

Capturing the perceived empowerment of individuals with an impairment in the context of a PGB and tourism participation

A case study



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Preface

Before you lies the thesis “Capturing the perceived empowerment of individuals with an impairment in the context of a PGB and tourism participation: A case study”. I proudly present to you my thesis which is written in the context of my graduation from the master specialisation Health & Society. I would have never envisioned the level of satisfaction and enthusiasm as I am experiencing right now. The main reason for this is that I am really excited about the interesting interviews I have had with different parties involved in the PGB system while collecting qualitative data.

At the start of this process, I had my doubts towards the quantity of research I needed to conduct alone. In the past, via collaboration with others I was at my best. This can also be traced back in the subject of my thesis since it focuses on the perspectives of different parties involved in the PGB system. However, I can honestly say that I did not experience any loneliness during the process of conducting this research. For this I want to thank some people,

At first, I would like to thank P. E. (Pieter) Cremers MSc, PhD student in the subject “Added value of leisure activities and holidays for people with disabilities”. Thank you that you were always there to support me and to provide me with feedback, besides your busy schedule. I really appreciated the constructive way of providing feedback and your positivism kept me going. As for sure I would like to thank my supervisor, dr. H. M. (Hilje) van der Horst, who was always willing to help me and to provide my work with feedback. Your perspective on the field of disabilities was an inspiration for this thesis. Furthermore, I really would like to thank my family and friends for always listening and helping me. I highly value their continuous believe in me.

At last, I would like to thank all individuals who have participated in my research and have helped me to recruit the participants I needed to successfully finish my research. Thank you very much.

Personally, I am really proud and excited of my thesis. I hope you enjoy your reading!

Babs Matthieu

Wageningen, July 11, 2017

Summary

Introduction

The Dutch government is aiming to temper the collective expenditures via, amongst others, the decentralisation of the responsibility and execution of the Personal Adjusted Budgets (PGB). This originated as a reaction upon the continuous increase in health expenditures. Alongside this action, the Dutch government ratified in 2016 the Convention on the Rights of Persons with Disabilities. With this ratification the Dutch government aims for full and effective participation in society of individuals with an impairment on an equal basis with others in society. Full participation in society includes the opportunity to participate in tourism. Since the decentralisation process of the PGB system, the number of responsible parties increased.

Aim and research question

The aim of this thesis is to identify the perspectives of different parties that are involved in the PGB system on the empowerment of individuals with an impairment. Included in this aim is the contribution of the PGB on the empowerment of individuals with an impairment and their tourism participation. The main research question is as follows:

How is empowerment of individuals with an impairment understood by different parties that are involved in the change in PGB system in 2015?

Methods

The research design of this thesis is qualitative. The research question is answered by twelve in-depth interviews. Participants are parents of individuals with an impairment who manage a PGB, organisations in the field of tourism, and responsible parties within the different Acts that are applicable in the PGB system. Interviews were analysed based on Creswell's six steps of qualitative data analysis.

Results

The participants of this research appear to have different perspectives on the empowerment of individuals with an impairment. These differences, accompanied with similarities, are elaborated via three ways to assess the empowerment amongst individuals. These ways include the barriers for empowerment, split up in intrinsic-, economic-, environmental- and interactive barriers, mechanisms for empowerment and four dimensions that define an empowered individual being self-determination, impact, competency and meaning.

Most of the participants identified more exogenous barriers than internal barriers. Parents were the exception to this by addressing more internal- than exogenous barriers. The organisations affiliated with the NBAV, the WMO consultant, the Youth consultant, the health insurer and the senior care buyer described more exogenous barriers which indicates that they take society responsible for the evolution of barriers that inhibit the development of empowerment amongst individuals with an impairment.

The addressed mechanisms for diminishing the barriers were all outside of the power of the individual with an impairment. This indicates that the participants perceive the responsibility of diminishing the barriers by the society surrounding the individual with an impairment.

Differences and similarities in the addressed dimensions of empowerment were identified. All participants recognized an increase in the dimension of self-determination. In addition, an increase in the dimension of meaning was described by the parents, the organisations affiliated with the NBAV and the senior care buyer. Differences were identified in the dimensions of competency and meaning. Whereby the parents identified the increase in the dimension of competency as a positive change since they used a PGB, the organisations affiliated with the NBAV, the health insurer and the senior care buyer addressed their concerns towards the effect of this increase on the individuals with an impairment. The dimension of impact caused a division between the perspectives of the participants. Whereas the parents, health insurer and the senior care buyer identified a positive increase, the municipal parties identified this increase as negative. A totally different view on the level of impact was described by the organisations affiliated with the NBAV. They touched upon a decrease in the level of impact which was identified as negative change.

Discussion and conclusion

Overall, all participants identified barriers for empowerment for individuals with an impairment, meaning that they share the perspective that individuals with an impairment are not fully empowered. However, a gradation appeared regarding the absence of empowerment and the addressed party that is responsible for the absence of full empowerment. All identified mechanisms, to diminish the barriers for empowerment, were executed by society. This vision is in line with the social model of disability which states that society needs to change as a part of the empowerment process of individuals with an impairment since the society does not take individuals with an impairment into full consideration. The different perspectives on the empowerment of individuals with an impairment and the barriers causing this absence of empowerment, indicate that a shared perspective is lacking. The absence of a shared perspective indicates a lack of collaboration between the parties involved in the PGB system. This can result in a waste of services and inflexible service provision. Subsequently, this does not lead to the desired tempering of health expenditures nor full participation in society by individuals with an impairment, as aimed for by the Dutch government.

Table of Contents

Preface	i
Summary	ii
Abbreviations	vii
Figures.....	vii
Tables	vii
1. Introduction	8
1.1 Background and context	8
1.1.1 The broader policy landscape	8
1.1.2 PGB and the big change	9
1.1.2.1 Before 2015	10
1.1.2.2 Since 2015.....	11
1.1.2.3 New set-up of the PGB system	11
1.1.2.4 Causes for change	13
1.1.2.5 Consequences after change.....	17
1.2 Objective	18
1.3 Aim and research questions	18
1.4 Outline	20
2. Conceptual Framework.....	21
2.1 Empowerment of the individual with an impairment	21
2.1.1 Assessing empowerment.....	23
2.1.1.1 Dimensions of an empowered individual	23
2.1.1.2 Mechanisms to become empowered	23
2.1.1.3 Barriers for empowerment	25
2.2 Social model of Disability	26
2.3 Collaboration different parties	28
2.4 Application theoretical framework.....	28
2.5 Case study at the NBAV	29
3. Methodology.....	30
3.1 Research design	30
3.2 Study selection.....	30
3.2.1 care office	30
3.2.2 health insurance company.....	31

3.2.3 municipality.....	31
3.2.4 organisations affiliated with the NBAV.....	32
3.2.5 parents of individuals with an impairment.....	33
3.3 Data collection	34
3.3.1 Biographical-Narrative Interpretive Method.....	34
3.3.2 Location	35
3.3.3 General points for consideration.....	35
3.4 Data analysis	36
3.5 Ethical considerations	36
4. Results.....	38
4.1. Theme 1: Effect of a PGB	38
4.1.1 Social network	39
4.1.2 Participation in society	40
4.1.3 Respite care	42
4.1.4 Feeling revived.....	43
4.1.5 Expansion own world.....	43
4.1.6 Enjoyment.....	44
4.1.7 Conclusion theme 1	45
4.2 Theme 2: Managing a PGB.....	45
4.2.1 Change in 2015	46
4.2.2 Relationship system.....	52
4.2.3 Being informed	55
4.2.4 Fraud	57
4.2.5 Flexibility	58
4.2.6 Conclusion theme 2	59
4.3. Theme 3: Freedom.....	60
4.3.1 Personalised care.....	60
4.3.2 Freedom of choice	63
4.3.3 Care customer.....	64
4.3.4 Conclusion theme 3	67
5. Discussion and conclusion	68
5.2 Answer research questions.....	68
5.2.1 First sub-research question	68
5.2.2 Second sub-research question.....	71

5.2.3 Third sub-research question	73
5.2.4 Concluding remarks	74
5.3 Implications for practice and research	77
5.4 Strengths and limitations.....	78
5.5 Conclusion.....	79
References	81
Appendix A: Articles in the Convention on the Rights of Persons with Disabilities.....	89
Appendix B: Flyer towards parents.....	91
Appendix C: Informed consent form.....	92
Appendix D: Creswell’s six steps of qualitative data analysis	93
Appendix E: Code tree	94
Appendix F: Suggestions for a qualitative good interview	95

Abbreviations

(Dutch version right)

PGB	Personal Adjusted Budget	<i>Persoonsgebonden budget</i>
ZIN	Care in Kind	<i>Zorg in Natura</i>
AWBZ	Exceptional Medical Expenses Act	<i>Algemene Wet Bijzondere Ziektekosten</i>
WMO	Social Support Act	<i>Wet maatschappelijke ondersteuning</i>
CIZ	Assessment Care Centre	<i>Centrum Indicatiestelling Zorg</i>
WLZ	Long-term Care Act	<i>Wet langdurige zorg</i>
ZVW	Health Insurance Act	<i>Zorgverzekeringswet</i>
CRPD	Convention on the Right of with Disabilities	Verenigde Naties verdrag inzake de rechten van personen met een handicap
NBAV	Dutch Branche Organisation for Customized Holidays	Nederlandse Branche Vereniging voor Aangepaste Vakanties

Figures

Figure 1	Overview of the number of individuals that needed to transfer to a new Act after the change in PGB system in 2015 (Zorgwijzer.nl, 2016)
Figure 2	Social model of disability (Dupree, 2011)
Figure 3	Overview of the described barriers by all participants
Figure 4	Overview of the described dimensions of empowerment of individuals with an impairment by all participants

Tables

Table 1	Overview of the change in responsible parties within the PGB system, the Acts they are responsible for and the type of care that can be requested from an Act.
Table 2	Barriers individuals with an impairment can experience before/during a holiday (McKercher, Packer, Yau & Lam, 2003)
Table 3	Overview of the participants abbreviations
Table 4	Overview of the topics raised by the participants concerning theme 1
Table 5	Overview of the topics raised by the participants concerning theme 2
Table 6	Overview of the topics raised by the participants concerning theme 3
Table 7	Code tree
Table 8	Suggestions to increase the quality of the course of the interview
Table 9	Suggestions to ask questions and to interpreted answers in the best possible way

1. Introduction

The aim of this research is to identify the perception of parties that are involved in the PGB system since 2015, on the empowerment of individuals with an impairment and the role of a personal adjusted budget¹ (PGB) on this empowerment and participation in tourism. A PGB is a budget which an individual with an impairment can receive when coping with a chronic impairment or disease. This budget can be used to hire the health care provider they prefer, at their requested time and place (PerSaldo, n.d.a.). This thesis contributes to a bigger PhD project looking at the meaning and value of tourism activities for people with disabilities in the Netherlands. Thereby, the focus of this research will be on the influence of the change in the PGB system in the connection between the empowerment of individuals and their participation behaviour, desires and needs in tourism. To start, it is important to specify the context and background of the connection between the possible empowerment and a received PGB by individuals. Therefore, the broader policy landscape will be described. After this, the role of PGB and the change in PGB system in 2015 is discussed. Finally, the aim and the research questions will be provided.

1.1 Background and context

1.1.1 The broader policy landscape

The Dutch welfare state, as it was set up after World War One, initiated that via usage of national schemes, invalidity, old age and sickness were covered. This was reached by means of a mandatory, contributory social insurance system which was achieved by the legitimization of insurance contributions as a part of the normal wages. Nevertheless, the Dutch welfare state desired to make large financial contributions to keep this system beneficial. In addition, citizens who did not had an income were not insured (Van Oorschot, 2006). As a result, the Dutch welfare state reformed after the Second World War. After this change, the social security and protection was expanded from those who only had an income to all Dutch citizens. This was a collective system, controlled by the Dutch government, whereby contributions were proportional to income instead of to risk. The Dutch government wanted to maintain solidarity by covering for the insurances for elderly and disability for all citizens (Van Oorschot, 2006). Nevertheless, the Dutch welfare state, characterized by its high level of collectivisation and solidarization, desired to change. The Dutch government identified a necessary change in order to temper the collective expenditures but still maintain solidarity (Van Oorshot, 2006; Council for Health and Society, 2015). With these changes the core tasks of the government are under investigation. This is mainly due to the questions related to the effectuation of Acts and regulations that arise with this change (Council for Health and Society, 2015).

A change, initiated by the Dutch government, included the reclassification of social services and decentralisation (Council for Health and Society², 2015). An example of such a change is the transformation of the PGB system. This particular change will be further elaborated upon from section 1.1.2 onwards. Decentralisation can be defined as ‘the devolution by central (i.e., national) government of specific functions, with all of the administrative, political and economic attributes that these entail, to local (i.e., municipal) government which are independent of the central government within a legally delimited geographic and functional domain’ (Faguet, 2004, p. 2). In practice the transfer of power and authority is from:

¹ In Dutch: Persoonsgebonden budget

² In Dutch: Raad voor Volksgezondheid en Samenleving

- Higher to lower levels of government or from national to subnational levels of government;
- Government to legally independent autonomous state organisations;
- Government to the private sector (WHO, n.d.).

The decentralisation process originates from the technocratic perspective of the Dutch government. This perspective entails that business aspects play a dominant role over social aspects in decision making processes (Costa-Font & Greer, 2013). When a government takes decentralisation in mind, they argue the costs and benefits of a particular allocation of authority. Thereby, efficiency of services are taken into account. A question that arises is for example: is a particular service cheaper when managed on the local level (Costa-Font & Greer, 2013)?

When starting the decentralisation process, risks and responsibilities are shifted towards local- or regional public organisations, private organisations and citizens. This change has two consequences. The first consequence relates to the opportunities in the field of health and society concerning personalisation. Due to a decentralisation process, more opportunities for new societal initiatives such as private care providers and social firms arise. However, decentralisation also creates doubts and tensions. It is possible that a decentralisation results in differences and inequalities between citizens in different municipalities, since municipalities and private organisations can arrange topics to their preference (Council for Health and Society, 2015). These topics vary from the arrangement of a domestic help by a municipality to the possibility to receive medical supplies by a health insurance organisation (PerSaldo, n.d.b.). A municipality located in a densely populated area needs to cope with different matters than a municipality in an area where people move out. This can result in tension amongst citizens and organisations of different municipalities (Council for Health and Society, 2015).

A second consequence is concerning the large amount of responsible parties involved in the process of decentralisation within the PGB system. Amongst them are individuals with an impairment, public- and private organisations. Thereby, public organisations involve municipalities and the government. Examples of private organisations are health insurance companies. With all these different responsible parties within the PGB system, the line between tasks and responsibilities between the Dutch government and the municipalities and private organisations has become vaguer in the past few years (Council for Health and Society, 2015).

1.1.2 PGB and the big change

As mentioned above, amongst the occurred reclassification of social services is the change in PGB. An individual with an impairment is qualified to receive a PGB, when he or she can justify that Care in Kind¹ (ZIN) is not a right fit (Z.I.C., 2016). The main difference between ZIN and a PGB is that via ZIN individuals with an impairment receive caring services and/or assistance via an institution or a supplier where, for example, the municipality has a contract with (PerSaldo, n.d.e.). However, when an individual with an impairment desires care of an institution that is not under contract with, for example, the municipality, they cannot receive this care via ZIN. A PGB can be a solution since it provides the opportunity for individuals with an impairment to buy caring services and/or assistance from any care provider (PerSaldo, n.d.e.).

An individual with an impairment is eligible to receive PGB when they are able to manage their PGB and only use their PGB for efficient support. Hereby, examples of managing the PGB are personally signing contracts with health care providers and checking whether agreements with

¹ In Dutch: Zorg in Natura

health care providers are complied. (Z.I.C., 2016). An individual qualifies for a PGB when coping with a chronic impairment or disease and as a result of this impairment or disease needs to hire a care giver to meet their required care (PerSaldo, n.d.a.). The PGB enables them to choose their own health provider, at their requested time and place and in the way they prefer. There are some restrictions to these options, since the choice must be approved by either the municipality or the health insurance company (PerSaldo, n.d.a.).

To have this system running properly, good data exchange is required between the municipalities and the health insurance companies. In the beginning of 2015 this exchange did not work properly which resulted in delays in payments for the care providers. This was caused by the introduction of a new method of disbursement (Pennarts & Heeringa, 2015). Before, individuals with an impairment received their PGB on their personal bank account. Subsequently, they were able to directly pay for their consumed health care services. This has changed since the Social Insurance Bank¹ (SVB) nowadays directly pays the care provider commissioned by the individual with an impairment (Atlas van Zorg & Hulp, n.d.). With this reform in financial transactions, initially municipalities and health insurance companies were in charge of the payment of the PGB (Pennarts & Heeringa, 2015). However, the municipalities delegated the payments to the SVB (NOS, 2015). This resulted in an increase in the amount of work of the SVB and delayed payments (Pennarts & Heeringa, 2015).

1.1.2.1 Before 2015

Before 2015, the PGB was entirely controlled on the national level by the government. An individual with an impairment could request a PGB in accordance with two Acts, being the Exceptional Medical Expenses Act² (AWBZ) and the Social Support Act³ (WMO) (Zorghulpatlas, n.d.a.). Since the AWBZ is an Act that is no longer applicable in the current PGB system, it will be approached in the past tense. The WMO is still part of the PGB system and will be approached in the present tense.

The structure of the PGB system before 2015 resulted in fraud and improper use of the PGB regulation. As a consequence, the Dutch government experienced high and unnecessary expenditures (Ministry of Health, Welfare and Sport, 2015).

AWBZ

The AWBZ covered the expenditures of long term care of elderly, individuals with a chronic disease or impairment. A PGB received from the AWBZ could be used for extramural care. This form of care included personal care, nursing, and guidance (Zorghulpatlas, n.d.a.). Examples of such practices were the administering of medication, wound care and help with washing and getting dressed (Zorgwijzer, 2016). To decide whether or not an individual with an impairment was qualified for a PGB from this Act, an indication was made via the Assessment Care Centre⁴ (CIZ). This decision included, besides the question on qualification, the amount of budget, for which time period the PGB would be provided and when the money would be disbursed (Zorghulpatlas, n.d.a.). An individual with an impairment was eligible for a PGB from the AWBZ when he or she was in need of costly, long-term care for dealing with an impairment or illness. Examples of such long-term care include treatment of psychiatric disorders or nursing care of the chronically ill (Zorgwijzer, 2014).

¹ In Dutch: Sociale Verzekeringsbank

² In Dutch: Algemene Wet Bijzondere Ziektekosten

³ In Dutch: Wet Maatschappelijke Ondersteuning

⁴ In Dutch: Centrum Indicatiestelling Zorg

WMO

The WMO is an Act which enables individuals with a chronic impairment or disease to live as long as possible in their own home (Rijksoverheid, n.d.a). With the PGB from the WMO an individual is able to buy the services they need to achieve this. These services are, for example, the organisation of day activities or a home care giver (Rijksoverheid, n.d.a). Efficient support include forms of care that ensure that the individual with an impairment is able to live more independently. This support should be client-focused and safe (Z.I.C., 2016).

1.1.2.2 Since 2015

One of the major changes that took place from January 2015 is regarding the responsible parties within the PGB system. Before 2015, tasks concerning PGB were handled by the Dutch government (Zorgwijzer.nl, 2016). The Dutch government changed the PGB structure moving from a claim and demand oriented system to a supply and result-oriented system. Hereby, the relationship between the individual with an impairment and care provider becomes reciprocal. It is no longer the individual who claims care and the care provider who provides care, but the individual with an impairment and the care provider who together chart the potential opportunities and obstacles. Thereby, finding potential solutions if necessary (Vereniging van Nederlandse Gemeenten, 2010). This shift in orientation resulted in a decentralisation process within the PGB system (Vereniging van Nederlandse Gemeenten, 2010). Thereby, the tasks shifted to the regional level, being the health insurance companies and the care offices, and the municipal level, being the municipalities (Zorgwijzer.nl, 2016). Within each Act within the PGB system, there is a clear distinction between which party, i.e. the municipality, the health insurance companies or the care offices, is responsible for which tasks. Nevertheless, this clear division between the different responsible parties within the PGB system does not exclude collaboration between the parties. All parties share the interest by ensuring good health amongst citizens and preventing (heavier) health- and care needs. Via cooperation between all parties, the use of expensive care can be reduced and unnecessary dependence amongst individuals with an impairment will be diminished (Soeters & Verhoeks, 2014). This is in line with the vision of the Dutch government to decrease the collective health expenditures (Van Oorshot, 2006; Council for Health and Society, 2015).

With the changes from 2015 onwards, an individual with an impairment does no longer get the money directly in their own bank account, but instead the SVB will do the payment to care providers commissioned by the individual with an impairment. Consequently, there is more regulation on the expenditures and the costs will be reduced (Ministry of Health, Welfare and Sport, 2015).

1.1.2.3 New set-up of the PGB system

As a result of the decentralisation process surrounding PGB, an individual who qualifies for a PGB can nowadays request this budget from four different Acts instead of two as before 2015. Thereby, the AWBZ has been terminated. Consequently, in total 800.000 individuals who received a PGB before 2015 were covered by another set of Acts after the change in 2015 (Zorgwijzer.nl, 2016). An overview of the specific numbers can be found in figure 1. With this change in Acts, the qualification measures to check whether an individual with an impairment is eligible for a PGB has changed too. Before 2015, individuals with an impairment were eligible to receive a PGB when they were in need of costly, long-term care for dealing with an impairment or illness (AWBZ) or when he or she desired to live at home as long as possible and was able to manage his/her own PGB (WMO). By changing the PGB system, these criteria became more specific since the new Acts are more focused on a specific area of care. For example, the Youth Act is focused on the care for children below 18. This specification was not

included in the PGB system before 2015 and therefore expands the qualification possibilities for individuals with an impairment to be eligible for a PGB.

These days a PGB can be requested under the following four Acts:

1. WMO: this Act was already present before 2015 (Rijksoverheid, n.d.a). Concerning this Act, only the responsible party changed. Before 2015 the Dutch government was in charge of this Act. Since the change, municipalities cover the responsibility (Municipality Wageningen, n.d.).
2. Long-term Care Act¹ (WLZ): from this Act a PGB can be requested by individuals who are in need for care for a longer period of time from a care office. These individuals can live in a care institution or request to receive this care at their own home. This latter form of receiving care is possible on one condition: the costs arising from receiving care at their own home do not exceed the expected costs which arise when receiving care at an institution. Within this Act, individuals with an impairment are able to buy their own health care services (Zorghulpatlas, n.d.b.). The care office allocates a PGB to the individual with an impairment and the SVB is in charge of the actual money transfer (Rijksoverheid, n.d.d).
3. Health Insurance Act² (ZVW): This Act existed since 2006 (ZorgWijzer.nl). With the change in PGB system in 2015, the responsibilities of health insurance companies expanded. Since then, it covers tasks which were initially part of the AWBZ, such as district nursing and care provided at an individual with an impairments home (ZorgWijzer.nl, 2014). An individual with an impairment is eligible for a PGB from this Act when he or she has a specific care request which makes it impossible to receive care from the home care organisations their health insurance company has contracts with. Examples of specific requests are the need of care at changing or unusual times, need of care at continuously different places, when care is difficult to schedule in advance, when there is a need for permanent care providers for specialized care or special aids and when care needs to be available 24 hours a day and on call (Z.I.C., 2016). Every health insurance company has their own regulations concerning the PGB which are described in the policy terms and conditions (Zorghulpatlas, n.d.b.).
4. Youth Act³: This Act includes that municipalities are responsible for all forms of youth help, for example assistance at home when a family has troubles, accompaniment for the young adult to make the right decision for care and making sure that the chosen form of assistance is really present (Rijksoverheid, n.d.b.). An individual with an impairment is eligible for a PGB from this Act when the parents/guardians can explain that care in kind is not suitable, when the child is under eighteen, when care is only purchased when it is client-focused and safe, when the municipality grants an individual facility to the child and when the parents/guardians are able to manage the PGB (Z.I.C., 2016).



Figure 1: Overview of the number of individuals that needed to transfer to a new Act after the change in PGB system in 2015

¹In Dutch: Wet langdurige zorg

²In Dutch: Zorgverzekeringswet

³ In Dutch: Jeugdwet

It is possible for an individual with an impairment to receive multiple PGBs' at one moment in time. This can occur when an individual is in need of supervision, care and nursing. In that case, an individual receives a PGB from the municipality and the health insurance company. It is important to note that an individual is only allowed to purchase services with a PGB received from the municipality for services that are carried out by the municipality. Subsequently, a PGB received from a health care insurance organisation can only be issued to services carried out by the health insurance organisation (Rijksoverheid, n.d.c). An overview of the different responsible parties from a certain Act within in the PGB system where an individual with an impairment can request a PGB from can be found in table 1.

