FACULTY OF PSYCHOLOGY
AND EDUCATIONAL SCIENCES

Autonomy in Social Work: A Search for Social Justice. The Case of Personal Budgets in the Care for People with Intellectual Disabilities

Toon Benoot

Supervisor: Prof. Dr. Rudi Roose
Co-Supervisor: Prof. Dr. Bram Verschuere

A dissertation submitted to Ghent University in partial fulfilment of the requirements for the degree of Doctor of Social Work and Social Welfare Studies

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Autonomie in Sociaal Werk: een Zoektocht naar Sociale Rechtvaardigheid. De Casus van Persoonsvolgende Financiering in de Zorg voor Personen met een Verstandelijke Beperking.

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Prologue

The process that led to this doctoral thesis had been coloured by two distinct terms: ‘Serendipity’- allowing for chance finds and accepting that what is found is not necessarily what was being looked for- and ‘that wonder works’ -which I suppose would be a valuable addition to the motto 'dare to think'. ‘Serendipity’ stands for an unsought, unintended or unexpected, but fortunate, discovery or learning experience. This notion is often linked to the idea that ‘everything happens for a reason’ - one that I myself have always considered to be a last straw when there are no more arguments-. In my view, this only makes sense once we have a look back. And in doing so, looking back over the past years of doing research, I can see that it was in many ways a serendipitous road, one where great moments as well as the most trivial events have made this work into what it is today, or what it will become.

It was a rather surprising chance that I was able to start this doctoral project immediately after graduating. Perhaps the fact that some people called me a 'teacher's pet' had something to do with it. But anyway, my graduation coincided perfectly with the start of an interdisciplinary research project by 'Professor Happy Sisyphus Rudi'. The evening of my proclamation turned out to be the first evening -of many to follow- of festivities with the department of social work and social pedagogy. It was on that evening that the seeds were planned for a special bond with my ‘assigned godmother’, one that turned into a relationship of mutual intellectual inspiration. Having been at work for less than two months, the plan changed 'serendipitously' for the first time: a study commissioned by the Flemish Government would take us to the Netherlands, Germany and England. This caused me to be away quite often, with colleagues and friends often forgetting where I was about to go next. It was at this point that I was given the name 'professional tourist' for the first time.

A not-to-be-missed note is that Rudi told me at the start that 'holidays are there not to be taken'. So, I did enjoy being a ‘professional tourist’. A while later, it was again Rudi that sparked an unexpected cause of events, by suggesting that I’d have a look at the capabilities approach. Soon after, I found myself on a plane to Cape Town and as it happened, this conference-trip aka ‘professional tourism’ laid the foundations for a deep and profound interest for that place and its people. There I discovered the existence of my 'inner geek', I met the embodiments behind the many texts that sparked my inspiration and drank a coffee with them or addressed them by saying 'you are like Beyonce to me'. A year later, my commitment to the Human Development and Capability Association brought me to Argentina and then to London, places where I met some highly interesting and warm acquaintances.

Another odd coincidence was that just on the last night of the Tissa-Conference, celebrating our shared ardour of being a social work researcher, my knee got dislocated, causing a memorable return trip. Precisely because of this incident, I was unable to climb many stairs a few weeks later at a congress in London. I spared myself the hurry after a seminar to move on to the next one, and so I got to chat with a South African researcher who made me excited to find out more about applications for a study stay abroad. And so, it happened. A study stay abroad at the University of Cape Town with Prof. dr. Judith McKenzie in Cape Town was approved, with visits planned to Stellenbosch University and The University of the Free State in Bloemfontein. What a delightful connection we had, and how interesting our cooperation would be. Until, as it happens, 2020 was reduced to a year of working from home.
What a delightful connection we had, and how interesting our cooperation would be. Until, as it happens, 2020 was reduced to a year of working from home.

What I had planned to do in South Africa -retreating myself into a bubble of writing with mutual learning experiences in a scenery of breath-taking views- happened to be quite the opposite: retreating myself into a bubble of writing (check) and a bubble of four, a bubble of ten, a bubble of fifteen, a bubble of five, a bubble of… within the confines of my own home. Nevertheless, 'professional tourism' made place for 'professional bubbling', allowing me to finish two articles, the introduction and the conclusion in just a few months. However, the most difficult part was yet to come: the writing of this expression of appreciation. For how could the serendipity that coloured this trajectory be understood without the very people surrounding me? How I wonder…

'Wonder works', with these words Gregory Benford concluded his eulogy of Jules Verne's work in his introduction of the 1992 reissue of the famous *From the Earth to the Moon*. Benford argued that we can grasp how much Verne changed the world by recalling real events that appeared first as acts of imagination in his novels. First, he reminds us that "The American submarine 'Nautilus', its name taken from 20,000 *Leagues Under the Sea,* surfaced at the north pole and its captain (not named Nemo, alas) talked by radio with President Eisenhower less than a century after the novel was published". Second, Benford recalls that "The explorer Haroun Tazieff, a Verne fan who had read *Journey to the Centre of the Earth,* climbed down into the rumbling throat of a volcano in Africa, seeking secrets of the earth's core. He goes on referring to events such as: "An Italian venturer coasted over the ice Arctic wastes in a dirigible just as Verne proposed", and: "A French explorer crawled into the caves of southern Europe, stumbled upon the ancient campgrounds of early man, and stood before underground lakes where mammoths once roasted over crackling fires – as Verne had envisioned". Bedford concludes praising so much wonder and imagination: "Many of his precisely envisioned dreams will never find an echo in actual events.

But Jules Verne saw huge possibility when others saw mere social mannerisms […]. Perhaps we can learn this from him: that potential lasts longer than details of the moment. And that wonder works.”

Perhaps the most significant lesson from this four-year process was that – Likewise Verne in his masterpiece 'from the earth to the moon' modelled his rocket based on the knowledge and experiences that were available in his 'current day' – the possibilities and potentials that are there, in the present, provide us with a window from which the future can be observed, if not created. What the participants in this study have indicated they consider to be valuable with regard to their care and support, and the multiplicity of possible ways in which they see their future, is permanently shaped by their past and present experiences. The more broadly the possibilities in the present can be conceived and fleshed out, the broader the possible future can be imagined. That is why I would like to thank colleagues, mentors, friends and family who have been part of how I have seen the world throughout the process of ‘being a researcher’, helping me to understand this world and broadening my possibilities to understand it. You have been constantly changing the structure, fabric and contours of my window on the world and reminded me ‘that potential lasts longer than the details of the moment'.

An – Ann – Amelie – Bram – Claudia – Eliot – Eveline – Evelyne – Floor – Franky – Free – Gerda – Guido – Griet – Hanne – Helmut – Heidi – Hilde – Ilse – Ine – Jack – Julien – John – Joy – Jonathan – Judith – Judy – Jochen – Juno – Joris – Karel – Kasper – Katrien – Kenny – Koen – Lieselot – Lisa Labath – Lieve – Lore – Lorrie – Loulou – Luc – Marlies – Max – Maria – Mia – Michel – Naima – Nele – Patrick – Robin – Rosella – Ruwayda – Rudi – Saan – Sarah – Shana – Tina – Tseggi – Wouter

Throughout this dissertation, illustrations are inserted from the hand of Henri de Montaut from the illustrated 1874 edition of Verne's *From the Earth to the Moon,* which are set to challenge the reader's imagination.

