like to receive a full-fledged support, which enables us to lead a life which fulfills our desires and aspirations, and that requires proper budgets on an individual level. Yet, we would like to see that the social security's funds destined for the disabled care are spent in the most efficient way. We do not wish to cost more to society than is required, not on an individual level, nor as a sub-group of society.

The times when disabled people where merely regarded as people suffering from an impairment, who needed to be cared for and protected, belong to the past now. Fortunately there is a new wind blowing in the disabled care sector. In the jargon the choice for the new paradigm is already revealed and to disabled persons inclusion, full-fledged citizenship, auto-determination and freedom of choice are no longer empty words. From the government we expect support instead of care, which is more than semantics, it reflects a whole new way of thinking.

A CHANGING (CARE) DEMAND

Care implies weakness and disease. Everybody, disabled as well as non-disabled persons, need care from time to time. To receive that care we sometimes count on the government or our mutuality or our complementary health insurance and most of the time we just need a doctor, or some extra attention and affection from a loved one. The ultimate goal of care is recovery, but for the majority of disabled people this does not apply.

Maybe that is the real reason why disabled care has become a purpose on its own? Is that why there is such a strong focus on the quality of the care, as if it were the ultimate goal? However, what disabled people are asking from the government and the care providers is something very different and cannot simply be translated into recognition categories.

Support on the other hand is needed in order to achieve something specific, to serve a specific purpose, in order to do, accomplish something. Support is needed to overcome certain obstacles, which are the result of our handicap or an unadapted society. The quality of support can be measured by the extent to which disabled persons are enabled to overcome those specific obstacles.

Support is a very precise work which depends on many variables. These variables are on the one hand defined by the disabled person, his or her personality, wishes, ambitions, preferences as well as the nature and gravity of the disability, chronic disease or impairment. On the other hand there are many variables defined by the environment: the family situation, the cultural and ideological background, an unadapted society and the direct environment, the social cohesion, schooling and education, certain life experiences, and so on. It is the interaction between these variables that define one's support needs.

That is why we need individual budgets, which enable us to define and organize what support we receive and also how we receive it, when we receive it and who provides it. Whether we can call our support good qualitative support or not depends on the extent to which our support enables us to lead the life we want to live. What counts is the result, the outcome, for the disabled person. Recently this peer-to-peer experience has been confirmed by leading experts in orthopedics[10].

It is essential to realize the major importance of demand steering on an individual level. In the current supply-oriented system many competent professional care providers go to great lengths to act in a very demand-oriented way. Certain facilities and services actively and purposefully carry out inquiries among their patients in order to adjust the demand to the patient's needs. But this demand-oriented approach can however not be mixed up with or compared to demand-steering. In relation to a standardized offer of recognition categories demand-oriented support can merely be considered a step into the right direction. In that case the offer absolutely has to be diversified, and support will need to be provided through a multitude of modules which are mutually easy to combine.

[10] van Loon, J., Van Hove, G., Schalock, R. & Claes, C. (2008) *Schaal voor persoonsgerichte ondersteuningsuitkomsten. Handleiding voor afname en standaardisering.* Onuitgegeven handleiding, Stichting Arduin – Universiteit Gent.

That is however very difficult to realize and shall probably never lead to the desired result. The care gradation project[11] is a good example of this. The project has started in July 2005. This project included the assessment of 17,000 disabled people, developing modules, the budget calculation per module and an investigation into the organization-related costs of facilities. Another objective of the project was the diversification and modulation of the various recognition categories by introducing 16 kinds of 'housing' modules and 9 kinds of 'daytime activity' modules. The project was also aimed at a redistribution of the existing budget in favour of those facilities who suffer from an understaffing since long time. This operation however met with resistance from the facilities, which retreated from the project; and finally the reform was abandoned. Also users protested against the care gradation, which was eventually based on real support and not on demanded or needed support.

Although VAPH looks upon care gradation as an important part of the care reform, until now the only result has been an assessment tool which still needs further testing, for example through the PGB-experiment.

There are many reasons why this care gradation does not live up to the expectations of disabled people[12] and it is difficult to regard it as a genuine care reform.