Table 1: Overview of the change in responsible parties within the PGB system, the Acts they are responsible for and the type of care that can be requested from an Act

PGB AND THE BIG CHANGE			
	RESPONSIBLE PARTY	ACT	TYPE OF CARE
Before 2015 National level	Dutch government	Exceptional Medical Expenses Act (AWBZ) Social Support Act (WMO)	Long-term care for elderly, individuals with chronic disease or impairment Care for individuals with chronic impairment or disease to live as long as possible in their own home. Examples: individual/group assistance, short stay, personal care, growth and education support, transportation tools, housing adjustments.
<div> <div>↓</div> Decentralisation process <div>↓</div> </div>			
Since 2015 Regional level	Health insurance companies Care offices	Health Insurance Act (ZVW) Long-term Care Act (WLZ)	District nursing and care provided at individual's home when specific care requests e.g. personal care for adults and assistance for children with an indication for intensive child care Care for a longer period of time. Can be provided in a care institution or at home. Examples: individual/group assistance, short stays, domestic help, personal care, nursing.
Municipal level	Municipalities via 1)WMO consultants 2)Youth consultants	1)Social Support Act (WMO) 2) Youth Act	1) See above 2) Care for all forms of youth help, so below the age of eighteen.

1.1.2.4 Causes for change

Two major changes have occurred within the Netherlands that have had an influence on the motivation of the PGB system amongst the Dutch government. Both changes will be further discussed.

1.1.2.4.1 Changing society

The first change that had an influence on the motivation for reformation of the PGB system is the continuous changing Dutch society. These changes relate to its demographics, change in lifestyle and improved technology. This ongoing changes result in an increase in the demand for health care and subsequently an increase in health costs (Ministry of Health, Welfare and Sport, 2014).

The first cause for this increase is the ageing population. Whereas in 2012, the Netherlands inhabited 2.7 million elderly, predication indicate that this number will further increase up to 4.7 million elderly in 2041. An increase in the number of elderly results in an increase in care request with 4% every year. This increase in demand for care is caused by a rise amongst elderly suffering from a chronic disease. Simultaneously, with the increase of the number of elderly, the number of potential workforce is decreasing. As a result, the number of working people for every elderly person is decreasing from four working persons for one elderly in 2012, to two working people for one elderly in 2040. This means that in the future, a smaller workforce is available who will carry the social burden such as health care (Zorgvoorbeter, 2016).

The second cause for the increase in demand for health care is the increased prosperity. Citizens are accepting less discomforts and have increasing requirements on care (VolgensNederland, 2012). A higher prosperity results in a different lifestyle which entails an increase in 'new' diseases such as obesity (VolgensNederland, 2012). An individual with an unhealthy lifestyle has an increased risk for chronic diseases which results in a greater demand for health care. As a result, the health care costs rise (in 't Panhuis-Plasmans, Luijben & Hoogenveen, 2012). The third cause for the increase in demand for health care and health costs is the improved technology. Due to the improved technology the tendency to deliver the requested care by, for example, individuals with an impairment has increased and nowadays more diseases and discomforts can be treated. It even occurs that a discomfort is treated even when there is a chance that someone might never experience the discomfort. This trend results in an increase in health costs (VolgensNederland, 2012).

The fourth and final cause for the increased demand for health care and the rise in health costs occurs due to the changing society whereby individuals let examine themselves at an earlier stage. Examples of such conditions are dyslexia and care for elderly. Nowadays, care providers get involved which results in an increase in health care costs (VolgensNederland, 2012).

The Dutch government claims that accessibility for all citizens will be ensured by stating that within the Netherlands everyone receives the care they need irrespectively to your income level or age. Nevertheless, to guarantee that citizens can still receive all the care they need in the future, the Dutch government needed to change the way health care was organised to temper the health care costs (Ministry of Health, Welfare and Sport, 2014, p. 3). By changing the rules concerning of the PGB system, the government aims to let individuals who are qualified to receive the PGB live at home longer which will keep the care affordable. By better responding to their personal situation and looking at what they can do themselves, people can continue to make decisions about their own live. Likewise, the care remains affordable (Zorghulpatlas, n.d.c.).

1.1.2.4.2 Convention on the Rights of Persons with Disabilities

The second change that had an influence on the motivation for reformation of the PGB system involves a Convention. The Convention on the Right of Persons with Disabilities¹ (CRPD) originates from a forceful call from individuals with an impairment across the world to have their human rights

¹ In Dutch: Verenigde Naties verdrag inzake de rechten van personen met een handicap

respected, protected and fulfilled in an equal manner with others. The CRPD embraces the human diversity and human dignity while addressing more comprehensively the challenges faced by individuals with an impairment (United Nations, 2014). Hereby, the CRPD defines an impairment not as a medical condition but as a consequence of the interaction between negative attitudes or an unwelcoming environment between the condition of particular persons (United Nations, n.d.). This interaction results in social and physical barriers that hinder the full and effective participation of individuals with an impairment on an equal basis with others in society. To prevent this from happening, since the interaction with an individual with an impairment needs to be based on them as an individual and not their impairment, the CRPD provides a legally binding instrument to protect and to promote the right of individuals with an impairment (United Nations, 2014). To achieve equality, it requires countries to provide rehabilitation, vocational education and health care for children and adults with an impairment at the same range and quality as provided to those without an impairment (Kanter, 2007). Hereby, its main message is that individuals with an impairment are entitled to all human rights and fundamental freedoms without any discrimination. An example provided in the CRPD to ensure equality is by establishing opportunities for individuals with an impairment to interact with others. By considering individuals with an impairment not as special, the environment must be shaped in such a way that they do not have to feel special when trying to interact with others. This can be ensured by having a reasonable accommodation in the individuals surrounding that facilitates interactions. This accommodation can be adjusted, e.g. by the presence of assistive devices and support persons, in such a way that interactions can be smooth. Thereby, it promotes full participation of individuals with an impairment throughout all domains of life (United Nations, 2014).

To reach this new full participation, numerous of different parties must be involved. These include, amongst others, the governmental officials, funds and programmes to professionals in areas such as health and support services, civil society organisations, representative organisations towards the general public on behalf of the individuals with an impairment, and individuals themselves (United Nations, 2014). The CRPD forces all parties to have a new way of thinking since the implementation of the Convention requires innovative solutions (e.g., the usage of pictures to discuss health-related topics for children aged 5-17 in various contexts and settings or the usage of e-learning for those who are working and living with an individual with an impairment such as teachers, caregivers, and families to reach 'social inclusion through knowledge') (Zero Project, 2016a; Delgadillo, in Zero Project, 2016b, p.1). This new way of thinking involves challenging the 'previous perceptions of disability – as a medical problem or a generator of pity or charitable approaches – and establish an empowering human rights-based approach to disability' (United Nations, 2014, p. 4).

When all parties recognize the equal right of all individuals with an impairment, they can demonstrate this by applying the 50 articles of the CRPD (United Nations, n.d.). An overview of all article titles can be found in appendix 1. The most applicable articles for this research are:

1. Article 19 – Living independently and being included in the community: via the application of this article parties recognize the equal right of all individuals with an impairment to live in the community while having access to the choices equal to all other individuals. Hereby, parties should take effective and appropriate actions to facilitate the full enjoyment of individuals with an impairment of this right and their total inclusion and participation in the society. This includes ensuring that: A) individuals with an impairment have the opportunity to decide for themselves where and with whom to live and it is not compulsory to live in a particular living arrangement. B) individuals with an impairment have access to residential, in-home and other community support services. These services can include personal assistance when needed to

support living and inclusion in society and to prevent isolation or segregation from the society. C) Community services need to be as accessible for the general population as for individuals with an impairment while being responsive to all individual's needs (United Nations, n.d.). With these services, the CRPD wants to ensure that all individuals with an impairment have equal rights while living in a community with equal choices as others. This equality occurs when individuals with an impairment have the opportunity to choose for themselves where and with whom to live instead of being obliged to live in an arranged accommodation (Perlin, 2008).

2. Article 20 – Personal mobility: this article states that all parties need to take effective measures to ensure personal mobility whereby the greatest possible independence of individuals with an impairment is ensured. In order to meet this article, parties need to, amongst others facilitate personal mobility of individuals with an impairment in the way they prefer, at the time they desires and at affordable costs (United Nations, n.d.).
3. Article 30 - Participation of individuals with an impairment in cultural life, recreation, leisure and sport: this article recognizes the rights of individuals with an impairment concerning their participation in cultural life, recreational and leisure activities and sports. In order to meet this article, parties need to, amongst others, ensure that: A) individuals with an impairment have access to cultural performances or services (e.g., theatres, museum and tourism services). B) Individuals with an impairment have equal access to services required for the organisation of recreational, tourisms, leisure and sporting activities (United Nations, n.d.).

The CRPD can only realize its goals if it is ratified by countries and those countries subsequently comply and enact the goals within their laws (Kanter, 2007). Nevertheless, ratification and enforcement of the CRPD remains a critical issue (Perlin, 2008). Countries experience a lot of pressure while implementing the far reaching changes since it challenges the principles of health care which are up till now widely accepted. This results in a delay in the implementation process of the CRPD (Freeman et al., 2015). In addition, there are obstacles a country need to overcome when enforcing a Convention. These obstacles include 1) limited enforcement of the people who will execute tasks to reach the conventions aims; 2) those who will carry out the tasks are either understaffed, underfunded, and may not have enough authority to comply with the human rights standards; 3) citizens or organisations may view the execution of human rights a task of the government and a 'fox guarding the henhouse' dilemma might occur (Perlin, 2008, p. 494). Furthermore, when the CRPD is ratified, a challenge regarding monitoring and evaluation arises. This due to the lack of robust monitoring frameworks to evaluate the implementation of the CRPD (Lang, Kett, Groce & Trani, 2011). The development of such a framework is also suppressed by challenges concerning data on impairment. Choosing a suitable definition of an impairment is proves to be difficult (Trani & Bakhshi, 2008).

The Dutch government signed the CRPD in March 2007 and ratified it in June 2016. According to Article 18 (a) of the Vienna Convention on the Law of Treaties, when signing a Convention a country is obliged to act upon the object and purpose of the CRPD. Consequently, the Netherlands needed to take the CRPD into account when designing new Acts and policies (Study and Information Centre Human Rights¹, 2012). The process from signing the CRPD to ratification took nine years for since ratification entails the incorporation of the CRPD immediately into the national legal system. Before immediate implementation can occur, the Dutch government wanted to measure the extent towards the country already complies with articles of the CRPD before making it a part of their legal system.

¹ In Dutch: Studie- en Informatiecentrum Mensenrechten

Furthermore, implementation of the convention has financial consequences for a country. The Dutch government demanded a cost-benefit analysis before ratifying the CRPD. Finally, since the CRPD involves many articles and subsequently requires collaboration between many parties, the process of implementation was difficult. In June 2016, the Dutch parliament approved the CRPD after taking into account the possible impact concerning its legislation, finance and collaboration. After this approval, the Dutch government needed to notify other parties that they ratified the CRPD according to article 33 of the Vienna Convention on the Law of Treaties (Rijksoverheid, n.d.e). This article further emphasises the task of the Dutch government to facilitate actions in different sectors and at different levels according to the CRPD. This can be achieved by developing a mechanism to promote, protect and monitor the implementation of the CRPD. Concerning the aspect of monitoring, individuals with an impairment and their representative organisations must be involved and fully participate in the monitoring process of the actions taken upon the CRPD (Overheid.nl, n.d.).

Since the ratification of the CRPD, the Dutch government must enforce the CRPD to their best potential. An example of action taken by the Dutch Government is according to article 20. The government tries to ensure personal mobility of the impaired individual via the facilitation of affordable transport when the individual demands it. Mobility is personalised via adjustments, such as additional guidance, that can be made for transportation (Study and Information Centre Human Rights, 2012).

1.1.2.5 Consequences after change

With the numerous changes in the Dutch society and the CRPD recently ratified by the Dutch government, the question arises whether or not the Dutch government is able to ensure compliance with the CRPD and whether it has an effect on the individuals with an impairment of the PGB system. Individuals with an impairment can use their PGB to be able to participate more in society (Ministry of Health, Welfare and Sport, 2010). The desire of the Dutch government to make individuals with an impairment more active in society is in line with article 19 of the CRPD. This article states that individuals with an impairment should be able to live in society where they have access to choices that are equal to the choices for individuals without an impairment. Nevertheless, the Convention stands for numerous statements, for example that individuals with an impairment should be as mobile as those without an impairment in article 20 or that an individual with an impairment should have equal access to tourism stated in article 30. Thereby, tourism participation results in an individual's community integration and subsequent an increase in empowerment of the individual with an impairment (Kosciulek and Merz, 2001). Nevertheless, Shaw, Church and Coles (2007) state that amongst individuals with an impairment in the United Kingdom a lack of money is one of three, besides illness and pressure of work, reasons for them not to participate in tourism during any one year. Within the Netherlands, individuals who are entitled to a PGB can use this budget to subsidize their more than general need for care and assistance. This need for care and assistance can arise during a holiday (Yau, McKercher and Packer, 2004). After the change in the PGB system, individuals with an impairment can use their PGB for from four different Acts (WMO, WLZ, ZVW, Youth Act) (PerSaldo, n.d.). It differs per Act how an individual with an impairment can deploy their PGB (PerSaldo, n.d.) :

- WMO and Youth Act: municipalities have a lot of freedom in legislation, also when it concerns holidays. It differs per municipality which exact rules apply. Nevertheless, when an individual with an impairment uses his or her PGB to buy care or assistance they can use this budget to buy the same care and assistance for when they are on holiday.

- WLZ: A PGB from this Act can be requested from a care office. Within the Netherlands there are 32 regions whereby every region has another care office that is responsible for the citizens within that particular region (RegioAtlas, n.d.). Individuals with an impairment can use their PGB to buy care services required during a holiday or to buy a full holiday. This last option is only applicable when:
 - o 7x24h of supervision and care is needed;
 - o A holiday is needed to relieve the immediate environment of the individual with an impairment;
 - o A protective environment is requested, in order to prevent that the individual with an impairment is not in a dangerous situation;
 - o And/or a therapeutic environment is needed, where therapeutic- and care facilities are available.
- ZVW: The application of a PGB originated from the ZVW differs per health insurance company. Therefore, no general regulations can be stated here (PerSaldo, n.d.d.).

With the recent changes in society, the reaction of the Dutch government to temper the collective expenditures via, amongst others, the reclassification and subsequent decentralisation of the PGB system, and the recent ratification of the CRPD which points out the importance of holidays for individuals with an impairment; the focus of this research will be on customized holidays and accommodation stays. Only these types of tourism participation possibilities are included since these organisations offer the needed care and assistance which results in a higher attendance price (Transcription ALV, 2016). With the decentralisation, the question rises whether the Dutch government is still able to keep up the CRPD which states that individuals with an impairment should have equal opportunities to fully participate in society while decentralising the PGB system with all its potential consequences? Participation involves the ability, for example, to move in and around the house, to move around locally by means of transport, to meet new people and based on that enter into social relationships (Ministry of Health, Welfare and Sport, 2010). These experiences and opportunities have an influence on the feeling of empowerment of individuals with an impairment. To reach equality in opportunities for participation amongst all citizens, good cooperation between parties involved in the PGB system is required. Collaboration will diminish unnecessary dependence amongst citizens and will encourage a citizens' participation concerning health and well-being (Soeters & Verhoeks, 2014). To investigate whether the parties involved in the PGB system share and act upon the vision of the Dutch government concerning the CRPD, the question rises whether the parties have the same or different perspectives on the empowerment of an individual with an impairment?

1.2 Objective

The objective of this thesis is to examine the perspectives of the different parties that became involved in the PGB system after the change in 2015 on the influence of the PGB on the empowerment amongst individuals with an impairment and their tourism participation.

1.3 Aim and research questions

The aim of this thesis is to assess how different parties involved in the PGB system view empowerment of individuals with an impairment. In addition, the perception of the involved parties concerning the role of PGB on the participation of individuals with an impairment in customized holidays is assessed. Based on this aim the main research question is formulated as follows:

How is empowerment of individuals with an impairment understood by different parties that are involved in the change in PGB system in 2015?

To find answer to this research question, **three sub-questions** are formulated. These sub-questions are all focused on different parties involved in the PGB system. The first sub-question covers the level of the Dutch government:

1. How do the different parties responsible for the execution of the Acts applicable in the PGB system understand the empowerment of individuals with an impairment?

Within this sub-question, three sub-questions arise:

- 1a. What is, according to the different parties responsible for the execution of the Acts applicable in the PGB system, the effect of the PGB on the empowerment of an individual with an impairment?
- 1b. How the different parties responsible for the execution of the Acts applicable in the PGB system link the effect of the PGB on the empowerment of an individual with an impairment to tourism participation?
- 1c. Has the role of the PGB on the empowerment and tourism participation of individuals changed after the change in the PGB system in 2015 according to the different parties responsible for the execution of the Acts applicable in the PGB system?

The second sub-question focuses on the members of the Dutch Branch Organisation for Customized Holidays¹ (NBAV). The NBAV is a branch organisation for tour operators and accommodation stays with the vision that everyone with an impairment deserves a pleasant holiday (NBAV, n.d.a.). More elaboration on the NBAV is done in chapter 2.5. For the organisations affiliated with the NBAV the second sub-question is:

2. How do the different organisations affiliated with the NBAV understand the empowerment of individuals with an impairment?

Again, within this sub-question, three sub-questions arise:

- 2a. What is, according to the organisations affiliated with the NBAV, the effect of PGB on the empowerment of an individual?
- 2b. How do the organisations affiliated with the NBAV link the effect of the PGB on the empowerment of an individual with an impairment to tourism participation?
- 2c. Has the role of the PGB on the empowerment and tourism participation of individuals changed after the change in the PGB system in 2015 according to the organisations affiliated with the NBAV?

¹In Dutch: Nederlandse Branchevereniging Aangepaste Vakanties

The final sub-question focuses on the parents of individuals with an impairment. The sub-question on the individual level is:

3. How do the parents of individuals with an impairment understand the empowerment of individuals with an impairment?

Thereby, three sub-questions arise:

- 3a. What is, according to the parents of individuals with an impairment, the effect of the PGB on the empowerment of individuals with an impairment?
- 3b. How do the parents of individuals with an impairment link the effect of the PGB on the empowerment of individuals with an impairment to the tourism participation amongst individuals with an impairment?
- 3c. Has the role of the PGB on the empowerment and tourism participation of individuals changed after the change in the PGB system in 2015 according to the parents of individuals with an impairment?

1.4 Outline

The remainder of this thesis is structured as follows: first, the **Conceptual Framework**, including different ways to assess the concept of empowerment, the social model of disability, literature findings on collaboration and the case study on the NBAV are discussed. Second, the **Methodology**, of this research will be discussed. This includes an elaboration of the used research design, the study selection, methods for data collection, data analysis and ethical consideration. The **Results** follow. These are split up in three themes derived from the interviews. Next, the **Discussion and conclusion** enlightens the findings of this thesis, the implications of this research for research and practice, provides an overview of the strengths and limitations of this research and the conclusion. This document includes six **Appendices**. The first appendix includes an overview of the Articles of the Convention on the Rights of Persons with Disabilities. The second appendix includes a flyer which has been spread amongst individuals with an impairment at a holiday destination. The third appendix includes the informed consent form. The fourth appendix includes Creswell's six steps of qualitative data analysis. The fifth includes the code tree used for data analysis. The sixth and final appendix includes suggestions for improving the quality of an interview.

2. Conceptual Framework

In order to answer the questions as described in the previous chapter it is important to gain a better insight into the concepts that play an important role in this research. Since the main concept of this thesis concerns the empowerment of individuals with an impairment and how this empowerment is defined by the different actors involved, it is important to first provide different definitions gained from literature. This will be done in chapter 2.1. Then, the concept of empowerment will be narrowed down into three chapters. These chapters include possible ways that the different parties in the PGB system can use in order to define empowerment and the role of a PGB on the empowerment of individuals with an impairment. Hereby, the first sub-chapter defines the dimensions of an empowered individual (2.1.1.1.). The second sub-chapter assesses the mechanisms that are needed for an individual with an impairment to become empowered (2.1.2.2.). The third and final sub-chapter defines barriers which can be experienced by an individual with an impairment that inhibit their ability to become empowered (2.1.1.3.). The second chapter of this conceptual framework further expands the vision of the CRPD concerning the guarantee of equality amongst individuals with an impairment and all citizens in society to a more operable method for this research. This will be done via the application of the social model of disability (2.2). The third chapter of this conceptual framework goes further in-depth about collaboration between parties involved in a system (2.3). The fourth chapter conceptualises the application of the conceptual framework for this research (2.4). The fifth and final chapter provides an insight in the case-study performed at the NBAV (2.5).

2.1 Empowerment of the individual with an impairment

Empowerment is a concept that can be approached from different angles (Quinn & Spreitzer, 1997). There are definitions that perceive the concept of 'empowerment' rather general. An example is the definition of Renblad (2003) which defines empowerment as a form of power which covers one's ability to decide things for themselves. Thereby, individuals have the opportunity to exert influence and to participate. Jacobs (2001) also emphasises the influence of individuals by defining empowerment as a mechanism which increases the influence of individuals over decisions and actions which influences their own health. A definition by Björk-Akesson, Brodin and Fälth (1997) defines empowerment from an equality perspective by perceiving it as a concept based on a philosophy with the foundation of equality amongst all people which arises from the strengths and resources of an individual.

When using the concept of empowerment in the field of social services and on the organisational level, more specific definitions arise. An example of this is made by Batliwala (2007, p. 113) who states that empowerment is a socio-political mechanism, that involves 'shifts in political, social and economic power between and across both individuals and social groups'. Also Kabeer (1994), perceived empowerment as a mechanism which includes the transformation of the relations of power between individuals and social groups. According to Kabeer (1994), social power shifts in three ways within the mechanism of empowerment; 1) by challenging the existing ideologies that justify social inequality; 2) by changing patterns of control over and access to economic, natural, and intellectual resources; 3) by transforming the institutions (e.g., family, government, and education) and structures that cause the current division of power (Kabeer, 1994). A definition that is more individual-oriented instead of group-oriented is from the DFID (2000, p. 11) which states that empowerment involves 'individuals acquiring the power to think and act freely, exercise choice, and to fulfil their potential as full and equal members of society.

As shown, there are multiple definitions for the concept of 'empowerment'. How empowerment is defined depends on the perspective that is taken. Is the main focus a group of people, then empowerment is more defined as a mechanism (Kabeer, 1994; Baltiwala, 2010). When the group consists of individuals with an impairment, empowerment be described as 'the process by which people gains some control over valued events, outcomes and resources (Fawcett et al., 1994, p. 471). However, when an organisation or author focuses on the individual, empowerment is more in line with the power of an individual (DFID, 2000). An example of such a definition is provided by Kosciulek and Merz (2001, p. 211) who state that 'empowerment is conceptualized as involving internal/psychological and situational/social aspects. Internal/psychological factors include a sense of control, competence, responsibility, participation, and future orientation. Situational/social aspects include control over resources; interpersonal, work, and organisational skills; and "savvy", or an ability to "get around" in society'.

The definition of empowerment by Kosciulek and Merz (2001) involves a level of participation. However, also the definition of 'participation' can have different interpretations depending on the context and the actors involved (Jager-Vreugdenhil, 2011). These interpretations can entail an economic level of participation, political or policy participation, educational participation, societal participation and social participation (Jager-Vreugdenhil, 2011). Within this research, the focus will be on the social participation. Social participation involves the participation of individuals with an impairment in a social network via informal contact (Jager-Vreugdenhil, 2011). This informal social participation refers to the personal involvement of an individual with an impairment in society (van Groenou & Deeg, 2010). This type of contact involves three factors. The first factor that is an indicator for informal social participation the size of an individual's social network. Van Groenou and Deeg (2010) state a positive correlation between the increase in the size of social network and subsequent an increase in empowerment. However, amongst individuals with an impairment the actual size of their social network can be irrelevant. Those with a high level of disability do not differ in other aspects, besides size, of their network structures and support (Morgan, Patrick & Charlton, 1984). A second indicator for informal social participation is the attendance in cultural activities. When an individual has more financial resources, he or she will participate more in cultural activities such as visits to museums, the movies, social-cultural centres and/or theatres at least once a month (van Groenou & Deeg, 2010). Third and final indicator for informal social participation is the attendance in recreational activities (van Groenou & Deeg, 2010). These attendances include visitations to a restaurant, bar, sports event, zoo, or amusement park at least once a month (van Groenou & Deeg, 2010). Jager-Vreugdenhill (2011) expanded this type of contact by stating that recreational activities also include a visit to nature- and recreational areas via tourism participation. Tourism participation can enhance or inhibit empowerment of an individual. Factors that enhance the empowerment of individuals include, for example, esteem, pride, confidence and the number of external contacts. Factors that inhibit empowerment are, for example, lack of knowledge about tourism, or lack of self-belief or skills (Cole, 2006b). When individuals participate in tourism, an increase in community cohesion can occur which results in an increase in social empowerment (Cole, 2006b).

Taking all these factors of empowerment in mind, it is interesting to see how the parties that play a role in the PGB system since 2015 assess the empowerment of individuals with an impairment.

2.1.1 Assessing empowerment

Above, multiple definitions of empowerment are stated. Within these definitions there is a difference in definitions between factors that define an empowered individual (Renblad, 2003) and factors that provide mechanisms that cause an individual with an impairment to become empowered (Batliwala, 2007; Kabeer, 1994; Kosciulek & Merz, 2001). Different parties can have different interests and therefore define empowerment in a particular way that may differ from another party (Kodner & Spreeuwenberg, 2002). To be able to provide a clear overview of how the different parties involved in the PGB system understand empowerment, different angles to define empowerment need to be distinguished. These can be identified from the literature. The first angle that can be taken by a party is defining empowerment based on the dimensions that define an empowered individual. The second angle that can be used by a party is perceiving empowerment based on mechanisms that cause an individual with an impairment to become empowered. The final angle that can be used by a party to define empowerment in relation to the PGB, is to describe the barriers that individuals with an impairment experience and how the PGB decreases these barriers that may result in an increase in empowerment.

