

Policy under Construction

Dutch Care Personal Budgets from 1995 till 2013

Lianne Heijnen

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IBMG, Erasmus University Rotterdam

Supervisor:
Kor Grit
Co-evaluators:
Job van Exel
Tineke Broer

Preface

Before you lies my master thesis. It is the final piece of my studies Health Economics, Policy and Law at Erasmus University Rotterdam. This master thesis brings five and a half years of studying to an end. A period I look back at with proud and joy. The past years have been a great experience for me. In the year 2007, I started studying Public Administration and Administrative Law at Tilburg University and in 2010, I received my Bachelors degree with a sufficient result. During the Bachelor programme, I developed an interest for the health care sector. To act upon this interest, I chose to continue my studies at Rotterdam and I can that I could not have chosen better. The past one and a half year have not always been easy, but I expanded knowledge of health and health care and had fun doing so. This master thesis combines my interests in as well policy as health care. It combines the best of both studies and with that, it is a perfect way of rounding off the last five and a half years.

Special thanks go, first of all, out to Kor Grit. During the entire process of writing this thesis, he helped me out, steered me in the right direction and provided me with good insights and advice. In addition, I would like to thank Job van Exel and Tineke Broer for the co-evaluation of the thesis. And I would like to thank Frans van der Pas, Jos de Blok, Jacques Bos, Marian van Beek, Wieteke Oegema, Paul Nibbeling and Harrie Bruisten for making time to supply me with needed information. Finally, I want to thank my friends and family for the support and motivation during my studies.

Someren, April the 8th 2013

Lianne Heijnen

Summary

In the past decades, the Dutch society, and the way it is governed, has changed. Market-mechanisms have been introduced and society has obtained a more active role. Similar changes are noticeable within the Dutch health care sector. In line with the developments and in line with a desire to resolve a gap between policy and public, the system of Personal Care Budgets was introduced. With the introduction of the Personal Care Budgets, society was able to participate in the health care sector. Personal Care Budgets were supposed to be an attractive substitute for Care in Kind. However, as time passed, the system started to show shortcomings. According to the Dutch government, it was inevitable to change the policy. Society did not accept the changes and accused the government of enlarging an input-oriented as well as an output-oriented gap between public and policy. This research takes a closer look at this situation by means of the following research question:

To what extent did the policy changes concerning the Personal Care Budgets of January 2012 affect the gap between policy and public and what can be learned from the past?

Two research methods are used to answer the research question; interviews and a document studies. The information gathered in the interviews, scientific literature and Dutch chamber documents is analyzed by the method of encoding, resulting in a conclusion as follows:

The policy changes concerning the Personal Care Budgets affected the input-oriented gap only to a small extend. At certain times, the government averted discussion, but she did not ignore Per Saldo throughout the entire process. The policy changes did not affect the output-oriented gap. What lessons can be learned? As the accusations coming from society are proved invalid, it appears that the issues concerning the policy measures were solved. However, that is not the case. In the case of the policy changes concerning the Personal Care Budgets, the degree of resistance was extreme. A recommendation towards the government is to take such high degrees of resistance seriously. The government should no longer avert discussion, has to look at alternatives and inform society on why given solutions are the best solutions and why alternatives do not fit. When the government had acted upon the high degree of resistance in this specific situation and had taken a closer look at the measures, a long

and intensive struggle could have prevented. The Dutch government has made the wrong decision. The policy measure offers a solution to issues that are not of such importance or which could easily be solved otherwise.

I plead for preservation of the system of Personal Care Budgets in the Netherlands. The need for care for patients will continue and that, in combination with Personal Care Budgets being cheaper than providing Care in Kind, makes it important that the system will be maintained. Two adjustments are necessary. First, to ensure that patients receive care that fits their wants and their needs, the current system has to be sorted out. Secondly, a new role for care offices has to be properly framed and has to be actually implemented.

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Introduction

Over the years, the Dutch society, and the way it is governed, has changed. Demographic, economic, social and technological developments have influenced social order (Noordegraaf, 2008) and looking at the way the Netherlands has been governed from the 1960s until now, large changes are noticeable. Where first the government was completely in control of regulating and controlling society, nowadays more and more is expected from society itself (Tonkens, 2006: 7). Similar changes, from government to market and a new role of society, are also noticeable within the Dutch health care sector. The new role of society contains a new role for the patient. Patients have a more active role within the health care arena than before the changes. Citizens or patients are in charge of taking their own responsibility to protect themselves from risk (Scott & Williams, 1991. In: Petersen and Bunton, 1997: 194) and to do so, the patients were given the possibility to exercise their new role, which they so badly wanted to have. By giving patients the possibilities to have a choice or voice concerning their care, the government also tried to reduce the gap between policy and public, or in this case policy and patient (Tonkens, 2006: 7), meaning the government tried to reduce an imbalance between the public services the government was offering before and the wishes of the citizen or patient.

The patient was given a choice and voice and was being made a part of the health care system. In line with this development, with this new ruling paradigm, is the introduction of the 'Personal Care Budgets', called 'Persoonsgebonden Budget' in Dutch, in the 1990s. The system of Personal Care Budgets stands for a sum of money, a budget, with what a budget holder can buy the care, nursing and counseling that he or she needs and wants (Dutch National Government, 2011). The system of Personal Care Budgets provides a concrete way to empower patients and to strengthen their position. It makes it possible for patients to live an independent and active life (Bosselaar, 2004: 11).

Over time, the Personal Care Budget-policy appeared to be a policy with problematic issues. The number of patients making use of Personal Care Budgets has risen to an extreme and predetermined assumptions, about Personal Care Budgets being a substitute for Care in Kind, appeared not to be true (Breda & Gevers, 2011: 27. Dutch

National Government, 2007. In: Breda & Gevers, 2011: 28). Due to these problems, the policy is in need of change according to the Dutch government. At the beginning of the year 2012, major changes were exercised within the Dutch health care sector due to inevitable cutbacks and also the system of Personal Care Budgets was supposed to undergo major changes. To make sure that there would still be budgets available in the future, the Dutch government took certain measures (Ministry of Health, Welfare and Sport, 2011). For example, as of 2012, only budget holders who have an indication for intramural care are entitled to get a budget, meaning that only people who need such a large amount of care that they are recommended to live in a nursing home or an institution of care can arrange their care themselves as of 2012 (Dutch National Government, 2011). The access to the system of Personal Care Budgets has been limited making it impossible for a large group of people to arrange the needed care themselves.

The changes the government passed through in January 2012 bumped into much resistance. The government was accused of enlarging a gap, which the government in the past desperately tried to resolve. The enlargement of the gap can be seen from two different angles. First, from the input-side. The accusations from this point are that the voice of citizens or patients is unheard and is being neglected in the policy-making process. Those who are touched by the decision are not represented within the policy-making process or the policy itself (Engelen & Sie Dhian Ho, 2004: 20. Beetham, 1991: 3-17. In: Boedeltje, 2009: 43). Per Saldo, the interest group for people who receive a Personal Care Budget, accused the government of the enlargement of the input-oriented gap. The second angle, more output-oriented, is about the responsiveness of a policy (Engelen & Sie Dhian Ho, 2004: 20. Beetham, 1991: 3-17. In: Boedeltje, 2009: 43). Does the service resulting from the policy satisfy the wishes of the patient? Society blames the government of performing poorly; she decreases the freedom of the patients and the care-supply will be less (Autivision, 2012). The possibilities or opportunities patients have received in the past are taken away and with that, the public services provided by the government do again not match wishes of the public and its interest groups. Despite of the resistance from society, the changes were passed through in January 2012.

The Netherlands has a problematic Personal Care Budget-policy. The government has tried to resolve issues, but bumped into resistance. I want to learn more about the

resistance and anger coming from society and what this means to the government. This thesis is about the issues surrounding the Personal Care Budget-policy. What are the issues? To what extent are they relevant? It is also about the relation between the policy changes concerning the Personal Care Budgets and the gap.

Is it true that the gap is back again, or at least is being enlarged? Are the accusations valid? Did the Dutch government act in an improper way? This thesis will set out the entire Personal Care Budget-policy and looks into the issues and the measures presumably resolving the issues, in the hope of giving recommendations on how to handle the problematic situation surround the policy. The following question will be guiding the research.

In what way did the policy changes concerning the Personal Care Budgets of January 2012 affect the gap between policy and public, and what can be learned from these developments?

Research design and methodology

In what way did the policy changes concerning the Personal Care Budgets of January 2012 affect the gap between policy and public, and what can be learned from these developments? This is the central question in this thesis. The following chapter sets out in what way an answer will be found on this descriptive and prescriptive research question.

Research design

To answer the central question in a structured way, the research is divided into several parts, all taking care of a certain aspect.

- Part I - Background and theoretical perspective;

The first part provides information about the background of the research question. Chapters regarding to the shift in the Dutch ruling paradigm, to the gap and to Personal Care Budgets will make the issue clear.

- Part II - The policy of Personal Care Budgets;

This part will set out the policy of Personal Care Budgets. On the basis of the 'policy theory'-method, part II will explain why the policy of Personal Care Budgets was introduced in the first place and why. Part II also sets out how this has changed as of the January 2012. It provides us with an understanding about why the policy had to change from the Dutch governments' point of view.

Policy-theory

A policy theory sets out the theory behind a certain policy and with that helps to find perspectives. A policy theory can be described as an accumulation of perspectives underlying a policy. Attention is being granted to the starting points for policy. Second, the objectives in relation to the policy instruments are being looked at, even as normative factors which could influence a policy. The policy-theory makes clear on

what basis a measure is taking and what the expected effects would be (Hoogerwerf, 1984. In: Korsten, n.d.: 3, 30-32).

- Starting point for policy;

The starting points for policy set out why a policy is designed in the first place. Why is a certain policy established (Hoogerwerf, 1984. In: Korsten, n.d.: 3, 30-32)? With regards to this research, the question asked is why the Personal Care Budget-policy was established years ago. What was the need for Personal Care Budgets in 1991?

- Normative relationships of factors;

When understanding a policy problem, it is important to also consider the normative assumptions. Values and facts are not always easy to separate and policymakers sometimes make, consciously or unconsciously, assumptions. There is a normative framework of interpretation that underlies the policy and in order to solve policy problems, one must know these interpretations or assumptions (Hoogerwerf, 1984. In: Korsten, n.d.: 3, 30-32). With regards to this research, the question asked is what assumptions the policymakers had in mind while constructing the policy.

- Goals in relation to policy instruments.

What are the goals and how do policy instruments fit these goals (Hoogerwerf, 1984. In: Korsten, n.d.: 3, 30-32)? With regards to this research, the question asked is what the relation between the policy goals and policy instrument is and to what extent these fit.

- Part III – Personal Care Budgets of 2012 and the Gap;

Part III will handle the policy measures, as they got into force in January 2012, in relation with the gaps. This will answer the first part of the research question; to what extent did the policy changes concerning the Personal Care Budgets of January 2012 affect the gap between policy and public?

The first chapter in part III will set out the policy-arena. Which parties are involved when accusing the government of enlarging the gap? The second chapter will focus in the input-oriented problem of the gap. What are the accusations that Per Saldo brings forward? And are these accusations valid? To what extent did the policy measures affect the input-oriented gap? The third chapter answer the same questions as the second chapter does, only focuses itself on the output-oriented gap. What are the accusations that society or the holders of a budget bring forward? And are these

accusations valid? To what extent did the policy measures affect the output-oriented gap?

- Part IV - The state of affairs of Personal Care Budgets in the end of 2012 and recommendations for the future.

The final part consists of three chapters and will round up the thesis. The first chapter in the part sets out the problems that remain. What were the problems of the Personal Care Budgets and to what extent are they relevant in the present? The chapter is about the current presence of the issues that have led to the policy change. The second chapter will answer the last part of the research question. What can be learned from the past? The final chapter consists of conclusions coming from the entire research. In what way did the policy-measures affect both gaps? What can be learned from the past? The final chapter also brings recommendations for the future and sets out what kind of research is necessary for the future.

Methodology

The research strategy is a case study. A case study is a qualitative research method which excels at bringing an understanding of complex issues or objects (Yin, 1984: 23). The contemporary phenomenon taking in a central role in this research is the policy of Personal Care Budgets. The objective of the research is to gain insight in the extent to which the debate between the Dutch government and society was based on valid arguments, in order to learn from the past and to perhaps prevent such situations in the future.

Research methods often used within a case study are document studies, interviews and observations (van Thiel, 2007: 59). In order to answer the central question in this research, I will make use of the first two methods.

- Document study;

A document study is comparable with a literature study (van Thiel, 2007: 59). In addition to the scientific literature used within a literature study, the document study also makes use of other documentation. Important literature within this research is national- as well as international scientific literature. The first part of this research will

be based on scientific literature. Other important documents are Dutch Chamber documents. These documents are of major importance to the second part of the research. Based on scientific literature, together with the Dutch chamber-documents, an answer will be found regarding to the three different perspectives underlying the Personal Care Budgets-policy.

An important document which contains information about the Dutch health care system is 'Health in Transition. The Netherlands: Health System Review' (Schäfer et al, 2010). This rapport serves as a guideline on terminology. Specific Dutch terms and concepts are translated into the English language in this document and in this research, I followed that terminology as much as possible.

- Interview.

The research method of interview is mostly used within the case-study (van Thiel, 2007: 108). Conducting an interview is obvious when it comes to attitudes, opinions, knowledge and feelings of persons ('t Hart et al, 1996: 26), and therefore, the interviews are of major importance to this research. The interviews are of importance to the third part of this research. Results within that part are based on data coming from the interviews.

The interviews are semi-structured interviews, which means that they are held by means of a topic list. The questions and answers are therefore not given in advance (Baarda et al, 1996: 26). The topics are determined by means of the objective of the interview. The objective of each interview is set out below. The topic lists are to be found in the appendix.

When talking about case studies, it is fact that data should be collected at different levels (Boeije, 2005: 21). The interviews conducted in this research took place at different levels. A lot of organizations are involved when it comes to Personal Care Budgets. To get a clear view on the attitudes, opinions, knowledge and feelings concerning the discussion surround the Personal Care Budgets, it is important to speak to as many organizations as possible. The following organizations are of importance.

- The Dutch government;

To answer the questions why and how the policy has changed as of January 2012, an interview with a Policy Officer of the Ministry of Health, Welfare and Sport would have been useful considering the validity of the research. Unfortunately, this was not

feasible. By means of an e-mail, the Ministry informed me that the organization is not available for interviews, because of the many requests for interviews they receive. Contact with the spokesperson on Personal Care Budgets from the Ministry did not lead to an interview with a Policy Officer. Because of the busy circumstances, a face-to-face interview turned in to a written interview. This eventually was cancelled to, meaning that part II completely is based on analysis of scientific literature and Dutch chamber-documents.