Because of the fact that every person (with a disability) is unique and needs a different kind of support, there is no end to the required diversification. The most extreme form of diversification is called customization or individualization which, according to economic science, is very expensive and which could be well justified within the framework of custom-tailored care[13] but eventually still is a form of supply-oriented organization. Apart from the question whether it can ever be carried out, customization would never lead to the same positive effects with regard to effectiveness and efficiency as compared to the market forces mechanism of demand-steering.

The main difference revolves around the question of who takes the final responsibility. In order for demand-steering to work effectively, it is essential that the responsibility for the organization of the support lies primarily with the disabled person and not with the government.

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[11] Vlaams Fonds voor Personen met een Handicap. (2010) *Zorggradatie info en documenten*, consulted on 03.03.2010, at http://www.vaph.be/vlafo/view/nl/3350294-Zorggradatie.html and http://www.vaph.be/vlafo/view/nl/3460575-Zorggradatie.html

[12] Huys J. (2006) *Zorggradatie is nog geen zorgvernieuwing* website van het Vlaams Gebruikersoverleg voor Personen met een handicap, consulted on 03.03.2010 at http://www.vgph.be/fileadmin/user_data/nationaal/Zorggradatie_is_nog_geen_zorgvernieuwing_J_huys__06.06.06.pdf

[13] prof. dr. Gemmel P. leading professor at the faculty of economy and business administration of the university of Ghent, working for the department Management, Innovation and Entrepreneurship, personal communication on 08.01.2010

WIN – WIN

The reform of the Flemish disabled care towards a regulated support market based on demand-steering as advised to the administration by the Expertise Centre, takes into account the very strong pressure exercised on the government expenditures since the recent economic crisis. Every Euro spent on public services must have a maximum effect. The government and its administration shall have to do their utmost best to ensure a maximum efficiency and already do this in different ways. For example by making their own functioning more independent and responsible, by stricter internal monitoring, and so on.

Our government has since long outsourced the services provided to people with a support need to the private non-profit sector. VAPH – as an independent agency which has a management agreement with the government – strictly regulates and controls these private non-profit organizations and also imposes stringent quality standards. Now, if the government were to put extra pressure on these care providers with regard to efficiency benefits, that would be counterproductive. It would meet with hard resistance and eventually all the parties involved would lose.

Especially in these times of crisis it would be a wise and responsible decision to choose for a system based on demand financing, which would indeed generate efficiency benefits, instead of opting for a supply-oriented system,

Efficiency is high on the political agenda, also in the welfare sector, as appears from one of the main strategic goals in the policy document of minister Vandeurzen:

> *"We encourage the government as well as welfare and health care agents to give attention to- and take initiatives in favour of a more efficient and effective functioning in order to create more care with the same means[14]."*

In the same document there is mention of an operational target (OD 4.6), which indicates that the minister wants to investigate how market forces may be the solution for organizational problems in the residential care:

> *"We [should] investigate the pros and contras of the organization of the residential care offer by public, private social profit and private commercial care providers."*

[14] Vandeurzen J., minister of Well-being, Public Health Care and Families (26.10.2009) *Beleidsnota Welzijn, Volksgezondheid en Gezin 2009-2014*, p. 56 - 64

Further in the document we can read that the minister wants to carry out these investigations in 2010. With regard to the offer in the elderly care a study has already started: Market forces and freedom of choice in the elderly care[15], but with regard to market forces in the disabled care sector, we have no knowledge so far of any study ordered by the minister.

The focus on an efficient government with relation to this sector is limited to administrative simplification and smart IT. This is regretful, because the policy memorandum on Economy by the Flemish prime minister Kris Peeters[16] contains a plea in favour of efficiency in the services and room for innovation in the care. As we can read in the strategic goal 5 concerning an innovative and knowledge-intensive economy:

> *"by means of cooperation, knowledge-sharing and user participation, we can encourage innovations in the care which will have a social (improvement and expansion of the service provided) as well as an economic surplus value (the "non-profit economy" as a growing market on an international level)."*

Also in the strategic goal 2 concerning more and stronger entrepreneurship, from the same policy memorandum, we can read:

> *"This presupposes that entrepreneurship also needs to be a point of interest for policy makers in all domains: entrepreneurship should therefore also be encouraged in other policy domains such as culture, education, well-being, social economy or scientific policy ..."*

This is a lost opportunity to reflect on the efficient use of the VAPH-budget and to redefine the VAPH employees' tasks as well as the role of people who rely on it. Wouldn't it be more efficient if people controlled their own care instead of an administration performing this task for thousands of people at the same time?