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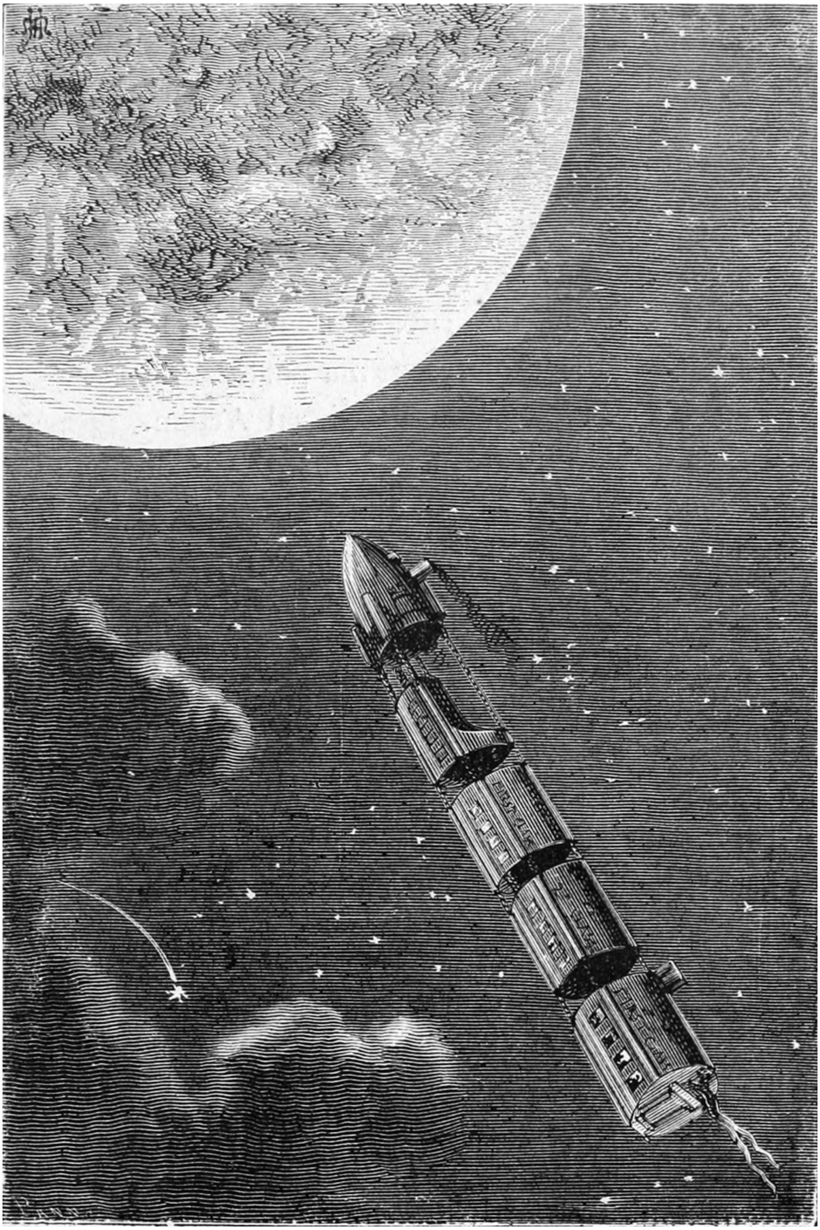
CHAPTER ONE

Introduction



1.1 Personal budgets: a case of social work and marketisation

The starting point of this dissertation lies in personalisation and marketisation tendencies in social work policy and practice (see Ferguson, 2007; Glendinning and Kemp, 2006; Kremer, 2006). In a remarkably short period of time, personalisation has become a key element of social work policy, philosophy and even legislation (Ferguson, 2007). Since the 1980s, many European countries have made greater use of market-based and managerial principles and policies (Kremer, 2006; Daly and Lewis, 2000; Glendinning and Kemp, 2006) for the delivery of welfare services (Fotaki, 2011; Hood, 2014; Le Grand, 1991; Otto, Polutta and Ziegler, 2009). And likewise, since the 1990s, modern welfare states have focussed on the personalisation of care (Brooks, Mitchell and Glendinning, 2017; Fotaki, 2011; Kremer, 2006; Wilberforce et al., 2011), shifting from 'traditional care' in care services to more individualised care in deinstitutionalised settings.

The convergence of the ideas of ‘marketisation’ and ‘personalisation’ (Arksey and Baxter, 2012; Da Droit and Le Bihan, 2010) has led to a major shift in the domain of care and support for people with disabilities (Dickinson, 2017; Kendall and Cameron, 2014; Mladenov, Owens and Cribb, 2015; Needham, 2011). Traditionally, welfare state delivery of social care for people with disabilities has tended to consist of services in an institutionalised or home setting. Walmsley (2005, p. 51) points to two main ideas that made people think of institutions as good places for people to live in. The first was “the idea that people with intellectual disabilities were dangerous and caused problems for society”. Secondly, it was thought that people with intellectual disabilities “should be looked after and cared for in ways that would enable them to live happy lives”. Today, we think it is important for people with intellectual disabilities to live in the community rather than in institutions, which are considered mistakes of the past.

With the introduction of ‘cash-for-care’ or personal budget schemes, governments aim to introduce more user choice (Stevens et al., 2011), and foster more personalised and flexible care arrangements for people with social- or health-care needs (Needham, 2011). We will refer to 'personal budget schemes' as a catch-all term for various personalised or 'cash-for-care' systems worldwide, since that is also the name used for the Flemish case we are studying. Cash for care systems include, amongst others, cash direct payments, individual budgets (Glendinning et al., 2008; Laragy, 2010) and personal budgets (Leadbeater, Bartlett and Gallagher, 2008).

In the context of these policies “social services are designed to fit their users, instead of users having to adapt to the services interests and decisions of service providers in this traditional care” (Mladenov et al., 2015, p.308). With a focus on aspects of social change and emancipation, personalisation is considered to result in a society that is fairer and more just (Payne, 2006). As such, a twofold task is set out in personal budgets, namely, to foster individual well-being and to contribute to social justice. This entails the dual mandate of social work for care and for control (Hauss, 2008). It is also not surprising that social work has a role to play in the ambition to contribute to personalisation, given the clear connection between the core elements of personalisation and the principles of social work (Lymbery, 2012; Hugman, 2007). For example, social work supports people in realising what they consider to be a 'good life' and in connecting to people's aspirations, social workers place the enhancement of well-being at the heart of their efforts (Tirions, Blok and den Braber, 2018; Robeyns, 2017). The International Federation of Social Work, too, assigns a prominent role to social work in the promotion of “empowerment and liberation of people” and the enhancement of well-being (IFSW, 2014).

Notwithstanding the centrality of social change and the promise to contribute to social justice, in both the conceptualisation of personalisation and the engagement of social work, research has shown that the implementation of personal budget schemes can become deeply individualistic (Ferguson, 2007). In line with other critical scholars (see Dean, 2015; Dowse, 2009; Owens et al., 2017), Lymbery (2012, p. 790) points to "the extent to which policy has become inseparable from neo-liberal notions of consumerism and individualisation" as "deeply troubling" for care practice, as this is far removed from "the transforming rhetoric with which it was introduced". In that vein, Ferguson (2007, pp. 400-401) declares that "given its acceptance of the marketisation of social work and social care, its neglect of issues of poverty and inequality, its flawed conception of the people who use social work services, its potentially stigmatising view of welfare dependency and its potential for promoting, rather than challenging the deprofessionalisation of social work, the philosophy of personalisation is not one that social workers should accept uncritically". This dissertation aims to make a contribution to this reflection on the engagement of social work with social justice for people with disabilities by building on how social work practitioners, managers of care institutions and people with intellectual disabilities receiving care and support relate to the concepts of autonomy and choice and to the promise of social justice and social change as embedded in personalisation and personal budget policies.

It is important for the reader to gain an understanding of the underlying dynamics, both social and political, that steered the introduction of personal budget systems across the globe (Arksey and Baxter, 2012; Laragy, 2010). This doctoral research is set up as interdisciplinary, combining a social work with a public administration perspective.

It is in this vein that we start with a brief description of three major drivers for the current era of personal budget schemes and subsequently discuss the shift from a supply-driven towards a demand-driven care and support system in Flanders. Thereafter, we proceed by drawing up the problem statement of this dissertation, expanding on its conceptual framework and outlining our research questions. Lastly, we provide an overview of the three studies that were conducted in this research.

The origins of the personal budget schemes

'Cash-for-care', or personal budget schemes, have been established in different welfare states with a large variation in their actual implementation (Dickinson, 2017; Benoot, Dursin, Verschuere and Roose, 2018). Administrations in liberal welfare regimes have a tradition of being more market-oriented in their approach to benefits and services (Arksey and Kemp, 2008; Laragy, Fisher, Purcal and Jenkinson, 2015). But personal budget schemes have also been introduced in social democratic nations such as Finland and Sweden, as well as in more conservative welfare states such as Austria and Germany and countries with liberal welfare regimes such as Canada, Australia and the UK (Arksey and Baxter, 2012; Timonen, Convery and Cahill, 2006), resulting in a wide range of applications. Personal budget schemes for people with disabilities have been the most explicit form of conceptualising personalisation and choice in social policy as they (a) provide a personalised budget based on an individual assessment, (b) can be controlled by the individual and her/his network to purchase services (rather than block-funded care providers), and thus (c) hold the promise of tailoring care to meet the specific needs of individuals (Dickinson, 2017; Timonen, Convery and Cahill, 2006). In this doctoral thesis we will not elaborate on systemic differences; however, we will explore the rationale for setting up and implementing these systems.