2.1.1.1 Dimensions of an empowered individual

The first angle that can be adopted by an actor involved in the PGB system is to focus on the dimensions of an empowered individual. Empowerment is in literature often described as a phenomenon on the individual level (Renblad, 2003; Seibert, Silver & Randolph, 2004; Menon, 1999). Hereby, empowerment is an intrinsic motivator based on cognitions of an individual about him- or herself in relation to their participating role in society (Seibert et al., 2004). This participation can be divided into four dimensions (Seibert et al., 2004):

- **Self-determination:** an individual is free to choose where to participate.
- **Meaning:** individuals feel that their life is important to them; they care about what they are doing.
- **Competence:** individuals are confident about their own ability to participate in society.
- **Impact:** individuals believe that they can have influence.

2.1.1.2 Mechanisms to become empowered

Besides focussing on factors on the individual level when defining empowerment, also factors that are outside of the power of individuals can influence the empowerment. By applying a more societal description to the concept of empowerment, organisational structures and policies become part of the empowerment (Seibert et al., 2004). Within the Dutch PGB system, organisational structures include the Dutch government, the municipalities, the health insurance companies and care offices. These parties are involved by being in charge in the decision making processes about whether an individual with an impairment is entitled to a PGB. When taking the concept of empowerment to a societal level, mechanisms that can cause an increase in empowerment can be defined when talking about an empowered individual. Thereby, the PGB can have an influence on these mechanisms and subsequent on the empowerment of individuals with an impairment. Examples of such mechanisms are personal assistance, perceived self-efficacy, being active, and information sharing (van Haaster, Janssen & van Wijnen, 2012; Ozer & Bandura, 1990; Seibert et al., 2004). These mechanisms are

highlighted since they are applicable in the setting of customized holidays. To provide a better insight in the way these mechanisms can influence empowerment, further elaboration will be done:

- **Personal assistance:** this mechanism of empowerment refers to the ability of individuals with an impairment to organise their necessary facilities (Haaster et al., 2012). It is an important measure for individuals with an impairment to be less dependent on welfare professionals and unpaid carers (Askheim, 2005). Personal assistance enables individuals with an impairment to fight against their exclusion and isolation and participate more in activities that are to their interest (Haaster et al., 2012). Personal assistance can be provided at all times. This can be at their own home or, when participating in tourism, at the holiday destination. Therefore, personal assistance can be provided in various forms. For example when an individual has a visual impairment and travels by plane, they nearly always fly with a personal assistant who is familiar with the impairment and with the desired assistance of the individual. This assistance can, in that situation, be required to explain the safety information provided at the beginning of each flight or differentiate between identically packed pepper and salt (Buhalis & Darcy, 2011). Nevertheless, personal assistance needs to be bought so financial resources are required (Askheim, 2005). The PGB can step in to fill the money gap so an individual with an impairment can fully participate in tourism.
- **Perceived self-efficacy:** This mechanism for empowerment relates to an individual's belief in their own capabilities regarding the action, motivation and cognitive re-sources required to exert control over given events (Ozer & Bandura, 1990). Individuals tend to avoid situations to which they do not trust on their own capabilities when coping with a situation. However, individuals undertake activities in settings where they perceive themselves as capable (Ozer & Bandura, 1990). These settings can be arranged in such a way that individuals with an impairment have a feeling of self-efficacy which has a positive effect on their perceived empowerment.
- **Being active:** Individuals with an impairment can experience a form of stereotyping when participating in tourism. This stereotyping can occur before the start of the holiday by customer service provision or at the holiday destination by the absence of adjusted settings, such as for example stair lifts. When an individual with an impairment wants to participate in tourism, they need to reject this imposed identity by society and gain a positive self-image of a healthy individual with an impairment (Deegan, 1995). They need to prevent that they become passive since the professional and social services often minimize the opportunity for individuals with an impairment to express their needs and to make choices or decisions about their lives (Renblad, 2003). Actions taken to prevent passivity can be done by using their PGB since that budget enables individuals to choose their own health provider, at their requested time, place and way (PerSaldo, n.d.a.). In this way, individuals with an impairment can decide for themselves to participate with organisations in the tourism sector that do not have a negative attitude and enables them to fully participate in tourism.
- **Information sharing:** this involves the distribution of sensitive information amongst different persons. This can be between individuals with an impairment who are in the same situation or it can be a 'transfer of power from the agency to the client' (Jansen & Geelen, 1996; Seibert et al., 2004; Hasenfeld, 1987, p. 480). When individuals with an impairment share information amongst each other, this can happen, for example, via peer support groups (Jansen & Geelen, 1996; Seibert et al., 2004). Information sharing between an organisation and an individual with an impairment can be achieved when the organisation fosters the active input of their

participants into their agency goals and policies and the way of thinking of practitioners is aligned with those of the individuals with an impairment (Tower, 1994). The sensitive information can contain costs, productivity and quality (Cole, 2006a).

An example of the importance of information sharing between individuals with an impairment sharing is regarding costs of a particular holiday. When individuals with an impairment experience extremely high costs or discriminatory attitudes with a tour operator they have the opportunity to communicate this to others via, for example, peer support groups. This might result in the prevention of bad experiences amongst others while joining a customized holiday with that specific organisation. As a result of this information sharing, individuals with an impairment are better informed in their decision making processes in the tourism sector. This knowledge is essential if they want to actively participate in tourism since ignorance is an important barrier for participation (Cole, 2006a).

2.1.1.3 Barriers for empowerment

In previous chapter, different angles to assess the empowerment of individuals with an impairment focus on the factors that increase a feeling of empowerment amongst individuals with an impairment. However, it might occur that parties assess the concept of empowerment based on factors that diminish the feeling of empowerment amongst individuals with an impairment. These factors are barriers that individuals with an impairment experience when participating in tourism, where barriers can arise since they desire unique services compared to those without an impairment (Yau et al., 2004). Examples of such a service is attendance opportunities during the holiday. These services must overcome the barriers caused by the environment, including architectural, attitudinal, and ecological factors; interactive barriers resulting from skill challenge incongruities and communication barriers; and intrinsic barriers emerged from an individuals perceived physical, psychological, or cognitive functioning (Smith, 1987). These barriers can be divided in internal- and exogenous barriers. Hereby, internal barriers need to be overcome before an individual with an impairment is able to become active in tourism and he or she has greatest control over these barriers (McKercher et al., 2003). Exogenous barriers are in the environment or via interaction with others. These types of barriers minimize the options for joining a customized holiday, reduce satisfaction and consequently inhibit traveling amongst individuals with an impairment (McKercher et al., 2003). An overview of these barriers can be found in table 2. When an organisation in the tourism sector is able to provide the requested services that diminish the barriers, an environment is created which enables individuals with an impairment to participate more actively and societal acceptance is easier (Yau et al., 2004; McKercher, Packer, Yau and Leam, 2003).

Nevertheless, participation in tourism via organisations that offer such services can result in higher participation costs. An example provided by a tour operator at an Annual general meeting of the NBAV described this difference between participation costs amongst individuals with and without an impairment. He stated that the participation costs for tourism amongst individual with an impairment can be double the price compared to the participation costs of individuals without an impairment due to the required additional services (Transcription ALV, 2016). The extra participation costs for tourism amongst individuals with an impairment can be covered by a PGB. However, do the parties involved in the PGB system recognize these services as factors that can diminish the barriers for empowerment and as response provide allow the usage of a PGB for these services?

Slight increases in participants' overall mean social network size were also noted, suggesting that home inaccessibility may have been a barrier to obtaining social support. (Fawcett et al., 1994)

Table 2: Barriers individuals with an impairment can experience before/during a holiday

INTERNAL		EXOGENOUS	
Intrinsic barriers	Economic barriers	Environmental barriers	Interactive barriers
Lack of knowledge	Affordability	Architectural / accessibility of accommodation etc.	Skills challenges and incongruities
Ineffective social skills	Income disparities	Ecological, paths, trails, hills etc.	Communication challenges
Health-related barriers	Need for travel companions / special facilities	Rules and regulations	Lack of encouragement to participate
Physical or psychological-related barriers		Safety	Attitudes of travel and hospitality industry workers
Is travel seen as a right?			Availability and accuracy of information.

Source: McKercher, Packer, Yau and Lam (2003).

2.2 Social model of Disability

Different perspectives can identify different barriers that individuals with an impairment face when participating in tourism. Whereby McKercher et al., (2003) identified, amongst others, intrinsic barriers, Davis (2016) only recognizes the barriers as a feature of society. A difference in perspectives can also be identified concerning the determination of an individual with an impairment. In the past, individuals with an impairment were described as persons with a disability. Thereby, disability refers to a divine punishment, moral failing or karma created by society (Shakespeare, 2006; Oliver, Sapey & Thomas, 2012). Consequential, disability can be formulated as ‘any restriction or prevention of the performance of an activity, resulting from an impairment, in the manner or within the range considered normal for a human being’ (Burnett & Baker, 2001, p. 4). When society accepts the situation of the individual with an impairment, the disability is removed and an impairment arises (Oliver et al., 2012). As a result, an impairment is defined as ‘a permanent or transitory psychological, physiological, or anatomical loss or abnormality of structure or function’ (Burnett & Baker, 2001, p. 4).

Before the acceptance occurred in society, individuals with an impairment were perceived as persons with a biological deficit. With this perception the medical model of disability was born. By perceiving disability as a biomedical disorder the individual is causing the problem him- or herself (Shakespeare, 2006; Swain and French, 2000). As a consequence, a disability is an individual struggle and a structural and public characteristic which causes the loss or limitation of opportunities to participate on the same level in society as individuals without a disability (United Nations, 2014; Shakespeare, 2006; Burchardt, 2004; Davis, 1990). In 1975 this perception changed due to a counter-reaction to the medical model of disability by the disability movement. This movement focussed mainly on social oppression, cultural discourse and environmental barriers (Shakespeare, 2006). As a result the social model of disability was developed (see figure 2). This model does not focus on individuals with disabilities nor on their personal experiences of impairment or the use of services; it focusses on the societal systems, structures and practices that do not take individuals with an impairment in consideration (Oliver, Sapey & Thomas, 2012) and it conceptualises the barriers that individuals with an impairment experience while participating in society (Burchardt, 2004). These

barriers arise when an individual is no longer able to perform certain tasks due to, for example, poor societal practices, bad design of buildings, the unrealistic expectation of others, the organisation of production or an unsuitable housing environment (Oliver et al., 2012). This conceptualisation is achieved while putting emphasis on the social, economic and environmental barriers which hinders equality (Burchardt, 2004). The social model of disability strives to get society accepting the impairment and thereby removing the disability. This vision can be traced back in the Convention which states that society must disassemble the barriers individuals with an impairment experiences that prohibits them to fully participate in society (United Nations, 2014). As result, when all barriers are removed the disability will be subsequently removed and an individual is no longer 'disabled' (Oliver et al., 2012).

According to Oliver (1990), the founder of the social model of disability, not the individuals with an impairment themselves, but society needs to change as part of the empowerment process of individuals with an impairment. Hereby, empowerment is imbedded in the standpoint whereby an impairment is a social oppression and emphasis is put on the role of service initiatives when breaking down barriers to physical, emotional and societal participation amongst individuals with an impairment (Barnes and Mercer, 2010; French and Swain, 2012). To reach this, independence and citizenship should be promoted (French and Swain, 2012). This independence can for example be developed by collaborating with individuals with an impairment in the development and delivery of services, which can lead to empowerment. Collaboration can include personalisation or user-led services (Davis, 1990). These services are associated with participation in the public sphere where the services are user-centred instead of provision-led (Cotterell et al., 2012). Therefore, the social model of disability perceives the concept of empowerment as a relationship between individuals with an impairment and the services they receive.

The social model of disability is a tool that provides assistance when examining situations and understanding the range of experiences of individuals with an impairment (Oliver et al., 2012). Situations that will be examined in this research will be the assessment of the way parties involved in the PGB system since 2015 perceive empowerment for individuals with an impairment. Thereby, the experiences of individuals with an impairment play an important role in this research since they are the experts concerning the level of impact by a change (Burchardt, 2004). This perspective in research is in line with the 'nothing about us, without us' principle (Charlton, 1998, p. 17) of the disability movement which means that individuals with an impairment need to be highly integrated in research by providing valuable insights (van Haaster, Janssen & van Wijnen, 2012).

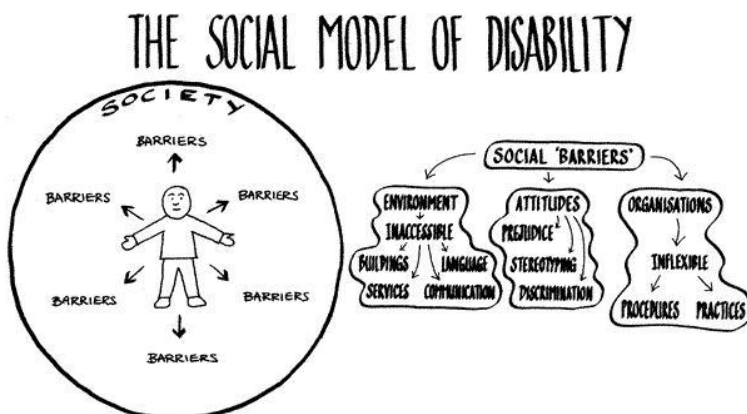


Figure 2: Social model of disability
Source: Dupree (2011)

2.3 Collaboration different parties

The social model of disability suggests that inequalities between individuals with an impairment and those without an impairment arise due to the way society handles the impairment (Oliver, 1990). A society consists of subsystems. Every system consists of a number of parties that interact and are interdependent (Hodgins & Scriven, 2012).

Within the PGB system, the decentralisation resulted in an increase in the amount of parties (Zorgwijzer.nl, 2016). There are factors that enhance and inhibit their collaboration. Three factors were identified in the literature that enhance the collaboration between parties involved in a system with regard to policy. Firstly, the flexibility of a policy is of importance. Flexibility includes the existence of an opportunity for local decision making and the availability of enough resources and autonomy amongst local actors to carry out central policies while addressing the needs of the local citizens (Agranoff & McGuire, 2003). Secondly, clear communication is necessary on the main content of a policy (de Leeuw, 2000; Laumann and Knoke, 1987). Thirdly, integration of the different parties with a system with regard to policy provides opportunity for greater efficiency and effectiveness, less duplication and waste of services, a more flexible service provision and better co-operative coordination and continuity (Kodner & Spreeuwenberg, 2002).

Two factors were identified in the literature that inhibit collaboration between parties within a system related to policy. Firstly, the amount of parties involved. When a system includes many parties, differences in interest and goals resulting in different approaches can arise. This can occur since parties can have different priority settings while working within the same policy. To overcome this, negotiation and adoption is required (de Bruijn and ten Heuvelhof, 2000; Hoeijmakers, de Leeuw, Kenis and de Vries, 2007). Secondly, parties working in the same system related to policy create their own unique connections with individuals with an impairment. These connections can create different perspectives amongst parties who collaborate in the same system (Hoeijmakers et al., 2007).

After a decentralisation process, the central government relies on the local parties for a successful execution of a particular vision (Agranoff & McGuire, 2003). Since the ratification of the CRPD, the Dutch government aims for equality amongst individuals with- and without an impairment (Study and Information Centre Human Rights, 2012). To ensure that this vision is translated into practice, collaboration between the different parties involved in the PGB system is needed. The absence or presence of collaboration has its effect on whether or not the parties involved in the PGB system conveys a unanimous perspective that individuals with an impairment are equal to those without an impairment.

2.4 Application theoretical framework

The social model of disability states that empowerment is a concept of relationship between individuals with an impairment and the by them received services (Keyes et al., 2015). In addition, the model states that society is responsible for the disability of individuals and that this disability can merge into an impairment when society changes whereby emphasis is put on the role of service initiatives (Barnes and Mercer, 2010; French and Swain, 2012). This model shows that it is of importance to address not only the individuals with an impairment, but also the actors by which they are surrounded when addressing their empowerment and their tourism participation (Davis, 1990). Therefore, this research will, besides focussing on the individuals with an impairment, also focus on the actors on the municipal level, governmental level and organisational level.

With the decentralisation process of the PGB system in 2015 the number of responsible parties increased. While decentralising the PGB system, the Dutch government ratified the CRPD

which aims for equality for individuals with an impairment. Within this research, the presence of a shared perspective amongst the parties involved in the PGB system on the equality of individuals with an impairment is investigated. It is important for good collaboration amongst local actors who work on the same policy but from different (power) positions to share a common interest, definition and goal (Laumann and Knoke, 1987; de Bruijn and ten Heuvelhof, 2000). This will be done via an investigation of the perceived empowerment of individuals with an impairment according to the (responsible) parties involved in the PGB system.

As mentioned before, empowerment can be approached from many different angles (Quinn & Spreitzer, 1997). A way to systematize these approaches, different ways to approach the concept of empowerment will be used. These ways involve the perception towards the concept of empowerment based on the dimensions that define an empowered individual, the mechanisms that make an individual empowered or the barriers that inhibit an individual to become empowered (Seibert et al., 2004; van Haaster, Janssen & van Wijnen, 2012; Smith, 1987).

2.5 Case study at the NBAV

In order to gain an answer to the research questions, a case study will be conducted. This case study will be executed at the NBAV. The NBAV is a branch organisation with the vision that everyone with an impairment deserves a pleasant holiday (NBAV, n.d.a.). Such an impairment can be deafness, ADHD, ADD, autism, blindness, dementia, multiple disabilities, acquired brain injury or visually, hearing, intellectual or physically impairment (NBAV, n.d.a.). To translate this vision into practice they developed the NBAV-certification mark. A tour operator or accommodation facility needs to get this certification mark to become part of the NBAV. When a tour operator or accommodation facility is affiliated with the NBAV, individuals with an impairment are ensured with high quality standards concerning communication and information, a clear and complete description of the holiday, accessibility of the accommodation and surroundings, perfect care, transparent pricing and reliable and well trained accompaniment (NBAV, n.d.b.).

The NBAV will be of great importance in this case study since the organisations affiliated with the NBAV will be included in this research as well as the parents of individuals with an impairment who join a customized holiday product offered by an organisation affiliated with the NBAV. Therefore, the NBAV will be the starting point considering the approach of parents of individuals with an impairment, tour operators and accommodation facilities.

The case study started with an Annual Members Meeting of the NBAV on the 30th of November 2016. During this meeting, all present representatives of organisations and accommodation facilities received an update concerning the larger PhD research and a quick introduction in what this MSc thesis research would contain. Furthermore, a workshop was held titled 'Effects of changes in government policy and legislation on your organisation and industry'. NBAV members brainstormed about the change in policies and what consequences they are recognizing on a daily basis due to this change. With this method categories were revealed as well as their importance (Schuurman, Speet & Kersten, 2004). These categories were put into a mind-map which provided a clear overview of the brainstorm session. The Annual Members Meeting was an opportunity to taste the atmosphere of the NBAV, to notify the representatives about the topic of this research and inform them that they might be approached in the future for an interview.

3. Methodology

This chapter describes the research design, study selection, data analysis and ethical considerations.

3.1 Research design

To get an insight in the perspectives of the different parties involved in the PGB system since 2015 concerning the empowerment of parents and the influence of a PGB and tourism on this empowerment, qualitative research was executed. This type of research is focused on obtaining information concerning what is of importance for a certain target group and why (Right, n.d.). Hereby, the aim is to identify the perception of different parties involved in the PGB system on the empowerment of individuals with an impairment. Therefore, this research is of exploratory nature (Bowling & Ebrahim, 2005). This identification will be done via the execution of interviews with different parties involved in the PGB system. Face-to-face interviews will be conducted, instead of, for example, interviews conducted by telephone or postal questionnaires, for numerous reasons 1) ambiguities can be clarified; 2) more complicated questions can be asked; 3) more information of greater depth can be obtained; 4) questions can be asked in a pre-determined order which minimizes question bias; 5) inconsistencies and misinterpretations can be checked (Bowling & Ebrahim, 2005). On the other hand, it is a time consuming method (Schuurman, Speet & Kersten, 2004).

3.2 Study selection

In total 12 interviews were held in a time range of 6 weeks. Amongst these 12 interviews, four were done with parents of individuals with an impairment, four with organisations affiliated with the NBAV, one with a WMO consultant, one with a Youth consultant, one with a health insurer and one with an employee of a care office. Parents of individuals with an impairment were included in this research to provide their perspective on their experienced empowerment and that of their child, the role of the PGB in this empowerment process and their tourism participation. The organisations affiliated with the NBAV are included in this research to cover the perspectives of the organisational level on how they perceive the empowerment amongst individuals with an impairment. Concerning the other participants within this research, they are included in this research to cover the perspectives of a responsible party within the particular Act they work regarding the empowerment of individuals with an impairment and the role of a PGB on this of empowerment and participation in tourism. Thereby, on the municipal level, the WMO consultant provides the perspective originated from the Social Support Act (WMO) and the Youth consultant from the Youth Act. On the regional level, the health insurer covers the perspective from the Health Insurance Act (ZVW) and the employee of the care office provides a perspective originating from the Long-term Care Act (WLZ). The inclusion criteria differed per included party. Below, the included parties are discussed.

3.2.1 care office

After an individual with an impairment receives an indication from the Assessment Care Center (CIZ), he or she can receive money for care from the Long-term Care Act (WLZ) via a 'care office'¹. This care office is in charge of all the care from the WLZ within its own region (Menzis, n.d.). The Netherlands is divided within 31 regions, all covered by another care office. These 31 care offices are part of a health insurance company (Ministry of Internal Affairs, n.d.). Which health insurance company is responsible for the care office differs per region, but it is always the biggest health insurance

¹ In Dutch: Zorgkantoor

company in the region (Zorgverzekeraars Nederland, n.d.). The care office included in this research was chosen based on convenience in location for the researcher concerning travel time. A senior care buyer in the WLZ was included in this research in order to cover the perspective from an organisation responsible for care from the WLZ on the empowerment of individuals with an impairment and the role of the PGB on this empowerment and tourism participation. A senior care buyer is responsible to buy the care at health providers for its customers. As result, customers can chose where to consume their required care amongst the health providers where the care office has a contract with. Thereby, they do not manage their own money but the care office is responsible for the money flows. When focusing on a PGB, the care office has no control over the bought care by individuals with an impairment. However, a care office is the financial source for a PGB from the WLZ and therefore, the senior care buyer is familiar with this process and included in this research. Additional insights from individuals with an impairment within the WLZ were conducted during a gathering of client councils at the care office. Client councils are present at care institutions and assure that the interests of residents at a particular care institution are taken into account by the board of a care institution (Rijksoverheid, n.d.f.). Thereby, close contact with the residents is required which gives client councils a lot of information about their citizens and their potential empowerment.

3.2.2 health insurance company

An individual with an impairment can receive a PGB from the ZVW since 2015 (SVB, n.d.). With this budget, services can be bought regarding nursing- and/or caring activities or intensive child care (PerSaldo, n.d.c.). Therefore, health insurance companies play a big role in the PGB system. To get a grasp of the perspectives of health insurers concerning the feeling of empowerment of individuals with an impairment and the role of a PGB on this empowerment and tourism participation, an interview was held with the team manager of a PGB team of a health insurance company. This particular person was chosen via purposive sampling. Purposive sampling is a sampling method whereby the included stakeholder is deliberately selected since it is suspected that they are informative (Bowling & Ebrahim, 2005). Via others who had contacts within this particular organisation, an interview was scheduled.

3.2.3 municipality

Since 2015, municipalities are in charge of the WMO and the Youth Act. Thereby, a WMO consultant or a Youth Act consultant decides during an appointment whether or not an individual with an impairment can apply for a PGB from the WMO or Youth Act. Thereafter, an employee of the municipality decides whether the particular individual is entitled to the PGB (Municipality Wageningen, n.d.).

Two consultants were included in this research. These two consultants were included to gain an insight on how they perceive the empowerment of individuals with an impairment and the role of a PGB on this empowerment and tourism participation. These consultants were included via convenience sampling. This type of sampling is also known as availability sampling with the primary advantage that sampling selects the most easily available participants in the way it is easiest for the researcher (Tansey, 2007). Within this research the included municipal party was chosen based on its convenience in location for the researcher.

The two consultants included in this research both worked at a centralised point in a city. They assist individuals with an impairment by helping them to find the best solution for their question or problem. Their provided advice is a firm advice. This means that when they advise an individual with

an impairment to not apply for a PGB from the WMO or Youth Act, that particular person often follows their advice. To ensure that this decision is a well-considered decision, consultants work closely together with an individual (Startpunt, n.d.a.).