Moreover, this policy change could also realize another goal, apart from the financial aspect. By assigning a new role to disabled people as full-fledged participants on a market which allows freedom of choice, self-determination and steering of demand, we can leave the legacy of the old 'individual defect' paradigm behind us. Now that the government has adopted the jargon and the spirit of the modern vision on disabled people and after having carried out some small-scale care reform experiments, it is time to effectively start reforming its regulations and structures as well as working towards the realization of the social care objectives.

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[15] Van Audenhove C. prof. dr. (15.10.2009) *Jaarplan* 2010 ontwerp, Steunpunt Welzijn, Volksgezondheid en Gezin, p. 9

[16] Peeters K., minister president van de Vlaamse regering en Vlaams minister van Economie (26-10-2009) *Beleidsnota Economie 2009-2014*

In this way we kill two birds with one stone: more efficiency and a better as well as a more modern policy. That represents a win-win situation for both citizens and the government.

… AND EVEN MORE ADVANTAGES!

A support market based on demand-steering can lead to yet another advantage, next to the necessary adoption of the modern vision on disability and next to the efficiency benefits as compared to the current policy.

For disabled people this translates into further emancipation and more empowerment. For the society as a whole this translates into a society which is richer, on a literal note as well as on a figurative level. Apart from creating more awareness and other positive effects produced by an inclusive society, you also have the possible returns on investment.

After all the social benefits will be much greater than the mere efficiency benefits made in the disabled care. Support which is controlled by a disabled person is much more likely to lead to social participation. Support based on demand-steering will be more focused on life in society and for people with a support need it will also offer more opportunities to take up meaningful roles and tasks.

Disabled people will also be able to do things for others. We will be needing less and less often special facilities and services since we shall be participating more often with the 'rest' (non-disabled people). Mainstreaming, openness and accessibility throughout society will become more self-evident.

Especially when a greater number of disabled people will gain access to the labour market, the financial social benefits will double. Less income replacement payments will be necessary and at the same time there will be more revenue from taxes on labour.

Demand financing with personal budgets shall also create employment for personal assistants, more specifically for groups of people who often have difficulties finding jobs such as poorly qualified young people, foreigners, older unemployed people, etc. It may be better if forms of support such as support while eating, support for correspondence, or providing hygienic care are provided to the budget holder by someone whom he or she trusts, than by a highly qualified person. So this offers many opportunities for poorly qualified people, i.e. those who have suffered most from the economic crisis by losing their jobs. Every person who is hired by a budget

holder (or a cooperative society of budget holders) and subsequently no longer receives state support (RVA, OCMW, ... ; *unemployment benefits, social welfare benefits*) represents a double benefit for the society as a whole.

The financial impact on families of a disabled person can be very substantial, but is not easy to calculate. Research has revealed that families with a disabled person in their midst run a higher risk of poverty[17]. Paid informal care can probably replace unemployment benefits or help avoiding crisis situations which can eventually lead to very high costs for society, etc.

These kinds of effects exist in reality, but until now they have not yet been statistically established. Such research is nonetheless required.

CONCLUSION

The Flemish disabled policy faces the challenge of realizing a reform which can cope with the rising number of care demands in times of economic crisis and at the same time deal with the changing nature of the care demands. This new policy should in the first place offer support opportunities instead of creating care (places). It has to focus on the result for the disabled person in terms of quality rather than stubbornly focus on (the control of) the quality of care (providers).

Further research is needed in order to be able to carry out this reform and to achieve a more efficient use of the available means whilst at the same time improving the quality of living of people with a support need. We also need more research on the cost of care and support so that we may carry out a correct budget determination. Furthermore, thorough research is required about the possible returns on investments after the implementation of demand-steering and financing, so that fair and well-founded policy decisions can be made.

The Expertise Centre advises the minister to fundamentally reform the current policy in consultation with the parties concerned. The funds destined for care and support of disabled people have to be used more efficiently by realizing a different distribution of tasks and a different organizing system. Not the VAPH but disabled people themselves should be able to rule their destiny.

Peter Lambreghts
Expertise Centre Independent Living

[17] International Labour Organization ILO (2003), *Time for equality at work*, p. 34