In the literature, we identified three factors that underpin this international policy shift: the ratification of the United Nations Convention on the Rights of People with Disabilities (UNCRPD, 2006); campaigns for autonomy led by advocacy groups for people with disabilities; and the creation of a 'care market' as a measure of new public governance.

The first major driving force is the ratification of the UNCPRD in Western welfare states. The Convention is a legally binding international human rights treaty that reinvigorates the intention to promote, protect and fulfil the rights and dignity of disabled people (see UNCRPD, 2006; Harpur, 2012). The states that endorse the UNCRPD demonstrate their recognition of the rights of people with disabilities and are required to take steps "to facilitate their full integration and participation in society" (ECCL, 2016, p. 18). This means that ratifying member states must take effective and appropriate measures to contribute to social justice in general and to enable people with disabilities to exercise their rights. The provision of personalised care by means of personal budgets can thus serve as an example of how governments and society as a whole try to find new ways to foster human development and social inclusion for all. The promotion and centralisation of choice and control for disabled people in policies on personal budget schemes can be traced back to the UNCRPD. In particular, attention is paid in these policies to Article 19, which stipulates that all persons with disabilities, regardless of the type or severity of the disability or the required level of support, have the right to live in the community, with choices equal to those of others (UNCRPD, 2006).

A second factor in the formation of the personalisation policy agenda is the campaigns of the disability movements (Morris, 2006) focussing on active citizenship (see Oskarsdottir, 2007). Social movements representing the interests of disabled people, such as the Independent Living movement and 'In Control' in England and 'Per Saldo' in the Netherlands, were responding to the restrictions on service users' autonomy and voice (Harpur, 2012). Since at least the early 1980s, the movement for independent living has been instrumental in promoting self-determination for disabled people in their daily lives (Priestley, Jolly, Pearson, Riddell, Barnes and Mercer, 2006). Traditional service delivery provides little opportunity for disabled people to take control of their lives and make decisions (Arksey and Kemp, 2008). In order to acquire greater choice and control in the care they receive, these movements advocated for the deinstitutionalisation of public services. Through redistributive measures such as personal budgets, in all their variations, they sought the enhancement of service users' autonomy (Owens, Mladenov and Cribb, 2017). Independent living advocates argue that if people with disabilities require personal support or other services to ensure their citizenship and social inclusion, such support should be financed and provided in such a way that the individual is in control. They therefore argue that people with disabilities should be entitled to personalised funding so that they can plan, purchase and control their own care and support arrangements (Stainton, 2002).

These campaigns are based on the politics of disability rights and argue for increased choice and control as essential elements of self-determination (Duffy, 2003; Shakespeare, 2006), putting the notion of 'autonomy' at the centre of the care and support agenda (Baxter and Glendinning, 2011; Boyle, 2004; Lymbery, 2012; Needham, 2013; Kendall and Cameron, 2014).

The third foundation of these policies is the creation of a 'care market' in which people can select the appropriate care that meets individual quality requirements (van den Berg and Hassink, 2008; Arntz and Thomsen, 2011). Although the campaigns of the disability movements for increased choice and control created apparent opportunities to give more input into decisions about health and social care services (Baxter and Glendinning, 2011), these movements have argued that a developed market for care provision is an essential element in making real use of the opportunities (Dowse, 2009; Brooks, Mitchell and Glendinning, 2017). Inspired by the ideology of new public management, the role of the market in the provision of care is growing and is promoting competition over prices and the quality of care services (Baines, 2010; Gevers and Breda, 2011). Markets and competition have been introduced as a tool to increase effectiveness and efficiency for a large variety of public services (Eikenberry and Kluver, 2004; Osborne, 2006). In some countries, such as Finland, an explicit objective of cash-for-care schemes has been precisely to induce the development of a home care market (Timonen et al., 2006). Leadbeater and Lownsbroug (2005) support a market in social care and present personalisation as the logical development of such market-oriented policies. In particular, Leadbeater's publication *Personalisation through Participation: A New Script for Public Services* (Leadbeater, 2004) has been extremely influential in the tendency towards personalisation in social work and social care in the UK. A policy and practice of social work based on personalisation is presented as a natural consequence of marketisation:

> Privatisation was a simple idea: putting public assets into private ownership would create more powerful incentives for managers to deliver greater efficiency and innovation. Personalisation is just as simple: by putting users at the heart of services, enabling them to become participants in the design and delivery, services will be more effective by mobilising millions of people as co-producers of the public goods they value (Leadbeater, 2004, p. 19).

The central argument for personalisation that Leadbeater (2004) puts forward refers to increased individual responsibility for personal care. Other authors have noted that the introduction of market principles in the context of public service delivery changed the role of citizens into that of ‘citizen-consumers’ (Owens, Mladenov and Cribb, 2017), and this is also the case with personal budget policies for people with disabilities (Wilberforce et al., 2011). The interplay of marketisation and the personalisation agenda is presented as a boost for the promotion of disabled people’s freedom and independence through relocating welfare resources from institutionalised and professionalised care to “self-driven consumers who sovereignly wield the power to buy” (Mladenov, 2012, p. 251). Financed by grants or vouchers, citizens are enabled to purchase services in the marketplace and are being compelled to choose between different providers to drive competition (Dean, 2015). This is expected to result in more efficient and effective services with a lower cost (Laragy, 2010; Mladenov, Owens and Cribb, 2015; Roulstone and Morgan, 2009; Tschanz, 2018). Or as Priestley, Jolly, Pearson, Riddell, Barnes and Mercer (2006, p. 1190) put it aptly: “Placing financial resources under the control of disabled people [...] challenges traditional assumptions about power and dependency and redefines purchaser-provider-user relationships”.

The Flemish personal budget system: ‘Persoonsvolgende Financiering’

The decree that regulates ‘Persoonsvolgende Financiering’ (see Ministerie van de Vlaamse Gemeenschap, 2014) is based on two concept notes of the Flemish Government: (1) the long-term vision entitled 'Perspective 2020 - a new support policy for persons with disabilities' (Department of Welfare, Public Health and Family Affairs, 2010) and (2) the concept note concerning direct payments for people with disabilities (Department of Welfare, Public Health and Family Affairs, 2013).

In 2010, Minister Vandeurzen outlined a long-term vision for the support policy for persons with disabilities, 'Perspective 2020', that was explicitly concerned with the citizenship and rights of disabled people (Department of Welfare, Public Health and Family Affairs, 2010, 2018). The vision seeks to apply the basic principles of the UN Convention on the Rights of Persons with Disabilities, which was ratified and implemented in Belgium in August 2009, within the Flemish policy context. Perspective 2020 argues that this ratification demonstrates the intention of the Belgian and Flemish government to actively realise the rights of disabled people, as "the convention intends to enable disabled people to enjoy the full realisation of their rights while treating them on equal terms by encouraging the authorised states (...) to create appropriate environments and measures" (Department of Welfare, Public Health and Family Affairs, 2010, p. 3, our translation). In that sense, the policy document prominently proclaims an underlying and innovative paradigm shift from a care- to a support-oriented approach (Roets et al., 2020). At the heart of this White Paper is the promise to enable people with disabilities to become well-informed users in a demand-driven care and support landscape (Geeraert et al., 2016). This concept paper is intended to have the care innovation for persons with disabilities well underway by 2020. Although Perspective 2020 is currently at the end of its life cycle in Flanders, the key policy components are likely to remain in the next policy plan of the Flemish Government for 2020–2025 (Roets et al., 2020). The second concept note on 'direct payments for people with disabilities' (see Department of Welfare, Public Health and Family Affairs, 2013) builds on a few points from the White Paper and is a more concrete expression of what the new funding system was intended to look like. It included concrete proposals on how to implement and guarantee central elements, such as 'demand-driven care' and 'care guarantee' in practice, as well as the introduction of a separate basic support budget and personal financing budget for not directly accessible VAPH support.

The decree PVF was approved by the Flemish Parliament on 23 April 2014 and gives every person with a disability the right to organise his or her support themselves, thereby moving beyond the former PAB and PGB schemes.