3.2.4 organisations affiliated with the NBAV

To include the perspective of the organisational level on the influence of the PGB on the participant, four organisations affiliated with the NBAV were included. These four organisations were chosen based on purposive sampling. This sampling method implies that as a researcher you have enough knowledge of the participants in order to choose the most appropriate for the research needs (Tansey, 2007). This knowledge was obtained via a questionnaire send out after an Annual Members Meeting of the NBAV. Within this questionnaire two questions were interesting for this research, being 1) 'Which recent changes in legislation have an effect on your organisation?' and 2) 'What kind of research do you think is needed in the industry?'. Based on the answers provided by the organisations, a list was made with organisations that could be included. Answers that resulted in being on this list concerning the first question had to contain the terms 'legislation change', 'change in PGB', 'influence PGB' or a similar variant. Answers that resulted in inclusion of an organisation on the list concerning the second question had to contain the terms 'influence/effect of product/service', 'influence PGB', 'finance participants' or a close synonym. When an organisation mentioned these terms it showed that they are affected by a change in Act or more specific a change in the PGB system and/or showed their interest in the area of this research.

Of the list, a total of four organisations affiliated with the NBAV were included in this research. These four were included because two are tour operators and two are accommodation providers. These organisations share the same goal namely ensuring that individuals with an impairment have a high qualitative adapted holiday (NBAV, n.d.a.). Of these four organisation, two are tour operators and two are accommodation facilities. The organisations that were included in this research are:

1) De Putse Hoeve

This is a luxurious five star group accommodation located in the village Kempen in the municipality of Bergeijk. It is located within an area with nature reserves, villages and cities. Groups can stay at this accommodation for recreational purpose and this accommodation stay also offers this opportunity for care groups (De Putse Hoeve, n.d.). Care groups who want to get away for a weekend or a midweek and demand more concerning accessibility due to age or an impairment, physical or mental, can stay at De Putse Hoeve.

De Putse Hoeve was included since they showed their interest for research towards the funding possibilities of participants. More specific, the answer provided to question 2 contained 'For accommodation stays mapping the possibilities of holidays with caring services with financing possibilities for participants'.

2) Landhoeve Zwieseborg

This accommodation is located in the rural town Loozen in the municipality of Hardenberg. It offers recreation and overnight stays for individuals with and without an impairment. Individuals can stay overnight at their hotel, campsite or in an adjusted group accommodation (Landhoeve Zwieseborg, n.d.).

This accommodation stay is included in this research since they addressed that the adjustments in PGB is having an influence on their organisation.

3) Stichting Poldermaat met Schik

This foundation is a tour operator that organises, with volunteers, holidays for everyone who needs assistance in and outside the Netherlands (Stichting Poldermaat met Schik, n.d.).

This foundation was included since they addressed in the survey that the current changes in the PGB has caused a lot of unclarity within their organisation.

4) Stichting Wielewaal

This foundation organises holiday day care, weekends, camping recreation and group holidays for children, youth and adults with an impairment. They offer holiday activities for individuals with a physical and/or intellectual impairment and/or ADHD/autism. These activities are assisted by volunteers (Wielewaal, n.d.).

This foundation was included since they showed interest in research concerning the influence of their services on their participants. This is in line with the area of interest in this research which focuses on the perceived effect of the PGB on individuals with an impairment and holiday services can be a part of this effect.

3.2.5 parents of individuals with an impairment.

Parents of individuals with an impairment part of this thesis since they are the service users of the PGB system. They have experiential insights and expertise that can have valuable contributions for the research (Bowling & Ebrahim, 2005). These insights and expertise will be on their experienced empowerment and the role of PGB in their empowerment process or that of their child and tourism participation. Their level of involvement will be in a consultation format, which means that the parents will be asked about their own perspective (Bowling & Ebrahim, 2005).

Using non-random convenience sampling, four parents were recruited to assess an interview with. Non-random convenience sampling includes that the parents were by chance found in one source (Bowling & Ebrahim, 2005). The organisations affiliated with the NBAV played the role of this recruiting process. When an interview was scheduled with an employee of the particular organisation, the employee was asked whether they could get in contact with individuals with an impairment for an interview. For the scope of this research only two organisations were approached, being a tour operator and an accommodation stay. These two organisations were open for cooperation which resulted in the recruitment of four parents of individual with an impairment available for interviews. It varied per organisation how the contact with these parents was maintained. Concerning the tour operator, who generated three interviews with budget holders, the employee kept in touch with the parents there was no contact between the parents and the researcher prior to the interview. Concerning the accommodation stay, which generated one interview with a parent, they preferred that the contact occurred mainly between the parents and the researcher. This contact was made via a flyer which was distributed in the accommodation stay. This flyer was provided by the researcher. The distribution of this flyer amongst individuals with an impairment was taken care of by the organisation. The organisation distributed the flyers amongst their accommodation stay. The flyer can be found in appendix B (in Dutch). In total two parents of individuals with an impairment responded upon the flyer by showing their interest for participation in this research towards the accommodation stay. Upon this request to get in touch, a date was scheduled via communication between the researcher and the accommodation stay whereby both interviews would be held. Unfortunately, when this date arrived, one of the parents cancelled. The interview with the other parent was held.

A general note must be made concerning the reference to individuals with an impairment who receive a PGB and the parents of individuals with an impairment who were interviewed for the continuation of this research. Since the individuals with an impairment were not able to participate in

an interview, their parents participated. These parents are the administrators of the PGB and have as result interesting insights for this research. Therefore, within this research the individuals with an impairment who receive a PGB will be referred to as parent.

3.3 Data collection

As mentioned before, a total of 12 interviews were held. These interviews were conducted in order to gain the perspective of that particular party on the empowerment among parents and the role of the PGB on the empowerment process and the parent's tourism participation. When all perspectives were obtained, differences and similarities between perspectives of parties were constructed.

3.3.1 Biographical-Narrative Interpretive Method

In order to prevent steering the participant in a specific way as much as possible, the biographical-narrative interpretive method (BNIM) was used. This method provides the opportunity to gain a more realistic and holistic view of the topic under research by letting the participant generating a story about themselves from their own perspective (Rosenthal, 2004; Wengraf & Chamberlayne, 2006). Rosenthal (2004) states that for social science in order to reach the social reality beneath the formal organisation of institutions, the actual human experiences and attitudes must be reached. To achieve this, the overall context of a participants current life and his/her resulting present and future perspective must be interpreted (Rosenthal, 2004). By providing the opportunity for the participants to tell their story on the empowerment of parents and the influence of a PGB on this empowerment and tourism participation, perspectives of all participants were collected. Subsequently, the BNIM enabled comparison between perspectives of different parties.

At the start of the interview itself, the approach was shortly introduced again as the interview started with the following sentence. This sentence differed a bit depending on the party to be interviewed. During the interviews with parents the following sentence started the interview: *"Please tell me your story concerning your life with regards to the PGB, which role does the PGB play in your life, how does the PGB affect you, and all events and experiences you may have with the PGB? You may start when and wherever you like. I will not interrupt, but I will make some notes for later on"*. The interviews with the organisations affiliated with the NBAV started with the following sentence: *"Please tell me your story concerning the way you think the PGB influences your holiday guests, what role does it play in their lives, how it affects them, and all events and experiences related to this. You may start when and wherever you like. I will not interrupt, but I will make some notes for later on"*. The interviews with the WMO consultant, Youth consultant, team manager of the health insurance company and senior care buyer of the WLZ started with the following sentence: *"Please tell me your story concerning the way you think the PGB influences the budget holder, what role does it play in their lives, how it affects them, and all events and experiences with this. You may start when and wherever you like. I will not interrupt, but I will make some notes for later on"*.

After mentioning the openings question, eight participants started telling their stories straight away related to the empowerment amongst parents and the influence of the PGB on this empowerment and the participation of parents in tourism. However, of the in total twelve interviews, four participants responded differently upon the openings question. Thereby, one parent emphasised that it would not bother him to be interrupted while telling his story. Another parent first asked whether she could start with whatever story she preferred. An organisation affiliated with the NBAV did not started immediately with telling her story, she first questioned how the researcher was able to generate results with all the different parties when the openings question is as broad as it was.

After answering this question, the participant started telling her story. The final participant who did not start his story right away was the WMO consultant. He needed clarification on the question before starting his story. This clarification was provided and he started with his story.

It differed per participant how much time they needed for telling their story. On average, the stories were told within fifteen minutes. Following this story, a question was asked by the researcher based on the information provided by the participant. Subsequently, a natural conversation originated.

Within the communication between the researcher and the participants the expression of a conversation was used to make them feel as comfortable as possible while sharing their stories. To prevent confusion within this document these conversations will be addressed as interviews since the BNIM is an interview technique.

3.3.2 Location

All participants were given the opportunity to decide where they wanted their interview to take place. Having this opportunity gives them a feeling of comfortability (Hutter & Bailey, 2011). Furthermore, Carter and Henderson (2005) recommend that the creation of a 'safe space' for participants is required when targeting participants views and opinions. The combination of feeling comfortable and being interviewed in a 'safe space' is important for participants in general.

Of the twelve interviews, three took place at the residence of the participant. The fourth interview with a participant took place at an accommodation stay. One interview with an organisation affiliated with the NBAV took place in a restaurant. This was due to convenience in location since the employee the tour operator drove the researcher around to the parents' addresses and the final address was far away from his office. The other three interviews with organisations affiliated with the NBAV and the four interviews with the WMO consultant, Youth consultant, the health insurer and the senior care buyer took place at their office. The location, date and time was mutually agreed upon.

3.3.3 General points for consideration

Since interviews were held with different participants and at different locations, there were general points that needed to be taken into account to ensure that the interview was conducted as accurately as possible. First, concerning the context of the interview, a good atmosphere had to be created. This was done by giving the participant the opportunity to choose where the interview was held. Therefore, flexibility was key. Second, the quality of the interview mainly depended on the course of the interview. This was ensured by assessing several suggestions of Schuurman, Speet and Kersten (2004). An overview of all the suggestions can be found in appendix F. The suggestions that were applied during the interview were firstly, giving the participant the opportunity to share their personal story which was made possible by not having a fixed interview scheme. Secondly, being prepared to compromise on the amount of information gained was a suggestion that was taken into account. Finally, a clear agreement about the time of the interview was discussed before the interview was held. Beforehand, a timespan of 30 minutes was agreed upon. However, if the story of a participant covered more time than 30 minutes the interview took longer than initially planned. Since there was no fixed interview scheme and the participant was in charge concerning which items were discussed, proper communication between interviewer and interviewee was of importance in order to ask questions and interpreted answers in the best possible way. Suggestions provided by Schuurman et al., (2004) were used to ensure a clear communication. This was done via three measures. Firstly, the participant was not interrupted when he or she was telling their story. Secondly, when a question was

asked regarding their story, this question was short, concrete and one question at the time. Thirdly, answers that were not directly understood were not labelled as irrelevant data. An overview of suggestions to ask questions and interpreted answers in the best possible way can be found in appendix F.

3.4 Data analysis

All interviews were, after consent was given for this, recorded and transcribed. Anonymity is maintained since all participants are only cited by profession or as participant, and a number of abbreviations. These abbreviations were WLZ, WLZ – client council, HIC, WMO, Youth, O#X, P#X. Further elaboration upon the abbreviates is done in chapter 4.1. The transcriptions of the interviews are analysed according to the Creswell's six steps of qualitative data analysis (Creswell, 2013). Since all interviews have a specific purpose, namely identifying the understanding of the involved participants on the concept empowerment amongst parents and the role of PGB on their empowerment, it is necessary to restore the responses in a relevant and usable form to fulfil this purpose.

After transcription of the interviews, transcriptions were read and text pieces were coded (steps 1, 2, 3). Step 3 identified the first codes namely administration, application of a PGB, change 2015, effect PGB, fraud, freedom of choice, informed, care consumers, money, opinion PGB system, participation in society, personalized care, relationship system, respite care, rules and regulations, social network. During the coding process, a code-tree was used (appendix E). This code-tree was generated while going through all transcriptions and assisted in the systematic approach of coding the data. Eventually, three themes were distinguished since these themes came up during all interviews on a regular basis (step 4). These themes were 1) Effect of the PGB on the parents; which includes the opinion of participants regarding the way the usage of the PGB makes the parent feel. This usage involves the social network which can be built via a PGB, the ability to participate in society and the relief of tasks and chores of the relatives and friends of parent's in the caring process which is defined as respite care, 2) Freedom in choice; this includes the perspective of the participants regarding the choice in services and devices that can be bought with the PGB. Furthermore, their opinion towards the position of care consumer amongst parents which gives the parents the opportunity to buy personalised care instead of receiving care without having any influence regarding the person who provides care or at what time, 3) Management of a PGB; which covers the participants' opinion concerning the change that the PGB system has undergone in 2015 and the PGB system as a whole, their thoughts upon the administrative part of the PGB, their thoughts regarding how and whether or not parents are well informed, their opinion on the relationships between parents and the parties involved in the PGB system, their opinion towards the rules that come with the ownership of the PGB, and their opinion with regards to fraud with the PGB. These three themes are the direct result of the answers provided by all participants. The themes were discussed via the perspectives of all participants and illustrated via quotes (step 5). Finally, data was interpreted by the researcher to discover how all participants perceive the empowerment of parents, the influence of a PGB on this empowerment and the tourism participation (step 6).

3.5 Ethical considerations

It is important that all participants are fully aware of what their participation in the research entails before agreeing to participate (Hennink, Hutter & Bailey, 2011). This awareness was created through

communication before planning the interview via the flyer, e-mail and/or phone contact. During this communication the aim of the research was discussed.

Before the start of every interview, all participants were given an informed consent form. In this consent was stated that participants had the chance to opt out at any point in time during the interview without any consequences. There was also stated that all data is confidential and that all data and results will be anonymous. This form can be found in Appendix C (in Dutch).

4. Results

In this chapter the findings of the interviews will be discussed. These results provide an answer to the question how different parties involved in the PGB system perceive the empowerment of individuals with an impairment. The analysis of the stories of all the participants was expected to provide a variety of factors that form the basis of their reasoning on the empowerment of parents. This chapter touches upon these factors by providing an in-depth and comprehensive overview of all relevant factors and contexts. Thereby, it provides an understanding on which factors appear to have an influence on the participant made possible via the PGB. This is done by directly citing the participants.

The parents, organisations affiliated with the NBAV, the WMO consultant, the Youth consultant, the team manager of the health insurance company and the WLZ senior care buyer were asked for their opinion regarding the influence of a PGB on the empowerment of the parent. In total twelve interviews were held. Within all twelve stories, certain factors were identified which are merged under three themes being 1) the effect of having a PGB on the participant, 2) The management task of having a PGB, 3) freedom of choice and its consequences for the participant.

4.1. Theme 1: Effect of a PGB

Within this chapter, each factors will be discussed alongside the quotes from the participants. Abbreviations will be used to systematically address which quote belonged to which participant. An overview of the abbreviations can be found in table 3.

Table 3: Overview of the participant abbreviations

P1	Parent 1	O1	Organisation affiliated with the NBAV 1	WMO	WMO consultant
P2	Parent 2	O2	Organisation affiliated with the NBAV 2	Y	Youth consultant
P3	Parent 3	O3	Organisation affiliated with the NBAV 3	HIC	Team manager at a health insurance company
P4	Parent 4	O4	Organisation affiliated with the NBAV 4	WLZ WLZ - client councils	Senior care buyer at a care office Client councils

Since the opening question of every interview indirectly referred to the perspective of the participants on the influence of the PGB on the parent's life, the effect of the PGB was a prominent topic in the stories. It differed per factor within this theme whether the different participant levels shared the same perspective. An overview of the topics raised by the different participants on this theme can be found in table 4.

Table 4: Overview of the topics raised by the participants concerning theme 1

	P1	P2	P3	P4	O1	O2	O3	O4	WMO	Y	HIC	WLZ
Social network	X		X	X	X	X	X	X		X		X
Participation in society	X	X	X	X		X		X			X	X
Respite care		X		X	X	X	X			X		X
Feeling revived		X			X	X	X	X				X
Expansion of own world	X	X	X			X		X				
Enjoyment		X	X	X	X							
Solution	X	X										

4.1.1 Social network

Nine participants (P1, P2, P3, O1, O2, O3, O4, Y, WLZ) described an important influence of the PGB in the construction and maintenance of the social network of a parent. Whereby P1, P2, P3 described the influence of the PGB on the ability of the parents to meet up with friends and to be able to still hang out with them after the caring services ended, others (O1, O2, O3, O4, WLZ, Y) described the influence of a PGB as that it increases the integration of the parents with individuals who they would otherwise not get in contact with. This can be reached by meeting new individuals while participating in an activity or holiday, or via an adaptation in the situation they live in. They all valued this particular effect of the PGB since they all saw the benefits of an increase in a participants social network. Parent 1 described this by addressing the main reason for joining a customized holiday.

P1: That is why we choose to go on a holiday with Ox, because he just really likes to be with his friends.

A friendship can also develop via the use of a PGB. This situation can occur when a parent hires a care provider and due to the close interaction between them a friendship develops over time. This friendship can sometimes continue after the caring services have been finished. Parent 2 addressed this by emphasising the friendship between his child with an impairment and their former care provider after the caring services had ended.

P2: He is always surrounded by nice people who still, even though we do not employ them anymore, stay in touch. They call twice a year, there are two, three who do that, who call and pick up Jules. So you maintain a network which is beautiful to see.

Besides obtaining caring services from individuals with a potential development of a friendship at a participants home, participants can also get in contact with new individuals while participating in activities financed by their PGB outside their home. Thereby, participants get out of their daily routine and meet up with others. This was indicated by organisation 3 who described the decrease in potential social isolation that individuals with an impairment face by organising customized holidays:

O3: you take people out of, I will just call it, their potential social isolation.

Thereby the opportunity arises that participants meet with individuals they would otherwise not have the opportunity to meet. This was addressed by organisation 2 by emphasising the opportunity for individuals with an impairment to interact with individuals without an impairment at their accommodation stay.

O2: Because of us they have the opportunity to meet up with other people. We have a mixture of individuals with and without an impairment which is experienced, I believe, as very positive amongst the participants.

This results in an integration between parents and others which is perceived as very positive by the participants. To mediate this interaction in a way, care providers deliver assistance. Organisation 2 addressed a positive experience between the interaction of parents and others by describing a story where the parents were on a customized holiday. Within this holiday, also individuals who were not part of the group of parents could participate. The expenditures of this holiday for activities were beforehand fixed which gave financial possibilities for extra, spontaneous activities. However, individuals outside the group of parents were so enthusiastic about the interaction with the parents, that they financially covered a spontaneous activity during the holiday for the parents and their assistance.

O2: They arrived at the hotel and while they are getting out of their bus this woman approaches and says 'you join us tonight at 20:00 on the ship because we decided that you are such a nice group of people, they will join us and we fixed it [financially]!' So when you are talking about integration, meeting new people, that is why these holidays are so amazing, it all goes so well.

The interaction between a group of parents and others can require assistance. Organisation 2 addressed this by describing a story of a group of parents who were on a customized holiday where also others participated. This interaction required some mediation to ensure a smooth interaction between both groups which was provided by the care providers.

O2: Well, what they often do in big busses, I do not know if you have ever been in such a big bus, but it is often that the bus driver mentions that everyone wants to sit in front of the big window. To enable this, we always rotate one place. Our group was in the back and there were three with autism and the assistance [care providers] thought 'okay this will result in the necessity of an explanation every time others will rotate since they will say 'but I sit here so I need to say seated here'. So they went to the bus driver and said 'bus driver, is it possible or will people object, we are okay in the back of the bus, if we stay there?'. The whole bus did not mind so they could stay seated.

4.1.1.1. Wrap-up

An effect identified by 9 participants (P1, P3, P4, O1, O2, O3, O4, Y, WLZ) is the positive effect of a PGB on the volume or maintenance of a participants' social network. The increase in social network is made possible by undertaking activities whereby participants have the opportunity to meet others. In such situations, the potential ineffective social skills and communication challenges of participants are put to the test. Participants identify that these barriers decrease by the mechanism of experiencing new interactions. Maintenance of a social network is made possible by undertaking activities where friends meet up. Since not all participants are able to go out of the house and catch up with friends when they want to, the health-related barriers that cause this obstruction are decreased.

4.1.2 Participation in society

Participation in society is an effect of the PGB on the parents that was referred to by eight participants (P1, P2, P3, P4, O2, O4, HIC, WLZ). All participants, except the WLZ senior care buyer, address this topic

in their stories with the effect on the participants of feeling normal in society. This feeling of being normal was achieved amongst the parents, according to the participants, by experiencing two situations. Firstly, the experience of being surrounded by individuals without an impairment was identified as a situation which has a positive effect on a parents. This was illustrated by parent 1 by describing that his child with an impairment went to an elementary school were also children without an impairment went to school.

P1: He went through the ordinary elementary school in his own way and when that was done, he could play very well with a classmate who organised everything and he did a lot with.

This is also addressed by organisation two. They state that they purposely enter into situations where also individuals without an impairment were since they perceive a positive effect of this interaction on the participant.

O2: We love to go to those places that also other people visit. On a really small-scale, so it can be as normal as possible.

Secondly, undertaking activities that individuals without an impairment also undertake is perceived as participation in society and being part of a society. This is illustrated by a quote of parent 3 who addressed the desire of her to make her child's life as normal as possible.

P3: He wants to go on holiday as well, that is beautiful. We are above the age of 50 and I do not want to say that he is not allowed to go on holiday with us, but you hope for him to have that experience with peers. My other son is also not going with us on holiday. He looks for a holiday with his friend or girlfriend. You want to make it as normal as possible.

The WLZ senior care buyer touched upon the topic of participation in society by addressing that the government stimulates a participation society, whereby collaboration between all citizens is promoted. This collaboration is made possible by participants hiring their relatives, friends and neighbours for providing caring services.

WLZ: Yes, there are possibilities which all have an influence and it is also more and more stimulated from the government that participation society, that we need to do more things together.

4.1.2.1. Wrap-up

Within the topic of participation in society, not all participants share the same vision. All four parents, two organisations affiliated with the NBAV, the health insurer and the senior care buyer emphasised the mechanism of a PGB which gives parents the opportunity to interact with individuals without an impairment with a social purpose. A PGB is a financial source that facilitates the opportunity for parents to be at a location where also individuals without an impairment are present. P1, P2, P3, P4, O2, O4, HIC identified that a PGB decreases the environmental barriers to get to that specific location and the interactive barriers regarding a lack of encouragement to participate. The WLZ senior care buyer addressed this with a focus on the supply and demand of caring services between parents and care providers rather than with a recreational goal. He identified a decrease in income disparities since the parents are able to cover up the potentially missed wage amongst friends, relatives or neighbours due the hours spend on care providing.

4.1.3 Respite care

Seven participants identified that the PGB can act as an instrument to take off some pressure of the shoulders of relatives of the parent (P2, P4, O1, O2, O3, Y, WLZ). Parents identified that having a child who has an impairment request more than only the parenting role. They also fill in the role of administrator because someone needs to be legally authorized to handle the financial part. The different roles a parent can play in their child's life is illustrated by a quote of parent 4:

P4: we are mentor, administrator, care provider and parent, which continues 24 hours per day.

These roles come with a certain pressure on the parents to regulate the PGB in a good way and providing care to their child, as illustrated by the quotes of parent 3 and 4:

P3: You are always busy with how do we handle this, what to spend the money on, sometimes we let him go on an extra holiday, however as a result we need to get him home more often so we can financially afford it.

P4: It is almost a company you need to run to ensure that the money is spend well and the care is well justified.

To decrease this pressure, children with a PGB can use their PGB to go on a holiday or an overnight stay. The caring services are taken over by care providers during the stay of a child with an impairment which the participants describe as a welcome shift of tasks for the parents.

O1: The family or partner is then often at home where they have the time to relax.

P2: During the day he goes to day care, he goes on holiday once in a while or stays overnight which really relieves me from my duties.

As a result, the Youth consultant described in her story that when the person who receives a PGB is away on holiday or another day activity, their relatives who normally look after them have more time to spend on themselves.

Y: When talking about children, it is also the release of pressure for the parents. Often when parents are overloaded and they have a child with problems, it is sometimes a day or half a day that parents can do something with their other children, which is also very important for the entire family.

Nevertheless, organisation 2 described that relaxation not only happens when being separated from the child with an impairment. This can also happen when both are joining a holiday.

O1: It also happens that people go together with their partner to relax.

4.1.3.1. Wrap-up

Individuals who receive a PGB can have family members who fulfil, besides parenting, one or more roles in order to manage the individuals' PGB. Participant 2, 4, organisations 1, 2, 3, the Youth consultant and the WLZ senior care buyer identify that these relatives can experience a lot of pressure due to the additional tasks. This can figure as a barrier for their feeling of empowerment. The PGB provides the opportunity for them to buy assistance who take over some of the tasks and thereby getting back their freedom of self-determination.

4.1.4 Feeling revived

A factor that was referred to by six participants (P2, O1, O2, O3, O4, WLZ) includes the effect of feeling revived amongst parents. The feeling of revival among participants results from activities being done and the change in behaviour before and after these activities due to the pleasurable experience. The organisations affiliated with the NBAV and the WLZ senior care buyer determined this effect based on their experiences with the parents themselves. Thereby they identified that the feeling of revival can be expressed on an emotion level or in a physical way.

O1: Definitely, they [the participants] become excited and cheerful. They really enjoy their holiday.

O4: The most extreme example is a man who is staying here, a man of around 80 years old, whose accompaniment says 'yes he has not been speaking for three years now', and on Friday afternoon says 'can I say thank you to the cook' which results in his accompaniment being totally flabbergasted because he could not talk right..