- Per Saldo;

Per Saldo is the most important interest group for people who receive a Personal Care Budget. To obtain information about the input-oriented and the output-oriented gap, there will be a face-to-face interview with Frans van der Pas, policy officer at Per Saldo. Objective in this interview is to trace the vision of Per Saldo on the issues surrounding the Personal Care Budgets, the solutions for the problems Per Saldo has in mind and the vision of Per Saldo on the input- as well as the output-oriented gap.

- Buurtzorg Nederland;

Buurtzorg Nederland is a national organization who provides a natural alternative for home care. This organization is mentioned by the government as a good alternative for Personal Care Budgets. Two interviews will be held with Buurtzorg Nederland. One with Jos de Blok, managing director at Buurtzorg Nederland, and one with Jacques Bos, nurse at Buurtzorg Nederland. Objective in the interviews is to trace to what extent Buurtzorg Nederland agrees or disagrees with being an alternative for Personal Care Budgets and how the provision of care is organized at Buurtzorg Nederland.

- ZuidZorg;

In order to learn more about home care offered in the Netherland and in order to verify the information given by Buurtzorg Nederland, an interview will be held with ZuidZorg, provider of home care and competitor of Buurtzorg Nederland. Marian van Beek will provide more information on the organization provides care and to what extent the provision of care is demand-oriented. To what extent do patients have a say when it comes to receiving care. The objective of this interview is find out more about what organizations can offer concerning Care in Kind and what they experience in offering that care.

- Mezzo;

Mezzo is the national association for informal caregivers and voluntary care. To obtain information on the problem of 'monetizing informal care', an interview with Wieteke Oegema, policy officer at Mezzo, will be held. Objective in this interview is to trace the vision of Mezzo on the issues surrounding the Personal Care Budgets, specified to the problem of monetizing informal care.

- Care offices.

As an answer to several issues, a new and more active role for care offices has been brought forward. In order to find out how the care offices feel about that measure, what the new role will bring for the future and whether it would have been answer to problems in the past, an interview with a policy officer of a Dutch care office is necessary. Objective of the interview is, first, to learn more about the current state of the new role for care offices. The second objective is to learn more about the view of care offices on the new role in combination with the issues of the Personal Care Budgets. Unfortunately, no care office had time meet with me face-to-face or talk on the phone, but two employees of two care offices, Paul Nibbeling and Harrie Bruisten, were willing to answer my question by means of e-mail.

Now it is clear what, how and why data is collected and what methods are being used, it is important to explain how the result are being analyzed.

For the analysis of both the interviews and the literature and documents, I use a method called 'encoding'. Collected data will be carefully read and after that divided into fragments. When applying encoding, themes or categories are sought within the data and they are then appointed with a code. This result in a list of codes (Boeije, 2005: 84). Information will be organized and the amount of data will be reduced. The information will be manageable and it is possible to compare data and draw up conclusions (Boeije, 2005: 94). In order to encode the information coming from the interviews, they will be transcribed literally.

Part I

Background & theoretical perspective

Chapter 1

A new paradigm within the Dutch social order

1.1 Developments within Dutch society

Over the years, the Dutch society, and the way it is governed, has changed. Demographic, economic, social and technological developments have influenced social order (Noordegraaf, 2008) and looking at the way the Netherlands have been governed from the 1960s until now, large changes are noticeable. Where first the government was completely in control of regulating and controlling society, nowadays more and more is expected from society itself (Tonkens, 2006: 7). This change, however, has taken quite some time.

The Dutch welfare-state, as we knew it before the Second World War, was characterized by multiple problems. First, a tenability problem (Grit & Meurs, 2005: 18). The welfare-state had led to high costs. The pressure on the public spending, coming from the high costs, rise to an extreme in the 1970s (Verhoest, Vervloet & Bouckaert, 2003: 13). This led to another problem during the 1990s, a controllable problem. How could the demand for governmental provisions be controlled? The demand from society for the provisions from the welfare-state increased to an improper amount (Trommel & van der Veen, 1999. In: Grit & Meurs, 2005: 18). Not only financing problems, as just described, led to crisis within the Dutch nation, also concerning the authority of the government questions were asked. Faith and confidence towards the government had decreased. Society did not trust the government to be able to solve social problems, which became more complex and plural during that time (Grit & Meurs, 2005: 18).

It was inevitable to review the public service and the question whether the government should limit its tasks to just core-business was asked. After this, the government was no longer completely in control. A search was set up to find a mixture between state and market as coordinating mechanisms (Verhoest, Vervloet & Bouckaert, 2003: 13). This search eventually has led to two changes. First, the role of the government as the coordinator of social order became smaller and second, a new measure was introduced: New Public Management. From around the 1980s and 1990s, the government was expected to govern on a more efficient and business-like way (Verhoest, Vervloet & Bouckaert, 2003: 14).

Before the previous change, the society was characterized as a society with passive citizenship. Citizens had access to different social and economic rights, without the government demanding anything in return from those citizens. With the upcoming changes regarding the controlling mechanism, society and its citizens obtained new political rights. The ideal type of an independent and deliberative citizen was born (Tonkens, 2006: 7). One of the main reasons for giving citizens political rights is to reduce the gap between policy and citizen (Tonkens, 2006: 7), a gap which occurred because citizens changed and began to expect more or different things from the government.

1.2 Dutch health care reforms

Similar changes, from government to market and a new role for society, are also noticeable within the Dutch health care sector. For a long time, the idea that the government should take care of its citizens was dominant in the health care sector (Scott & Williams, 1991. In: Petersen and Bunton, 1997: 194). Just like in the United States of America and other western countries in the world, the Dutch health care arena was marked by trust-based, principal-agent relationships to overcome information gaps (Tuohy, 2003: 195). However, around the same time that New Public Management occurred, an ideological shift away from the notion that the state has to protect the health of the citizens took place. As of that time, citizens or individuals were supposed to take responsibility to protect themselves from risk (Scott & Williams, 1991. In: Petersen and Bunton, 1997: 194). Since then, there has been a development of introducing 'regulated competition' into the Dutch health care system. The market has been introduced as new governing mechanism. A shift from 'government' to 'governance' tries to capture the complexity of steering relations in health care. The state has become increasingly dependent on other actors, private as well as public, in regulating and supervising health care (Ngo et al, 2008: 4). Western democracies throughout the world were shifting away from the government and started, in the hope of resolving the upcoming problems regarding to efficiency and the new role of the citizen, to include market or quasi-market mechanisms in the public health systems to provide incentives for efficiency (Ranade, 1998. In: Blank & Bureau, 2010: 112). To overcome the problems concerning the new role of the citizen, the Dutch government gave institutions for care more freedom to arrange their own policies, in the hope the

patient would receive a central role within the health care arena and therefore to overcome the gap between policy and patient (Tonkens, 2006: 7). The government, however, remains a certain regulation position (Dutch National government, 2011), evidence at the time suggested that a totally free market in health care can produce neither equity nor efficiency (Wells, Ross & Detsky, 2007. In: Blank & Burau, 2010: 112).

The changes over the years have led to a structural reform in the Netherlands in 2006. The reform can be seen as a longstanding political wish to completely introduce market mechanisms like managed competition and to change the role of the government from direct steering of the system to safeguarding the process from a distance (Schäfer et al, 2010: 22, 26). The reform introduced a single compulsory insurance scheme, in which multiple private health insures compete for insures persons. Dutch health insurers now can negotiate to a certain extent with health care providers on price, volume and quality of care. The government is in charge of controlling quality, accessibility and affordability of health care from a distance, but as of 2006, responsibilities are in hands of insurers, providers and patients (Schäfer et al, 2010: 22). To act on their responsibilities, patients have been given tools to make active decisions when talking about health care (Schäfer et al, 2010: 26).

1.2.1 *Choice & Voice*

The patient has received more opportunities to express their desires, grievances and concerns at macro level (in decision-making of health care systems), meso level (in hospitals or health insurance organizations) and at micro level (for example individual treatment plans) (Wildner et al, 2004: 248-264. In: Saltman et al, 2004). The opportunities to express themselves, or the way patients can participate, is expressed in voice- or choice options. Choice and voice are two of the most significant means through which the public is able to participate in public services. Choice gives the public, or in this case the patients, the possibility to position themselves as consumers and therefore it gives patients the option to choose good providers over bad (Greener, 2008: 255-265). Voice positions the user of public services as citizens, voice implies that citizens hold the right to participate in public services either through a political process, such as elections, or through their direct involvement in the running or delivery of services themselves (Greener, 2008: 255-265). Albert O. Hirschman (1970) follows a

similar path in explaining choice, which he refers to as exit, and voice. Voice refers to an institution's ability to allow consumers or patients to give feedback about products or services, and its ability to listen to the feedback given. Choice however, tends to be reduced to providing people with the options of making a choice whether to use a service or not, the choice- or exit option (Benschop, Horstman and Vos, 2003: 141).

1.2.2 Personal Care Budgets within the health care reforms

Patients were given a voice and choice, and were being made a part of the health care system. In line with this development, with this new ruling paradigm, is the introduction of the Personal Care Budgets, called 'Persoonsgebonden Budget' in Dutch, in 1991. The Personal Care Budget is a sum of money, a budget, which a budget holder uses to buy the care, nursing and counseling that he or she needs and wants (Dutch National Government, 2011). Personal Care Budgets are in line with the previous described participation at micro level. Patients received more opportunities to express their desires concerning their individual health care plans. Before the Personal Care Budgets-system, patients were provided with care on the basis of Care in Kind. In that case, care office arranged which providers of care delivered the indicated care (Klabbers, 2009: 218). The care office, together with the health provider, determined how and when a patient received the indicated care. With a Personal Care Budget, the patient determines that his- or herself (Dutch National Government, 2012). With a Personal Care Budget, patients are given choice as well as voice. Choice because patients can choose between Care in Kind or a Personal Care Budget to arrange their needed care. When choosing for a Personal Care Budget, a patient is also given voice. Patients are given a voice at micro level to set up their own care. They obtained direct involvement in the delivery of services (Greener, 2008: 255-265). Patients have become consumers using the budget, setting up their own individual treatment plan and choose who provides the care. Within the Personal Care Budget, choice can also be detected, because patients can, using their voice, choose between more providers of care. This combination of choice and voice makes the system of Personal Care Budget to be a powerful instrument. Patients have a choice, and this choice is extended with a voice (Kremer, 2006: 385. Wildner et al, 2004: 248-264. In: Saltman et al, 2004. Greener, 2008: 255-265).

Chapter 2

A gap between policy and citizen

2.1 The gap

As explained in previous chapters, the Dutch society of the Dutch social order has changed over the past decades, due to several demographic, economic, social and technological developments (Noordegraaf, 2008). These developments and the changed social order have also led to changes within the relationship between the government, or the policy-side, and the society, or the citizen-side. The relationship between either sides, or the way they work together, has changed from a society with passive citizenship to a society where citizens are independent and deliberative (Tonkens, 2006: 7. Greener, 2008: 255-265). A similar development is noticeable within the health care sector. The societal change and the development from passive citizens or patients to active citizens or patients did not come without consequences. Citizens and patients started to demand more from government and they wanted to be involved. The new and different demand of the upcoming 'new citizen' of 'new patients' created a gap between the policy-side and the society-side.

A gap is generally defined as a conspicuous difference or imbalance and a problematic situation resulting from that imbalance (The Free Dictionary, 2012). On basis of this definition, the gap between policy and citizen in the Netherlands will be explained in the following paragraphs.

2.1.1 An imbalance: a changing citizen, patient and government

After the Second World War, the Dutch government was struggling with financial problems (Verhoest, Vervloet & Bouckaert, 2003: 13). Together with a decrease in trust from society to government (Grit & Meurs, 2005: 18), it was inevitable to review the public service and the question whether the government should limit its tasks to just core-business was asked (Verhoest, Vervloet & Bouckaert, 2003: 13). For the past decades, there has been an emphasis on reducing the role of the government and on reforming the government system by adopting aspects of private sector practice (Batley & Larbi, 2004: 1). As of then, the government changed in two ways. First, the role of

the government as the coordinator of social order became smaller and second, New Public Management was introduced (Verhoest, Vervloet & Bouckaert, 2003: 14). The changing government was to be seen as a possible solution for resolving the gap between public and policy. However, not only the government changed, also society changed. The changes concerning trust and confidence in the government have got to do with changes concerning the role of citizens and patients. Julian le Grand (1997) describes the societal changes using metaphors. Before the second world war, public servants (the policy-side) were perceived as public-spirited altruist, called 'knights', and the service users (the citizen-side) were seen as passive, called 'pawns'. As of the 1980s, the policy-side came to be seen as essentially self-interested, called 'knives' and the citizen-side came to be regarded as consumers, called 'queens' (Welshman, 2006). The citizen-side obtained more political rights (Tonkens, 2006: 7) and with that the service-users were seen as consumers, which made the policy-side to be seen as essentially self-interested (Welshman, 2006). Trust and confidence towards the government decreased as the citizen-side became known as 'queens' (Grit & Meurs, 2005: 18. Welshman, 2006).

The description by le Grant (1997) makes the imbalance clear: the citizen-side became 'queens', citizens became more independent and lost trust and confidence in the government (Grit & Meurs, 2005: 18. Welshman, 2006). The welfare-state, as a caring and paternalistic state, is too much interfering for the upcoming citizen as 'queens'. The welfare-state turns citizens, patients or consumers into 'pawns', into passive and apathetic users of public services (Klingemann & Fuchs, 1995. In: Boedeltje & Cornips, 2004: 2). The upcoming 'queens' did not want, and need, interfering governments. Society started expecting another way of public service provision. Society wanted to have a say in the provision of services, in order to make sure that the outcome matched their preferences. The balance between what the government offers as public services and what society wants disappeared. The provision of public services, process as well as outcome, no longer corresponded to the wants and needs of society.

2.1.2 Problematic situation: policy versus citizen

The upcoming imbalance between societal wishes and public service provision led to a problematic situation. The administrative relationship between government, the policy-side, and society, the citizen-side, no longer fits. The imbalance and the different

administrative relationship between both sides had led to disappointment and dissatisfaction within the citizen-sided and citizens turning against the government (Klingemann & Fuchs, 1995. In: Boedeltje & Cornips, 2004: 2).

The general definition of a gap: a conspicuous difference or imbalance and a problematic situation resulting from that imbalance. In this case there is an imbalance concerning the provision of public services and the wants and needs of society. Society wants to be a part within the construction of public services and they want the outcome to match their preferences. This all has led to the problematic situation that disappointment and dissatisfaction rule within society.