Four fundamental objectives emerge from the two concept notes and form part of the basis of the final decree. In the first place, the Flemish government aims to guarantee, by 2020, care and support for people with disabilities in the most urgent need of support (Department of Welfare, Public Health and Family Affairs, 2010; Ferket et al., 2019). Secondly, (potential) users need to be well informed to be able to apply for and receive the necessary care and support. A third goal of PVF is to realise tailor-made care and support for users. This implies a certain flexibility that should enable persons with disabilities and their families to tailor their care and support to their specific needs and situation at all times. Finally, the Flemish Government aims at care and support for persons with disabilities that enables their full participation in society, with an emphasis on inclusion and 'vermaatschappelijking van de zorg'. The latter is a catch-all concept that is difficult to translate (for a similar idea of a 'Big Society' in the UK, see Goodley and Runswick-Cole, 2015) and a 'participation society' that has been formally introduced and implemented in the Netherlands (see Grootegoed, Broër and Duyvendak, 2013). These four objectives are translated into specific policy decisions and in the implementation of the system of personal budgets.

In chapter four, we will provide a brief overview of this profound change in the organisation of the Flemish care landscape and discuss some of the instruments and interventions aimed at achieving these objectives, as well as how the VAPH intends to strengthen them further in the future.

1.2. Problem statement: towards a scientific study of a pedagogy in the context of personal budgets

Personal budgets as an ambiguous concept

Alongside the premise that personalisation and marketisation, embodied in personal budget schemes, can contribute to a socially just care and support practice for people with disabilities, critiques and concerns about the development and implementation of personal budget schemes in practice have been shared by a number of scholars (e.g. Dean, 2015; Dowse, 2009; Ferguson, 2007; Galvin, 2004; Leece and Leece, 2006; Mladenov et al., 2015; Needham, 2011; Owens et al., 2017; Roets et al., 2020; Yeandle and Ungerson, 2007) One of the main critiques is that personalisation proceeds from an ambiguous conceptual point of view (Ferguson, 2007; Houston, 2010; Lymbery, 2010), as reflected in the strained relationship between the three pillars of personal budget policies: the ratification of the UNCRPD (2006), the campaigns for autonomy of advocacy groups for people with disabilities and the creation of a 'care market' as a measure of new public governance. This strained relationship between the various grounds on which personal budgets are based has been the subject of three major criticisms in the literature: firstly, the emphasis on individualisation; secondly, the introduction of personal budgets seen as a convenient savings campaign; and thirdly the focus on 'consumerism' always putting social justice in second place.

The first critique is aptly formulated by Clarke (2005), who argues that the emergence of personal budgets has been dominated by a concern to 'liberate' people with disabilities from the state, an idea which aligns with key themes of New Labour thought, including individualisation, responsibilisation and the transfer of risk from the state to the individual (Beck, 1992; Broadhurst, Hall, Wastell, White and Pithouse, 2010; Ferguson, 2007).

It is precisely because of concerns over the individualising effect of the marketisation of public services (Arksey and Kemp, 2008) that the introduction of cash-for-care as a mode of service provision was strongly opposed in Scotland (Pearson, 2006). Care practices within a context of personal budgets are claimed to be characterised by an intensifying pursuit of efficiency (Clarke, Newman and Westmarland, 2008), with emerging pressure on the accountability relationships of social professionals and -possible- direct payments recipients (Ellis, 2007; Caldwell, 2007; Doty et al., 2010; Brooks et al., 2015). It is argued that a financing system driven by consumer choice would potentially realise competition in the social care market as well as take away control from care professionals and give it to care users (Da Droit and Le Bihan, 2010, Kodner, 2003, Arksey and Kemp, 2008). This critique of extensive individualisation suggests that the notions of service user choice, control and autonomy, promoted by the campaigns of the disability movements (Morris, 2006), in fact are the main ideas behind personal budget schemes for people with disabilities.

Second, critical scholars point to a more pragmatic objective of cost reduction in social care, which appeared to be a crucial consideration for governments introducing personal budget schemes (Galvin, 2004; Yeandle and Ungerson, 2007). Because personal budget schemes are thought to involve less bureaucracy and outsource the 'transaction costs' associated with organising care for the recipient, they are seen as being cheaper than in-kind service delivery (Schore et al., 2007; Slasberg, Beresford and Schofield, 2012). Indeed, research shows that personal budget schemes might bring some substantial improvements over traditional care arrangements from a cost-efficiency perspective (Stainton and Boyce, 2004). The essential value of efficiency might lead to a context in which accountability for the allocation of resources takes precedence over the meaning of their use.

A third point of critique lies in the centrality of the policy rationales focussing on individual responsibility, choice and self-determination of disabled people in the targeted flexible market of service delivery. Scholars such as Dowse (2009), Dean (2015) and Garett (2018) point to the challenges for people with -intellectual- disabilities that this particular interpretation of freedom and autonomy might create, as it defines them as consumers in a care landscape that privileges competency, capacity and individual welfare independence. This dominant ableist rhetoric (Williams, 2001; Goodley, 2014) might paradoxically mark people with intellectual disabilities as different and disabled (Dermaut et al., 2019). In line with this critique, Leece and Leece (2006) observed that the personal budget scheme in the UK might be creating a two-tiered system in social care where more affluent, middle-class people reap the many benefits of cash payment. And although these policy reforms are rooted in the UNCRPD, critical academic research has concluded that tendencies towards marketisation always curtail the social justice agenda in personal budget practice (Mladenov et al., 2015; Needham, 2011; Ferguson, 2007).

A social work perspective on the practice of personal budgets

In this dissertation, we research personal budgets for people with disabilities from a social work perspective. This is particularly important since a wide range of scholars (see Baxter and Glendinning, 2011; Brooks et al., 2017; Dew et al., 2013; Fleming et al., 2016; Jones et al., 2012; Laragy and Ottmann, 2011) point to the challenging balance between the various grounds on which personal budgets are based, which we have outlined above. The twofold task that is set out in personal budgets – to foster individual well-being and to contribute to social justice and social change – in fact mirrors the dual mandate of social work (Hauss, 2008; Hugman, 2007).

Notwithstanding the centrality of social change and the promise to contribute to social justice in the conceptualisation of personalisation, research has shown that the implementation of personal budget schemes can become deeply individualistic (Ferguson, 2007). In addition to this individualistic turn, Spicker (2013) draws attention to the observation that "neither the theory nor the practice [of personalisation] offers adequate justification for developing a programme of personalisation for all of the groups, all of the time" (p. 1272). From this, we explore the potential contribution of a social work perspective to personal budgets, paying attention to both personal well-being and social justice. The centrality of social change, social well-being, human rights and social justice in personal budget schemes in general and the Flemish PVF system in particular raises an issue of special interest for social work (Lymbery, 2012; Hugman, 2007), as the global definition of social work articulates:

> Social work is a practice-based profession and an academic discipline that promotes social change and development, social cohesion, and the empowerment and liberation of people. Principles of social justice, human rights, collective responsibility and respect for diversities are central to social work. Underpinned by theories of social work, social sciences, humanities and indigenous knowledge, social work engages people and structures to address life challenges and enhance wellbeing. The above definition may be amplified at national and/or regional levels (IFSW, 2014).

From this global definition, four elements can be discerned that serve as a global template for social work involvement: the concepts of social change, social well-being, human rights and social justice (Hugman, 2007). These are concepts that can easily fit within personalisation and personal budget schemes and that are reflected in the four objectives of the Flemish PVF system:

1. guarantee care and support, 2. ‘well informed users’, 3. tailormade care and support and 4. inclusion and ‘vermaatschappelijking van de zorg’.

Major social change is promised as an essential feature of the policy change. Well-being is highlighted through the guaranteed “adequate, appropriate, and high-quality support” (Department of Welfare, Public Health and Family Affairs, 2010, p. 22), while the themes of human rights and social justice are central to the disability movement, which is based on the politics of disability rights and has strongly influenced the policy (Lymbery, 2012; Morris, 2006; Shakespeare, 2006). Moreover, the Flemish long-term vision 'Perspective 2020', which paved the way for PVF, is explicitly concerned with the citizenship and rights of disabled people as it seeks to apply the basic principles of the UNCRPD.