The WLZ senior care buyer is not able to observe parents that receive a PGB from his care office. Nevertheless, client councils get a regular update on how the parents for whom they are the voice, experience the PGB and their empowerment. This update is provided by their volunteers who undertake activities preferred by the parent. However, to become aware of what a parent desires during the day this particular client council wrote, in collaboration with the parents themselves, a life book. This book covers every detail of a parent's life and can be used by volunteers to personalise activities. The creation of a life book requires man hours of a care provider which can be covered by a PGB.

WLZ – client council: We discovered via life books that a client of us was very enthusiastic about reading books and that she used to pass by the library once a week when she was younger. Nowadays, she goes to the library with volunteers and even though she is not able to read anymore, she still liked it a lot.

4.1.4.1. Wrap-up

That parents experience a change in behaviour as result of undertaking particular activities is described by multiple participants, mainly being the organisations affiliated with the NBAV. Thereby revive refers to an expression in behaviour of the participants concerning their enthusiasm for a particular event or experience. Despite the identified barriers in communication challenges and incongruities amongst parents in their expression of experiencing a feeling of revive, the organisations affiliated with the NBAV, participant two and the client councils within the WLZ identified this effect.

4.1.5 Expansion own world

Six participants (P1, P2, P3, O2, O4, HIC) described in their stories that due to a PGB the parent is able to expand their participation in society which has a positive effect on the parent. This expansion entails an increase in participation in society and discovering parts of their society which they did not get in contact before. Among the participants that identified this effect, they labelled this as a normal effect by stating that it should not be a special occasion for an individual with an impairment to desire new experiences since this is also not perceived as special for those without an impairment.

O2: I also enjoy being in a new environment, meeting new people, experience other things. To see and to experience. Yes, individuals with an impairment are no different, they have the same wishes and the same ideas about it.

The PGB enabled parents to undertake activities that they did not do for a long period of time. Examples that were provided by the participants included activities such as going on a holiday whereby activities as being on a bus, walking in the forest, eating fresh home-made food and sitting on the terrace were undertaken.

O4: Sitting outside on a terrace last week when it was 20 degrees and then they say 'sitting on a terrace, I do not even know how long it has been since I did this'. Sitting in a touring car 'I cannot remember the time I sat in a bus, ever', so it is also a different type of experience.

The experience, made possible by the PGB, of undertaking activities that do not happen on a regular basis, parents feel like they are more active in society. Undertaking such activities makes them feel part of society.

P1: He thinks it's great. Then he just participates in society. Just like his sister goes on a holiday, he does that too. So also a feeling of being one with society.

Expanding a parent's world by undertaking new activities results in a feeling of being independent. For children with an impairment whereby their parents cover multiple roles, this feeling of independence already arises when they are away from home. Because the interaction between the child and parent can be very intense and a separation once in a while is perceived as a relief for the child.

P2: He is also separated from me. That is also nice for he. Because here he is fully dependent on his father and family for everything. There he is independent and can he be someone else then he is here.

4.1.5.1. Wrap-up

Concerning the expansion of own world, all participants identified a positive effect of the PGB on the participant since the budget enables them to undertake activities that they do not experience on a daily basis. Examples of such activities that were provided touched upon the independence of participants, and indirectly the increase in self-determination and competence, when doing something by themselves and what they desire. Therefore, a switch in personal assistance was identified as a required source to reach the expansion. With the personal assistance, chosen and bought by the parent, barriers present via limitations in accessibility were overcome and an increase in empowerment could be reached.

4.1.6 Enjoyment

According to four participants (P2, P3, P4, O1) the feeling of enjoyment arises amongst parents when being able to use their PGB for activities that they desire. Thereby, enjoyment can be defined as the pleasurable feeling of doing a particular activity by showing that he or she is excited to participate or comes back after an activity full of enthusiasm. Parent 3 identified this enthusiasm by describing that his child with an impairment was always excited to join an organised activity.

P3: You could see that based on his expressions, how he spoke and if you came to get him there or if you took him there it was never a problem, it was always good. So that also indicates something.

This feeling of enjoyment arises when a parent is able to participate in activities that he or she desires. Parent 4 illustrates this by describing activities that his children with an impairment do which makes them enjoy themselves during the day.

P4: Because they really like it. They find 'snoezelen' (snoezelen is a therapy for people with, amongst others, autism and developmental disabilities. It places the parent in a soothing and stimulating environment which are designed to deliver stimuli to various senses) amazing in a small room because everything fits there, they enjoy cooking food, my son is really into painting, they find making music fantastic, being able to hit the drum so they can release some steam, cycling, they like to walk.

4.1.6.1. Wrap-up

Three parents and one organisation affiliated with the NBAV touched upon the feeling of enjoyment that arises when parents undertake those activities they desire and wish for. Thereby, their perceived meaning of life could be triggered and positively increased.

4.1.7 Conclusion theme 1

When looking solely at table four, the absence of the WMO consultant stands out. In addition, the team manager of the health insurance company and the Youth consultant are not largely present in this theme. Four parents, four organisations affiliated with the NBAV and the WLZ senior care buyer, with additional input from the client council, paid more attention to the topics in this theme. When focusing on the different topics, differences per parties that addressed the topic can be revealed.

All in all, the effect concerning the topics raised by the participants mainly focused on encouraging parents to spread their wings. Although it is interesting to identify that not all parents identified the topics within this chapter, participants that did address them have to a certain extent matching ideas about the effect on the empowerment of parents.

4.2 Theme 2: Managing a PGB

The effect of a PGB on the parent is often described as a positive effect as shown in previous chapter. However, before being able to experience these positive effects, parents need to be capable in managing a PGB. Their way of management must be in line with all the rules and regulations set by the different responsible parties within an Act in order to (continuously) receive a PGB. All participants described the management of a PGB in their stories as a sensitive process where difficulties often arise. A process that added to the difficulty level of managing a PGB is the change within the PGB system in 2015. Therefore, an elaboration on what the participants identified as the change in 2015 will be provided. The steps that are involved in the management process of a PGB starts with the parent being informed about the possibilities, rules of the PGB. After obtaining the appropriate knowledge, parents need to request a PGB from the responsible party, depending on which Act the parent fits in. Participants had different visions on the relationship between the parent and the responsible parties within the PGB system. An overview of the topics related to managing a PGB raised by the different participants can be found in table 5.

Table 5: overview of the topics raised by the participants concerning theme 2

	P1	P2	P3	P4	O1	O2	O3	O4	WMO	Y	HIC	WLZ
Change in 2015												
➤ Decentralisation ¹	X	X	X	X	X	X	X		X		X	X
➤ Money ¹	X	X	X		X	X	X	X	X			
➤ Rules ¹	X	X		X	X				X		X	X
➤ Decentralisation ²		X		X	X		X		X	X		X
➤ Money ²	X	X	X		X	X	X	X	X	X	X	
➤ Rules ²	X	X		X	X	X	X	X	X		X	
Relationship system	X	X		X	X	X	X		X	X	X	X
Being informed	X	X	X	X	X	X	X		X	X		
Fraud	X	X	X		X				X	X		

4.2.1 Change in 2015

As discussed in the chapter 1.1. of this report, a lot has changed in 2015 concerning the PGB system. This chapter further elaborates upon how the change in 2015 was identified and valued by the participants. Followed up by an overview of the observed influence of this change on the parents by the participants. Three main factors can be identified in the stories of the participants when describing the change in 2015, being the decentralisation process, a change in budget, and a change in rules and regulations.

Eleven participants described (P1, P2, P3, P4, O1, O2, O3, O4, WMO, HIC, WLZ) how they defined the change in PGB system in 2015 within their stories. However, when focusing on the three main factors, not all eleven participants touched upon all three factors.

4.2.1.1. Decentralisation

The topic of decentralisation was addressed from two different angles. The first angle focuses on the acknowledgement of 10 participants (P1, P2, P3, P4, O1, O2, O3, WMO, HIC, WLZ) of a decentralisation process being present during the change in PGB in 2015. The second angle focuses on the judgemental value placed by six participants (P2, P3, O1, WMO, Y) towards the effect of this process on the parents.

4.2.1.1.1. Defined change

Ten participants (P1, P2, P3, P4, O1, O2, O3, Y, WMO, HIC, WLZ) described the change in 2015 as an alteration in the PGB system via an addition of responsible parties to the system.

P2: More and more executing organisations take part.

Although decentralisation was brought up by almost all participants, not all participants discussed what the effect, according to them, was in general due to the decentralisation process. Six participants (P2, P3, O1, O3, WMO, Y) did discuss the influence. Between them, two different perspectives can be identified. Whereby four participants (P2, P4, O1, O3) addressed the lack of clarity in the divided responsibility among the different parties within the PGB system, two participants (Y, WMO) described that although municipal parties within the PGB system received more tasks, less mistakes are made than before this addition. The four participants that touched upon the lack of clarity see this as a result of the increase in bureaucracy which comes with too many procedures and a shift in responsibilities. With the increase in parties that became involved in the PGB system, participants identified ambiguity among these parties concerning who is responsible for which part of the PGB system. This ambiguity

¹ Participants that defined the change in 2015 by describing this topic

² Participants that described the effect of this topic within the change in 2015 on parents

is illustrated by a quote of parent 4 who described a group of parents who had no clue to which Act they belonged after the change in 2015 since the parties involved in the PGB system had forgotten them to reallocate.

P4: The entire PGB system with care profiles is 100% oriented on people who live in an institution. They actually did not thought about the people who lived at home, they just forgot them. So for the forgotten group, that's what they call it, PerSaldo needed to do everything possible to also graft the entire system to the people living at home. As the forgotten group, we could use the transitional Act. So we needed to wait whether we could stay within the WLZ or make a downgrade towards the WMO on the municipal level. We are happy that we still make use of the WLZ nowadays and that the indication we received covers a year. If you are assigned to the WMO, that is a whole different story. People there just got the additional tasks and also try to make the most out of it.

Previous quote of parent 4 described the addition of tasks for the WMO consultants within the PGB system since the change in 20015. The increased amount of tasks and the absence of skills to manage these tasks was also recognized by O3.

O3: You are trying to realize something, but it has to be financed and that is the main question. You see that the effect in development, in particular the change of the AWBZ (Exceptional Medical Expenses Act) to the municipality, the municipality does not exactly know what and how everything works.

The story of the WMO consultant also identified that the municipality had more tasks since the change in 2015. However, neither the WMO consultant or the Youth consultant address the inability of the municipality parties towards their service provision as mentioned by the other participants (P4, O3) They address the opposite within their stories, by describing that municipal parties strictly control the rules and regulations indicating that they have everything under control.

Y: By a PGB, we ask people to submit a plan. We can then call the care farm itself to check. In case of a re-indication, we can also ask a report of what did you do over the past year and how did you work on those goals. We will do that via telephone or via a report. So it is actually exactly the same you keep checking. You keep watching whether everything is managed as it should be.

4.2.1.1.2. Effect on parents

Seven participants (P1, P2, P4, O1, O3, HIC, WLZ) described the effect of the decentralisation process in 2015 as a negative effect. All seven participants mentioned that the increase in responsible parties within the system has made it harder for participants to manage their PGB as it should be. The parents addressed the increase in difficulty due to the increase in bureaucracy in the PGB system.

P2: Over the years a lot has happened with the PGB. The bureaucracy has become enormous. As a budget holder you always have to pay special attention, you almost need to be inventive to do the correct thing. Once you accidentally do something wrong, you are the bad guy.

That an increase in parties has a negative effect on the parents is also identified by organisation one and the health insurer. Both mentioned that the increase in responsible parties within the PGB system has caused that parents do not oversee the PGB system anymore since it has become too complex.

O1: Due to the change in PGB, I have the idea that people do not really know where to get everything. For example, they ask where they can receive their care while being here. I send them so the people of home care, but also in my private life I notice that responsible parties always send people to another party without really helping them out.

HIC: There is still a lot of uncertainty about certain grey areas where everyone will end up. Especially by the children you see that they are send from one place to another without getting certainty

The identification of a negative effect of the decentralisation process on the parents by the WLZ- client councils is in line with the perspectives of organisation one and the health insurer. However, their argumentation on the cause of this negative effect is not as specifically described in their stories but refers to the decentralisation process in general. Thereby, they state that the change puts the adaptability of parents to the test which does not have a positive outcome.

Client Council: Why change to change? If it is going okay let it be. It seems that the governments wants to do hip and want to change everything, but if there is something that elderly do not desire it is change.

Organisation three touches upon the effect of decentralisation on the parents from another perspective. He states that parties within the PGB system react towards the decentralisation process in a way that is harmful for the parents. This occurs when care providers only offer services to those parents who receive a PGB from the WLZ and thereby rejecting those who receive a PGB from the WMO. This decreases the freedom of choice amongst parents while determining their health provider.

O3: But what we really see is that there are health care institutions that only allow people with a PGB from the WLZ because that is simply better organized.

4.2.1.2. Money

The topic of money was addressed from two different angles. The first angle focuses on the acknowledgement of a financial change in PGB being present since the change in 2015. This was described by eight participants (P1, P2, P3, O1, O2, O3, O4, WMO). The second angle focuses on the judgmental value place towards the effect of this financial change on the parents. This was described by ten participants (P1, P2, P3, O1, O2, O3, O4, Y, WMO, HIC).

4.2.1.2.1. Defined change

How the financial change in the PGB is described differs among the participants. Four participants (P1, P2, P3, WMO) addressed the change in responsible party of the money, nowadays the SVB instead of participants themselves.

P1: Yes everything has changed, but when we started with the PGB the money was also stored at the SVB. As a cutback they decided to give the money to the participant themselves and nowadays it is like it used to be.

WMO: In the past, you received the PGB by getting a lot of money on your bank account. Nowadays you do not receive the money yourself.

The four organisations affiliated with the NBAV were mostly concerned with the decrease in the amount of money available amongst participants to spend this on holiday participation.

O1: Previously, they had money and they really need to justify that part. In addition, they also had an amount that did not need any explanation where it was spent on. I think vacations are not included in the final part of their budget and they are no longer allowed to spend it on holidays.

4.2.1.2.2. Effect on parents

Ten participants (P1, P2, P3, O1, O2, O3, O4, Y, WMO, HIC) identified an effect of the change in the financial part of a PGB on the parents. Differences between the participants arise when describing this effect. Three parents and the WMO consultant (P1, P2, P3, WMO) addressed the effect of centralized stored money instead of the parents controlling it themselves via their own bank account. This does not result in less tasks to be completed by the parents. The three included parents in this research (P1, P2, P3) addressed the large amount of steps they needed to go through before receiving a budget for a particular activity or excursion, which they perceived as a burden. This is illustrated by the quote of parent one who recognizes that before the change in 2015, parents had more power over their PGB and there were less rules related to the payment. This has changed since 2015 by the large amounts of rules surrounding the payment.

P1: before we could, for example, you decided how much a holiday would cost. We determined, if Herman said then and then the payment needs to be done, we got then and then money from our bank account. Now that has to be broken up into an hour wage. They have to make an account with so many hours and so many sessions. I think it is all split up into hours.

This vision of the amount of tasks being a burden is not shared among the WMO consultant and Youth consultant. Although they addressed the increase in tasks for parents since the change in 2015, the burden is not pointed out in their story.

Y: People also have to submit a budget plan themselves including what they want to do with the money. Earlier, they got a bag of money and then they could spend it on whatever they desired, but now there are some codes that need to be used when spending money.

Four organisations affiliated with the NBAV described the effect of a decrease in money to be spent on holidays amongst the participant. They perceived this as a negative effect by stating that due to a decrease in PGB, less parents are able to go on holiday since it becomes a financial struggle.

O3: For the first time in the history of our organisation, we are looking where we draw the line whether it is doable or when it is not possible any more. So at a certain moment you need to say, okay we will not allow those people on our holidays. If the municipality only gives us €250,- per participant from their PGB for an entire weekend it does not work out.

The health insurer addresses the omitted money amongst those who did not get a new indication after the decentralisation. This happened since the rules became stricter and therefore the application

conditions were tightened since 2015. As result, a group of parents did not get a new indication and therefore experienced a loss in their income to buy care services.

HIC: There have been a lot of outflows in the beginning that did not requested a new indication, but also a group that did received an indication at the AWBZ but not anymore.

The identified decrease in money, and subsequently a financial struggle, by four participants (O1, O2, O3, O4, HIC) was also described by the participants. The financial struggle was also identified in the stories of the participants.

P1: we are cut short as PGB users on day spending. Before it was nine days and it decreased to six or seven days. I do not know that exactly. So you have to get the same amount of care with much smaller budget.

4.2.1.3. Rules

The topic of rules was addressed from two different angles. The first angle focuses on the acknowledgement by five participants (P1, P2, P4, O1, WMO) on the presence of changes in rules and regulations since 2015. The second angle focuses on the judgmental value place by nine participants (P1, P2, P4, O1, O2, O3, O4, HIC, WLZ) towards the effect of the change in rules and regulations on the parents.

4.2.1.3.1. Defined change

Five participants (P1, P2, P4, O1, WMO) paid attention to the rules of the PGB system in their stories. They all state that since the change in 2015 the amount of rules increased. Thereby, they identified these rules as really firm, whereas in the past everything was more loosely organised. These rules are related to the definitions and conditions that change on a continuous basis. As a consequence, the justification of every bought services via a PGB require a lot of paperwork which is illustrated by the quote of parent two.

P2: It started since 2015, last year. We had to fill in and describe as much as possible. Then you received it back because it was wrong and had to correct it again. If you correct, you should also of course adjust it with the holiday provider or the health care provider. So there are so many steps you have to do, while it is just the same as last years.

4.2.1.3.2. Effect on parents

The effect of the identified increase in rules on the parents was described by nine participants (P1, P2, P4, O1, O2, O3, O4, HIC, WLZ). Between them, differences can be identified. Two parents (P1, P4) addressed in their stories that due to the increase in rules, more and different tasks are requested from them. This requires constant adaptation and learning.

P4: Everything requires adjustment and learning.

The required continuous effort to understand the PGB system of parents is also recognized organisation 1 and the health insurer. Organisation 1 described the possible nescience amongst parents in their story as a result of the constant changes in rules.

O1: Because of the change in PGB, I have the idea that people do not really know where to get everything. For example, they ask from whom they will receive care here. I send them to home care. But I also recognize in my private life that people do not get the right information.

This is also described by the health insurer who states that the change in rules is not explained well enough towards the parents.

HIC: I think that the transition from the AWBZ and how it went up till now, people are not made aware of what it actually means.

Five participants (P2, O2, O3, O4, WLZ) involved the Dutch government in their argumentation of the effect of increase in rules on parents. Two participants (P2, WLZ) indicated that the government aimed for more family members, friends or other people to become involved in providing care to the parent. According to them, this can be achieved by being independent in your care request.

WLZ: What you see is that the government promotes that more and more people live longer in their own home, but living at home is according to us district nursing. Because as long as you are home, you are still in your own environment with the people you know and often with relatives.

Parent 2 further elaborates on the role of the government by stating that the government did not have the best response on the existing defects of the PGB system in 2015.

P2: Instead that the government says that we need to check a little more, or better check and tighten the procedures, be more testable and better applicable, no we will set new regulations. New executive organisations must be ready by next week. Then everything goes entirely wrong.

Four organisations affiliated with the NBAV described the effect an increase in rules on the parents from a different perspective. This perspective included that due to the new rules, which included amongst others a decrease in the amount of budget, the possibility of parents to participate on a holiday is decreased which results in a lower participation level amongst this group.

O1: I have the impression that fewer guest stay over. Guest do not come anymore who did receive a PGB.

This decrease in tourism participation amongst parents is according to three organisations affiliated with the NBAV (O2, O3, O4) in conflict with, what they perceive as, a human right. Thereby, indicating that being on holiday is a human right.

O2: So they may, in our opinion, allow anyone with an impairment to make use of that right. Again, it is not statutory, but I think it is a human right.

4.2.1.4. Wrap-up

Ten out of the twelve participants addressed the change within the PGB system as a change with a negative effect on the parents (P1, P2, P3, P4, O1, O2, O3, O4, HIC, WLZ). Two participants (Y, WMO) did not address this negative effect, but purely described what has changed for the parents.

Within the first group, the degree of negative impact identified differs. The parents address the negative impact rather lightly by addressing mixed feelings towards the change in 2015. They

identify the changes that have an adverse effect on their feeling of empowerment towards managing a PGB. However, all four perceive themselves as capable in managing their PGB. Nevertheless, they acknowledged that this is not the case amongst all parents in the Netherlands. The other six participants (O1, O2, O3, O4, HIC, WLZ) only address the negative effects of the change in the PGB system. Four organisations affiliated with the NBAV identified these negative effects as barriers for empowerment, being a decrease in available money for a PGB and an increase in administrative tasks for the parents due to an increase in rules since 2015. The health insurer addressed the negative effect of the increase in rules mainly by pointing out the feeling of uncertainty and ignorance amongst parents. The WLZ senior care buyer did not go in depth about the actual effect of the change in PGB on the participant. However, two individuals of client councils showed their frustration towards the changes within the PGB system by addressing the negative effect of change for parents.

The second group, including the WMO consultant and the Youth consultant, did not address a negative effect of the change in 2015 on the parent. The WMO consultant did identify a change in the PGB system regarding the decentralisation, money and rules. The Youth consultant identified a change in the PGB system by addressing the decentralisation process. Both shared their perspective on the effect of a change regarding the storage of the money.

4.2.2 Relationship system

Eleven participants (P1, P2, P4, O1, O2, O3, Y, WMO, HIC, WLZ) described the interaction process between the parents and the parties involved in the PGB system. Within their stories, they mainly described the relationship between the parents and the care office, and between the parents and the WMO consultant.

Starting with the relationship between the four parents and the care office. Between them a clear distinction can be found when defining the relationship between both parties. The parents addressed negative thoughts when describing past interactions with the care office via telephone or paperwork. Thereby, they referred to defects by the care office.

P1: I have already talked about it to the care office with the man who is in control over there. And he stated that there must be a settlement that it will be paid before. He would figure it out, but I have never heard of it since.

P2: Then you get a lady on the phone the first time who says 'yes I do not know how it works' and that will take a while..

Besides communication concerning question from the parents side, the CIZ, an organisation who provides money towards the parents when they have an indication for a PGB from the care office, does check-ups via phone. Parent 4 experienced that as a nerve wrecking interaction.

P4: The first time you get in touch with the CIZ is via phone. So you get in touch with people on the phone and you do not know what they are going to ask, what they want, what their opinion is. It is a kind of questioning the suspect or something else you can think of. So the first time is a bit of scanning.

These negative thoughts towards communication between the care office and the parents is not shared with the WLZ senior care buyer. He states that the influence of the care office towards the

parents is low. This level of intensity occurs since only checks-up are executed to investigate whether the bought care is provided and not goes in detail about whether the quality of the provided care is as high as it should be. However, he did not further elaborate upon the method used for the check-ups, being via phone or in a real-life setting.

WLZ: Yes it [check-ups] is there, but only to check whether the care has been provided. Not regarding the quality requirements.

Furthermore, he states that good communication via phone is present between the care office and the parents. Thereby, describing a situation whereby the parent immediately approached the care office via phone and good communication between both parties arose.

WLZ: It also happens that people commit fraud, who wrote more hours than was actually provided. But we hear that fast enough from the customer whose own contribution goes up because they will say 'I have never received so many hours of care'.

Besides the negative thoughts when describing the relationship between the care office and the parents via phone or paperwork, positive experiences were expressed when describing a home visit of the care office.

P4: by then it was still the controller. Two, three weeks ago we received a letter of the care office 'you will get a home visit' and then they called it a consultant. Well, at least, that sounded more friendly. A consultant sounds like someone who wants to help.

Regarding the relationship between the parents and the WMO consultant, four participants (P4, O1, O3, WMO, HIC) touched upon this relationship in their stories. Thereby, the parent, the organisation affiliated with the NBAV and the health insurer expressed negative thoughts towards this relationship. However, the WMO consultant expressed neutral thoughts towards this relationship. The negative thoughts were regarding the incapability of the WMO consultants since they have more tasks than they can manage. Parent 4 expressed his relieve that he was re-assigned to the WLZ instead of the WMO due to the difficulty and incongruities with a PGB from the WMO.

P4: People who are appointed to the municipality have a lot more things to deal with that are not going well. Because, ignorance and incapability, the money is not earmarked for what they receive from the government. So the money can also be spent on a football field, a swimming pool or a cinema, and municipalities have different thoughts about that.

That the amount of tasks are too many for the WMO consultants is also recognized by the health insurer. Consequently, the rough relationship between the parents and the WMO consultant created stress for the parents. This is illustrated by a quote of the health insurer which describes the anxiety amongst parents regarding potential failure of payment by the municipal parties. This inhabited the parents' freedom of choice and autonomy.

HIC: That was our first customer day, we had a man who was quite upset because he said 'I could easy arrange everything with you, but it is very difficult with the municipality, and if I do not get that part of my budget I still do not have my freedom of choice and autonomy because

with only half of my budget I cannot get things done', so that makes it very difficult for those individuals.

Difficulty with the money of the PGB is also recognized by the organisation 3. He described that care providers only accept parents with a PGB from the WLZ instead of from the WMO due to the problems that arise with dealing with a municipal party.