2.2 Beyond the gap: efforts of the Dutch government for reducing the gap

2.2.1 Problems underlying the gap

In order to resolve the problematic situation which was created, to resolve a situation in what society was dissatisfied with the government's actions, it is important to detect two underlying and different problems that come with the gap. The annoyance and dissatisfaction ruling within society can be divided into two different issues or problems; an input- and an output oriented problem.

Governments strive to get the support from society, to get 'permission' from its citizens, in order to reduce imbalances or gaps. This is known as support, or even legitimacy (Scholten, 1975. In: de Graaf, 2007: 39). Legitimacy is defined as following: "where power is acquired and exercised according to justifiable rules, and with evidence of consent, we call it rightful or legitimate" (Beetham, 1991: 3. In: Boedeltje, 2009: 43). Based on this definition, two different forms of legitimacy can be identified:

- Input legitimacy;

The emphasis concerning input legitimacy is on the support of society for authority and for the prevailing rules of the system. It is about participation of those who are being touched by a decision and about the representation of their preferences and interests (Engelen & Sie Dhian Ho, 2004: 20. Beetham, 1991: 3-17. In: Boedeltje, 2009: 43). Within the Netherlands, the participation can be exercised by several kinds of

associations, among which interest groups. These associations fulfill an important task in uniting diverse groups of citizens and concerning connecting citizens with the government, politics and business (van den Berg et al, 2008: 65. Putnam, 2000: 22-23).

- Output legitimacy.

Output legitimacy can be seen as responsiveness of a policy or a decision. It is about to what extent the output or outcome from collective decision-making is in line with the wishes and preferences from society. Output is the actual and targeted result of a policy-making process. It is the primary policy effect. Outcome is what subsequently happens with the output, outcome is the result of actions by individuals based on their individual decisions. The difference between output and outcome makes clear that political interventions can have effects that was not anticipated on, these effect can be positive as well as negative (Engelen & Sie Dhian Ho, 2004: 20. Beetham, 1991: 3-17. In: Boedeltje, 2009: 43).

The input-oriented problem concerning the gap would be that the voice of citizens or patients is unheard and being neglected in the policy-making process. Those who are touched by the decision are not represented within the policy-making process or the policy itself. The output-oriented problem is about the responsiveness of a policy. Does the service resulting from the policy satisfy the wishes of the patient? Does the service, as presented, coincide with the service the patient wants to see presented? Do patients, in the end, get what they want?

2.2.2 Solutions resolving the gap

Traditional institutions, despite the changes the government already had undergone (Noordegraaf, 2008), could not cope with the social changes and the upcoming problems to which they have led (Klingemann & Fuchs, 1995. In: Boedeltje & Cornips, 2004: 2). New ideas about policy-making, in which hierarchical structures were replaced with more horizontal modes of cooperation between government and society, arose (Kooiman, 1993. In: Boedeltje & Cornips, 2004: 3). In order to resolve the problems and to decline the gap, the government had to pursue changes within policy-making and give other social actors more political rights (Tonkens, 2006: 7). Interactive

governance and demand-based governance were introduced (Boedeltje & Cornips, 2004).

- Interactive governance.

Letting society influence policy, giving society a choice or a voice, is an important source of creating legitimacy. Direct participation of society could be seen as a mechanism to link political decisions with preferences and wishes from society. In order to create direct participation, social actors were given more political rights (Tonkens, 2006: 7). These social actors would for example be social and private organizations and even individual citizens. Within the Netherlands, patients or patient organizations are indicated as a third party within health care, next to providers of care and insurance companies. Patients and patient organizations are acceded as stakeholders and have become more and more a part of the consultation structure in the Dutch health care system (van den Bovenkamp, Grit and Bal, 2008: 3-4).

Interactive governance originates from a tradition of corporatism. The Netherlands has a tradition of societal corporatism. Corporatism can be defined as a system of interest representation. This interest representation can be from above, which is called 'state corporatism', or from below, which is called 'societal corporatism'. Representation is exercised by several kinds of associations (Berger, 1981: 104-105). After the Second World War, when the Netherlands was characterized as a welfare state, the tradition of societal corporatism has arisen. However, in a moderate form where only certain associations or organizations were able and allowed to influence policy (van Dijk & Sap, 1997. In: Balkenende, 1997: 153). Interactive governance is a modern form within societal corporatism, arose in the 1990s. As of that time, patients and patients organizations were able and allowed to influence policy and not only certain associations were privileged to do so.

The influence of patients or patient organizations as actors within the process of policymaking would not only resolve the input-oriented problem of the gap but it also prevents political decisions from resistance, as society got more and more critical towards the government (Norris, 1999. In: Boedeltje & Cornips, 2004: 3), being an answer to the output-oriented problem of the gap. Interactive governance could make it more likely that policy-outputs match with the societal preferences (Scharpf, 1999. In: Boedeltje & Cornips, 2004: 4). The introduction of interactive governance can be seen as an attempt to improve legitimacy. It can be seen as an attempt to reduce the input-

oriented problem of the gap, which may subsequently lead to less output-oriented problems (Scharpf, 1999. In: Boedeltje & Cornips, 2004: 4).

- Demand-based governance;

Demand-based governance is the situation where the user of social services, within the field and within the legal framework of facilities, is able and allowed to make the decision concerning the establishment of his or her own life and concerning the services, products and suppliers used to realize the preferred lay-out of his or her own life (Bosselaar, 2004: 15). Demand-based governance can be described as policy-making based on the initiative and/or acknowledged needs and wants of the recipient (Randma-Liiv, 2007: 467-487). In scientific literature, demand-based is indicated as policy driven by demand (Bosselaar, 2005). Policy is made on the basis of the wants and needs of society. Therefore, policy matches societal preferences. The responsiveness of policy will improve with demand-based governance and there will be less output-oriented problems.

Chapter 3

The Dutch system of Personal Care Budgets

3.1 Personal Care Budgets; a definition

One of the icons of the Dutch reforms, revealing the tools and options for patients to make active decisions, is the system of Personal Care Budgets. With the introduction of this system or this budget, patients have become consumers (Kremer, 2006: 385). Patients were being made a part of the system and were given the right to participation through choice and voice, reducing an output-oriented gap. Patients wanted to have a say, and with the introduction of the Personal Care Budgets, they received to do so (Kremer, 2006: 385. Tonkens, 2006: 7. Wildner et al, 2004: 248-264. In: Saltman et al, 2004. Greener, 2008: 255-265).

In the year 1991, the Personal Care Budget-system was introduced nationally within the Netherlands as an experiment. In the year 1995, due to positive experiences and good results, the Personal Care Budget became a part of the Dutch health care system (Miltenburg, Mensink & Ramakers, 1993). The number budget consumers grow rapidly and therefore also the costs. This resulted in plans to reform the system in the year 2003 (Pijl & Ramakers, 2007: 81). The changes introduced in 2003 led to the system as we knew it up to the year 2012.

‘A Personal Care Budget can be described as a system in what budget holders can manage their own care. Budget holders receive a budget with what they can employ a care-worker who cares according the budget holder’s wishes’ (Kremer, 2006: 385).

Before the system of Personal Care Budgets was introduced, patients received care on the basis of Care in Kind. Care offices arranged which providers of care delivered the care the patient needed (Klabbers, 2009: 218). As of the year 1995, patients with an indication for care because of long-term illness, handicap or old-age, can choose between Care in Kind or a budget to arrange it themselves. Care in Kind means a lower workload and less responsibility, but it also means less participation and monitoring (Grit, van den Bovenkamp & Bal, 2008: 83).

A Personal Care Budget strengthens patients as consumers and gives them autonomy. With their own budget, patients are able to define an individual definition of good care. The Personal Care Budget recognizes the want and need from patients to have the last word on how, when and under what conditions care should be provided (Kremer, 2006: 385).

A study, exercised in 2007, states that one of the main reasons for budget holders to choose for a Personal Care Budget is that with the budget, the budget holders have freedom. Patients want to choose their own care and also, patients want to have more influence on the way the health care is provided. It is important for patients to purchase and organize care by themselves and the use of Personal Care Budgets is an excellent way to do so. It is an excellent way for the patient to participate and to be a part of the health care system. 'Freedom, independence and self-management of life' are common terms when it comes to Personal Care Budgets. Another important reason is the fact that with a Personal Care Budget, budget holders can receive certain forms of care, which cannot be provided on the basis of Care in Kind (Ramakers, de Graauw et al., 2007: 264).

Regarding the Dutch governmental and health care reforms, the system of Personal Care Budgets is an excellent example of participation for patients throughout choice as well as voice on the micro level (Wildner et al, 2004: 248-264. In: Saltman et al, 2004. Greener, 2008: 255-265). It also can be seen an answer to an output-oriented problem of the gap. The system of Personal Care Budgets provides a concrete way to empower patients and to strengthen their position. It makes it possible for patients to live an independent and active life (Bosselaar, 2004: 11).

3.2 The content of the Personal Care Budgets

Up till 2012, several types of care could be arranged on the basis of the system of Personal Care Budgets. The source of the budget differs per type of care. One of the sources is the 'AWBZ', which stands for 'Algemene Wet Bijzondere Ziektekosten' or 'General Exceptional Medical Expenses Act'. Everybody can get dependent on long term care and support because of illness or a handicap. To get the long term care when needed, all Dutch citizens are automatically insured through the General Exceptional Medical Expenses Act. The act covers medical expenses which are not

covered by health insurance companies and are unaffordable for patients (Dutch National Government, 2012). The other source is 'WMO'. WMO stands for 'Wet Maatschappelijke Ondersteuning' or 'Social Support Act'. This act arranges that people with a limitation get the care they need concerning facilities, help and support. The Social Support Act is executed by local governments. The General Exceptional Medical Expenses Act is executed by the Dutch national government (Dutch National Government, 2012).

Within the system of Personal Care Budgets, different types of care can be arranged. For the greater part, it concerns extramural care. But also intramural care, as in short-term and long-term residence, can be arranged. The different types of care are described below.

- Domestic help;

When a patient is in need of aid within the household, he or she can pay somebody to help with the budget he or she receives. The help can go from laundry, housecleaning and cooking to grocery shopping and other chores around the house. Domestic help can be organized throughout the Social Support Act (Per Saldo, 2012).

- Individual guidance;

Patients can have mild up till sincere hindrance due to the health condition or handicap and therefore a patient can be in need of guidance in form of support, practices or supervision when doing the daily activities. Help, paid throughout the General Exceptional Medical Expenses Act, for instance helps with maintaining social contacts, the planning of daily activities, regulating finances or problematic behavior (Per Saldo, 2012).

- Group guidance;

When patients are in need for daytime activities to replace different form labor or school, he or she can get guidance in group form. This type of care provides patients with day programs with sorts of labor or schooling to maintain skills and to stock as much independency as possible. Also group programs can help patients to deal with problematic behavior. Care in the form of group guidance is paid throughout a budget from General Exceptional Medical Expenses Act (Per Saldo, 2012).

- Personal care;

Patients in need of aid with everyday actions such as getting out of bed, showering, getting dressed, eating, drinking and going to the bathroom, can get help which is paid with a budget coming from the General Exceptional Medical Expenses Act (Per Saldo, 2012).

- Nursing;

A budget coming from the General Exceptional Medical Expenses Act is there for patients who need help with using medication, wound care or artificial respiration (Per Saldo, 2012).

- Short-term residence;

Short-term residence is one of the sorts of care that falls within the General Exceptional Medical Expenses Act. With short-term residence, patients can have weekend- or vacation shelter, short-term residence is not meant to be a living form. Short-term residence is introduced to temporary release the people surrounding the patient, for instance family or the partner (Per Saldo, 2012).

- Long-term residence.

Next to short-term residence, there is also long-term residence. This type of care is arranged by the General Exceptional Medical Expenses Act. It makes it possible for people who are in need of that much care that they cannot live at home, to live in a care institution (Per Saldo, 2012).

3.3 Organizations surrounding Personal Care Budgets

Holders of a Personal Care Budget are confronted with multiple organizations. It is not just about the government and the care provider. Next to these two major organizations are other important organizations: the Needs Assessment Centre, care offices and interest groups (SVB, 2012). These organizations take in different roles concerning the Personal Care Budgets. The first two of these, the Needs Assessment Centre and the care offices, are important organizations for patients in order to receive a Personal Care Budget. The third type, the interest groups, is important concerning the substance of the policy of Personal Care Budgets.

- The Needs Assessment Centre;

The Needs Assessment Centre indicates the entitlement to care (SVB, 2012). The centre assesses a patient's situation and then decides what type of care is required and in what amount (Schäfer et al, 2010: 158-160). Having the indication, the patient knows how much care he or she can receive and in what form (CIZ, 2012). The Needs Assessment Centre sends the indication to a care office, which then is responsible for paying out the budget or arranging Care in Kind (Schäfer et al, 2010: 158-160).

- Care offices;

With the introduction of market mechanisms and the changed role of the government in the past years in the Netherlands, an open health care system was created (Schäfer et al, 2010: 22, 26). Health insurance companies are, since the changes, private organizations. They have become market players (Schäfer et al, 2010: 25). However, when it comes to care which is covered by the General Exceptional Medical Expenses Act, it has to be on a non-profit basis. The provision remains in hands of the insurance companies, but these have for a license to set up a care office (Schäfer et al, 2010: 35). A care office is the organization that pays out the budget. According to the indication a patient received from the Needs Assessment Centre, the care office decides how high the budget is the patient will receive and for how long. This is all encountered in a contract. Based on that contract, the patient will have to look for care providers his- or herself (SVB, 2012).

Budgets are paid out in advance. On the basis of the size of the budget, the care office will determine if the payment occurs once a year, half yearly, quarterly or monthly. For the budget holder, the budget must not be seen as income. However, for those who are being paid with the budget, the care providers, it is income. When a budget holder does not spend the entire budget, the care office is entitled to take parts of the budget back (CVZ, 2012). The care offices carry-out policy, they do not determine what is in it. The government determines the legal framework (Zorgverzekeraars Nederland, n.d.).

- Interest groups.

As explained, the Netherlands has a tradition of societal corporatism. A new form the societal corporatism, which occurred just before the Personal Care Budgets were introduced, is interactive governance. Not only certain organizations were allowed to influence policy as of then, patients and patient organizations also received a say. Patients can be represented. This representation then is exercised by several kinds of

associations, among others interest groups. They fulfill an important task in uniting diverse groups of citizens and in connecting citizens with the government, politics and business (van den Berg et al, 2008: 65. Putnam, 2000: 22-23). The interest groups intervene in the policy-making process and represent citizens or patients, to make sure that they are being heard and that they get what they want (Scharpf, 1999. In: Boedeltje & Cornips, 2004: 4). The most important interest group, when talking about Dutch Personal Care Budgets, is 'Per Saldo'. Next to the role of intervening concerning the substance of the policy of Personal Care Budgets, Per Saldo also offers information and guidance to individual budget holders.