This transformative nature is reflected in the mandate of social work to support clients on an individual level while at the same time engaging in discussions about the structural nature of the problems and to realise broader social reform (Powell, 2001; Roose et al., 2012), a position in which social workers act as intermediaries who aim to address private issues related to the public sphere (Bouverne-De Bie, 2015; Schiettecat, Roets and Vandenbroeck, 2018). The tension and ambiguity caught in this intermediary position of social work needs to be highlighted and reflected on, as it is an abiding feature of social work (Bouverne-De Bie, 2015). This ambiguity should be neither resolved nor abandoned, as both elements are fundamental to realising the objectives of social work (Bouverne-De Bie, 2015; Roose et al., 2012). Lorenz (2016, p.13) states that “especially in conjunction with the ‘personalisation of care’ […] the temptation is to by-pass the need to negotiate explicitly between the individual aspirations of clients for achieving their goals and the political determinants of available options as has been the central mandate of social work”.

The ‘by-pass’ noted by Lorenz (2016, p. 13) refers to a social work practice that attempts to realise and implement personal budgets understood from a managerialist point of view, with a focus on autonomy as consumerism and an increased individualisation (Ferguson, 2007; Owens et al., 2017), which hampers the dual mandate of social work. This requires a search for a pedagogical perspective on social work. This pedagogical perspective in our research refers to the deliberative character of social work practice, one that is characterised by a context-oriented view of what human dignity and autonomy might mean to an individual in a given context. In addition to the question of how to contribute to the realisation of human dignity and social justice, a pedagogical perspective on social work is essentially concerned with becoming aware of multiple possible understandings of human dignity and the acknowledgement of these ambiguous meanings in a given context. Taking a pedagogical stance in social work requires that the primary question for social work in the realisation of well-being and a ‘good life’ for people with disabilities is not about a one-sided determination of how people with disabilities can achieve the greatest degree of self-sufficiency and independence. In positioning social work critically in the face of personal budget schemes in the care provided for people with disabilities, social work is supposed to be reflexive and to question the inherent complexity in the practices, trying to bridge individual experiences and aspirations to occasions that affirm social citizenship and promote social equality on a broader socio-political level (Lorenz, 2013, 2016).

The ambition to bring about social change and to contribute to a more socially just society is a common thread throughout personal budget schemes, not to mention the Flemish PVF policy. Due to the interplay of different agendas, the pursuit of a socially just practice is not consistently realised.

The early rhetoric of personalisation was undoubtedly ‘transformational’ (Payne, 2006), focusing on aspects of social change and the wider emancipatory aspects of personalisation to ensure that society could be transformed into one that was fairer and more just. This initial transformational and emancipatory idea has been criticised for moving towards a view of empowerment as a private responsibility and a narrower translation of personalisation from an individualistic perspective (Ferguson, 2007), as a mechanism to enable individuals to achieve their hopes and desires. The extent to which personal budget policies have become inseparable from “neo-liberal notions of consumerism and individualisation” is considered to be “deeply troubling” for developing a care practice (Lymbery, 2012, p. 790) that is concerned with social justice. It is argued that a one-sided focus on individual autonomy and responsibility (Lorenz, 2016) that adheres to market principles (Ferguson, 2007) is presented as if there were no possible alternatives, thereby hampering the debate on social policy making.

This dissertation therefore examines how different parties in the care relationship contribute to a socially just pedagogical perspective on 'the act of social policy making' (Lorenz, 2016), and how these stakeholders position themselves in the debate about where the focus of social change and social justice, on the one hand, and individual well-being, on the other, should be situated in the context of personal budgets for people with disabilities. The mandate of social work is seen as a pedagogical one that consists of adhering to the premise, at a personal and political level, that there are always alternatives and that alternatives must be based on joint negotiations between all participants (Lorenz, 2013).

We will address the question of how the aspirations and needs of persons with disabilities are positioned in respect of the intention to empower them as 'self-determining subjects', on the one hand, and how the pursuit of inclusion and social justice is shaped in relation to those persons who are not self-determining and who will always be in a dependent position, as well as being in need of principles of solidarity, on the other. In other words: in what way might a practice be shaped that addresses ‘a good life’ for people with disabilities according to their individual preferences and choices and relates to the social justice agenda? In order to flesh out this exploration of bridging individual interpretations of well-being with social justice, we make use of the capabilities approach as a research perspective.

1.3. Conceptual framework: a capabilities approach as sensitising framework

> "A capabilities approach begins from a conception of the person as a social animal, whose dignity does not derive from an idealized rationality, it offers a more adequate conception (than a contract-theory) of the full and equal citizenship of people with impairments and of those who care for them" (Nussbaum, 2006, p. 99).

In the following section we elaborate on the capabilities approach and what aspects of that approach are included in this research. First, the capabilities approach is presented as a theory of justice (Nussbaum, 2006; 2011; Sen, 1992, 1999, 2009) that can provide valuable levers for social work in general and for an understanding of the socially just nature of personal budget schemes in particular. We elaborate on the dual ambition of the capabilities approach as a normative framework that promotes both well-being at the individual level and the socially just character of a society by reducing and eventually eliminating deprivations of freedom. Second, we explain why the more deliberative approach of this theory of justice, as developed by Sen (1999), will be of value for this research. We go on to focus on four key concepts on which this approach is based: capabilities, functionings, resources (or commodities) and conversion factors. Thereafter, three core characteristics of the capabilities approach are explained, as well as their relevance for this research: the centrality of freedom, the recognition of diversity and the focus on 'the good life' instead of on 'rights'.

The capabilities approach as a theory of justice

The focus of this research is on the opportunities for persons with disabilities to shape for themselves the care and support they need, to contribute to their autonomy and to do so in a socially just way. In doing so, we search for a deepening of the pedagogical perspective on social work, in which the pedagogical is concerned with the constant rediscovery of what is righteous and socially just. To reflect on this socially just pedagogy, it is important to use an approach that combines the interaction between the individual and their context from both an individual and contextual perspective. Throughout this dissertation we therefore make use of the conceptual framework of the capabilities approach, in some chapters as a background to orient the discussions, in other chapters as a guiding framework.

The capabilities approach was developed by Amartya Sen (1992, 1999, 2009) as a conceptual framework that challenges social inequalities and enables us to theorise the pursuit of social justice and equality. This framework is meant to provide a process-oriented instead of an outcome-based approach to social welfare, measuring more than just outcomes as indicators of justice and equality (Saito, 2003; Nussbaum, 2006). In a capabilities approach, the individual person will be at the forefront, but always in relation to his or her context (Walker, 2005). Starting from the observation that the individual is intrinsically connected with the context, an evaluation of their ability to be a member of or engage in a society implicitly entails an evaluation of that society (Sen, 2009). According to the capabilities approach, to live a good life entails being free to make autonomous choices about the way people want to live their lives, and to be able to realise the desired choices. In addition to focusing on what people are actually able to be and to do, the capabilities approach recognises the role of 'goods and services' that are available, and of course where they are missing or not appropriate (Alkire, 2010).

It is therefore important to look at obstacles that hinder the freedom to live the life that is reasonably considered worth living (Sen, 2009). This means that the development of well-being and ‘a good life’ depends on social and policy arrangements and relations with others, and well-being within a capabilities framework is therefore always realised with and through interactions. This corresponds with the position of social workers as intermediaries aiming to address as well as build on private issues related to the public sphere (Schiettecat, Roets and Vandenbroeck, 2018).

The potential value of a capabilities approach for researching social work and practices of personalisation and personal budgets is easy to demonstrate. Robeyns (2003) describes the capabilities approach as a broad normative framework for the evaluation of individual well-being and social arrangements, the design of policies and proposals about social change in society. The international definition of social work (IFSW, 2014) includes several values or goals that are at the heart of the capabilities approach, such as enhancing people's real freedoms, the importance of social justice and respect for diversity, and the promotion of well-being (Robeyns, 2017, in Tirions, Blok and den Braber, 2018). Furthermore, these themes are echoed in the four objectives of the Flemish PVF system (Department of Welfare, Public Health and Family Affairs, 2010, 2018): (1) ‘To guarantee care and support’ aligns with the promotion of well-being for all persons with disabilities; (2) ‘Tailor-made care and support’ echoes respect for the diversity of ways in which persons wish to receive care; (3) ‘Informed citizens’ aligns with the creation of real freedoms for people to choose how they want their care to be organised; and (4) ‘Vermaatschappelijking’ and inclusion are presented as ways of realising social justice. Furthermore, due to the integration of multiple dimensions of human life and situating people explicitly in the context and structures in which they live (Brummel, 2017; Sen, 2009; Robeyns, 2016), the capabilities approach can offer a good counterbalance to the one-sided approaches that tend to dominate debates on social issues, such as neoliberal or economic analyses (Robeyns, 2017). Within the scope of this research, where we look at personal budgets from a pedagogical perspective on social work, and thus at the intersection of personal well-being and contribution to a socially just society, such an approach has considerable value.