O3: What we see is that there are health care institutions that allow only participants with a PGB in the WLZ, because they are simply better organised.

When describing the relationship between themselves and the parents, both WMO consultant and Youth consultant indicated that they pursue a strict relationship. This relationship entails that either the WMO consultant or the Youth consultant are totally aware of what happens with the PGB budget and they have it under control every step of the way. They do not address the impact of this firm control on the parents.

Y: We really want to know that it achieved the goal that it is intended for. The number of hours described etc. It is not that free, as municipality you keep supervision on all the expenses.

The three organisations that addressed this topic did not go in-depth regarding a specific relationship between the parents and a responsible party. They expressed their negative perception on the different responsible parties by addressing their inconsistency and incapability. They perceive this as a decrease in clarity for the parents and an increased feeling amongst parents that they are not as well informed as they should be.

O2: The biggest problem is that those who implement the regulations often do not know how the regulations need to be implemented or that they do not give the same interpretation of how to apply those rules.

The health insurer did not perceive this negative effect on the parents while describing her own relationship as a health insurer with the parents. Thereby, the intensity of the contact depends on the needs of the parents. This version of customized supply is favourable for the parents since they can receive help when needed.

HIC: Recently one of our insured passed away who we had intensive contact with. They applied for a PGB two years ago, and the woman was diagnosed with ALS. Many insurers may say, it is intensive care so it is WLZ, we deliberately choose to say that they belonged within the ZVW especially because people can still mentally decide. It goes very fast and they often need bigger budgets than they can get within the WLZ. So from that moment on we have been in touch, we have adapted all kind of things in our procedures, regularly meetings here, he also has been here, I have been at their home, but also my case managers passed by their home, he attended our customers day and we have always been in touch concerning how they experienced their PGB and what issues they ran into.

Besides describing the intensive contact concerning assistance when a participant has a PGB, the health insurer also described the advising- and controlling role when someone applies for a PGB. The health insurance company has a controlling role in checking whether a PGB is the best solution for the participant and his or her situation.

HIC: We are trying to be more involved in the application, that we are included at the start and are in control because there are dilemmas since we cannot have an opinion on the quality of the care services, however if you identify during the application that a PGB makes a situation even worse or overloads the care giver that is not the intention of a PGB. So we always talk about it and try to always look for a solution.

4.2.2.1. Wrap-up

A contradiction can be found between the parents and the WLZ senior care buyer concerning the communication between both parties. The parents identify a barrier in the difficult communication processes with the care office via paperwork or telephone, while the WLZ senior care buyer does not indicate this difficulty by mentioning a mechanism for empowerment, being that his customers approach them easily when they need it. Although the WMO consultant does describe in his story the addition of tasks towards the municipal parties since the change in 2015, he and the Youth consultant do not give an indication of the concerns that do exist among the participants, the organisations affiliated with the NBAV and the health insurance company about a potential incompetence of municipal parties to be responsible for a part of the PGB system. Organisations affiliated with the NBAV expand the experienced incompetency of the municipal parties by stating that all responsible parties within the PGB system are lacking which is a barrier for the empowerment of individuals with an impairment.

4.2.3 Being informed

With the change in PGB in 2015, the amount of rules within the PGB system as mentioned in previous chapter increased. Eleven participants (P1, P2, P3, P4, O1, O2, O3, Y, WMO, HIC, WLZ) identified that the parents are responsible for staying up to date of all the rules within the PGB system.

WLZ: That is what you have with a PGB, you need to stay up to date and be able to calculate everything.

Being informed is described as a very difficult task for parents by ten participants (P1, P2, P3, P4, O1, O2, O3, Y, WMO, HIC). Concerning the aspect of difficulty, two perspectives on the topic can be identified. The first perspective focuses on what causes this difficulty for parents while trying to be informed about the rules of the PGB system. The second perspective goes further in detail about the perceived effect of this struggle amongst parents. Regarding the first perspective, the Youth consultant addressed that choosing for a PGB is a well-considered decision and only those who put the required amount of effort in being totally up-to-date about the system receives the rewards, being a PGB.

Y: If you are able to manage a PGB yourself, it means that you have thought about it critically or at least you will be questioned whether you thought about it critically what it means to manage a PGB yourself.

The large amount of effort that is required to be fully informed about the PGB system is also identified by the parents themselves. This amount of effort is needed since, as they described, the system is very complex.

P1: At the beginning I took a lot of classes at them [PerSaldo]. How to manage a PGB, how to do this, how that, because it is not easy at all.

P3: I mean my husband and I are both in the case sector so you know a bit how it goes, but I sometimes think about the people who are not in this sector. It is not easy for them. We realized that we knew where how to manage a PGB, where to get the information

Three organisations affiliated with the NBAV (O1, O2, O3) also described the difficulty parents experience when trying to stay up to date with the latest change in rules. They identified the increase in rules, as a result of the decentralisation process, as a cause for this difficulty. Subsequently, they emphasised the potential complications amongst parents while trying to manage their PGB. This is illustrated by a quote of organisation one who describes that parents often do not know where to get the right information about the rules applicable in the PGB system. Eventually, parents start asking questions to the organisation although they are not responsible for the provision of information.

O1: We are as a care institution not responsible for it (providing information on the rules within the PGB system), but people often do not know it so eventually they start asking questions to us about how the PGB system works.

The second perspective applicable on the theme of being informed, is the effect of this difficulty on the parents. Parent one expressed a feeling of frustration towards the difficulty of the PGB system as a result of the increase in the amount of administrative tasks due to miscommunication or rules and regulations that changed without being aware of it.

P2: As budget keeper you need to be aware and almost inventive to do the right thing. Year to year definitions change, year to year conditions change, year to year administrative procedures change. When you do something wrong accidentally, you are totally to blame..

Although frustration was not explicitly described in the stories of the other three parents, all four parents addressed their insecurity concerning their participation in the PGB system. They emphasised that they do their best to be informed, however the fast changing rules made it difficult to execute the administrative tasks in a good way.

P4: Would I not be well informed? Because I always try to do the right thing. Things of the government, the SVB gives you information, care office, PerSaldo, so would I have missed something?

This level of insecurity about the PGB system and their level of management of a PGB amongst parents is also identified by three organisations affiliated with the NBAV and the health insurer (O1, O2, O3, HIC). Thereby, they state that it is difficult for parents to make the right decision concerning their PGB since they are not fully up to date about the PGB system.

O3: Yes, because people make weird choices or they do not have any idea how to buy the correct care.

Additionally, these four participants (O1, O2, O3, HIC) emphasised the difficulty in understanding the big change in rules since 2015 for parents. This is illustrated in a quote of the health insurer who described how the change in PGB system in 2015 was done via logical steps for the health insurance company, however these steps are not always logical for the parents.

HIC: There was a woman who had become blind, visually sighted, her vision had deteriorated, and she did not understand why she was getting less budget. However, the AWBZ had been transferred to the Health Insurance Act (ZVW) and subsequently a new indication was provided. So there have been logical steps for us, but that can be difficult for someone to understand.

4.2.3.1. Wrap-up

This chapter touches upon the responsibility, identified by eleven participants (P1, P2, P3, P4, O1, O2, O3, Y, WMO, HIC, WLZ), of parents to stay fully informed about the PGB system. Four parents, four organisations affiliated with the NBAV and the health insurer addressed this responsibility as a burden for the parents. They addressed this high level of responsibility as a difficult task to try to stay up-to-date with the changes happening on a continuous basis within the PGB system. Thereby, they acknowledged the barrier of lack of knowledge and skills about the PGB system. In addition, addressing the correct responsible party within the PGB system to receive the most accurate information is often difficult amongst parents according to organisations affiliated with the NBAV and the health insurer. They emphasised that by ensuring that when the mechanism of proper information sharing between them and the parties with the right information exist, these barriers can be overcome. Although all four parents experience a level of insecurity, which is also defined by the organisations affiliated with the NBAV and the health insurer, they perceive themselves as well informed and subsequently described the dimension of competency when managing a PGB. The WMO consultant and the Youth consultant did not identify this responsibility as a barrier for empowerment, by addressing it as measure of motivation amongst parents while applying for a PGB. Finally, the WLZ senior care buyer agrees with all parties that it is the responsibility of the parent to be informed in order to manage a PGB in the best possible way. However, he does not address the defects of the parties within the system.

4.2.4 Fraud

Six participants (P2, P4, O1, Y, WMO WLZ) touched upon a sensitive topic with the PGB system, namely fraud. Amongst them, different approaches appear while by explaining the cause for fraud. Parent two blamed the fast changing definitions of functions as a reason for fraud. According to him, terminations change every year which makes unintentional fraud happen easily.

P2: One year you received it [a PGB] for reason 1, thereafter it becomes b and you still fill in a, then you are accused of fraud and you are in the wrong. That kind of strange things are in this system and I am not happy with it.

The WMO consultant approached this causation of fraud from the opposite perspective by mentioning that parents intentionally commit fraud by misusing one of the main aspects of the PGB system, the freedom of choice. Parents have the opportunity to choose someone they know and feel comfortable with who can provide care. The WMO consultant describes in his story that some parents send an invoice which is too high for the amount of care that is actually provided, but because they have a friendship with the care provider.

WMO: The rumbling at that time, because if you are my care provider and I have money for two hours per week to spend and you perform for one hour per week, I say I tell you what, I

pay you just for two hours per week because I like you, and then you will get paid twice as much.

Continuing on the inability aspect concerning on the administrative part of the PGB by the parents, three participants (P4, WMO, WLZ) indicated that it often occurs that parents hire a third party that takes over the management part of the PGB for them. However, it sometimes happens that this third party misuses their position.

P4: You want that individuals who are not able manage it, they often switch to help, agencies, people are offering all kinds of help to take care of that. And yes, 99% will be loyal, but that 1% apparently does not. It is often a lot of money you get allocated to and then the temptation is big to do wrong things with that.

The WMO consultant stated, as also indicated by parent 4, that it is not always the parent who is to blame for fraud. The WMO consultant described that in the past, third parties requested a PGB in the name of madam/sir X without that particular person being aware of this request. In such a situation, the parent has no control over the fraud situation.

WMO: There are a lot of malicious companies that simply lost money on the name of Mr or Mrs. who could not really do anything about it. So PGBs were requested for people who did not even knew they had a PGB. But I think that that is over. You only have a PGB when you are entitled to it.

However, according to the WLZ senior care buyer it also happens that parents are aware of the fraud caused by a third party and bring it to a hold.

WLZ: It happens, fraud, by declaring more hours than actually provided. But we hear it quick enough from the customer whose contribution goes up, because they will state 'I have never had so many hours of care'.

4.2.4.1. Wrap-up

Different parties involved in the PGB system have different perspectives on the causation of fraud. The included parents in this research perceive themselves as a victim of the system, addressing a decrease in a feeling of influence on their own situation due to the ambiguity in rules concerning administrative tasks and misuse by third parties. This tempers their feeling of empowerment. The WMO consultant indicated that parents are partly to blame for fraud by describing, as also addressed by the WLZ senior care buyer, the third parties make use of the inability of participants to manage their own PGB. However, the WMO consultant also states that parents purposively commit fraud whereby participants believe that they have a big impact. The WLZ senior care buyer addressed this fraud by a third party by indicating the strength of participants to bring this form of fraud to a hold. Thereby he addressed the dimensions of competency and impact of individuals.

4.2.5 Flexibility

An effect of the PGB that was only mentioned by three participants (P1, P2, HIC) was the ability of participants to use their PGB in order to (re)organise their lives. This possibility was addressed in the

stories when coping with certain problems that arise. In life unexpected events, such as the death of a significant other or a necessary change in care settings, happen. Schedules of parents are often fixed which makes it a non-flexible setting. The PGB can be used in order to add some flexibility to the situation by being able to solve problems yourself instead of going to institutions who needs to solve it for you. Immediately on the spot decision making is made possible. The flexibility, made possible with a PGB, is illustrated with three quotes. Firstly, parent two illustrates this flexibility by describing the situation whereby he needed to cope with the loss of his wife and subsequently the increased amount of tasks he needed to perform besides his working activities. Secondly, parent one illustrates the flexibility by describing a story whereby the environment at a hockey club was not supportive of her child with an impairment and they decided to take matters into their own hands and to switch to another hockey club. The third and final quote is of the health insurer who described that individuals with receive a PGB have the ability to organize their lives in such a way that is pleasurable for them.

P2: Like I just said, my wife pas away in June and all of the sudden things need to be fixed. I was still working and thought damn how do I need to fix this. Fins, my sun, he has down syndrome, he goes to his day activities. I was most of the time gone at 07:00 for work and at that time he just gets out of bed. Then I found someone, from the neighbourhood, even from this street, who starts off the day with Fins. This means that, I started working less, that I only had to start of the day once a week and start later at work. So we had a solution!

P1: But Thom was not allowed to participate in the games because he was not good enough. We heard other parents saying, oh don't do too much with Tom because it will temper your own developments. All that weird stuff. So as result we went to Uden.

HIC: You see a clear divide between people who use their PGB in order to get a grip on life, to organize their lives and to finance their care, that is the group we are talking about at the moment.

4.2.5.1. Wrap-up

That the PGB can be the solution for a parents is mentioned by two participants and the health insurer. The PGB can function as a mechanism that provides parents with flexibility and a grip on life by giving them opportunities to organize and finance their lives in the way they prefer. Thereby, the required health services stay affordable.

4.2.6 Conclusion theme 2

When looking solely on table five, topics related to managing a PGB were described numerous times by all participants. All in all, a proper management of a PGB by the parents involves an adequate level of knowledge about the PGB and having the ability to foster a good relationship with the party who is responsible for a PGB from a particular Act. This is something all participants agree upon and they identify the challenge for the parents in this management process. It is interesting to identify a difference in the visions amongst the participants concerning the influence of the change in 2015 and the party to blame for potential fraud. Whereby the parents addressed that managing a PGB became a much more difficult task since the change in 2015 with the challenge to be fully informed, they perceive themselves as still able to manage it in a proper way. They indicated that their manageability is put to the test but they described themselves as motivated, flexible and persistent enough to continue their participation within the PGB system. This is also identified by the health insurer. The

WMO consultant has a totally different view on the motivation of parents by stating that the number of PGB request did not rise since 2015. Furthermore, by only describing situations where the parent was to blame for the fraud and the communication between the municipal parties and the parents were good, the WMO consultant indicates that managing a PGB is a too big task and responsibility for parents. The organisations affiliated with the NBAV and the WLZ senior care buyer indicated that managing a PGB is not the best option for every participant since it can be a too big task. The organisations blame for this incapability the different responsible parties within the PGB system that are not able to provide the mechanisms of sufficient support and information towards the parent to enable them to be the best manager of their budget as possible and to reach a dimension of empowerment. The WLZ senior care buyer has a different vision on this by stating that due to the incapability of the parents to manage their PGB, third parties were hired. According to him, these third parties committed fraud.

4.3. Theme 3: Freedom

The PGB gives parents a lot of freedom. This freedom originates from the opportunity to choose the care provider they desire with the money they receive from a PGB. Subsequently, personalised care can be bought with the money received from the PGB. Thereby, parents are in the role of care consumer instead of care receiver. This causal relationship, which includes receiving the PGB and becoming a care customer, was described by almost all participants. Table 6 provides an overview of the participants that touched upon the topic of freedom related to the PGB

Table 6: Overview of the topics raised by the participants concerning theme 3

	P1	P2	P3	P4	O1	O2	O3	O4	WMO	Y	HIC	WLZ
Personalised care	X	X	X	X	X	X	X	X	X	X	X	X
Freedom of choice	X	X	X	X			X	X	X	X	X	X
Care customers	X	X	X	X			X		X		X	X

4.3.1 Personalised care

All twelve participants (P1, P2, P3, P4, O1, O2, O3, O4, Y, WMO, HIC, WLZ) described that with the freedom of choice made possible by a PGB, parents can buy the care from those individuals or institutions they feel most comfortable with. All participants identified the importance of personalised care for the parent. Although the participants share the same vision on the importance of providing personalised care, when a service can be defined as personalised differs. Thereby, the effect on the parents is perceived differently.

Five participants (P1, P2, P3, P4, HIC) described that the main reason amongst parents to apply for a PGB is the ability to buy personalised care. This care can be provided by either a friend or relative, or a care institution under the condition that the intentions and actions concerning the care provision correspond.

P1: All children, at that time they were children, of his own age. That is actually one of the main reasons why we chose for a PGB.

HIC: We have a large group of parents who receive intensive child care from the ZVW, so their children are seriously ill. You often see that the parents of the children provide care 24 hours per day which is quite intense. Especially when you have young children, it has a lot of impact

if a lot of different care providers come to their house. So a PGB can prevent this and I think that the most important motive of applying for a PGB is the tailored care.

The parents addressed that their wishes are taken seriously by the care providers. Thereby, they indicate that the care providers act upon their wishes.

P2: But is it more personal, well-tailored to the person and the contact is much more direct. You do not have to do with the management, but you have to deal with the health care provider directly, which I personally like a lot.

P4: We think it is extremely important that it does not seem like our children have an impairment, that is really important. Their day care too, they ensure that they wear their pants neatly, that the zippers are closed for example. If they make a mess of themselves, that the day care ensures that they still look nice, they also think that is important.

The importance of meeting up to the parents' wishes and therefore being aware of their desires is also indicated by the organisations affiliated with the NBAV and the WLZ – client councils (O1, O2, O3, O4, WLZ). A client council within the WLZ touched upon the importance by describing a story whereby the care institution was not up to date about the desires of a parent which had negative consequences for the parent.

WLZ – client council: In my institution, it has ever happened that a resident had too few pyjamas in his closet. A volunteer bought a pyjama at the Hema with stripes. Afterwards it turned out that the resident had been in Dachau! So you know resident!

The organisations affiliated with the NBAV ensured that they are up-to-date about the desires and needs of the parents by letting the parents decide on a day programme.

O2: With the support and a mild form of support it is, ehm, coming up with ideas with the people themselves on a holiday of what can be done in the area. How are we going to do that? And well, we also want that the travellers, because it is their holiday, do as much as they want to do.

However, it also happens that parents have an impairment that inhibits them to actively think about the content of their day program. Organisations describe that at such moments, they need to be able to see from a parent's behaviour what they desire to ensure that they have the most pleasurable holiday as possible.

O2: I always say that as a travel assistance you need to read how your holiday quest experience it.

The WLZ – client councils described the method of a life book to ensure that the caring services are adapted to the needs of the parents. Volunteers develop this book in accompaniment with the parent in order to figure out what type of services fit to the parent. This high amount of personal attention results in a feeling of comfort and being taken seriously among the parent. Activities in response to this life book gives parents a feeling of excitement.

WLZ: Via the use of the life book we found out that a customer was very happy to read books and in the past went to the library once a week. Now she goes to the library with volunteers and even though she cannot read anymore, she found it amazing.

Parent 1 addressed that buying personalised care is a win-win situation. Argumentation provided by all parents that underline this statement are regarding the financial compensation for the care provider instead of them being a volunteer, and the possibility to choose whoever they want for providing the necessary care.

P1: I did not have so much time, but my daughter could also do something. She has her driver's licence and can pick up and bring Fins from time to time by car. So I said 'you know, what if you are going to spend a few hours per week with Fins and I will pay you out of the PGB'. So here every side has an advantage and you have a win-win situation.

Buying services desired by the parents was also recognized by the WMO consultant, the Youth consultant and the health insurer. They state that with a PGB, parents are able to buy care of care providers that are not connected to the municipality or health insurance company.

Y: It is a bit of customized provision of care. If you do not have it in your general amenities package, the appointments that you have, there are still possibilities to meet your special wishes.

HIC: You also see that people with different cultural backgrounds, other languages, or other language areas, want nobody else or due to cultural religious considerations do not want strangers nearby.

The organisations affiliated with the NBAV further described personalised care as not only adapting the caring services but also the care setting towards the needs and desires of the parents. Thereby, parents have the opportunity to develop themselves via activities within these settings.

O3: This summer we had one girl who never dared to go into the swimming pool after having a bad experience and who now with all the patience of the volunteers and showing her 10 times by other participants is in the swimming pool with the use of a lifting machine. That is beautiful.

O4: We try to with pictures in the room for people with dementia, because they also come here on a regular basis, to recall images from the past. These are small things, but you do provide them with a bit of experience which they perceive as pleasurable.

4.3.1.1. Wrap-up

All participants address the importance of personalized care for parents. The parents themselves indicate that the use of personalised care gives them power, a feeling of satisfaction and being taken seriously. This feeling is a result of an experience that feels secure and comfortable instead of a feeling of fear which adds to their empowerment. This indicates that they highly value their personalised care. This value was also described by the other participants. The organisations affiliated with the NBAV and the WLZ client councils perceived the importance for personalized care since it diminished the lack of encouragement to participate amongst parents and it increased the dimension of competency. The organisations achieved this by letting the parents feel alive. This was done by making a day

programme whereby personal development via challenges was tackled. The WLZ client councils addressed the importance of being aware of the background of the parent and their personal wishes by emphasising that it enables you to undertake activities that fit them which causes a feeling of pleasure and being alive amongst the parents. The municipal parties also identified a positive effect of the personalised care for parents, however did not further go in detail about how this positive effect influences the parents.

4.3.2 Freedom of choice

Ten participants (P1, P2, P3, P4, O3, O4, WMO, Y, HIC, WLZ) expressed the freedom of choice that the PGB creates for parents. However, different opinions towards this level of freedom were expressed within the stories of the participants. The parents only addressed the positive side of a high amount of freedom. The organisations affiliated with the NBAV only identified the amount of freedom for parents without describing it as a positive or negative consequence of a PGB. On the other hand, the WMO consultant, the team manager of a health insurance company and the WLZ senior care buyer identified contradictory effects of this high level of freedom.

The parents indicated a feeling of independency by being able to choose their own care provider. This choice can be made without the necessity to check with care institutions which gives them a feeling of autonomy and control.

P4: The best part of a PGB is that you can use it for different ways without asking beforehand whether it is possible and allowed.

P3: It means that we are in control of what we buy. We like that a lot.

Two organisations affiliated with the NBAV (O3, O4) also described the independence amongst parents. They identified that their holiday guest have the opportunity to go on a holiday with them or another travel agency.

O3: Where you want to spend it on is your choice.

All four parents perceived themselves as a better person to buy care services compared to the institutions. Their argumentation for this statement is based on the up-to-date knowledge they have regarding their child's desires and needs which care institutions are missing.

P1: We chose for a PGB because we could buy the care that we thought was the best care for Tom and we were not dependent on an institution that just delivers certain people.

The WMO consultant, the health insurer and the WLZ senior care buyer had their doubts concerning the level of freedom amongst parents. They stated that parents miss a part of the quality guarantee when buying the caring services of the by them selected care providers instead of contracted care providers by the responsible parties.

WMO: Yes if you say I know a very nice company that, maybe even my brother in Alkmaar, who also sells wheelchairs, I would like my brother to do that. That is nice, however if you have broken engine today, I do not know if your brother from Alkmaar can provide a repair or replacement today. So you lose a bit of guarantee. That is, I think, less positive of a PGB.

The care office questioned the ability of the parents to make a good decision between the quality of care and the desired care providers by the parents.

WLZ: Health care providers under contract need to meet quality requirements. Staff must be trained, they must participate in education. We impose requirement on budget rations, that they have sufficient resources. Everything you can imagine, while with a PGB, which is a big thing within the Netherlands, the customer does that themselves. However, if the care is delivered by a neighbour who accidentally gives the injections, that is allowed. However when we choose the care services that is not possible at all. That really must be someone who is trained in nursing activities. There is a very big difference.

The possibility to choose the preferred care by parents, also come with demands. Besides the beneficial feelings of independence and freedom, a lot of obligations arise. The health insurer indicated in her story that the positive effects of the high level of freedom might take the overhand amongst parents and fade away the responsibilities that come along.

HIC: Yes you have freedom of choice, but you must be able to fulfil obligations. We must be able to see that you can manage, that you can handle the budget, that you can make arrangements with your health care provider, and often people do not think about that, that it also involves obligations.

4.3.2.1. Wrap-up

All participants addressed the high level of freedom, caused by the PGB, as the opportunity for parents to choose their own health care provider, at their desired time and place. This is something that care institutions cannot provide. The parents illustrated that they experienced a feeling of independency, autonomy and control when being able to fully rely on their own capabilities in choosing the right health care provider. They are able to choose their own personal assistance which is a mechanism that creates the dimensions of meaning, self-determination, competence and impact. This level of freedom is also identified by the other participants. However, where the parents only identified the advantages of having a lot of freedom, they did not address the counter effects which are indicated by the WMO consultant, health insurer and the WLZ senior care buyer. These participants expressed their doubts about the parents ability to make a good decision between a good quality health care provider or the health care provider they feel most comfortable with but could lack a good on quality. This indicates that they question the skills of parents to make a deliberate decision by doubting the maximum level of self-determination and impact a parent can handle.

4.3.3 Care customer

Being able to purchase the personalised care is made possible via a PGB. Within the stories of eight participants (P1, P2, P3, P4, O3, WMO, HIC, WLZ), the new position of parents in the health care system is discussed. With an impairment, daily costs and costs for activities and holidays are higher than for individuals without an impairment. The parents use their PGB to finance these extra expenditures. However, as described in chapter 4.2.1.2., the amount of money parents receive from their PGB has decreased over the years. As result, parents need to negotiate with the care provider which puts them in a different position than before when they did not received a PGB. Within this chapter, the switch in roles from a care receiver to a care customer will be further elaborated upon.