Part II

The policy of

Personal Care Budgets

Chapter 4

The theory behind the Personal Care Budgets; a problematic theory?

A policy theory sets out the theory behind a certain policy and with that helps to find perspectives. A policy theory can be described as an accumulation of perspectives underlying a policy. Attention is being granted to starting points for policy and the objectives in relation to the policy instruments are being looked at, even as normative factors which could influence a policy (Hoogerwerf, 1984: 3-24. In: Korsten, n.d.: 30-32).

This chapter sets out the different perspectives of the policy-theory regarding to the Personal Care Budgets and the problems that came with it.

4.1 Personal Care Budgets and its problems

4.1.1 *The need for Personal Care Budgets in 1991*

In the year 1991, the Personal Care Budget-system was introduced nationally within the Netherlands as an experiment. Four years after that Personal Care Budgets became a part of the Dutch health care system, due to positive experiences and good results (Miltenburg, Mensink & Ramakers, 1993. Pijl & Ramakers, 2007: 81). What were, at first, the reasons for introducing such a system in the Netherlands? What were the starting points for this policy?

The first reason links to the changed role of society, the want and need from society to participate within the system. Society, used here as a collective name for citizens and patients, wanted to participate. To overcome an output-oriented problem, the government arranged a system for patients to participate (Beetham, 1991: 3-17. In: Boedeltje, 2009: 43). The introduction of the Personal Care Budget-system made it possible for patients to participate at micro-level. It provided patients with choice and voice, which patients wanted and needed and so, an output-oriented gap has been overcome by the government.

Coherent with the need for a system, which provides patients with voice and choice, is the need for a system which overcomes the problems of Care in Kind. Care in Kind is an inflexible way of providing care. Patients or users are dependent on care offices and providers, the care they prescribe and the times they set the care will be delivered (Miltenburg, Mensink & Ramakers, 1993. Pijl & Ramakers, 2007: 81). The system of Personal Care Budgets does not only give patients the freedom to choose what care will be delivered, but also provides a freedom to arrange when care will be delivered.

Another reason for introducing Personal Care Budgets back in 1991, besides care becoming more patient-oriented and demand-oriented, is that self-management will eventually lead to better health outcomes (van den Bovenkamp, Grit and Bal, 2008: 10). Health care innovation will be encouraged and health care professionals are relieved (SER, 2008: 13). The matters which patients experience within their life with a disease or disability and the contacts they have with health care are on the basis for this. Individual experiences and experiential knowledge provide expertise in decision making. A greater diversity of experiences and views, along those of care professionals and health insurers, creates opportunities for new and original solutions (van den Bovenkamp, Grit and Bal, 2008: 12).

The government saw a way to overcome an output-oriented gap by introducing the system of Personal Care Budgets. In addition to the gap, other benefits would be obtained. The Personal Care Budgets were supposed to be a substitute for Care in Kind. Care has to be paid for, regardless to the method of paying-out. The government can pay for the care itself, or 'pay' the patients, so that they can buy the care themselves. The system of Personal Care Budgets was supposed to be just a budgetary neutral system (Dutch National Government, 2007. In: Breda & Gevers, 2011: 28).

4.1.2 The need for change

As stated by the Dutch government, it is inevitable to change the policy regarding Personal Care Budgets (Veldhuijzen van Zanten-Hyllner, 2011: 1). Personal Care Budgets are mostly funded by the General Exceptional Medical Expenses Act. This act provides care and support for long-term illness, disability and aging. The General Exceptional Medical Expenses Act was established in 1968 and since then it has improved and is expended. Health care use has increased, costs have risen and the

bureaucracy is more rampant. The appeal to General Exceptional Medical Expenses Act-care has increased, neither society nor the clients is hereby served (Veldhuijzen van Zanten-Hyllner, 2011: 1-2).

Measures are needed to make General Exceptional Medical Expenses Act-care future-proof. The General Exceptional Medical Expenses Act is of high quality for the most vulnerable in society with need for long-term care and this quality must be guaranteed in the future. To guarantee the high quality in the future, also regarding to quality of the Personal Care Budget-policy, measures are inevitable (Veldhuijzen van Zanten-Hyllner, 2011: 1-2). The General Exceptional Medical Expenses Act is in need of change, and with that, so is the system of Personal Care Budgets. Within the appeal to General Exceptional Medical Expenses Act-care rising, the appeal to a Personal Care Budget has increased. The number of persons demanding a Personal Care Budget has, as to be seen in figure 2, increased to an extreme. From 2003 up till 2006, the number of budget holders doubled (Breda & Gevers, 2011: 27). This extreme increase in number of users, and therefore an extreme increase in costs, can be appointed to two unexpected and undesired developments; improper use and the monetizing of informal care. These developments have led to an unnecessary appeal to collective resources.

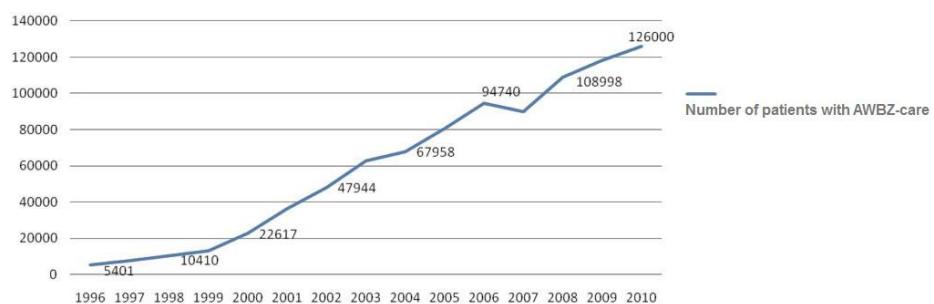


Figure 1: The number Personal Care Budget-users (Breda & Gevers, 2011: 27)

4.1.2.1 Improper use of Personal Care Budgets

The major disadvantage for budget holders is the administrative burden that comes with a Personal Care Budget. To overcome this disadvantage, a whole new market has emerged. A new market of mediation agencies which, for remuneration, assist users and potential users of a Personal Care Budget with processing administration and purchasing health care (Grit, van den Bovenkamp & Bal, 2008: 85). A part of the Personal Care Budget-users, about 10 percent (Ramakers et al., 2007. In: Grit, van

den Bovenkamp & Bal, 2008: 85), seems to be unaware of the fact that they should pursue the management of their health care themselves. The cost of mediation may be paid from the budget. This leads to money going to the mediation agencies, money which should have been spent on health care (Skipr, 2010: 415. Grit, van den Bovenkamp & Bal, 2008: 85). This new market of mediation agencies not only dislocates money, it also is susceptible to fraud. For the mediators, it is really easy to stab the money in their own pockets (Bruinsma & Stoffelen, 2010).

Next to the above, the Personal Care Budgets are used by health care providers as an addition to the regular care contract. If a provider wants to deliver more care than has been agreed on with the care office, or when the space within contract is exhausted, patients are referred to a Personal Care Budget by the health care providers (Skipr, 2010: 415). The money coming from the Personal Care Budgets has been spent in an improper way.

4.1.2.2 Monetizing informal care

Monetizing informal care literally means payment of informal care. One can speak of monetizing informal care if there are strong indications that the unpaid informal care giving prior to the Personal Care Budget is replaced by paid informal care giving (Ramakers & van den Wijngaart, 2005: 40). There is the suspicion that a part of the budget holders has applied for a budget to pay for existing informal care. This means that scarce care budget is used for something that already was being done for 'free' (Tjadens, 2004. In: Grit, van den Bovenkamp & Bal, 2008: 86).

4.1.3 *Normative assumptions*

The system of Personal Care Budgets was supposed to be a substitute for Care in Kind (Dutch National Government, 2007. In: Breda & Gevers, 2011: 28), but this predefined and consciously made assumption appeared to be incorrect. The growth in expenditure concerning Personal Care Budgets has not led to a reduction in growth of Care in Kind (Veldhuijzen van Zanten-Hyllner, 2011: 24). The two unexpected and undesired developments as described above, have led to an extreme increase in users of the budgets and an unnecessary appeal to collective resources. The policy problems are reflected within the execution phase.

Not only false assumptions concerning economic budgetary issues play a role when it comes to problems with Personal Care Budgets. It is important to understand these normative assumptions. They play a major role in finding a solution for the problem (Hoogerwerf, 1984. In: Korsten, n.d.: 3, 30-32). The government adopted some assumptions, including the Personal Care Budget system as a substitute for Care in Kind (Dutch National Government, 2007. In: Breda & Gevers, 2011: 28), which, according to the government, subsequently proved not to be correct in executing the policy. Other assumptions relate the budget holders. These are implicit assumptions which the government on forehand did not define. The assumptions are unconscious assumptions which during the execution of the policy appeared to be wrong. Two false assumptions were made regarding the budget holders. First, the government expected that budget holders to be able to deal with Personal Care Budgets. The government expected that budget holders had the capability to execute and manage a Personal Care Budget rightfully. This appeared to be wrong, as a whole market of mediation agencies emerged to help out the holders of a budget (Grit, van den Bovenkamp & Bal, 2008: 85). The second assumption concerning the budget holder is about motivation. Can we trust the budget holder in spending collective resources? With the introduction of the Personal Care Budget system in 1991, patients have become consumers (Kremer, 2006: 385). They wanted to have a say, and with the introduction of the Personal Care Budgets, they received that (Kremer, 2006: 385. Tonkens, 2006: 7. Wildner et al, 2004: 248-264. In: Saltman et al, 2004. Greener, 2008: 255-265). However, giving the patient an amount of freedom and the opportunity to set-up their own health plans, gives patients the possibility to manage collective resources. To make it possible for society to manage collective resources, the government had to trust society. In order to fully exploit the self-management of patients, trust is needed. However, also common sense is important (WRR, 2012: 11), as appeared within the execution phase. The government fully trusted society and thought of citizens and users of the Personal Care Budgets as responsible and reasonable citizens. Responsible citizens are proactive paragons of civic engagement, enhancing the social fabric and selflessly crafting themselves, their families and their neighborhoods to achieve greater economic independence, social capital and wellbeing (Brown & Baker, 2012: 3). Responsible citizens are enjoined to make choices, pursue preferences and seek to maximize the quality of their lives inasmuch as they correspond with the advice they are given (Brown & Baker, 2012: 38). A responsible citizen has a strong focus on collective interest (Tonkens, 2006: 10). Reasonable citizens are committed to

searching for fair terms of social cooperation, a reasonable citizen get guided by moral lines in the sand (Eberle, 2002: 213). Assuming a citizen or users who is guided by morals and focuses on the collective interest, abuse of the system is not something one would expect to happen.

Chapter 5

Towards a new policy in 2012

A report concerning the Personal Care Budget-policy, written by the Dutch government in 2011 and published publicly in October 2012, gives a good summary on the issues and problems of the policy from the point of view of the government. The policy was introduced in 1991 to overcome an output-oriented gap and to satisfy a changed society who wanted to have voice and choice. The introduced self-management would also lead to more health innovations. The instrument of Personal Care Budgets was supposed to be a great substitute for Care in Kind. However, later on problems started to show. An explosive growth in costs makes it impossible to continue with the policy as it was before 2012. Costs elsewhere in the General Exceptional Medical Expenses Act did not drop after the introduction of Personal Budgets. The explosion of costs is attributed to an explosion in clients who use a Personal Care Budget. The Personal Care Budget is a popular instrument because of the possibility to pay out informal care givers (monetizing informal care) and because of the flexibility in which health care can be arranged. The administrative burden does not play a role in the decision to choose for a Personal Budget, because of the mediation agencies (improper use). Another issue has come to light after years of experience with the Personal Care Budget-policy. Wrong assumptions appeared to be made at the start of the policy concerning the behavior of the budget holder. The government trusted them to use the instrument on a proper and honest way (motivation) and believed that the budget holder was able to use the instrument rightfully (capability). A lack of these two also contributed in the explosion in costs of the instrument (interdepartmental working group of the Ministry of Health, Welfare and Sport, 2011: 3-6). The following chapter sets out what the government would have done to overcome the problematic issues and make the instrument to be a solid instrument.

Practice shows that there is reason to make remarks on the system of Personal Care Budgets. Given the problems of the policy as mentioned, the Dutch government chose to change the policy, with limited input from other stakeholders. The following three measures were implemented in January 2012, in order to make the policy solid (Veldhuijzen van Zanten-Hyllner, 2011: 24):

- Restricting access to a Personal Care Budget;

Restricting access to a Personal Care Budget means that the option to choose for a Personal Care Budget for new budget holders with a extramural indication is no longer available as of January 2012 (Veldhuijzen van Zanten-Hyllner, 2011: 3). Only current budget holders who have an indication for intramural care are entitled to choose for a budget, meaning that only people who need such a large amount of care that they are recommended to live in a nursing home or an institution of care can arrange their care themselves as of 2012. People who now receive a budget, but are not indicated with an indication for intramural care, will lose the budget as of January 2014 (Dutch National Government, 2011). The right to health care continues to exist for these budget holders, but they are no longer able to manage their own care throughout a Personal Care Budget (Veldhuijzen van Zanten-Hyllner, 2011: 3). Given the attractiveness of the previous policy-arrangements, the government expects a significant drop in demand for General Exceptional Medical Expenses Act-care with the new policy-arrangements (Veldhuijzen van Zanten-Hyllner, 2011: 4).

- Decentralization of extramural care to the Social Support Act.

Extramural care is transferred from the General Exceptional Medical Expenses Act to the Social Support Act. Patients receive guidance from the local government (Ministry of Health, Welfare and Sport, 2011).

- Compensation Arrangement Personal Care

For people for whom it is truly impossible to receive proper care on the basis of Care in Kind, another measure was created at the beginning of 2012. This measure is called the 'Compensation Arrangement Personal Care'. Under certain strict conditions, some patients are allowed to use this arrangement, with what they get access to an individual budget for the purchase of care. The Compensation Arrangement Personal Care has the same rates and rules for purchasing care as the Personal Care Budget (CZ, 2012). To qualify for the arrangement, the patient must demonstrate that he or she cannot receive the necessary care on the basis of Care in Kind. The patient also has to have an indication which states that he or she is in need of at least ten hours of care per week (CZ, 2012).