A deliberative approach

Sen (1999, 2009) and Nussbaum (2006, 2011) are the two most influential theorists of the capabilities approach. Their work displays a great deal of similarity, but there are also some differences in their elaboration of the approach. The main difference is the manner of defining the central capabilities, i.e. the most important capabilities to which all other capabilities are linked. Here, Sen (1999, 2009) holds the opinion that a public dialogue or 'public reasoning' should be cultivated as a way of deciding which freedoms and capabilities are considered important in a specific society. In this view, therefore, it is not adequate to determine from a theoretical perspective which prioritised capabilities are important to every human being. Instead, a democratic process should enable people to express their own preferences. Nussbaum (2011), on the other hand, departs from common denominators about what people consider to be of value in a life. She argues that there should not be a dialogue in every specific situation about which capabilities are important. To this end, Nussbaum (2011) theorises a list of ten 'central capabilities', which indicate a basic level that every human being should reach in order to lead a dignified and good life. Nussbaum's approach is more explicitly normative than Sen's highly deliberative approach.

In this research, the deliberative approach of Sen (1999) is more appropriate as we want to focus specifically on the personal, social and physical circumstances of the professionals and the persons with disabilities involved in care institutions in the context of personal budgets in Flanders. The deliberative nature of the capabilities approach allows us to reflect on a pedagogical perspective on social work that is explicitly concerned with becoming aware of multiple possible understandings of autonomy, 'the good life', human dignity and the acknowledgement of these ambiguous meanings.

It is argued that the capabilities approach (CA), by focusing on the substantive freedom of the individual to do or to be that which she or he values, is better able to accommodate the diversity of human beings and the complexity of their circumstances (see Burchardt, 2006). In this vein, it relates to the pedagogical perspective on social work (see Bouverne-De Bie, 2015; Lorenz, 2016). On the other hand, critiques have been formulated by Dean (2009) on the point of the CA prioritising individual liberty over social solidarity and the freedom to choose over the need to belong. However, capability theorists such as Burchardt (2006) and Robeyns (2003) stress that while the approach focuses on the freedoms and achievements of individuals, these individuals are located in society and are connected to others (Sen, 2009; Robeyns, 2003). The focus on the individual is therefore ethical (as each individual person is of moral worth) and need not imply ontological individualism (the individual as most important) or methodological individualism (Robeyns, 2005). Following this line of argument, this research will make use of the CA as a conceptualising framework (see Deneulin, 2008) to theorise and understand social justice in personalisation policy and practice rather than an evaluative tool (Sen, 1999) of an individual’s quality of life.

Key concepts

As there are various capability theories rooted in the capabilities approach (e.g. Nussbaum's theory of justice (2011) and the theory of disadvantage of Wolff and De-Shalit (2007)), Robeyns (2016) distinguishes 12 central features that appear across the diversity of capability theories and make up the bedrock of the capabilities approach. Four of these characteristics are the key concepts: resources, capabilities, functionings, and conversion factors, presented schematically in figure 1.

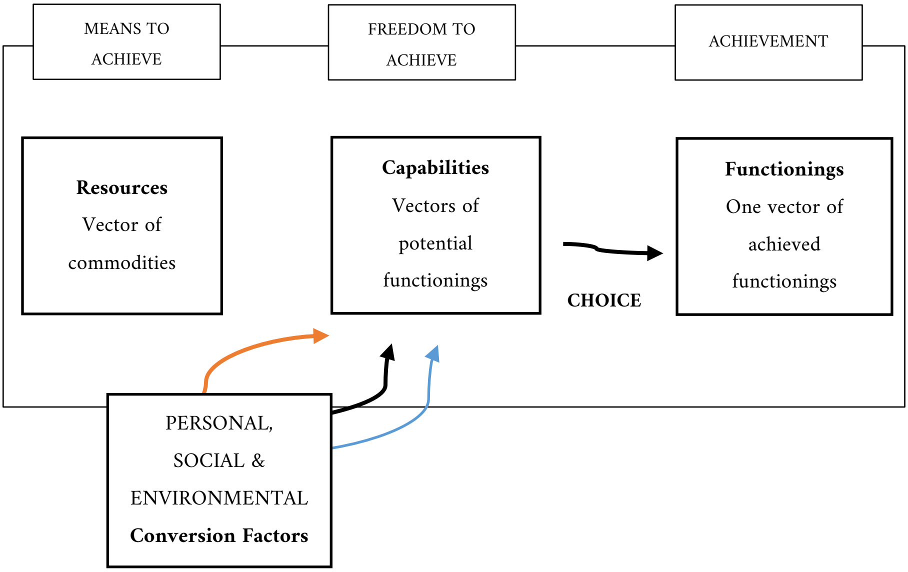


Figure 1. The key concepts of the capabilities approach. Author adaptation of Robeyns, 2003.

1. Capabilities: The freedom to achieve

The capabilities approach makes a distinction between means and ends of well-being and development. Only the ends have intrinsic importance, whereas means are mere instruments to achieve the goal of increased well-being and development (Robeyns, 2003). From this distinction between means and ends, well-being should be discussed in terms of people's capabilities to function. These are people's effective opportunities and freedoms (capabilities) to lead the kind of life they want to lead, to do what they want to do and be the person they want to be (Sen, 1992, 1999). Once they effectively have these freedoms, they can choose to act on those freedoms in line with their own ideas of what a valuable life would be, resulting in functionings.

2. Functionings: Achievements

Capabilities are 'real freedoms' (Robeyns, 2003) and refer to different combinations that people can make of available functionings, whereas functionings are "the different things a person can value doing or being" (Sen, 1999, p.3). Capability is thus a set of 'vectors of functionings', reflecting the person's freedom to lead one type of life or another (Sen, 1992). The exact nature of the functionings and therefore what individuals find important is subjective and context bound:

> "A functioning is an achievement, whereas a capability is the ability to achieve. Functionings are, in a sense, more directly related to living conditions, since they *are* different aspects of living conditions. Capabilities, in contrast, are notions of freedom, in the positive sense: what real opportunities you have regarding the life you may lead" (Sen, 1987, p. 36).

3. Resources and commodities: Means to achieve

Another crucial conceptual distinction in the capabilities approach is the distinction between resources or commodities on the one hand and functionings on the other. Resources or commodities are goods and services which help to achieve a certain functioning (Robeyns, 2003, 2016). Resources and commodities include concrete matters such as transportation if a person wishes to visit a distant friend, having a telephone when a person depends on interim jobs, but also fundamental matters such as access to health care, education, housing, or sufficient income (Tirions and den Braber, 2018). They should not therefore be thought of exclusively as income or money – as this would restrict the capabilities approach to analyses and measurement in market-based economies (Robeyns, 2005; Sen, 1992, 1999).

4. Conversion factors

The relation between the resources and the achievements of certain beings and doings is influenced by three conversion factors: personal, social and environmental characteristics. 'Conversion factors' are in general material and social conditions (Walker, 2019) that interact and affect in divergent ways (Robeyns, 2017). Their interplay converts resources of different kinds into capabilities and capabilities into functionings, in both enabling and constraining ways (Sen, 2002; Robeyns, 2017). Firstly, personal factors (e.g. physical condition, intelligence) influence how a person can convert a given commodity into a functioning (Nussbaum, 2011; Robeyns, 2005; Walker, 2019). Personal factors, such as having a poor physical condition or never having learned to cycle, will cause a bike to be of limited help to enabling the functioning of mobility. Social factors, such as public policies, gender roles or power relations, play a role in the conversion from characteristics of the good to individual functioning, as do environmental factors (e.g. infrastructure, institutions, public goods) (Nussbaum, 2011; Robeyns, 2003).

To stick with the example of the functioning of mobility: if there are no paved roads, or if a society imposes a social or legal norm that women are not allowed to cycle without being accompanied by a male family member, then it becomes much more difficult or even impossible to convert the good into a functioning (Robeyns, 2003).