Due to the PGB, a parent is able to directly buy care themselves instead of receiving care via an institution under contract by the care office, health insurance company or municipal parties. Parents experience their position in the PGB as really pleasant. By being able to buy their own caring services, the care providers need to take them more seriously. This type of empowerment is defined as consumer choice. Within this type of empowerment, parents develop a different relationship with the parties involved in the PGB system. Before, this was a care relationship whereby the parents received the care provided by care institutions. The usage of PGB transformed this relationship into a relationship whereby the parents and the care institution collaborate on an equal level in order to see whether the provided care can be improved. A parent is independent of the care provider since they can decide for themselves at any moment in time whether they like the care provider or not, as illustrated in the quote of parent 2.

P2: You choose a small-scale provider yourself. Do you like it? Fine. If not, then you go to another. That is the freedom you have.

A feeling of power, independence and control arises amongst parents when not relying on other responsible parties within a certain Act to arrange care for them, but by arranging it themselves. As result, care providers need to seduce them to buy their care instead of the caring services of their competitors which puts them into a good position to negotiate about the price.

P4: Organize it yourself and not having to ask other people who arrange it for you and you have to deal with that. That does not sound good.

P2: And if you buy your care yourself, you are taken seriously because you are just part of their customer base. I decide. You are independent. So as a health care customer, I find the PGB a wonderful tool to keep the health care provider sharp.

The possibility to negotiate was also described by the WMO consultant. He experienced that parents can receive their caring services for a lower price than when it was arranged via the municipality.

WMO: You also see that care can be cheaper with a PGB. We see totally different tariffs if someone wants to hire someone via a PGB instead of when they arrange it. Sometimes half, two-third of the hour rate we pay as a municipality.

Organisation 3 identified this independence of the parents by emphasizing that parents can buy the services they desire any time, everywhere. Therefore, she indicated that it is of importance for her organisation to anticipate on the wishes of the parent. When a parent desires service A, and the organisation initially only offers service B, the organisation starts offering service A.

O3: We notice it, but since 2015 we are offering besides the group holidays also stays overnight because a part of our holiday quests, parents, told us 'my child is going once per month, or once per two months to an overnight stay, however that particular location has closed so can you do anything about it? We told, that an overnight stay is almost like being on a holiday for a weekend. And we are good in organising that, so we started renting accommodations and people can let their children come there now for an overnight stay.

The WLZ senior care buyer also identified the high level of control amongst parents. He stated that as a care office you have a bag of money which is reserved for customers who receive a PGB. When the

PGB is distributed over his customers, the amount of money is theirs and the care office is no longer allowed to do anything with that money. This indicated that the parents have total control over their expenditures with their PGB whereby the care office only is the controlling factor to check whether the care is provided. This gives parents a lot of freedom and power.

WLZ: Yes the PGB is a legal right and when you have an agreement for PGB for that particular client, that money is initiated for that. So we cannot do anything with it anymore even when they

The health insurance company also acknowledged the financial freedom and independence of parents to buy their own care. She stated that parents can buy their desired care which enables them to participate in society.

HIC: From that point of view, they actually buy a piece of their own freedom to just be able to organize their lives, to arrange the care in such a way that they can participate in society in a normal way.

However, the WLZ senior care buyer also perceived a disadvantage of the amount of freedom. Since the care office only controls whether the care is actually provided, they do not take the quality of the consumed care into account. He indicated that it happens that parents do not pay enough attention to the quality of the care since they value the particular organisation or person that provide the care more. He stated that participants cannot handle the amount of freedom and control to the best extent by setting their priorities wrong.

WLZ: What you also see happening, but I should not say that, but especially what you see is that there are PGB settings, if there would be an inspection they would fail. The quality of not high.

The WMO consultant also touched upon the possibility of a decrease in quality by mentioning that not all parents can handle all the tasks and responsibility.

WMO: I am not a big supporter of the PGB in general because it involves a lot of responsibility. You have to search for your own health care provider, compile your care agreement, manage all the administration and I think that in the Netherlands we have generally good health care providers and then you do not have the hassle, however with a PGB you do.

4.3.3.1. Wrap-up

Being able to buy their own care instead of receiving care chosen by the health insurer, care office or municipal parties puts parents in a powerful position. All participants that touched upon the new position of parents perceive it as a positive change. This change occurred by enhancing a feeling of independence and power amongst parents due to the possibility to negotiate with care providers and the reaction of care providers acting upon their wishes. Thereby, the dimensions of competency and impact are triggered amongst parents. However, the WMO consultant and the WLZ senior care buyer also identified a negative effect of the new role for parents by stating that parents can be too convinced of their own abilities and thereby forget the quality of the care services. They state that not all parents are able to negotiate and handle the freedom of choice due to a lack of knowledge and skills to make the best decision between health care providers.

4.3.4 Conclusion theme 3

The PGB gives parents a lot of freedom which is something all participants agree upon. However, how this freedom is defined differs. Eight participants (P1, P2, P3, P4, O3, WMO, HIC, WLZ) touched upon all three effects originating from the freedom. Three participants (O1, O2, O4, Y) only addressed one or two effects within their stories. Overall, the parents addressed mainly the positive effects of their freedom. Thereby, the dimensions of independence, autonomy and control developed. Within the position of a care customer, personalized care can be bought. The organisations affiliated with the NBAV and the WLZ client councils also identified the large amount of power amongst parents by indicating that they adapt their services to the needs of the parents. The WMO consultant and the WLZ senior care buyer had mixed feelings towards the large amount of freedom amongst parents. This was indicated by emphasising that the quality of care could be forgotten.

5. Discussion and conclusion

The aim of this thesis was to identify the perspective of the parties involved in the PGB system on the empowerment of individuals with an impairment, and the influence of the PGB on this empowerment and the tourism participation. Based on this aim, three sub-research questions were identified. These were answered in this discussion based on the findings of this thesis. In addition, findings were reflected upon based on previous research and conceptual concepts. This chapter also elaborates upon the strengths and limitations of this thesis and the implications for research and practice. The chapter was completed with the conclusions of this thesis.

5.2 Answer research questions

The research questions were answered by interviews with parties involved in the PGB system, organisations affiliated with the NBAV and parents combined with findings from the literature. Insights regarding the perspectives of the participants on the empowerment of individuals with an impairment is gained by assessing which angles of the concept of empowerment they have addressed.

5.2.1 First sub-research question

The first sub-research question aimed to identify the perspectives of the different levels of responsible parties involved in the PGB system on the empowerment of individuals with an impairment, the influence of the PGB on this empowerment and their tourism participation. For each party involved in the PGB system, the by them addressed barriers, mechanisms and dimensions of empowerment will be described.

On the municipal level, the WMO consultant and the Youth consultant are the responsible parties regarding the WMO and the Youth Act. Since they both work for the municipality and consequently interact frequently, their perspectives will be integrated. The municipal parties identified in total three barriers, of which two were exogenous barriers and one was an internal barrier. Regarding the exogenous barriers, one could be identified as an interactive barrier and one as an environmental barrier. The interactive barrier was described by questioning the skills of individuals with an impairment to make the best decision between quality of services and the familiarity with the care provider while spending their PGB. The environmental barrier was addressed by emphasizing that individuals with an impairment were not able to buy their desired care when this was from care providers who did not have a contract with the municipalities. The internal barrier was identified as an intrinsic barrier. This barrier related to the lack of knowledge amongst individuals with an impairment which created the opportunity for third parties to commit purposively fraud.

The municipal parties did not address many mechanisms for individuals with an impairment to decrease the barriers. One mechanism, which decreased the environmental barrier, was identified. According to the municipal parties, the rules of the Dutch health care system inhibited the opportunities for individuals with an impairment to choose between every care provider within the Netherlands while consuming care. The municipal parties identified the development of the PGB as an instrument to overcome this barrier. The PGB creates freedom of choice for individuals with an impairment since care can also be bought from care providers that do not have a contract with the municipality.

Corresponding with the low amount of identified mechanisms, only a two dimensions of an empowered individual were described. Both dimensions, being the increase in self-determination and impact, were addressed by identifying the increase in freedom and autonomy regarding where to buy

care. However, the municipal parties expressed their concerns for both dimensions. The positive effects were questioned by addressing the incompetency of individuals with an impairment to find a balance regarding the quality of care and services provided by professional care institutions or by informal care givers. They addressed that individuals with an impairment can become too convinced of their own abilities while managing their PGB. A factor that could not be identified as a barrier or mechanism but is of importance when assessing the perspective of the municipal parties on the empowerment of individuals with an impairment, related to the identified decrease in responsibility. This level of responsibility, and its decrease, was recognized by assessing the change in storage of the PGB which is nowadays at the Social Insurance Bank instead of on the bank account of the individual with an impairment. When categorizing the decrease in responsibility to a dimension of empowerment a decrease in impact can be identified. The municipal parties perceived this decrease as a positive effect for the individual with an impairment.

The health insurer identified six barriers for empowerment when describing stories related to the influence of the PGB on the empowerment of individuals with an impairment. Amongst the six barriers, four were identified as exogenous barriers and two as internal barriers. Regarding the exogenous barriers, one was an environmental barrier and three were interactive barriers. The environmental barrier related to ambiguity amongst individuals with an impairment concerning the rules of the Dutch health care system. The first interactive barrier related to the lack of encouragement amongst individuals with an impairment to participate in society. Their caring needs could not always be met in the past which inhibited their participation possibilities. The second identified interactive barrier was caused by the abundance of tasks for individuals with an impairment while managing their PGB and the questioned decision-making regarding the quality of care. The third and final interactive barrier originated from the lack of available information regarding the rules applicable in the PGB system for individuals with an impairment. Regarding the internal barriers, both were classified as economic barriers. The first economic barrier related to the emergence of income disparities between individuals with a PGB since the change in the PGB system. With the transformation in Acts within the PGB system, individuals with an impairment were re-classified amongst the current existing Acts. The health insurer addressed that this re-classification did not turned out well for all individuals with an impairment. She referred to those individuals who were placed by the WMO since 2015 and experienced troubles with the pay-outs resulting in financial insecurity. The second economic barrier related to the affordability of undertaking activities and consuming caring services for individuals with an impairment.

Three mechanisms were described which tackled four barriers that inhibited the perception of the health insurer for an empowered individual with an impairment. The environmental barrier related to the rules within the Dutch health care system and the interactive barrier regarding the lack of available information was lowered via the mechanism of personal assistance provided by the health insurer. However, she identified that individuals still experience difficulties regarding the new rules of the PGB system originating from the change in 2015 despite the effort of the health insurance company. The interactive barrier, related to the lack of encouragement to participate in society, was decreased by the financial incentive of the PGB. The PGB provided individuals with an impairment the opportunity to buy personalised care at their desired time and place. This ensured that individuals with an impairment were able to participate in society via, amongst others, work. The affordability barrier was diminished by the PGB since it covered the missed income amongst friends and relatives who provided caring services and subsequently worked less hours at their work.

The health insurer touched upon an increase in three dimensions of empowerment, being the dimensions of self-determination, competency, and impact. They identified an increase in the dimensions of self-determination and competence by addressing that the PGB functioned as an income for individuals with an impairment and subsequently increased their opportunities to participate in society. The identified increase in the level of impact resulted from the personal assistance provided by the health insurers. The adaptation of the services to the needs of the individual with an impairment indicated a high level of influence. On the other hand, a questionable increase in the dimension of competence was identified. With the abundance of tasks while managing the PGB and questioned decision-making by individuals with an impairment, the health insurer addressed that they overestimate their competence. This was not perceived as a positive aspect of empowerment. Also, a decrease in the dimension of competence was recognized. The health insurer addressed that they do everything within their capacity to assist individuals with an impairment in overcoming the lack of available information regarding the rules of the PGB system. However, she described that although their efforts, individuals with an impairment are still insecure while managing their PGB which related to a low competency level. Another barrier that was not overcome, but influenced the level of impact amongst individuals with an impairment, is the existence of income disparities. The health insurers emphasised that the delayed PGB payments by the municipality caused a feeling of concern amongst individuals with an impairment since they are financially dependent of the municipality.

The senior care buyer, complimented with the perspectives of the client councils, identified four barriers for empowerment when describing stories related to the by them identified empowerment of individuals with an impairment and the influence of a PGB on this empowerment and tourism participation. Three barriers were identified as exogenous barriers, of which two were caused by the environment and one via interactions. One barrier was identified as an internal barrier. The first environmental barrier related to the change in PGB system in 2015. The client councils of the WLZ categorized the change in PGB system as an unnecessary change only executed by the Dutch government to show that they are innovative. They addressed that continuous changes, such as the change in PGB system, have a negative effect on individuals with an impairment. The second environmental barrier related to the constraints in choices for individuals with an impairment regarding care providers. They identified the influence of the Dutch health care system by inhibiting the individuals with an impairment options to buy care from every care provider. They recognized that care could only be received, before the existence of the PGB, from contracted care providers by the care office. The interactive barrier was addressed by the identification of the misuse caused by third parties involved in the PGB system. According to the senior care buyer, third parties misuse their position by claiming more PGB from an individual with an impairment than they are entitled to. The internal barrier was classified as an intrinsic barrier caused by the ineffective social skills of individuals with an impairment. The client councils addressed this by describing the lack of integration amongst residents at a care institution when this was not facilitated by the care providers.

For three barriers, being the interactive barrier, the intrinsic barrier and the environmental barrier related to the rules of the Dutch health care system that inhibited the freedom of choice in care providers, mechanisms were described that diminished the barriers for empowerment amongst individuals with an impairment. For the environmental barrier related to the negative effect of the change in the PGB system on individuals with an impairment, no mechanism was described. In addition, three mechanisms that were not related to an identified barrier were described. The intrinsic

barrier related to ineffective social skills was diminished by facilitating an environment which stimulated interactions amongst residents. The interactive barrier was decreased by the individual with an impairment taking control and action. This was achieved by getting in contact with the care office about the misuse of the third party which resulted in counteracting the misuse of third parties. Mechanisms that were not linked to identified barriers, but did have an impact on getting a grasp of the perception of the senior care buyer regarding the empowerment of individuals with an impairment related to the role of the Dutch government and the importance of personal assistance. Concerning the role of the Dutch government, two angles were identified. Firstly, the Dutch government promotes that individuals with an impairment live longer at home instead of in care institutions. A identified positive effect of this was that individuals with an impairment are longer surrounded by their family, friend and familiar care providers. On the other hand, an identified negative effect indicated that it also results in being in a worse health condition when entering a care institution. Secondly, the Dutch government aimed for a participation society whereby citizens increasingly interact which results in an increase in social interaction between the individuals with an impairment and their surroundings. This identified mechanism for empowerment related to the importance of personal assistance. The client councils addressed the importance of personal assistance and attention in mapping the needs and desires of the individual with an impairment to ensure that they can be a part of the participation society.

The senior care buyer, and inclusively the client councils, described simultaneously increases and decreases in the dimensions of empowerment. The dimension of competency was increased by the creation of a participation society. However, it also decreased by having a worse health condition when being institutionalized at a care institution after living longer at home and the ongoing changes within the PGB system that added to the ambiguity in rules amongst individuals with an impairment. Still, the increase in freedom of choice was identified as a stimulating factor for the level of competency of individuals with an impairment. The senior care buyer addressed his concerns towards the high level of competency by stating that high quality care is not guaranteed. An increase in the level of impact was identified by addressing the active approach and subsequently the exert of influence by individuals with an impairment upon the fraud committed by third parties. An increase in the level of self-determination was recognized by an increased freedom of choice to be able to buy care from care providers that are not under contract by the care office. Furthermore, an increase in the dimension of meaning was identified. This increase resulted from the personalised care which enabled individuals with an impairment to do the things they loved most and by the increase in interaction which increased, according to the client councils, the value of life amongst individuals with an impairment.

5.2.2 Second sub-research question

The second research question aimed to identify the perspective of the organisations affiliated with the NBAV on the empowerment of individuals with an impairment and the influence of a PGB on this empowerment and their tourism participation. The organisations identified in total six barriers, of which four were identified as exogenous barriers and three as internal barriers. Regarding the four exogenous barriers, two were categorized as environmental barriers and two as interactive barriers. The environmental barriers related to the continuous adaptation of the environment to ensure that individuals with an impairment can have a tourism experience without feeling abnormal and the unclear rules within the PGB system. The interactive barriers were identified by the lack of encouragement for individuals with an impairment to meet up with friends or to make new friends

caused by the absence of opportunities, and the inadequacy of available information and clarity for individuals with an impairment regarding the rules of the PGB system. Concerning the three internal barriers, two were identified as intrinsic barriers and one as an economic barrier. The interactive barriers related to the lack of knowledge amongst individuals with an impairment concerning the rules within the PGB system. They blame the responsible parties within the PGB system for the presence of this barrier. In addition, a question that was raised many times by the organisations affiliated with the NBAV emphasised on the opportunity to participate in tourism being a right for individuals with an impairment. The economic barrier related to the difficulty amongst individuals with an impairment to participate in tourism for financial reasons since 2015.

For almost all barriers, mechanisms were described to diminish the barriers. For two barriers, being the statement that travelling must be seen as a right and the financial difficulties to participate in tourism, no mechanisms were addressed. A mechanism to overcome the environmental barrier of the continuous adaptation of the environment was described by the effort of the organisations to adapt the environment of the holiday destination in such a way that an individual with an impairment could behave as they desired to. Actions that describe this adaptation is a holiday destination were also individuals without an impairment participate under personal assistance or the adaptation of transport via bigger busses or personalising the dining room with pictures from the past which triggers individuals with dementia. Due these efforts, individuals with an impairment could perceive themselves as capable which increased their perceived self-efficacy. The organisations affiliated with the NBAV described the same mechanism when coping with the environmental barrier of indistinctness of rules within the PGB system. The interactive barrier of inadequacy of available information and the intrinsic barrier of lack of knowledge were diminished by addressing that the organisations take on the role of mediator by either providing information on the rules within the PGB system towards the individuals with an impairment or by providing assistance in showing where the individual could receive the right information. A mechanism for diminishing the interactive barrier concerning the lack of encouragement for individuals with an impairment to meet up with friends was by organising activities and holidays by for their specific target group. These were organised by carefully adapting their offer to the desires and needs of the individuals with an impairment.

After emphasizing on the diminished barriers via mechanisms, the organisations affiliated with the NBAV described the individuals with an impairment as relatively empowered. They identified the influence of the PGB on the empowerment of individuals with an impairment via two ways, being constructive and deconstructive. The constructive influence of the PGB on individuals with an impairment was described by two approaches. First being the availability of personal assistance offered by the organisations affiliated with the NBAV. This service was described as a service that caused an increase in the self-determination of individuals with an impairment by having the opportunity to choose the provision of care. The second influence of the PGB which caused an identified increase in the empowerment of individuals with an impairment referred to the opportunities for personal development. These opportunities were created by organising activities and holidays that encouraged an individual with an impairment to participate in society. Examples of such activities were, while being on holiday, a visit to a museum, having a drink in the hotel or an activity that challenged the individual. These challenging activities were adapted to the desire of the individual with an impairment. An example of such a challenge was the experience of a girl with an impairment who went in the swimming pool after avoiding it for years. Argumentation provided regarding the deconstructive effect of a PGB on the empowerment of an individual with an impairment was identified in two ways. Firstly, the decrease in amount of budget since the change in

2015. This decrease in financial freedom resulted, according to the organisations affiliated with the NBAV, in a decreased competency level since individuals with an impairment experienced a decrease in the possibilities to participate in tourism. Secondly, the organisations affiliated with the NBAV described a decrease in impact amongst individuals with an impairment. The ambiguity in rules inhibits the confidence of the organisations regarding the awareness amongst individuals with an impairment about their level of influence within the PGB system.

5.2.3 Third sub-research question

The third research question aimed to identify the perspective of parents of individuals with an impairment regarding their empowerment and the influence of a PGB on this empowerment and tourism participation. The parents identified in total five barriers, of which two were exogenous barriers and three were internal barriers. Regarding the two exogenous barriers, one was an interactive barrier and one an environmental barrier. The environmental barrier related to the lack of opportunities in the environment for parents to meet up with friends, to expand their world, by undertaking activities such as being on a bus, walking in the forest, sitting on a terrace, and to participate in tourism. The interactive barrier related to the communicative challenges. Communicative challenges between in parents and the responsible parties within the PGB system sometimes decreased their feeling of competency and independency. Regarding the three internal barriers, two were intrinsically caused and one was an economic barrier. The economic barrier was referred to as the higher expenditures in daily life amongst individuals with an impairment compared to those without an impairment. These expenditures related to the costs of caring services and social- and leisure events. The three intrinsic barriers related to a lack of knowledge amongst parents regarding the PGB system, ineffective social skills and health-related barriers. Concerning a lack of knowledge, the parents included in this research did not perceive themselves as uninformed about the PGB system. They did address the difficulty and big amount of effort that is required to stay up to date about the continuous changing rules within the PGB system. Health-related barriers were not explicitly addressed by the parents. Nevertheless, they did address the need for caring services and assistance when undertaking activities which indicated.

For almost all barriers, mechanisms were described to overcome the barriers. The communicative challenges between the parents and responsible parties being an exception. Mechanisms described to overcome the environmental barrier is the offer of services. These services include the effort of care providers and organisations affiliated with the NBAV to organise events in an adapted environment which enabled parents to fully participate. A mechanism to overcome the economic barrier was the usage of a PGB. Concerning the barrier related to a lack of knowledge, they emphasised that correct information sharing between them, the responsible parties within the PGB system and other organisations such as PerSaldo, up to date knowledge is ensured. In-effective social skills could arise when the impairment of a parent made the expression of emotions and desires difficult. This was tackled by the care provider being a friend of the individual with an impairment and subsequently was familiar with their desires. When this was not the case, an open relationship between the individual with an impairment or their administrator and the care provider ensured that expectations corresponded and desires were known. In both cases, the expectations and desires of the parent needed to be identified via either their administrator or by deeply investing in a relationship.

After emphasizing on the diminished barriers via mechanisms, the parents identified themselves as an empowered individual. Although they addressed their insecurities concerning their

management of a PGB due to the fast shifting rules within the PGB system, all four touched upon the four dimensions of an empowered individual with a positive view. Within their stories, these dimensions were intertwined. A PGB gave them the opportunity to request for care at their desired moment and time. In addition, they perceived themselves as in control regarding where and when the caring services were bought. This indicates their feeling of self-determination and impact. Furthermore, the dimension of meaning was identified throughout their stories. They care about what they are doing which was identified in the big amount of effort put into being up to date about the PGB system. In addition, the joy after participating in society, undertaking new activities, hanging out with friends was often described. This participation was made possible by their PGB. This budget enabled hiring their friends as care provider, spending their day activities at their desired location and subsequently made them feel one with society.

5.2.4 Concluding remarks

Like the social model of disability, this research focussed on a societal system by conceptualising the identified barriers experienced by individuals with an impairment while participating in society. Participants of this research described barriers that inhibited the participation of individuals with an impairment in society. Differences amongst the participants in the identified barriers can be analysed. An overview of the different barriers described by the participants can be found in figure 3. When looking at the absolute number of barriers identified, the maximum divergence included a difference of two identified barriers. This occurred in three barrier domains, being the interactive-, intrinsic- and economic domain. The health insurer and organisations affiliated with the NBAV addressed most barriers, six in total. On the contrary, the municipal parties addressed three barriers. The parents and senior care buyer were in the middle with respectively five and four barriers. Besides providing an overview of the different barriers indicated by the participants within this research, taking solely the number of identified barriers does not ensure that the right conclusions are drawn concerning the perceptions of the participants on the empowerment of individuals with an impairment. As an illustration, the municipal parties addressed a relatively low number of barriers. However, other participants addressed barriers caused by inadequate actions of the municipal parties. This was not recognized by the municipal parties which can be an explanation of differences between them and the other participants. Finalising the identified barriers, almost all participants identified more exogenous barriers than internal barriers. Parents were the exception by addressing more internal barriers than exogenous barriers. This indicated that parents feel responsible for the arise of barriers for empowerment. However, the other participants distinguished more exogenous barriers which indicated that they take society responsible for the evolution of barriers that inhibit the development of empowerment amongst individuals with an impairment. Most of the participants, except the parents, thoughts regarding the barriers are generally in line with the social model of disability which states that barriers in society inhibit full participation. Nevertheless, like the parents, they too identified internal barriers which pointed out that they not fully see an individual as an impaired individual, but still as an disabled individual.