Restricting the access to Personal Care Budgets seems odd. The access to the system of Personal Care Budgets has been limited, making it impossible for a large group of

patients to arrange the needed care themselves. Patients were being made a part of the system and were given the right to participation through choice and voice, reducing an output-oriented gap. Patients wanted to have a say, and with the introduction of the Personal Care Budgets, they received that. With these new measures, which are executed as of January 2012, the possibilities or opportunities patients had received in the past are taken away and with that, the public services provided by the government do again not match wishes of the public. However, the government argues that health care in the Netherlands has changed over the past decade and that objectives, which at first were tried to achieve with the introduction of the Personal Care Budgets, are achieved by other instruments. First, extramural care has in the past years established innovations which have led to more choice and options for patients, one of the objectives of the Personal Care Budget policy. Next to that, organizations which provide Care in Kind have become more professional and more flexible, answering to one of the shortcomings from previous Care in Kind organizations. 'Buurtzorg Nederland' is one example of such an organization (Veldhuijzen van Zanten-Hyllner, 2011: 23). Buurtzorg Nederland focuses on good care. The organization provides professional and dedicated interest in the personal situation of the client, it delivers professional care, arranges things around and make sure patients are able to decide and agree on the needed care themselves (Buurtzorg Nederland, 2012). Recapitulating, the government finds it permissible to pursue policy changes, because of innovations within the extramural care and the upcoming of organizations such as 'Buurtzorg'. These two developments have made the system of Personal Care Budgets redundant. The objectives of the system have been reached otherwise (Veldhuijzen van Zanten-Hyllner, 2011: 23).

Chapter 6

The Spring-agreement

The measures, implemented as of January 2012, received much resistance. Particularly the first measure, the measure that limits the access to a Personal Care Budget. The holders of a Personal Care Budget did not agree with the taken measures and accused the government of enlarging the gap between policy and citizen. Despite the resistance coming from the budget holders, the changes were passed through. But not for long. On April the 23th, the Dutch government resigned and on May the 25th, a new coalition-agreement was presented. Under the name 'Spring-Agreement', new measures were taken to get through the economic crisis (National Aid Guide, 2012), new measures which again affected the Dutch Personal Care Budgets.

The Spring-agreement states that the measures concerning Personal Care Budgets will be softened. This, however, will be in a limited extent. In 2011, the government decided that there had to be cutbacks of 700 million euro's. This has been reduced with 150 million euro's in the Spring-agreement. Meaning that cutbacks of 550 million euro's instead of 700 million have to be made. This softened measure still affects the system Personal Care Budgets (Veldhuijzen van Zanten-Hyllner, 2012: 10. Naar-Keuze, 2012), leaving the issues concerning the gap unresolved.

6.1 Restricting access to a Personal Care Budget

As of January 2012, the access to a Personal Care Budget got restricted. This measure has been partially reversed within the Spring-agreement. Not only patients who are indicated with 'long-term residence' care receive the option to choose for a Personal Care Budget, also other types of care can be arranged throughout a Personal Care Budget again. Patients who are indicated with 'guidance', as well individual as group, remain unable to claim a Personal Care Budget (van den Elzen, 2012. Veldhuijzen van Zanten-Hyllner, 2012: 10).

6.2 Decentralization of extramural care to the Social Support Act

Extramural care was transferred from the General Exceptional Medical Expenses Act to the Social Support Act. Patients would receive guidance from the local government as of January 2012 (Ministry of Health, Welfare and Sport, 2011). This measure has been declared controversial. The measure was expected to cause a behavioral change. The government now sees that that assumption was based on insufficient evidence and decided to cancel the measure (Veldhuijzen van Zanten-Hyllner, 2012: 12).

6.3 Other measures

Two other important measures are passed through according to the Spring-agreement.

- Access to a Personal Care Budget after one year of Care in Kind;

Related to the measure restricting the access to the system is this new measure. Patients are only eligible for a Personal Care Budget after they have used Care in Kind for one year. There has been made an exception for patients who are indicated an indication for intramural care and need long-term residence care. The one-year-period does not account for that group of patients (Veldhuijzen van Zanten-Hyllner, 2012: 10).

- A changed role for care offices.

Described in the Spring-agreement is that care offices have to take in a much more active role. They no longer just approve the budget plans from applicants, care offices are now supposed to talk face-to-face to the applicants. Care offices must talk to applicants to get a clear view on why someone chooses for a Personal Care Budget (van den Elzen, 2012). The face-to-face conversation should also make clear whether an applicant is better served with a Personal Care Budget or with Care in Kind. The care office must provide the applicant with correct information and guidance (Veldhuijzen van Zanten-Hyllner, 2012: 10).

The following figure shows the transformation of the system throughout the years. It shows how the system changed at what period of time.

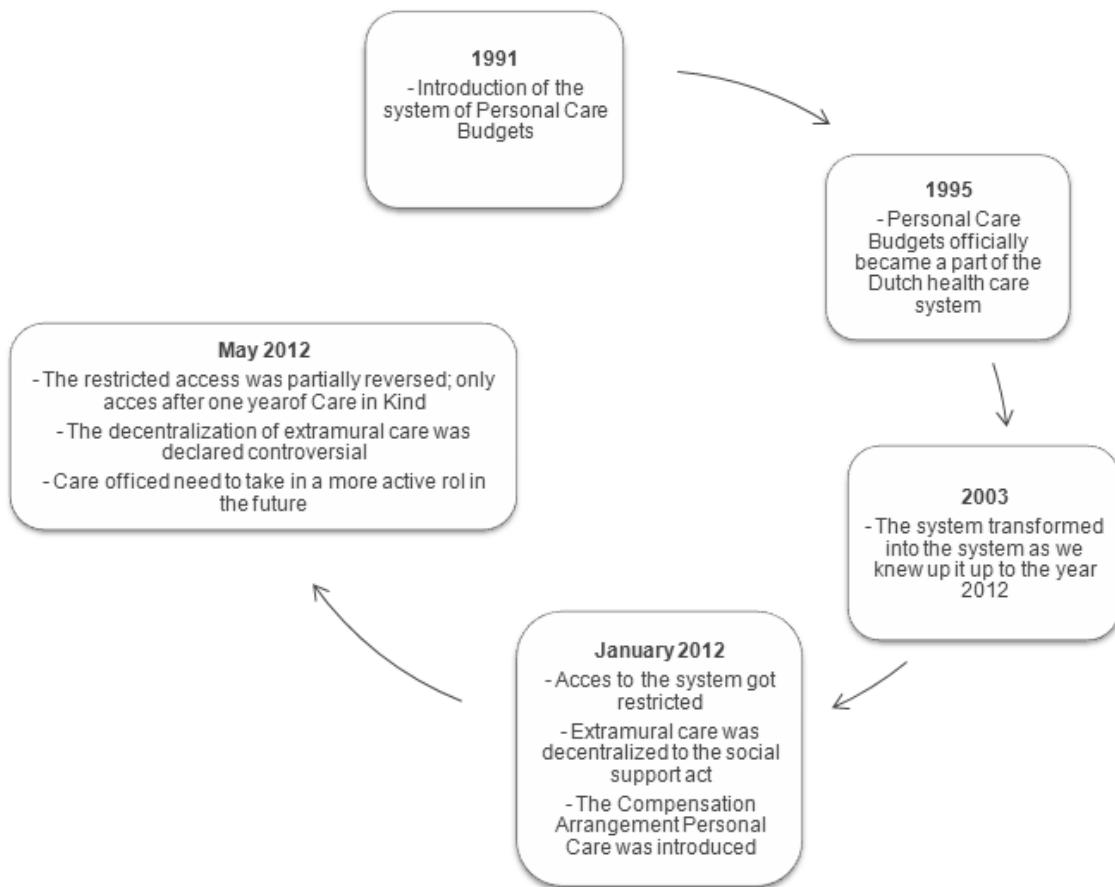


Figure 2: The transformation of the system of Personal Care Budgets (Heijnen, 2013)

Part III

Personal Care Budgets of 2012 & the Gap

Chapter 7

Indicating the parties in the discussion

The policy measures, as passed through by the government, received much resistance from society, particularly the measure which restricted the access to a Personal Care Budget. Concerning that measure, the government was accused of enlarging a gap, which the government in the past desperately tried to resolve. This chapter sets out and defines the different parties within the discussion concerning an enlargement of the gap. The following chapters set out the discussion itself and will check the tenability of the accusations.

As explained in chapter 2, the gap can be seen from two different angles. First, there is the input-oriented problem of the gap. This captures the problem the public feeling unheard or neglected in the policy-making process. Those who are touched by the decision are not represented within the policy-making process or the policy itself (Engelen & Sie Dhian Ho, 2004: 20. Beetham, 1991: 3-17. In: Boedeltje, 2009: 43). Per Saldo, interest group for people who receive a Personal Care Budget, accuses the government of enlarging the input-oriented side of the gap. The input-oriented side of the gap refers to a discussion between Per Saldo and the government. This specific discussion does not involve the content of the policy, it is about the policy-making process. The second angle, the output-oriented gap, is about the responsiveness of the policy (Engelen & Sie Dhian Ho, 2004: 20. Beetham, 1991: 3-17. In: Boedeltje, 2009: 43). Does the new policy, meaning a policy with restricted access, match the wants and needs of society? The budget holders accused the government of enlarging the output-oriented side of the gap.

Chapter 8

The input-oriented problem of the Gap

8.1 The input-oriented accusations

The most important interest group, when talking about Dutch Personal Care Budgets, is 'Per Saldo'. Per Saldo was founded in 1995 by people who have disabilities themselves and who strive for self-management of care for patients (van der Pas. Per Saldo. Personal Communication, September the 5th, 2012).

8.1.1 *Per Saldo was ignored*

Per Saldo, as the interest group for people who receive a Personal Care Budget, accuses the government of creating an input-oriented gap. The government promised to involve Per Saldo in the process of redefining Personal Care Budgets for the year 2012. However, when decisions were actually taken, Per Saldo felt ignored (Skipr, 2010: 415). This has been mainly felt on the point of 'the self-management argument', the greatest controversy between the government and Per Saldo. Per Saldo strives for self-management of care for patients and it was that self-management that the government wanted to cut back when restricted the access to a Personal Care Budget for many budget holders. Per Saldo felt ignored in finding solutions that would prevent the demolition of self-management (van der Pas. Per Saldo. Personal Communication, September the 5th, 2012). Frans van de Pas explains it as follows:

"We have been ignored during the last policy-making process. What we do as an interest group, we try to keep in close contact with government officials and the State Secretary to make sure policies and decisions match to wants of people with a disability. But the government executes its own policy. We do not decide for, we just supplement. We supplement based on discussions and conversations, which are interwoven with the daily practice. That is a feature of our work. We constantly keep in touch with people from the community about what they need. The collision that occurred last year was a typically political maneuver from the government to show thoroughness. It has been political haggling which has broken Personal Care Budgets down" (van der Pas. Per Saldo. Personal Communication, September the 5th, 2012).

8.1.2 *Discussion got averted*

As said, Per Saldo finds they got ignored in finding solutions that would prevent the demolition of self-management. Not only did the government ignore Per Saldo, the government also did not engage in the discussion. Per Saldo stands for self-management of care for patients (van der Pas. Per Saldo. Personal Communication, September the 5th, 2012). As an argument for the limitations in access to a Personal Care Budget, the government reports the following:

“Extramural care has established innovations in the past years which have led to more choice and options for patients, one of the goals of the Personal Care Budget policy … Next to that, organizations which provide Care in Kind, became more professional and more flexible, answering to one of the shortcomings from previous Care in Kind organizations” (Veldhuijzen van Zanten-Hyllner, 2011: 23).

Per Saldo responds to this argument by saying that the government averts discussion. The government decided that innovations have led to a new situation in where a Personal Care Budget is less necessary for the patients (Veldhuijzen van Zanten-Hyllner, 2011: 23) and did not give Per Saldo an opportunity to respond or contradict to the given argument, an opportunity Per Saldo did have in previous discussions. Per Saldo does not agree with the statement that innovations have led to a new situation in which Personal Care Budgets are unnecessary. Per Saldo finds it important that people with a disability can live their own life and fit the needed care in to that life, without having to adapt to a certain organization. Per Saldo states that organizations for Care in Kind are not able to provide in a certain flexible way that the patients can achieve self-management. However, the government does not want to hear what Per Saldo has to say and sticks to former adopted position (van der Pas. Per Saldo. Personal Communication, September the 5th, 2012).

“The government averted the discussion by saying that self-management is also possible within Care in Kind. However, the obstructions within Care in Kind are of such matter that patients are unable to accomplish self-management. The government does not want to hear this” (van der Pas. Per Saldo. Personal Communication, September the 5th, 2012).

8.2 Validity of the accusations

The first accusation of Per Saldo concerning the input-oriented problem of the gap is that the government ignored Per Saldo during the policy-making process. This was mainly felt on the greatest controversy between both parties, 'the self-management argument'. Per Saldo feels as she was ignored in finding solutions that would prevent the demolition of self-management (van der Pas. Per Saldo. Personal Communication, September the 5th, 2012). This accusation is not valid. The government promised to involve Per Saldo in the process of redefining Personal Care Budgets for the year 2012. Per Saldo feels as though when decisions were actually taken, the range of ideas and recommendations coming from Per Saldo were placed out of side. This however does not automatically mean that Per Saldo was ignored during the entire process. The relation between Per Saldo and the government is quite well. The government describes the relation with Per Saldo as "a good collaboration" (Dutch National Government, 2009) and Per Saldo admits that "some of the advice gets incorporated in national policies" (van der Pas. Per Saldo. Personal Communication, September the 5th, 2012). The government has the formal right of decision-making (Degenkamp, 2007: 41), Per Saldo does not. In this specific situation, Per Saldo does not agree with the output of the policy-making process. However, they were involved in the policy-making process, they were not ignored and therefore, the accusation is not valid.

Not only feels Per Saldo as though they were ignored during the process, they also feel as though the government refused to engage in discussion. In the second accusation, Per Saldo accuses the government of averting discussion.

As an argument for the restriction in access to a Personal Care Budget, the government states that innovations and developments, for example the organization Buurtzorg Nederland, have led to a new situation in where a Personal Care Budget is less necessary (Veldhuijzen van Zanten-Hyllner, 2011: 23). Per Saldo disagrees with this argument. Per Saldo states that providers of Care in Kind do not provide in such a flexible way that patients can achieve a certain level of self-management. Also other organizations, including Buurtzorg Nederland, disagree with the government. Jacques Bos, nurse at Buurtzorg Nederland, states the following:

“What I think is important concerning a Personal Care Budget, and what might be the actual purpose of the policy, is that people are able to control their own conduct. What you can see is that we, Buurtzorg Nederland, are a part of the Personal Care Budget policy. A part of the care arranged with a Personal Care Budget, we can do ... However, Buurtzorg Nederland is not a replacement for the Personal Care Budgets. We expect a certain level of flexibility back from the patient. As nurse, I take a piece of the self-management of the patient away from them and I expect the patient to respect and understand that. Next to that, we cannot provide all of the care arranged with Personal Care Budgets” (Bos. Buurtzorg Nederland. Personal Communication, November the 2nd, 2012).