By means of conversion factors, the capabilities approach recognises the complex ways in which various factors intersect, interrelate and influence the lives of people (Walker, 2019). The capabilities approach thus evaluates societies and policies according to their impact on people's capabilities, their real opportunities and freedoms. While functionings and capabilities are of ultimate concern, this brief introduction shows that other dimensions can be important as well. The capabilities approach thus regards well-being in a comprehensive and integrated manner, and much attention is paid to the links between material, mental and social well-being, and to the economic, social, political and cultural dimensions of life (Nussbaum, 2006; 2011; Robeyns, 2003; Sen, 1992; Walker, 2019).

Core characteristics

'Freedom'

The capabilities approach draws on the principle that everyone should be able to or be enabled to lead a life that he or she wants to live. This makes 'freedom' a key concept in this approach. Freedom serves the expansion of people's 'capabilities', the opportunity freedoms each person has to choose a plurality of functionings (achievements) that make up a flourishing life that people have reason to value (Sen, 1999; Alkire, 2010). Sen (1992) also emphasises the importance of freedom for a society to blossom, since real opportunities for people to lead a life they themselves have reason to value generate more human well-being and development in society as a whole.

Freedom in interconnectedness, a relational perspective, is of paramount importance in the CA (Tirions and den Braber, 2018), since it is only in relation to others and embedded in a community that people are able to shape their existence (e.g. Lister, 1997). To the extent that appropriate circumstances do not present themselves (Nussbaum, 2000), people can only be free in a society that enables and guarantees freedom. In this sense, the individual development of each citizen is linked to a collective and social responsibility to be concerned about the real opportunities and freedom of others to flourish (Bonvin, 2011; Walker, 2006). From this point stems the societal responsibility to focus on the creation of opportunities for persons with disabilities, whose opportunities are often significantly impeded (e.g. Dubois and Trani, 2009; Nussbaum, 2006, 2011; Sen, 1992; Trani, Bakhshi, Bellanca, Biggeri and Marchetta, 2011). Translated into social work practice, it is about focusing on developing, realising and securing freedoms (Tirions and den Braber, 2018) at both the individual and societal levels, that create the opportunities and potentials for people to live a life that they consider valuable.

'The recognition of diversity'

A second central feature within the CA is the recognition of diversity as a specific human condition. Individual citizens differ from one another based on their personal history, characteristics, values, goals, environment and ability to convert resources in well-being (Sen, 1999). Additionally, the choices people (can) make are bound to their very personal characteristics, which means that each individual needs different combinations of functions in order to achieve the same level of well-being. In the case of personal budgets, providing a budget as a resource does not mean that all individuals will be able to make preferred decisions and organise their preferred support. The CA considers not only achievements in the evaluation of one's well-being, but also the real freedoms a person has to achieve this.

Inequalities should therefore be viewed multi-dimensionally, because the functioning 'not having a job' makes no reference to the freedoms people have to achieve this outcome (Robeyns, 2003). This recognition of diversity is especially acknowledged in the consideration of the importance of conversion factors. The CA acknowledges interpersonal variations in the conversion of resources into functionings, recognising the complex ways in which various factors intersect, interrelate and influence the lives of people (Sen, 1992; Robeyns, 2017; Walker, 2019). Furthermore, human diversity is not perceived as a complication, as something that expects policy to build in exceptions 'later on', but a fundamental aspect of the pursuit of equality (Sen, 1992). The central role of human diversity within the capabilities approach prompts the full acknowledgement that everyone has special needs (Mansell, 2006), and acknowledges the necessity of policy to allow customised interventions (Mitra, 2006; Biggeri, Bellanca, Bonfanti and Tanzi, 2011).

'The good life'

Third, the capabilities approach focusses on 'the good life' instead of on 'rights' (Robeyns, 2016). The CA focuses on quality of life based on the question of 'what people can actually do and be'. In addition to the question of 'what a good life is' (Robeyns, 2005), it is important to look at barriers that hinder the freedom to live the life that is considered to be reasonably worth living (Sen, 2009). This focus supports looking at actual opportunities for a good life, the capabilities. From the awareness of different ideas of the good life follows the recognition of the fact that two people with identical capability sets are likely to end up with different achieved functionings, as they will probably have made different choices (Robeyns, 2003). This serves as another reason why capability, and not achieved functioning is the appropriate political goal for policies that aim to contribute to social justice (Otto, Walker and Ziegler, 2018).

A capability-informed socio-political approach focuses on the creation of opportunities for people so that they are able to develop freely according to personal standards of 'the good life' (Sen, 1999; Nussbaum, 2000).

This brief exploration of the CA teaches us that it covers the full range of what a dignified life for a person entails. In the capabilities approach, the definition of 'disabilities' is placed within the wider spectrum of human well-being and development, shifting the focus from the specificities of the disabling situation to looking at establishing equality in terms of options and choices (Mitra, 2006; Nussbaum, 2006; Trani et al., 2011). To promote the capabilities of persons with disabilities, public policies affect the factors that allow individuals to convert resources into real freedoms from which they can make choices (Otto, Walker and Ziegler, 2018; Robeyns, 2005). In this vein, Sen states that people with disabilities may need different types and varying amounts of capability inputs (policies, resources, social norm changes, infrastructure, etc.) to reach the same level of well-being as the non-disabled citizens in society (Sen, 1999, 2009).

Embedded in the theoretical framework of the CA, our research aims to think beyond functionings, outcomes of personalised care and the logic of a care market. This approach emphasises the shift towards the question of the expansion of 'human capability' and real freedoms, which focuses on the ability of people with disabilities to lead lives they have reason to value and to enhance their substantive choices regarding their care and support. In doing so, we gain insight in the capability-promoting character of personal budget policies (Bonvin, 2011; Otto, Walker and Ziegler, 2018) and how they might strengthen democratic social power (Wright, 2010).

This democratic aspect is a central notion of capability-promoting policies that is committed to the aim of social and political justice, which apart from the commitment to provide all people with genuinely equal access to the material and social means necessary for living flourishing life, also emphasises that “people should be able to contribute to the collective control of conditions and decisions that affect their common fate” (Otto, Walker and Ziegler, 2018, p. 303). From the above we learn that a capability-informed framework allows us to scrutinise both individual well-being under a personal budget policy and whether a policy aiming at the realisation of a good life itself can be described as just.

1.4. Research aims and questions

This dissertation focusses on the development of socially just care and support practices within a changing policy context and system shift towards personal budgets that expects practices to move from supply-driven to demand-driven care in the sector for people with disabilities in Flanders. We have indicated that personal budget policies have become inextricably linked with a one-sided focus on individual autonomy and responsibility, which is the central problem in this research. We therefore aim to reflect on the potential contribution of a socially just pedagogy to the social work practice of personal budget schemes. A social work practice where the focus is on the correct implementation of the policy on personal budgets is central will focus on the realisation of the envisaged idea of autonomy, whereas a pedagogical perspective on social work is concerned with awareness and acknowledgement of the ambiguous meaning of autonomy and its potential meaning in a given context. It is in this vein that this research aims to explore how the theoretical insights of the capabilities approach as a theory of justice can contribute to our understanding of personalised care and support for people with disabilities as part of a social justice agenda. And last but not least, we aim to gain insight into what people with disabilities themselves consider to be a 'good life' and what personalisation and personal budgets mean to them in the pursuit of living the life they deem valuable. Accordingly, this aligns with the aspiration to stimulate academic and public discussion of the understanding of what a socially just policy and practice of care and support for people with -intellectual- disabilities might entail. These broad research aims were specified in the main question this dissertation will tackle:

> **How can a socially just pedagogy – aware of the ambiguous and deliberative character of autonomy – be conceptualised in relation to a system based on marketisation and personalisation?**

Our main research question is divided into five sub-questions that are addressed in three studies, each of which is extensively explained in the following chapters. The three studies each focus on a particular component of the interplay between the elements of marketisation, personalisation and social justice, associated with the paradigm shift towards personal budget schemes, each involving multiple practices and stakeholders.

Bearing in mind the aims of this research and the research questions, adopting a qualitative research stance was the logical consequence. We sought to capture different perspectives on and experiences with personal budgets, from social professionals who make decisions about the allocation and use of a budget, through managers in care facilities, to people with intellectual disabilities who receive care and support within this system. The general problem statement covers differing perspectives, which required us to adopt a multi-method approach. As a consequence, we applied different qualitative methods of data collection and analysis in three distinct studies. These studies are briefly presented in the following paragraphs, of which further extensive elaboration can be found in Appendix I.