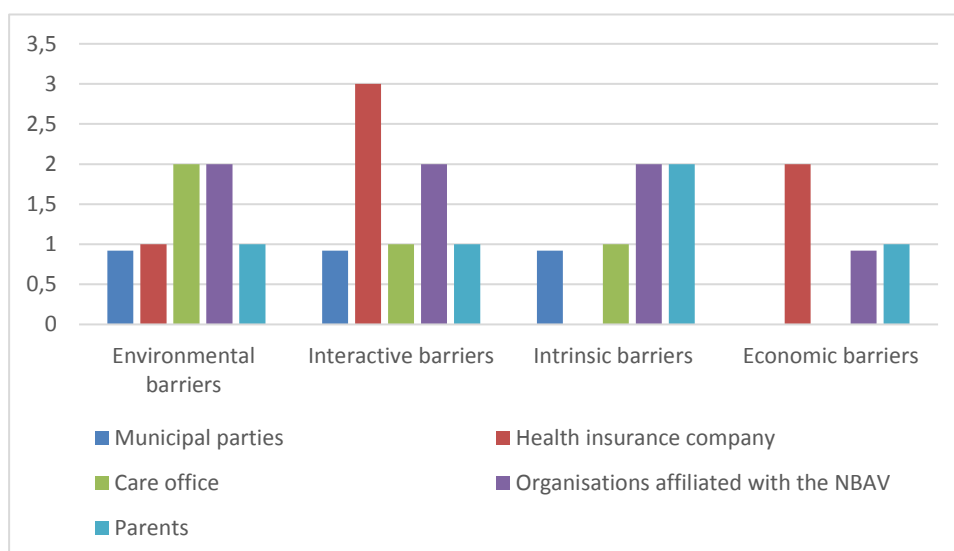


Figure 3: Overview of the described barriers by all participants

Mechanisms that were described by participants all related to the society surrounding the individual. Examples of mechanisms that were recognized by most of the participants were the importance of adaptation of the environment and the creation of possibilities for social interactions. A mechanism recognized by most of the participants was the importance of adapting the environment in such a way that it enables individuals with an impairment to fully participate. The municipal parties were an exception to this. Opportunities for the adaptation of the environment was via the possibility for individuals with an impairment to buy personalised care and the availability of personal assistance. Adapted environments created the freedom for individuals with an impairment to decide for themselves whether they desired full participation in society or not. Another often discussed mechanism was the creation of possibilities for individuals with an impairment to meet up with friends or family. If society develops more moments for them to interact, individuals with an impairment experience more freedom of choice of when to participate. Overall, the categorized mechanisms for diminishing the barriers were all outside of the power of the individual with an impairment which corresponds with the vision of the social model of disability.

Based on their experiences with individuals with an impairment, the identified barriers and acknowledged mechanisms for empowerment led to different perspectives amongst all participants regarding the empowerment of individuals with an impairment. An overview of these dimensions can be found in figure 4. Amongst the perspectives of the participants on the presence or absence of a particular dimension for empowerment similarities and differences were identified. The first similarity was shown in the increase in the dimension of self-determination. This was identified as positive (towards the plus on the x-axis) by all participants. However, not all participants were as positive towards this increase. The municipal parties and the senior care buyer expressed their doubts towards the lack of quality guarantee resulting from the high level of freedom for individuals with an impairment while managing their PGB and subsequently their caring services. A second similarity was identified concerning the dimension of meaning. Three participants (groups) touched upon this dimension, being the parents, organisations affiliated with the NBAV and the senior care buyer. All perceived this as a positive change for the individual with an impairment resulting from a feeling of revive. The first difference was identified concerning the dimension of competency. The parents

identified this increase as a positive increase. However, organisations affiliated with the NBAV, the health insurer and the senior care buyer addressed their concerns towards the effect of the increased level of competency on individuals with an impairment. This is shown in the movement towards the minus on the x-axis in figure 4. The second difference concerned the dimension of impact. Whereas the parents, health insurer and the senior care buyer identified a positive increase, the municipal parties identified this increase as negative. A totally different view on the level of impact was described. The organisations affiliated with the NBAV touched upon a decrease in the level of impact which they identified as negative, the other participants identified an increase in the level of impact amongst individuals with an impairment. Differences between the participants that identified an increase in the level of impact was identified. Whereas the municipal parties addressed this as a negative change, the parents, the health insurance company and the senior care buyer identified it as a positive change.

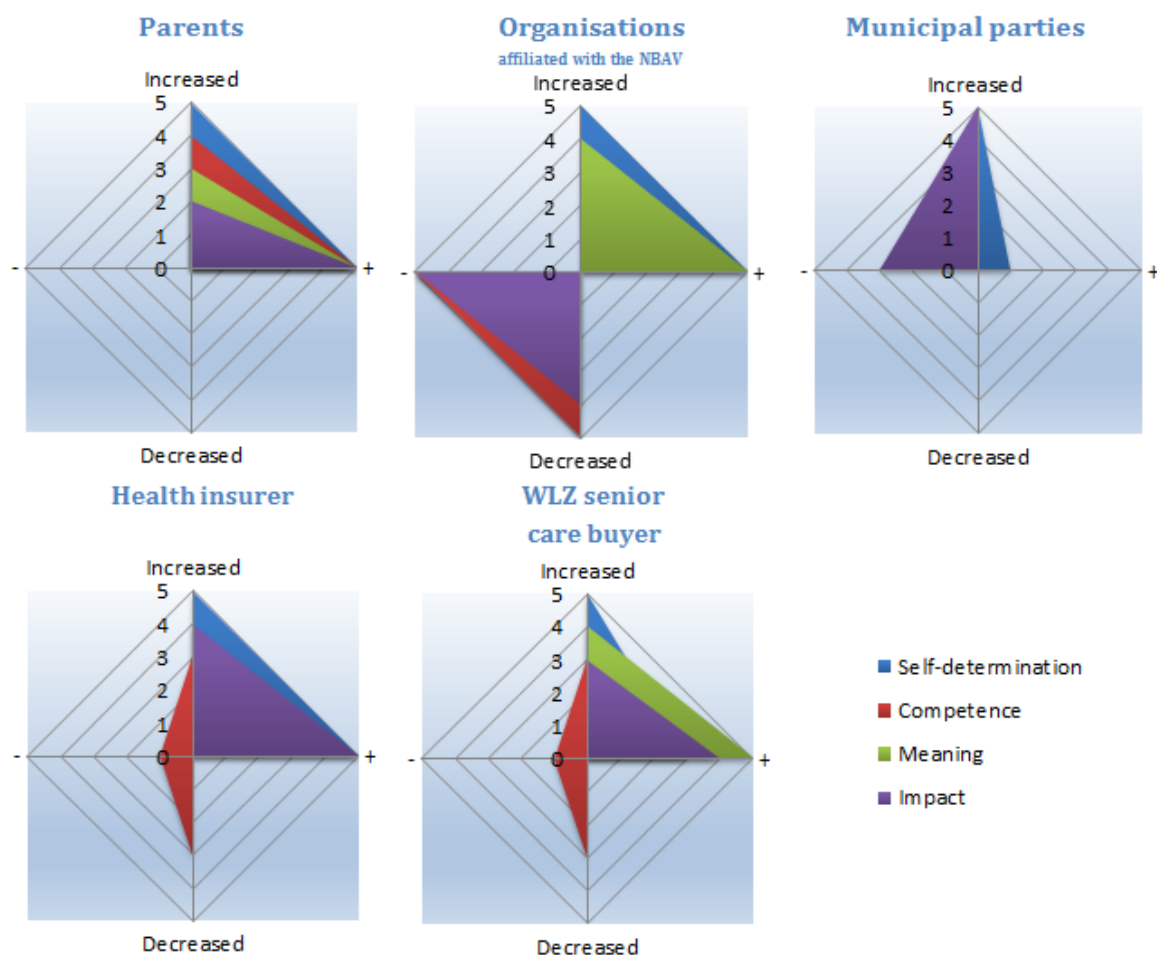


Figure 4: Overview of the described dimensions of empowerment of individuals with an impairment by all participants ^{1,2,3}

¹ A described increase is covered with a +5 on the y-axis, subsequently a described decrease is covered with -5 on the y-axis

² When both an increase and a decrease were described, this is visualised with a score of +3 and -3 on the y-axis

³ When all dimensions covered the same area, a small difference on the y-axis was applied so all dimensions were shown on the graph

Although the Dutch government has the goal to diminish the barriers for full participation in society in order to reach equality amongst others, different barriers and different mechanisms were described within the stories of the participants related to the behaviour of the environment towards individuals with an impairment. This indicated that equal participation is not reached yet and a shared perspective within the same system on the empowerment of individuals with an impairment is absent. Collaboration requires clear communication between all parties involved in the PGB system concerning the main content of the different Acts and its consequences on the individuals with an impairment. However, the lack of integration of the different perspectives indicate that collaboration between all actors is not at its best.

5.3 Implications for practice and research

The results of this theses were relevant for both research and practice. Results were relevant for research since they provided an insight in the current level of conformity amongst the different parties involved in the PGB system concerning their opinion of influence of a PGB on individuals with an impairment. Further research can expand this knowledge by addressing how the level of conformity can be further increased by conducting a relational strategy. This involves the connection of the different parties involved in the PGB system which enables them to tackle the identified barriers. Furthermore, the adoption of a relational strategy increases information exchanges which might decrease the ambiguity in rules of the PGB system. With this strategy, it is important to take into account the perspectives of the different parties involved in the PGB system and the possible role they see for themselves when tackling the barriers.

The results were also relevant for practice since the different perspectives on the empowerment amongst the participants indicated that they identify other influences of the PGB on the empowerment of individuals with an impairment. These differences in views, with the possibility of differences in mechanisms to empower the individual, can be overcome by the launch of clear guidelines by the Dutch government on how to diminish barriers that hinders full and effective participation of individuals with an impairment on an equal basis with others in society. The development of guidelines must be done in close collaboration with the individuals with an impairment since this will increase the compatibility of the guidelines. This compatibility is about the degree to which the guidelines, and the subsequent actions by parties involved in the PGB system, are in accordance with the social norms, experiences and needs of individuals with an impairment.

The results of this thesis were also relevant for research and practice since it expanded the knowledge on the perceived additional value of a PGB on the empowerment of individuals with an impairment by the different parties involved in the PGB system. Further research can expand this knowledge even further by assessing how a financial stimuli can contribute to the increase of empowerment amongst individuals with an impairment.

Results were relevant for research and practice since they expanded the scientific knowledge on the differences that can arise between policy and practice. The Dutch government aims to reach equality for all since the ratification of the Convention on the Rights of Persons with Disabilities. However, multiple barriers were identified by the participants related to the impairment of an individual when reaching for full participation in society. The identified barriers, and subsequently identified

mechanisms to diminish the barriers, can be used in order to continue improving the environment surrounding an individual with an impairment so equality is reached.

5.4 Strengths and limitations

Strengths and limitations of the interviews were identified. A strength of the interviews was that professionals from all relevant sectors, participating in the PGB system, participated in the interviews. This increased the reliability of the findings since these professionals were able to provide a holistic overview of the different perspectives present amongst parties involved in the PGB system on the empowerment of individuals with an impairment. However, the aim of this qualitative study was to generate theoretical saturation and not to generalize the findings. Therefore, it was expected to find participants from the different responsible parties within the PGB system supplemented with the organisations affiliated with the NBAV and the parents themselves fit and willing to participate within the timeframe. However, this appeared to be easier said than done. Selection bias might have occurred since all participants were included based on purposive or convenience sampling. These are non-random sampling strategies and it is therefore unknown whether the findings of these parties can be generalised. Although the generalisability is unknown, it was still relevant to include these in the interviews since they provided the perspective of parties on the individual-, organisational-, municipal- and regional level on the empowerment of individuals with an impairment.

Another strength related to the included participants refers to the inclusion of the type of organisations affiliated with the NBAV. Of the in total four included organisations, two were accommodation stays and two were tour operators. This provided a balanced perspective of the organisations affiliated with the NBAV. A limitation of the included parents can be identified since the interviews were held with the parents of individuals with an impairment. This was needed since their children were not in a position to participate in an interview. However, the inclusion of four parents in the interviews was still relevant since they managed the PGB for their children which put them in contact with the PGB system and they could, according to them, identify best the influence of a PGB on their children's empowerment.

Another limitation regarding the included participants refers to the differences in numbers of each included party involved in the PGB system. Of the in total twelve interviews, four were executed with parents, four with organisations affiliated with the NBAV, one with a WMO consultant, one with a Youth consultant, one with a health insurer and one with a senior care buyer of a care office supplemented with input from client councils. This difference in numbers has two explanations. Firstly, it was assumed the WMO consultant, Youth consultant, health insurer and senior care buyer had a perspective that covered for other employees in their position since they work with national legislations and subsequently have similar interactions with individuals with an impairment where they relied upon when assessing the empowerment of individuals with an impairment. On the contrary, tour operators and accommodation stays are not bound to national legislation since they interact with individuals who receive a PGB from different laws instead of only one. In addition, organisations affiliated with the NBAV could experience different interactions with individuals with an impairment since they organise the interaction moments themselves (for example via a holiday abroad or a day-trip within the Netherlands). This freedom in interaction possibilities could result in having different sources per organisation affiliated with the NBAV to assess the empowerment of an individual with an impairment and the influence of a PGB. This freedom of interaction possibilities also

counts for the included four parents. All have their own life-story which covers different life experiences. A second explanation relates to the difficulty to schedule an interview with a WMO consultant, a Youth consultant, a health insurer and a senior care buyer. As result, due to the limited time frame it was not possible to include more employees at their position.

Another strength of the interviews was the usage of the biographical-narrative interpretive method. This method gave the participants the opportunity to tell their stories about their experiences related to the empowerment of individuals with an impairment. They were able to speak uninterruptedly and without any steering by the researcher. However, in reality the interviewing method was not executed entirely according to this described approach. It involved effort by the researcher to put aside one's traditional methodological methods. It occurred that participants asked the researcher for guidance and affirmation when sharing their stories. Although the researcher attempted to stay silent, it occurred that the researcher reacted upon their questions. This resulted in undesirable situation whereby the researcher tried to accommodate the participant by providing guidance of affirmation. This may have led to steering the participant. However, when a structured or semi-structured interview scheme would have been used this steering would be much more present with the consequence of a low validity of this research. Therefore, the usage of the BNIM has additional value to this research.

5.5 Conclusion

The stories of responsible parties within the PGB system, the organisations affiliated with the NBAV and the parents enabled to understand how the empowerment of individuals with an impairment, the influence of a PGB on their empowerment and tourism participation was perceived by the different parties acting in the PGB system. This way, this research represents the aim to assess how different parties involved in the PGB system perceive the empowerment of individuals with an impairment. In addition, the perception of the involved parties concerning the role of a PGB on the participation of individuals with an impairment in customized holidays is assessed. This aim is relevant since it provides an insight in whether the parties involved in the PGB system identify full participation, as aimed for by the Dutch government after ratifying the Convention on the Rights of Persons with Disabilities, and subsequently an empowered individual with an impairment after the tempering the collective expenditures by reclassification the PGB system.

It was found that the different parties have different perspectives on the empowerment of individuals with an impairment who receive a PGB. These perspectives were specified by addressing barriers for empowerment, mechanisms that inhibit these barriers, and dimensions of an empowered individual, these factors are (mostly) interconnected.

Overall, all participants identified barriers for empowerment for individuals with an impairment, meaning that they share the perspective that individuals with an impairment are not (yet) fully empowered. However, a gradation appeared regarding the absence of empowerment and the party responsible for the absence of full empowerment. Whereby the parents perceive themselves as relatively empowered, they mostly addressed internal barriers that inhibit them to fully experience the feeling of empowerment. The organisations affiliated with the NBAV identified individuals with an impairment not as fully empowered, but put the responsibility of this absence of empowerment on the different responsible parties within the PGB system. The health insurer and the senior care buyer described individuals with an impairment as quite empowered. However, they did not addressed this as only positive by recognizing too high competency levels which eventually could have a negative

effect on the individuals with an impairment. At last, the municipal parties. Both the WMO consultant and the Youth consultant did not described a fully empowered individual with an impairment. They touched upon an increase in two dimensions of empowerment, however did not perceived these increases as positive which illustrates their displeasure with the PGB system. A general note is made that the overall feature of the PGB, being an opportunity for individuals with an impairment to buy their own care, at their requested time and place, appeared to be the starting point for the derived barriers, mechanisms and subsequently dimensions of empowerment.

The different visions on the empowerment of individuals with an impairment and the barriers causing this absence of empowerment, indicate that a shared perspective is lacking. The absence of a shared perspective indicates a lack of collaboration between all parties acting within the PGB system. This can result in a waste of services and inflexible service provision which does not lead to the desired tempering of health expenditures nor a full participation level in society by individuals with an impairment, as aimed for by the Dutch government.

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Appendix A: Articles in the Convention on the Rights of Persons with Disabilities

Article 1 - Purpose

Article 2 - Definitions

Article 3 - General principles

Article 4 - General obligations

Article 5 - Equality and non-discrimination

Article 6 - Women with disabilities

Article 7 - Children with disabilities

Article 8 - Awareness-raising

Article 9 - Accessibility

Article 10 - Right to life

Article 11 - Situations of risk and humanitarian emergencies

Article 12 - Equal recognition before the law

Article 13 - Access to justice

Article 14 - Liberty and security of the person

Article 15 - Freedom from torture or cruel, inhuman or degrading treatment or punishment

Article 16 - Freedom from exploitation, violence and abuse

Article 17 - Protecting the integrity of the person

Article 18 - Liberty of movement and nationality

Article 19 - Living independently and being included in the community

Article 20 - Personal mobility

Article 21 - Freedom of expression and opinion, and access to information

Article 22 - Respect for privacy

Article 23 - Respect for and the family

Article 24 - Education

Article 25 - Health

Article 26 - Habilitation and rehabilitation

Article 27 - Work and employment

Article 28 - Adequate standard of living and social protection

Article 29 - Participation in political and public life

Article 30 - Participation in cultural life, recreation, leisure and sport

Article 31 - Statistics and data collection

Article 32 - International cooperation

Article 33 - National implementation and monitoring

Article 34 - Committee on the Rights of Persons with Disabilities

Article 35 - Reports by States Parties

Article 36 - Consideration of reports

Article 37 - Cooperation between States Parties and the Committee

Article 38 - Relationship of the Committee with other bodies

Article 39 - Report of the Committee

Article 40 - Conference of States Parties

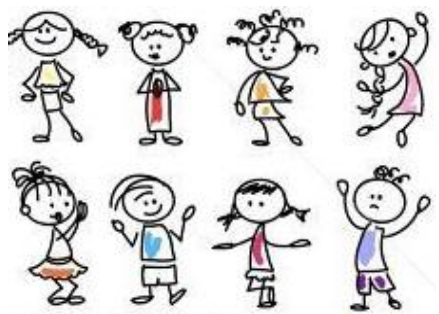
Article 41 - Depositary

Article 42 - Signature

Article 43 - Consent to be bound
Article 44 - Regional integration organizations
Article 45 - Entry into force
Article 46 - Reservations
Article 47 - Amendments
Article 48 - Denunciation
Article 49 - Accessible format
Article 50 - Authentic texts

Appendix B: Flyer towards parents

Er is veel veranderd binnen het persoonsgebonden budget; wat vindt u daarvan?



Mijn naam is Babs Matthieu. Tweedejaars MSc student Health and Society aan de Wageningen Universiteit. Dit onderzoek is voor mijn afstudeerscriptie.

Mocht u willen deelnemen op de onderstaande data, zou u dan minimaal 2 dagen van te voren een email willen sturen op babs.matthieu@wur.nl? Dan kunnen we samen de exacte tijd bepalen. Voor meer informatie over dit onderzoek kunt u te allen tijde contact met mij opnemen.

Ik hoop u voldoende te hebben geïnformeerd en dank u bij voorbaat hartelijk voor uw deelname aan dit onderzoek wat voor mij van grote waarde is.

Met vriendelijke groet,
Babs Matthieu

Deel uw mening!

Beste meneer, mevrouw,

Hierbij wil ik u uitnodigen om deel te nemen aan een scriptie onderzoek dat wordt uitgevoerd door Wageningen Universiteit in samenwerking met de Nederlandse Branchevereniging Aangepaste vakanties (NBAV).

- Doel onderzoek: het in kaart brengen van de verschillende visies op en de effecten van de veranderingen in het PGB systeem.
- Doel interview: in ± 30 min. de visie van de vakantieganger of een ouder en/of verzorger op de verandering in het PGB systeem in kaart brengen + invloed van het PGB systeem op dagelijks leven.
- Uw anonimiteit is gewaarborgd en antwoorden of gegevens worden onder geen enkele voorwaarde aan derden verstrekt, tenzij u hier toestemming voor verleend.
- U kunt zonder opgave van redenen uw eventuele deelname voortijdig afbreken en binnen 24h na het interview uw toestemming intrekken.
- Er is mogelijkheid tot terugkoppeling na het interview indien gevraagd.

Donderdag 30 maart / Vrijdag 31 maart
Tussen 16:00 - 20:00
Vlasakkerkamp 19, 7772 MK, Hardenberg

Appendix C: Informed consent form

Toestemmingsverklaringformulier (informed consent)

Titel onderzoek: Het persoonsgebonden budget; een inventarisatie van de invloed van het persoonsgebonden budget door inzichten van verschillende perspectieven in Nederland.

Verantwoordelijke onderzoeker: Babs Matthieu

In te vullen door de deelnemer

Ik verklaar op een voor mij duidelijke wijze te zijn ingelicht over de aard, methode, doel en [indien aanwezig] de risico's en belasting van het onderzoek. Ik weet dat de gegevens en resultaten van het onderzoek alleen anoniem en vertrouwelijk aan derden bekend gemaakt zullen worden. Mijn vragen zijn naar tevredenheid beantwoord.

Ik begrijp dat audiomateriaal of bewerking daarvan uitsluitend voor analyse en/of wetenschappelijke presentaties zal worden gebruikt.

Ik stem geheel vrijwillig in met deelname aan dit onderzoek. Ik behoud me daarbij het recht voor om op elk moment zonder opgave van redenen mijn deelname aan dit onderzoek te beëindigen.

Naam deelnemer:

Datum: Handtekening deelnemer:

In te vullen door de uitvoerende onderzoeker

Ik heb een mondelinge en schriftelijke toelichting gegeven op het onderzoek. Ik zal resterende vragen over het onderzoek naar vermogen beantwoorden. De deelnemer zal van een eventuele voortijdige beëindiging van deelname aan dit onderzoek geen nadelige gevolgen ondervinden.

Naam onderzoeker:

Datum: Handtekening onderzoeker:

Appendix D: Creswell's six steps of qualitative data analysis

Step 1

Organise and prepare the data for analysis

Step 2

Read carefully through all the data

Step 3

Detailed analysis with a coding process

3.1 Get a sense of the whole. Read all the transcriptions carefully. Evoked global thoughts and possible themes of codes.

3.2 Try to identify the underlying meaning instead of the actual data.

3.3 Make a list of topics. Cluster together similar topics. Form these topics into columns that might be used as major topics to structure data.

3.4 Use these topics to structure data. Abbreviate the topic as codes and write the codes next to appropriate segments of text. This structure process is used to see whether new topics and codes emerge.

3.5 Find the most descriptive wording for your topics and turn them into categories. Look for ways of reducing your total list of categories by grouping topics that relate to each other.

3.6 Make a final decision on the abbreviation of all codes and create an overview.

3.7 Assemble data corresponding to each category in and perform a preliminary analysis.

3.8 Recode your data when necessary.

Step 4

Organise and structure data using the different codes. These descriptions per code enables the analysing process.

Step 5

Determine and elaborate data from different codes and themes is be represented in qualitative narrative.

Step 6

A final step in data analysis involves interpreting the data.

Appendix E: Code tree

Table 7: code tree

Code	Explanation; Any reference regarding:
Administration	Administrative tasks related to the PGB
Application PGB	Expenditures made possible by the PGB
Change 2015	Changes since 2015
Effect PGB	The actual influence of the PGB on participants
Fraud	Fraud with money of the PGB
Freedom of choice	The freedom to choose any care provider
Informed	The knowledge of participants concerning the PGB system
Care consumers	The vision of care consumers instead of care receivers
Money	The availability of money for a PGB
Opinion PGB system	The efficacy of the PGB system
Participation in society	The participation in society by participants
Personalized care	The personalisation of services available via PGB
Relationship system	Interaction between different parties involved in the PGB system
Respijtzorg	The disburden of the relatives/friends/care takes of the participant
Rules	The rules within the PGB system
Social network	The influence of a PGB on the social network of participants.

Appendix F: Suggestions for a qualitative good interview

Table 8: Suggestions to increase the quality of the course of the interview.

- ✓ An interviewees experience is the starting point, therefore interviewees must be able to share their own personal stories;
 - ✓ The interviewer must be calm and clear.
 - ✓ An interview schedule must not be fixed since side tracks can yield relevant information;
 - ✓ The interviewer must be prepared to make compromised on the amount of information they can obtain from an interviewee;
 - ✓ Take time to acquainted and to build a relationship;
 - ✓ Make clear agreement about time of the interview. However, the duration can depend on the capabilities and limitations of the interviewee. The maximum time of an interview is one hour.
-

Source: Schuurman, Speet and Kersten (2004).

Table 9: Suggestions to ask questions and interpreted answers in the best possible way

Asking questions must include:

- ✓ Short, clear and concrete questions;
- ✓ A maximum of neutrality;
- ✓ Asking one question at the time;
- ✓ No interruption of the interviewee;

Suggestions that can make the interpretation of answers as pure as possible. Interviewer must:

- ✓ Be aware of own presuppositions;
 - ✓ Be aware of non-verbal body language;
 - ✓ Confirm what is being said without any value to it;
 - ✓ Not label answer which are not directly understood as irrelevant results
-

Source: Schuurman, Speet and Kersten (2004).