Wieteke Oegema is a policy officer at Mezzo, the national association for informal caregivers and voluntary care and she contradicts to the government arguments as well:

“A Personal Care Budget provides the patient with an opportunity to retain control. Moreover, Care in Kind is not always sufficiently available for specific audiences and does not always unite with the wishes from the patient, for example in terms of flexibility ... Custom work is essential and a Personal Care Budget is often the only solution that can contribute to quality of care” (Oegema. Mezzo. Personal Communication, September the 5th, 2012).

The government disregarded the responses from Per Saldo and pursued with their own statement, which appeared to be false based on information from different organizations such as Buurtzorg Nederland and Mezzo. The government stood her grounds, despite the criticism. The second accusation is valid, the government averted discussion.

8.3 To what extent did the policy changes affect the input-oriented gap?

Half of the first part of the research question can now be answered.

To what extent did the policy changes concerning the Personal Care Budgets of January 2012 affect the input-oriented gap between policy and public?

The policy changes concerning the Personal Care Budgets of January 2012 affected the input-oriented gap between policy and public to a small extend. At certain times, the government averted discussion. However, the government did not ignore Per Saldo. The government did not take away the opportunity to express oneself on macro level (decision-making level). Those who are being touched by the decision were represented within the policy-making process. The government has the formal right of decision-making, Per Saldo does not agree on the content of this decision.

Chapter 9

The output-oriented problem of the Gap

9.1 The output-oriented accusations

Not only an input-oriented gap was felt after announcing the policy-measure, also an output-oriented gap was felt. Budget holders feel as though the measure, which restricts the access, does not correspond with their wants and needs. The criticism of the budget holders was expressed extensively in the Dutch media in the year 2012.

“The new arrangements are patient-unfriendly” (Nu.nl, 2012).

“It is logical the government has got to do something about rising health care costs. However, the abolition of the Personal Care Budgets is not the solution, it creates problems. Some patients are not able to use the care they need without receiving a budget to arrange it themselves” (Autivision, 2012).

“The result of this cut is that people will be chased into care institutions, while the government says she wants to increase the personal responsibility” (Trouw, 2012).

Not only was the criticism expressed throughout the Dutch media. Budget holder who are being touched by the measure which takes away their right to receive a Personal Care Budget as of 2014, gathered on June the 23rd 2011 to protest against the policy measure and to make sure the government heard their voice.

“About a thousand people have protested in The Hague against the abolitions of the Personal Care Budget ... The protesters find the proposed measures to be a slap in the face of anyone who uses a Personal Care Budget” (RTL, 2011).

9.1.1 *The available care does not fit the needs of the budget holder*

The budget holders were not pleased with the policy measure that restricts the access to a Personal Care Budget. The government hides behind the argument that no one is deprived of the right the health care (Veldhuijzen van Zanten-Hyllner, 2011: 4), but that

is not what the budget holders accuse the government of. As of January 2012, the possibility for new patients to choose for a Personal Care Budget elapsed (Veldhuijzen van Zanten-Hyllner, 2011: 25), meaning that that group of patients no longer has the right to a Personal Care Budget. People who already have a Personal Care Budget are allowed to use it until January 2014, but after then, the access for a large group of budget holders is limited to (Veldhuijzen van Zanten-Hyllner, 2011: 25). The budget holders who do not have the indication for intramural care accuse the government of taking away the care they want and need. The budget holders want to have the opportunity to choose when and how what care gets delivered. They need the budget to live an active life (van der Pas. Per Saldo. Personal Communication, September the 5th, 2012). The opportunity to live that life is taken away with the introduction of the policy-measure.

“It is necessary that people with disabilities can live their own life and fit the needed care into that life. Instead of that, budget holders now would be stuck with organizations where they have to adjust to that organization” (van der Pas. Per Saldo. Personal Communication, September the 5th, 2012).

9.1.2 Voice and choice are taken away

In the past, patients were given a voice and choice. Patients were being made a part of the health care system, to overcome a gap between policy and patient. Patients now feel as though the policy measure which restricts the access to the Personal Care Budgets takes away their choice and voice. Patients who are in need of extramural care no longer have the opportunity to choose between Care in Kind and a Personal Care Budget. And they no longer can use their voice to set up their own individual treatment plan and choose who provides the care they need when they want it.

9.2 Validity of the accusations

The first accusation from the side of the budget holder towards the government is that the available care does not fit their wants and needs. The group of patients who receive extramural care want to have the opportunity to choose when and how what care gets delivered and they need it to live an active life (van der Pas. Per Saldo.

Personal Communication, September the 5th, 2012). The patients feel as though the opportunity to live that life is taken away with the introduction of the policy-measure.

State Secretary of Ministry of Health, Welfare and Sport, Marlies Veldhuijzen van Zanten-Hyllner (2011: 25), responds to this accusation by stating:

“I am aware of the impact that these measures have on patients and providers of care. Care innovations have been established within the extramural care sector in the past years. A very good example is ‘Buurtzorg Nederland’. The process of these care innovations is still going on, but is has been advanced in such way that I find it justified to take these measures” (Veldhuijzen van Zanten-Hyllner, 2011: 25).

One of the three reasons for introducing the system of Personal Care Budgets was to overcome problems of the system of Care in Kind. Care in Kind was known as an inflexible way of providing care (Pijl & Ramakers, 2007: 81), and patients wanted a certain level of flexibility when it comes to their care. The government now states that this reason for introducing the system no longer holds, because health innovations have been established (Veldhuijzen van Zanten-Hyllner, 2011: 25). Did the innovations lead actually to an appropriate replacement of the Personal Care Budgets that would achieve the same objective?

“No, we are not a substitute for Personal Care Budgets … We cannot provide all of the care arranged with Personal Care Budgets … For example, a person with a mental disability who needs help running the household, in that case you have to go to another organization” (Bos. Buurtzorg Nederland. Personal Communication, November the 2nd, 2012).

“Buurtzorg Nederland most certainly is a positive development, but it is not the answer to self-management of care for patients. Buurtzorg Nederland is small-scale, it has short lines. That is an advantage of organizations like Buurtzorg Nederland. Buurtzorg Nederland is not able to provide care to a patient who travels through the whole country for his or her job and needs care on several different places. The argument from the government is full of rubbish” (van der Pas. Per Saldo. Personal Communication, September the 5th, 2012).

The government’s argument on Buurtzorg Nederland being able to replace the Personal Care Budgets appears to be false. As stated by Buurtzorg Nederland itself

and explained in chapter 8, Buurtzorg Nederland is not a substitute for Personal Care Budgets. However, the response of Per Saldo can be seen as false to. Per Saldo states that Buurtzorg Nederland is not able to provide care in specific cases (van der Pas. Per Saldo. Personal Communication, September the 5th, 2012). Buurtzorg Nederland disagrees with Per Saldo:

“I do not agree with Per Saldo. If a person knows that he will be in Eindhoven on Monday for work, in Breda in Tuesday and in Leeuwarden on Wednesday and so on, there most certainly are options. This is where Buurtzorg Nederland is ahead of older organizations which provide home care, we will contact other teams of Buurtzorg Nederland to see if there can be made arrangements. Organizationally it is possible. Clients also can go on a holiday, that also has to be arranged. The indication for care can be transferred to another team. We are very flexible concerning that” (Bos. Buurtzorg Nederland. Personal Communication, November the 2nd, 2012).

Marian van Beek is an employee of ZuidZorg, an organization which provides care in the South-East of the Netherlands. She confirms the statements being made by Buurtzorg Nederland.

“In the past several years, our delivery of care has changed towards community-based-teams. The teams have become smaller, which means that less different caregivers surround the client. This is an answer a need of many clients, they wanted less faces at their beds ... It has created a kind of trust, in the relations atmosphere it means that it now is less of a big step for clients to ask for what they would like. And because caregivers now often see the same clients, they get a better insight in the specific situation of a client, and therefore, they are able to provide appropriate care for a specific situation ... Clients go on vacation and the indicated care then has to be provided by other organizations. For a person who travels through the whole country for his or her work, similar arrangements can be set up” (van Beek. ZuidZorg. Personal Communication, December the 12th 2012).

Despite Buurtzorg Nederland and other organizations being organizationally able to arrange care in specific situations, the fact that they do not provide all the care that could be arranged with a Personal Care Budget remains.

This, however, does not mean that it is impossible to arrange such care provision. Required forms of care which cannot be provided by an organization such as Buurtzorg

Nederland are provided by other organizations. Buurtzorg Nederland can get in contact with these other organizations and in the past, Buurtzorg Nederland has experienced good collaboration with the organizations. According to Jacques Bos (Buurtzorg Nederland. Personal Communication, November the 2nd, 2012), a lot is possible at Buurtzorg Nederland due to the flexible attitude of the organization. Collaboration with other organizations or informal caregivers can lead to a complete as possible supply of care for a patient (Bos. Buurtzorg Nederland. Personal Communication, November the 2nd, 2012).

“Cooperation with other organizations is progressing well. We will take care of the nursing part. We help the client to get out of bed, we wash him, we dress him. Then someone from another organization will come to take the client into the city for other activities. Buurtzorg Eindhoven Stratum is situated in a complex called ‘Petazzie’. Petazzie is a neighborhood support office which arranges different types of care for people in this neighborhood. Social support, case management, housing counseling. ‘Conquest’ is located here for people who need mental care. ‘Lunet’ is here to help mentally disabled people. Petazzie guides and supports people who receive care from one of the organizations here. Concerning collaboration, a lot is possible. We try to help, guide and support on multiple levels. We can switch between organizations. This way, we always try to find the right solution, to deliver the right care for a person, based on dialogue with that person” (Bos. Buurtzorg Nederland. Personal Communication, November the 2nd, 2012).

For exceptions, for patients for whom it is impossible to receive proper care on the basis of Care in Kind, another measure was created at the beginning of 2012. This measure is called the ‘Compensation Arrangement Personal Care’. To qualify for the arrangement, the patient must demonstrate that he or she cannot receive the necessary care on the basis of Care in Kind (CZ, 2012). So even in very specific cases, patients can receive the care they need.

Recapitulating; the counter-argument of the government stating that organizations such as Buurtzorg Nederland are a replacement for the Personal Care Budgets is invalid. Buurtzorg Nederland is not able to provide care in the same as care can be delivered with a Personal Care Budget. However, a lot is possible within Buurtzorg Nederland and when collaborating with other organizations or informal care givers, it is possible to deliver a complete set of care to a patient (Bos. Buurtzorg Nederland. Personal

Communication, November the 2nd, 2012). Meaning that the argument from the public or from the budget holders, stating that they do not receive the care they want and need, is also invalid. The current available delivery of care makes it, with some adjustments, possible that patients live the actively life which they desire. There is care available to arrange that. For patients who really cannot receive care in the basis of Care in Kind, exceptions can be made and they will receive a Compensation Arrangement Personal Care (CZ, 2012).

The second accusation is about the government taking away the voice and choice option from society. As explained in the previous paragraph, the provision of care has undergone certain innovations. The provision of care innovated in such a way that patients can receive the needed and wanted care, even without the Personal Care Budget. The organizations, which provide care in the basis of Care in Kind, innovated in a way that they have become flexible organizations in where patients can express their desires and wishes (Bos. Buurtzorg Nederland. Personal Communication, November the 2nd, 2012). The option to choose between a Personal Care Budget and Care in Kind is gone for a large group of budget holders with the new policy arrangement restricting the access. However, within the treatment plan, the voice and choice of the patient did not completely vanish. Patients can still use their voice to set up a treatment plan, in collaboration with the provider. Patients also do have a choice in who provides them with the needed care. Patients can choose between different providers of Care in Kind. This means the accusation is partly valid. Many patients no longer can choose between Care in Kind or a Personal Care Budget, so in a way their voice has vanished. But it remains possible to choose who provides the needed care and organizations who provide care have innovated in such a way that patients can think a long in their treatment plan.

9.3 To what extent did the policy changes affect the output-oriented gap?

The second half of the first part of the research question can now be answered.

To what extent did the policy changes concerning the Personal Care Budgets of January 2012 affect the output-oriented gap between policy and public?

The effect of the policy changes concerning the output-oriented gap is minor. Budget holders state that they cannot receive the care they need anymore. The government responds by saying that organizations such as Buurtzorg Nederland are replacements for the Personal Care Budgets. The counter-argument of the government is invalid. Buurtzorg Nederland is not able to provide in the same way a care can be delivered with a Personal Care Budget. However, a lot is possible within Buurtzorg Nederland and when collaborating with other organizations or informal care givers, it is in most cases possible to deliver a complete set of care to a patient. This means that also the statement from the budget holders is mostly invalid. The current available delivery of care makes it, with some adjustments, possible that patients live the actively life they desire. There is care available to arrange that. For patients who really cannot receive care in the basis of Care in Kind, exceptions will be made and they can receive a Compensation Arrangement Personal Care. The second accusation from the budget holders, stating that their options to express their voice and choice are taken by the government is not completely valid. The provision of care has innovated in such a way that patients can receive the needed and wanted care, even without the Personal Care Budget. The organizations, which provide care in the basis of Care in Kind, have innovated in a way that they have become flexible organizations in where patients can express their desires and wishes. The option to choose between a Personal Care Budget and Care in Kind is gone for a large group of patients with the policy changes. However, within the treatment plan, the voice and choice of the patient is still there. Patients still can use their voice to set up a treatment plan, in collaboration with the provider. Patients also do have a choice in who provides them with the needed care. Patients can choose between different providers of Care in Kind. The patient still can participate in the system.

Part IV

The state of affairs of Personal Care Budgets in the end of 2012 and recommendations for the future

Chapter 10

Remaining issues behind the policy of Personal Care Budgets

Measures were needed to be taken to make General Exceptional Medical Expenses Act-care future-proof (Veldhuijen van Zanten-Hyllner, 2011: 1-2). Looking at part 3 of this research, it appears that the issues concerning the policy measures are solved. The accusations towards the government, including patients not receiving proper care after the policy changes, are proved not to be valid. This, however, does not automatically mean that the problems have been completely solved. This chapter briefly sets out the issues of the Personal Care Budgets-policy and to what extent these issues are still relevant in the end of 2012. This chapter covers the current presence of the issues that have led to the policy change.

10.1 Too many users and an unnecessary appeal to collective resources

One of the issues, addressing problems of the system of Personal Care Budgets, has been the extreme increase in costs. The extreme increase in costs was appointed to the development of an extreme increase in users. This extreme increase in users would have been the result of a magnetic or attracting effect of the Personal Care Budget-policy. The magnetic or attracting effect was caused by two developments; improper use of the Personal Care Budgets and the monetizing of informal care. These two developments have led, according to the government, to an unnecessary appeal to collective resources and have caused an extreme increase in users.

10.1.1 *Improper use of Personal Budgets*

A major disadvantage for patients using the Personal Care Budget is the administrative burden coming with it. To overcome this burden, a market of mediation agencies had emerged (Grit, van den Bovenkamp & Bal, 2008: 85). The costs of the mediation were paid with the Personal Care Budget, leading to money going to the mediation agencies which should have been spent on health care (Skipr, 2010: 415. Grit, van den Bovenkamp & Bal, 2008: 85). The market of mediation agencies not only dislocated money, it also was susceptible to fraud (Bruinsma & Stoffelen, 2010).

In the year 2012, it became impossible for holders of a Personal Care Budget to spend part of the budget to the deployment of mediation agencies. It has been made impossible to justify money being spent on mediation agencies as of 2012 (Care Office Friesland, 2012). It appears to be that the problem of improper use of Personal Care Budgets has been resolved with removing the possibility to spend part of the Personal Care Budget on mediation. But that is not the case. There is another issue underlying the issue of improper use of Personal Care Budgets.

The original idea of the Personal Care Budget is that patients themselves orchestrate the needed care. However, a lot of patients using a Personal Care Budget do not want that budget. Research has shown that forty percent of the holders of a budget actually prefers Care in Kind (Saers, 2011). When Care in Kind appears to fail in providing the proper care for a patient, the patient is automatically redirected to a Personal Care Budget. It is therefore not surprising that patients desperately cling to mediation agencies for help. A new role for care offices, as suggested by Per Saldo in the past, seems to be the answer (van der Pas. Per Saldo. Personal Communication, September the 5th, 2012. Saers, 2011).

“We have seen that the care being offered by Care in Kind has been little innovative, it does not respond to social change. We see that about forty percent of the holders of a budget was sort of forced to choose for a Personal Care Budget, he or she had to take a Personal Care Budget” (van der Pas. Per Saldo. Personal Communication, September the 5th, 2012).

“The Personal Care Budget-policy appears to be sort of the waste pit of the General Exceptional Medical Expenses Act, because the supply of Care in Kind fails. A study by consultancy organization ITS shows that forty percent of the holders of Personal Care Budget actually prefers Care in Kind. It is time for care offices to make a move. They must ensure with their procurement that mainstream providers adapt their provision of care to the needs for care ... Care offices have to make sure that applicant for a Personal Care Budget understand the process of using the budget. This can be realized by requiring that applicants prepare a care plan stating how they want to organize their care” (Saers, 2011).

Care offices are able to determine whether a patient is more suited with Care in Kind or with a Personal Care Budget. As shown in chapter 9 of this research, Care in Kind has

innovated. The current available delivery of care makes it, with some adjustments, possible that patients live the actively life they desire. There is care available to arrange that. A more active and guiding role for care offices is described in the Spring-agreement of 2012. As of 2012, care offices no longer just approve the budget plans from applicants, they are now supposed to talk face-to-face to the applicants. Care offices must talk to applicant to get a clear view on why someone chooses for a Personal Care Budget, which would make clear if an applicant is better served with a budget or with Care in Kind. Care offices must provide the applicant with correct information and guidance. Next to that, the care office is obligated to visit risk groups regularly (van den Elzen, 2012. Veldhuijzen van Zanten-Hyllner, 2012: 10). This new role for the care offices in the Netherlands rules out the issue of improper use of the Personal Care Budgets. People will receive care on the basis of a system that suits them the best and it is an attempt to prevent fraud. Dutch care offices are positive about this development. Care offices will get an impression in advance about why a person wishes to receive a personal care budget and can, subsequently, check whether the person is able to deal with the obligations relating to the budget. Care offices believe that they, with their new role, can guide a patient towards the type of care that suits them best. They also believe that a big part of the fraud can be prevented this way. At the moment, it is still unclear how the new role is going to be arranged, but it will avoid part of the previous issues in the future.

"I confirm the added value of the face-to-face conversations to our current telephone conversations. It often occurs that clients do not realize what the self-control in the present system is all about. The face-to-face conversation will clarify it all. And it can also lead to clients making different choices ... An investigation, which is going as we speak, will make the exact role of the care office clear ... My personal opinion is that a face-to-face conversation should have been a part of the policy of the Personal Care Budget from the beginning. I cannot say there would not have occurred problems, but it would have made a difference" (Nibbeling. Zorg en Zekerheid Care Office. Personal Communication, December the 12th, 2012).

"It is in all cases positive that the care office gets an impression in advance about why the insured wishes to use a Personal Care Budgets. Besides that, the care office gets an impression whether an insured can deal with all the obligations relating to the Personal Care Budget ... At the moment, there is an investigation going on the organization of the new role of the care office. We are dependent on

the national choices that still have to be made ... A part of the problems concerning Personal Care Budgets can be solved in this way and I am positive about the future. Previous problems could have been prevented" (Bruisten. CZ Care Office. Personal Communication, December the 12th, 2012).

10.1.2 Monetizing informal care

The second problem the government brings forward concerning the extreme rise in costs of the Personal Care Budget is the monetizing of informal care. This is an issue which would attract people to choose, unnecessary, for a Personal Care Budget. Monetizing informal care literally means the payment of informal care. Scarce care budget would have been used to pay for something that already was being done for 'free' (Tjadens, 2004. In: Grit, van den Bovenkamp & Bal, 2008: 86). Research shows that a minor part of the informal care sector is being paid throughout a Personal Care Budget. Only five percent of all informal caregivers in the Netherlands is being paid from a Personal Care Budget (van Haaster et al, 2012: 90). The research also shows that informal caregivers achieve impressive results and that their willingness to provide care is hardly affected by the potential to be paid throughout a Personal Care Budget. There is no evidence that shows that we can speak of aggravating monetizing of informal care. There are a few cases, but in such small proportion that is hardly affects the greater whole (van Haaster et al, 2012: 91-92).

10.1.3 An important reason behind the extreme growth

The number of budget holders has increased extremely indeed, as the chart in chapter 4 has indicated. But the number of patients for Care in Kind increased as well, although to a lesser extent (Sadiraj et al, 2011: 9). The assumption of the Personal Care Budgets being a substitute for Care in Kind appeared to be wrong in 2011, when the policy changes were drafted. But it is important to also look at the reasons behind the increase. As well the numbers of patients for a Personal Care Budget as the number of patients for Care in Kind within the General Exceptional Medical Expenses Act have increased in the past years and this is mainly due to the aging of people in the Netherlands. Why a larger growth in patients for a Personal Care Budget than in patients for Care in Kind? The growth in Personal Care Budgets can be explained by the supply offered in the past. The supply of Care in Kind lacked, leaving a group of

patients renouncing care. They were in need of care, but the provided care at that moment fell short. The providers of Care in Kind could not provide the care they needed. With the upcoming of the system of Personal Care Budgets, that group of patients was able to receive the care they needed and the total group of patients requiring for a Personal Care Budget increased (Sadiraj et al, 2011: 9). Research shows that this development is of great contribution to the extreme growth in the number of patients using the Personal Care Budget. This also plays a big part in the explosive growth in costs.

As mentioned in chapter 9, the current provision of care in the Netherlands has innovated. Meaning that a part of the group of patients, as just described, can now also make use of the provision of Care in Kind. There might be a shift from patients using a Personal Care Budget to patients using Care in Kind.

10.2 Wrongly assumed assumptions

10.2.1 Personal Care Budgets as a substitute for Care in Kind

When the policy of Personal Care Budgets was implemented within the Netherland, it was supposed to be a substitute for Care in Kind (Dutch National Government, 2007. In: Breda & Gevers, 2011: 28). Care has to be paid for, regardless to the method of paying-out (Dutch National Government, 2007. In: Breda & Gevers, 2011: 28). However, the growth in expenditure concerning Personal Care Budgets has not led to a reduction in growth of Care in Kind (Veldhuijzen van Zanten-Hyllner, 2011: 24), which was supposed to happen. The government took this as one of the issues for justifying the need for change concerning the Personal Care Budget-policy.

Due to demographic changes, the number of patients in need of General Exceptional Medical Expenses Act-care has increased. Next to that, the new system of Personal Care Budgets was able to provide patients with care which they in the past could not receive (Sadiraj et al, 2011: 9). The fact that the extreme rise in users can be partially explained by the aging of the population and the new provision possibilities of care, makes it impossible to check whether the assumption of the Personal Care Budgets being a substitute for Care in Kind would have been a rightfully assumption. It is then strange, and not correct, that the government took this issue as one of the issues for

justifying the need for change concerning the Personal Care Budget-policy. The government's position on changing the policy was based on the observation of rising costs. It is too early to check whether the substitute-assumption of false or true. A similar situation has occurred in Germany. There it has shown that the effects of the group of 'new care recipients' will eventually fade out as the growth of the group stagnates overtime. To as well Care in Kind as the system of Personal Care Budgets applies that the costs have increased in the past years and based on examination of the Netherlands Institute for Social Research it is possible to state that when there would be no Personal Care Budgets in the Netherlands, the costs of Care in Kind would also have increased extremely (Sadiraj et al, 2011: 20).

In addition to it being too early to check whether the assumption of Personal Care Budgets as a substitute for Care in Kind is true or false, it is also fact that care provided on the basis of Personal Care Budgets is lower in costs than care provided on the basis of Care in Kind.

"Personal Care Budgets are, in terms of spending, less expensive than Care in Kind is ... Economically, it is better when someone chooses for a Personal Care Budget. At the moment, we spend about 23 billion euro's on General Exceptional Medical Expenses Act-care. 2.3 billion is spent on Personal Care Budgets, which is 10 percent. The number of patients having and using a Personal Care Budget is about 20 percent. The other 80 percent make use of Care in Kind. That 80 percent consumes about 90 percent of the General Exceptional Medical Expenses Act-budget" (van der Pas. Per Saldo. Personal Communication, September the 5th, 2012).

The numbers above, as mentioned by Frans van der Pas, are confirmed by the Netherland Institute for Social Research (Netherland Institute for Social Research, 2011). However, it is not explained why the 80 percent of Care in Kind-users consume 90 percent of the General Exceptional Medical Expenses Act-budget. This might have something to do with the types of care the 80 percent of Care in Kind-users have been indicated for. When they are indicated for more care than the other 20 percent, it is not strange that they consume a higher amount of the General Exceptional Medical Expenses Act-budget. Nevertheless, the fact remains that the use of Personal Care Budgets is often cheaper than the use of Care in Kind. The Personal Care Budgets being cheaper than Care in Kind has to do with a difference in providers of care within both systems. Only professional providers provide care within the system of Care in

Kind. Patients are supposed to pay the same professional providers of care with the budget, but the budget can also be used to pay informal caregivers or private care providers. In addition to the less expensive wages, patients who receive a Personal Care Budget arrange the care themselves, which saves organization- and execution costs (Sadiraj et al, 2011: 11-14). At the moment, it is too early to check whether the assumption would be true or false. The government has rushed herself in to a position which concludes that the assumption is false and that, therefore, the policy should be changed. Evidence and research however make clear that it is not correct to take in a position on the assumption at the moment. Due to aging, the costs for care would anyhow have increased. In case Personal Care Budgets would have never been introduced in the Netherlands, the costs for Care in Kind would have increased extremely too. The effects of the group of 'new care recipients', patients who did not make use of care until it was possible to get the right care on the basis of Personal Care Budgets, will eventually fade out. In addition to this, it is a fact that the costs of Personal Care Budgets are lower than the costs of Care in Kind, which might even mean that the assumption could, financially speaking, be true.

10.2.2 Budget holders are capable and have the right motivation

An implicit and unconscious assumption regarding patients was made by the government before putting the Personal Care Budget-policy into force in 1991. The government expected patients to have the capability to execute and manage a Personal Care Budget rightfully. Next to that, the government expected the patients to have the right motivation in spending collective resources in the Netherlands. Assuming that patients are guided by morals, abuse of the system is not something one would expect to happen. According to the government, this assumption appeared to be false in the execution phase of the policy as a whole market of mediation agencies emerged to help out patients with the administration and with the purchasing of health care. However, as explained in chapter 10, in the year 2012 it became impossible for holders of a Personal Care Budget to spend part of the budget to the deployment of mediation agencies. Next to that, there is a new role for the Dutch care offices. As of 2012, care offices no longer just approve the budget plans from applicants, they are now supposed to talk face-to-face to the applicants. This way, care offices get a clear view on why someone chooses for a Personal Care Budget. They also get a clear view on whether the patient is capable to handle a Personal Care

Budget. Care offices must provide the applicant with correct information and guidance (van den Elzen, 2012. Veldhuijzen van Zanten-Hyllner, 2012: 10). Next to the capability of patients, the government finds that patients do not have the right motivation in using the Personal Care Budgets. Patients would unnecessary choose for a Personal Care Budget for the payment of informal care. Scarce care budget would have been used to pay for something that already was being done for 'free'. However, research shows that a minor part of the informal care sector is being paid throughout a Personal Care Budget. There is no evidence that shows that we can speak of poor motivation of patients. There are a few cases, but in such small proportion that is hardly affects the greater whole. Is it fair to adopt or change policies based on a small group of bad people, instead of a large group of good people? And besides the care offices, in their new role, monitoring the capability of the patients, they also verify the motivation of the patient. The few cases of poor motivation can be ruled out this way.

Chapter 11

Learning from the past

Looking at the third part of this research, it appeared that the problems concerning the policy measure of restricting the access to the system of Personal Care Budgets were solved. Society accused the government of enlarging a gap and this was proved not to be completely valid. However, in my opinion, the degree of resistance coming from society calls for a closer look to all the issues and problems surrounding the policy of Personal Care Budgets. Chapter 10 explored to what extent the issues, which have led to the policy changes, are still relevant. Even if the accusations from society were not completely valid, the question remains to what extent the policy measure actually was going to solve the problems. This chapter answers the last part of the research question and brings recommendations for the future. What can be learned from the past? Recommendations are based on the policy in general and on how to handle the gaps.

11.1 What to do with the policy of Personal Care Budgets

11.1.1 Solving the wrong issues

The resistance coming from society has led to taking a closer look at the issues mentioned concerning the Personal Care Budget-policy. Looking closer to the issues, it can be stated that the Dutch government was trying to solve problems that were not that relevant. There is no evidence that shows that we can speak of aggravating monetizing of informal care. As of 2013, it is impossible for holders of a Personal Care Budget to spend part of the budget to the deployment of mediation agencies. Next to that, a new role for Dutch care offices will prevent fraud and will check whether a patient is capable to deal with a Personal Care Budget or is better suited with Care in Kind. The argument from the government that the Personal Care Budgets would not be a substitute for Care in Kind, which was supposed to happen when the policy was put to force, does not hold for an argument to change the policy of Personal Care Budgets. It is impossible to check if the assumption would hold, given the demographic changes. The government's reasoning to change the policy now seems strange. The policy

measure would offer a solution to issues that are not of such importance or which could easily be solved otherwise. The high costs, which are appointed to the extreme increase of users, are not due to the issues the government argues. The extreme increase in users is to a large extent due to demographic developments within Dutch society. The government tried to solve the wrong issues.

11.1.2 Recommendations concerning the policy of Personal Care Budgets

The government tried to solve issues with a measure which was harsh on society. That the measure was harsh appeared from the resistance being shown by society. What should now be done with the policy?

Problems need to be addressed. The system of Personal Care Budgets seems quite expensive, but the extreme increase in costs is mainly due to the extreme increase in users. And this extreme increase in users is due to the aging of the population and to the influx of patients who previously did not claim care because Care in Kind lacked in providing what they needed. The effects of these developments are now noticeable in society. It is not the issues the government addressed that have led to the extreme increase in costs and the measure of restricting the access to the system is not the answer to the problem of high costs. People who now have a Personal Care Budget are indicated to receive care and will still need care in the future. Abolishing their Personal Care Budget does not change the need for care. The ex-holders of a Personal Care Budget will rely of Care in Kind in the future. The need of care for patients will continue and together with advantages of the system, it is important that the system will be maintained and will not be restricted for a large group of patients.

A major advantage, next to the system providing unique care for specific cases of patients, of the system of Personal Care Budgets, is that the budgets are in many cases cheaper than Care in Kind would be. This has to do with difference in providers of care within both systems and with a saving for organization- and execution costs. Restricting access to the system would therefore only be more expensive, rather than cost saving which was the goal of the reforms of the Personal Care Budget-policy. The measures should be cost saving. However, with the government keeping the wrong issues in mind, the measures could in the end be the opposite of cost saving. The need for care of the patients will no matter what remain. This in combination with the fact that

the system of Personal Care Budgets is cheaper than Care in Kind, makes me plead for the preservation of Personal Care Budgets in the Netherlands.

The preservation of the system could reduce the costs for General Exceptional Medical Expenses Act-care in general and would make the Compensation Arrangement Personal Care redundant. However, it is important and necessary that the system undergoes minor adjustments to eliminate current issues and to prevent other issues in the future. It is important to redesign the system in such a way that only patients who really need it, who really would benefit from it and are able to deal with it use it. Patients should receive care on the basis that suits them best, that way, money available for General Exceptional Medical Expenses Act-care will be spent to the proper purpose.

- Sorting out the current system;

Only patients who really need it, who really would benefit from it and are able to deal with it use it should receive a Personal Care Budget, in order to make sure money does not get lost. Research has shown that about forty percent of the holders of a budget actually prefer Care in Kind. When Care in Kind appears to fail in providing the proper care for a patient, the patient automatically was redirected to a Personal Care Budget. These patients do not know how to handle a Personal Care Budget and it is therefore not surprising that patients desperately asked mediation agencies for help. To make sure money available for General Exceptional Medical Expenses Act-care will be spent to the proper purpose, it is important that these patients are filtered out.

- Actual implementing and proper framing of the new role of care offices.

The new role of the care offices can be of great contribution in the future. It will resolve current issues. It helps in preventing fraud and will match the right patients to the right type of care. The new role is of great contribution in the continuing existence of the Personal Care Budgets. This continuing existence is profitable for as well patients as the government. The patients can still make use of the system and for the government it will be cost-saving. Unfortunately, the role of the care offices has not been fully implemented and framed yet. To make sure the system fully functions in the future it is important that, in the short term, the role for care offices will be proper framed and implemented.

11.2 How to handle the gaps

Interest groups are of great concern within the Dutch tradition of societal corporatism and interactive governance. They fulfill an important task in uniting diverse groups of citizens and in connecting citizens with the government, politics and business. The interest groups intervene in the policy-making process and represent citizens or patients, to make sure that they are being heard and that they eventually get what they want and need. Per Saldo fulfills this task on behalf of the holders of a Personal Care Budget and the relationship between the government and Per Saldo is therefore of great importance. The relation between Per Saldo and the Dutch government is generally quite well. In this specific case, Per Saldo accused the government of enlarging an input-oriented gap. An accusation that is only partly valid. The government averted discussion with Per Saldo at a certain moment, but did not ignore Per Saldo during the entire policy-making process. The effect of the policy change on the output-oriented gap is also minor. This, however, does not mean that the gaps are not of importance and nothing can be learned from the entire situation. This paragraph brings recommendations on how to handle similar gaps in the future.

It is important to state out that gaps cannot be prevented. Situations of imbalance between the government and society will always be present. There always will be groups who resist against public policy. It is impossible to satisfy everybody. Angry and frustrated citizens or patients, who will resist to policy, will always exist. It is not the government's responsibility to prevent gaps from occurring (Duineveld & Beunen, 2006: 14-18).

Even though gaps cannot be prevented, a lesson can be learned from the debate between the Dutch government and society. My recommendation relates to the degree of resistance. In this specific case, the resistance is extreme. Negative feelings towards the government are extensively publicized in the media and even demonstrations were organized. My recommendation towards the government is that, even though she was accused wrongly and she does have the formal right of decision-making, she has to act upon this high degree of resistance. The resistance coming from the holders of a Personal Care Budget called for a closer look on the entire situation. The accusations were not completely valid, but it is clear that the measure affects an enormous part of the users. The resistance is justifiable. The government should take the resistance

from society seriously, look at alternatives and inform society on why given solutions are the best solutions and why alternatives do not fit the problem. A good way to arrange all this is not averting discussion, which she did as explained in chapter 8. When the government had act upon the high degree of resistance in this specific situation and had took a closer look at the measures, a long and intensive struggle could have been spared.

11.3 What can be learned from the past?

The final part of the research question can now be answered.

What can be learned from previous developments?

It is important to state out that situations of imbalance between the government and society will always be present. Gaps cannot be prevented and the government has got no responsibility to prevent gaps from occurring. Besides that, the government has got the formal right to decision-making and she, for the most part, accused wrongly by society. This, however, does not mean that no lesson can be learned from the debate between the government and society. The degree of resistance was extreme in the case of the policy-changes concerning the Personal Care Budgets. The accusations were not completely valid, but it is clear that the measure affects an enormous part of the users. The resistance is justifiable. The government should take the resistance from society seriously, look at alternatives and inform society on why given solutions are the best solutions and why alternatives do not fit the problem. A good way to arrange all this is not averting discussion. When the government had act upon the high degree of resistance in this specific situation and had took a closer look at the measures, a long and intensive struggle could have been spared.

Chapter 12

Conclusions, discussion and limitations

12.1 Conclusions

Central question which was being answered in this research is:

To what extent did the policy changes concerning the Personal Care Budgets of January 2012 affect the gap between policy and public and what can be learned from the past?

Measures were needed to be taken to make General Exceptional Medical Expenses Act-care future-proof. Measures specific oriented to the policy of Personal Care Budgets bumped into much resistance from society, leading to gap between policy and public. This gap can divided into two different gaps, an input-oriented gap and an output-oriented gap. Society accused the government of enlarging both types of gaps. However, the policy changes concerning the Personal Care Budgets affected the input-oriented gap between policy and public only to a small extend. At certain times, the government averted discussion, but she did not ignore Per Saldo throughout the entire process. The policy-changes did not affect the output-oriented gap.

As the accusations coming from society are proved invalid, it appears that the issues concerning the policy measures were solved. However, the high degree of resistance calls for a closer look at the issues. Looking closer to the issues, it can be stated that the Dutch government did not offer the right solution. The governments reasoning to change the policy radically and with that limit the access to a Personal Care Budget seems strange. The policy measure offers a solution to issues that are not of such importance or which could easily be solved. The high costs, which are appointed to the extreme increase of users, are not due to the issues the government argues. The extreme increase in users is to a large extent due to demographic developments within Dutch society. The government tried to solve the wrong issue.

I plead for the preservation of the Personal Care Budgets in the Netherlands. The system of Personal Care Budgets seems quite expensive, but the extreme increase in costs is mainly due to the extreme increase in users. And this extreme increase in

users is due to the aging of the population and to the influx of patients who previously did not claim care, because Care in Kind lacked in providing what they needed. It is not the issues the government addressed that have led to the extreme increase in costs and the measure of restricting the access to the system is not the answer to the problem of high costs. People who now have a Personal Care Budget will still need care and are indicated to receive care. Abolishing their Personal Care Budget does not change their need for care. The need for care for patients will continue, and that in combination with Personal Care Budgets being cheaper than providing Care in Kind, makes it important that the system will be maintained and will not be restricted for a large group of patients.

What can be learned from the past? It is important to state out that situations of imbalance between the government and society will always be present. Gaps cannot be prevented and the government has got no responsibility to prevent gaps from occurring. Besides that, the government has got the formal right to decision-making and she, for the most part, accused wrongly by society. This, however, does not mean that no lesson can be learned from the debate between the government and society. The degree of resistance was extreme in the case of the policy-changes concerning the Personal Care Budgets. The accusations were not completely valid, but it is clear that the measure affects an enormous part of the users. The resistance is justifiable. The government should take the resistance from society seriously, look at alternatives and inform society on why given solutions are the best solutions and why alternatives do not fit the problem. A good way to arrange all this is not averting discussion. When the government had act upon the high degree of resistance in this specific situation and had took a closer look at the measures, a long and intensive struggle could have been spared.

Having established that the implemented measure of 2012 which restricts the access to the Personal Care Budgets is not the right solution for the problems concerning the Personal Care Budget, it is the framing of the policy that again is open for discussion. Considering the advantages for the patients and the lower costs of Personal Care Budgets, in my opinion it is important that the system will be maintained and will not be restricted for a large group of patients. However, the system is in need of adjustments. First of all, it is of importance that only patients who really need it, who really would benefit from it and are able to deal with it use it should receive a Personal Care Budget,

in order to make sure money does not get lost. About forty percent of the current holders of a budget actually prefers Care in Kind. To make sure everybody receives care that fits their want and needs, the current system has to be sorted out. The second adjustment is that the new role for care offices has to be properly framed and actually be implemented. In the short-term, research has to be performed on how these two adjustment can be accomplished on a proper manner.

12.2 Discussion and limitations

In this research, I focused on a discussion between the government and the Dutch society. In order to get a good and correct view on the opinions, feelings, reasons and knowledge from both sides, an interview with the Dutch government was of great importance. Unfortunately this was not feasible, as explained in the Research design and Methodology-section. The government was not available to respond. On the basis of an analysis of documents and scientific literature, I have tried to create the best view coming from the government as possible. However, specific opinions and reasons might less present in that data and therefore, the view from the government in the discussion with Per Saldo and the patients might be not exactly as it is in the daily practice. Although an interview would not change the facts coming from the documents and the literature, it might clarify certain reasoning from the government, what then might influence the opinion on the way the government has acted in this specific policy making-process. An example visualizing this limitation is my opinion on the fairness considering adopting or changing policies based on a certain group of people. Is it fair to adopt or change a policy based on a group of people who have bad intentions or simply do not know how to handle what is asked of them? Or should it be based on the larger group of people who have the right capabilities and motivation? In my opinion it should be the last. Based on the analysis of the document, the government has adopted the policy-measure in which she restricted the access to the Personal Care Budgets based on the first group. Maybe the government has got legitimate reasons to do so? An interview with the government could have shown the reason from the government to do so and with that it might have led to new or different insights. For following research, I strongly advice to include an interview with the government.

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Appendix 1

Topic list ‘Per Saldo’

Objective:

Trace the vision of Per Saldo on the issues surrounding the Personal Care Budgets, the solutions for the problems Per Saldo has in mind and the vision of Per Saldo on the input- as well as the output-oriented gap.

Topic list:

1. Introduction
 - Personal introduction
 - Short introduction of the thesis
 - Objective of the interview
2. The organization ‘Per Saldo’
 - Background and history
 - Objectives and mission
3. Per Saldo’s view on the issues surrounding the system of Personal Care Budgets
 - Improper use
 - Monetizing informal care
 - Assumption on the budgets being a substitute for Care in Kind
 - Assumption on capability and motivation of budget holders
4. The restricting policy measure
 - The role of Buurtzorg Nederland
 - Ideas for other solutions to resolve problems
5. The gaps

The relation between Per Saldo and the government in general
The role of Per Saldo in constructing the policy measures of 2012
6. The end of the interview

Appendix 2

Topic list ‘Buurtzorg Nederland’

Objective:

Obtain information on how care is provided within Buurtzorg Nederland and on the extent to what Buurtzorg Nederland agrees or disagrees with being an alternative for Personal Care Budgets.

Topic list:

1. Introduction

- Personal introduction
- Short introduction of the thesis
- Objective of the interview

2. The organization ‘Buurtzorg Nederland’

- Background and history
- Objectives and mission

3. The provision of care

- The role of the patient/client in the process: demand-oriented
- The present and the past

4. Buurtzorg Nederland as a substitute for Personal Care Budgets

- Buurtzorg Nederland’s view on the statement
- Buurtzorg Nederland’s view on the opinion of Per Saldo on the statement

5. The end of the interview

Appendix 3

Topic list ‘ZuidZorg’

Objective:

The objective of this interview is find out more about what organizations can offer concerning Care in Kind and what they experience in offering the care.

Topic list:

1. Introduction

- Personal introduction
- Short introduction of the thesis
- Objective of the interview

2. The organization ‘Zuidzorg’

- Background and history
- Objectives and mission

3. The provision of care

- The role of the patient/client in the process: demand-oriented
- The present and the past

4. Buurtzorg Nederland as a substitute for Personal Care Budgets

- Zuidzorg’s view on the statement
- Zuidzorg’s view on the vision of Buurtzorg Nederland’s on the statement

5. The end of the interview

Appendix 4

Topic list ‘Mezzo’

Objective:

Objective in this interview is to trace the vision of Mezzo on the issues surrounding the Personal Care Budgets, specified to the problem of monetizing informal care.

Topic list:

1. Introduction

- Personal introduction
- Short introduction of the thesis
- Objective of the interview

2. The organization ‘Mezzo’

- Background and history
- Objectives and mission
- Informal care giving

3. Monetizing informal care

- Mezzo’s view on the monetizing of informal care

4. The policy measures of January 2012

- Effect on informal care giving
- Consequences for the future

5. The end of the interview

Appendix 5

Topic list ‘Care Offices’

Objective:

Objective of the interview is, first, to learn more about the current state of the new role for care offices. The second objective is to learn more about the view of care offices on the new role in combination with the issues of the Personal Care Budgets.

Topic list:

1. Introduction

- Personal introduction
- Short introduction of the thesis
- Objective of the interview

2. The organization

- Background and history
- Objectives and mission

3. The new role for care offices

- View on the new role
- Realization of the role
- The new role and the past

4. The end of the interview