- *Study* 1. *International exploratory study of social justice in the implementation of personalisation and marketisation principles*

To gain a better understanding of the relationship between the different rationales for introducing personal budget schemes in practice, our focus was on previously implemented systems of personal budgets. After all, the Flemish PVF policy had only just been introduced. The Policy Research Centre for Welfare, Public Health and Family of the Flemish Government commissioned us to carry out an exploratory study of experiences with the implementation of personal budget policies in three neighbouring countries (see final report: Benoot, Dursin, Verschuere and Roose, 2018).

This study was commissioned to learn from the difficulties and opportunities experienced in personal budget schemes in the Netherlands, England and Germany with regard to the realisation of the right to care and the accessibility of care. This first study aims to contribute to the first two research questions: (1) *How do professionals deal with the implementation of personal budget policies in practice?,* and (2) *What does the implementation of personal budget schemes, in which autonomy and control are central, mean for our understanding of social justice in practice?* In that light, we conducted semi-structured qualitative interviews with 31 social professionals in the three countries, focussing on the way in which the right to social services is realised in the application, assessment and allocation practice of personal budgets. This broad overview of personal budget policies in practice enabled us to draw lessons from the implementation and realisation of these systems in relation to individual well-being and social justice.

- *Study 2. Personalisation, marketisation and the pedagogical project*

Secondly, the policy on Personal Budgets in Flanders (PVF) and the relationship with guaranteeing the right to social services and care are scrutinised. In contrast with systems of personal budgets for people with disabilities in neighbouring countries, the technical specificity of the Flemish Personal Budget system results in it having less far-reaching influence on the application-indication-allocation phases. As a result, care institutions remain important centres in the decision-making processes and in negotiating and reasoning about what ‘meaningful care’ is and how the notion of autonomy is shaped in personal budget practice in Flanders. This study therefore focusses on the care institutions as spaces (places and time) where processes of discussing care and support for people with disabilities take place in Flanders.

We obtained data from a qualitative study with directors of a group of care facilities belonging to an interest group called KWAITO, in order to address the third research question: *What is the meaning of the Flemish personal budget scheme for the pedagogical project in care institutions*? In this study, we thus shed light on the ways in which a socially just pedagogy can be developed in care institutions in relation to the ideas of personalisation and marketisation.

- *Study 3. Personalisation and 'a good life' as pedagogical and social justice questions*

The objective of this third study was twofold. First, we wanted to complement the previous study, on the perspective of directors of care institutions, with an in-depth understanding of the personal budget scheme in practice through eliciting the experiences of persons with disabilities in a residential care context. Second, we wanted to present these experiences in relation to the policy objective to guarantee a better quality of care through autonomy and independence, contributing to knowledge of the pedagogical meaning of autonomy. The third study therefore focussed on how people with intellectual disabilities make use of their formal choice and control in the practice of personalised service delivery, and what people with intellectual disabilities value as a meaningful concept of autonomy. Two research questions were addressed in this third study: (4) *What do people with intellectual disabilities value with regard to their care and support in a Flemish care institution*? and (5) *What elements create opportunities for people with intellectual disabilities to be able to do and be what they value*?. Through an ethnographic research stance, making use of photovoice as a research tool, we aimed to foreground what ten people with intellectual disabilities who live in an institutionalised setting and who spend much of their lives there deem valuable for living a 'good life'.

From this visual data, we engaged in conversations with the participants about the meaning of a personal budget in respect to the things they consider valuable. Through bringing the experiences of persons with disabilities to the fore and relating these experiences to the policy objective to guarantee a better quality of care through autonomy and independence, we ultimately aim to gain insight into the pedagogical meaning of autonomy.

How can a socially just pedagogy – aware of the ambiguous and deliberative character of autonomy – be conceptualised in relation to a system based on marketisation and personalisation?

STUDY	RESEARCH QUESTIONS	METHODOLOGY	CHAPTER
Study 1 International exploratory study of social justice in the implementation of personalisation and marketisation principles	1.How do professionals deal with the implementation of personal budget policies in practice? 2.What does the implementation of personal budget schemes, in which autonomy and control are central, mean for our understanding of social justice in practice?	Semi-structured qualitative interviews with 31 social professionals	2 & 3
Study 2 Personalisation, marketisation and the pedagogical project	3.What is the meaning of the Flemish personal budget scheme for the pedagogical project in care institutions?	Semi-structured qualitative interviews with 15 managers of care institutions, followed by a focus group.	5
Study 3 Personalisation and 'a good life' as pedagogical and social justice questions	4.What do people with intellectual disabilities value with regard to their care and support in a Flemish care organisation? 5. What elements create opportunities for people with intellectual disabilities to be able to do and be what they value?	Ethnographic data collection through a participatory research project (photovoice) and qualitative interviews with 10 persons with intellectual disabilities.	6 & 7

1.5. Overview of the chapters

The dissertation consists of eight chapters. After this introduction, five chapters follow in each of which the research questions discussed above are addressed, ending with a general conclusion. To conclude this introductory chapter, we highlight the contents of each chapter.

CHAPTER TWO

The Rise of 'the Ideal Client':
The Right to Social Services in the Dutch and English Practice of Personal Budget Schemes

In this chapter, we tackle the research question how professionals deal with the implementation of personal budget policies in practice. This qualitative study draws on semi-structured interviews with 25 social professionals, practitioners and policy makers in England and the Netherlands, as part of an exploratory study of the translation of personal budget policy rationales into practice.

CHAPTER THREE

Lessons from Ricoeur's 'Capable Human Being'
for Practices of Personalisation in Three European Countries

Personal budget schemes for people with disabilities are imbued with a conception of autonomous and rational individuals. In the third chapter of this dissertation, we present an analysis of 15 social work professionals' reflections on the practical implementation of personal budget policies in England, Germany and The Netherlands.

Through a conceptualisation of 'a capable human being', rooted in the capability approach, we deepen our understanding of the social justice character of personal budget schemes in practice and contribute to the research question what the implementation of personal budget schemes, in which autonomy and control are central, means for our understanding of social justice in practice.

CHAPTER FOUR

The Flemish Research Context

In chapter four, we will provide a brief overview of the profound change that the transition towards demand-driven care brought about for the organisation of the Flemish care landscape. We will discuss some of the instruments and interventions put in place to achieve the four key objectives of PVF, as well as how the Flemish government and administration (VAPH) intends to further strengthen them in the future.

CHAPTER FIVE

Personal Budgets and the Pedagogical Project
of Care Institutions in Flanders

In chapter five, we turn our attention to the Flemish personal budget scheme. Disability services in Flanders are explicitly expected to develop a demand-driven provision of care services as part of the implementation of PVF. This transition stems from the move towards autonomy and self-determination for disabled people and is aimed at deinstitutionalising the care for people with disabilities. We show empirically how managers of 12 Flemish care institutions are tackling the introduction of personal budgets and in what way this influences the ability to shape their pedagogical project.

CHAPTER SIX

A Visual Report on what is of Value for People with Intellectual Disabilities in a Care Organisation

In this chapter, we aim to uncover how people with intellectual disabilities deal with freedom of choice regarding their support through a qualitative, participatory research project. We introduce the method of photovoice in an attempt to find answers to the research question what people with intellectual disabilities value with regard to the care and support provided by a Flemish care organisation. In doing so, we challenge the current representation of people with intellectual disabilities by putting them in charge of documenting their care and support and by extension their own lives.

We describe how the project was carried out and the facilitating and obstructing factors we encountered. The analysis of the images collected and the related personal stories throw light on what the participants individually value for living a life they deem valuable.

CHAPTER SEVEN

Aspirations of People with Intellectual Disabilities as Opportunities

Chapter seven will draw on the results of a qualitative study involving ten people with intellectual disabilities concerning their idea of ‘a good life’ in a residential care setting, within a context of personal budgets. We make use of qualitative interviews following a photovoice project in which people with intellectual disabilities documented their lives in order to research what they deem valuable and aspire to.

We make use of the capabilities approach framework for focusing on the meaning of personal budgets for people with intellectual disabilities to be able to do and be what they value in ‘the now’ and for their capacity to ‘imagine their future’.

CHAPTER EIGHT

General Conclusion

In this last chapter we will first summarise the main findings of the previous chapters. Thereafter, we will reflect on what can be learned from the key themes emerging from our findings in relation to our quest for a socially just pedagogy concerning autonomy in social work and for deepening the pedagogical perspective on social work.

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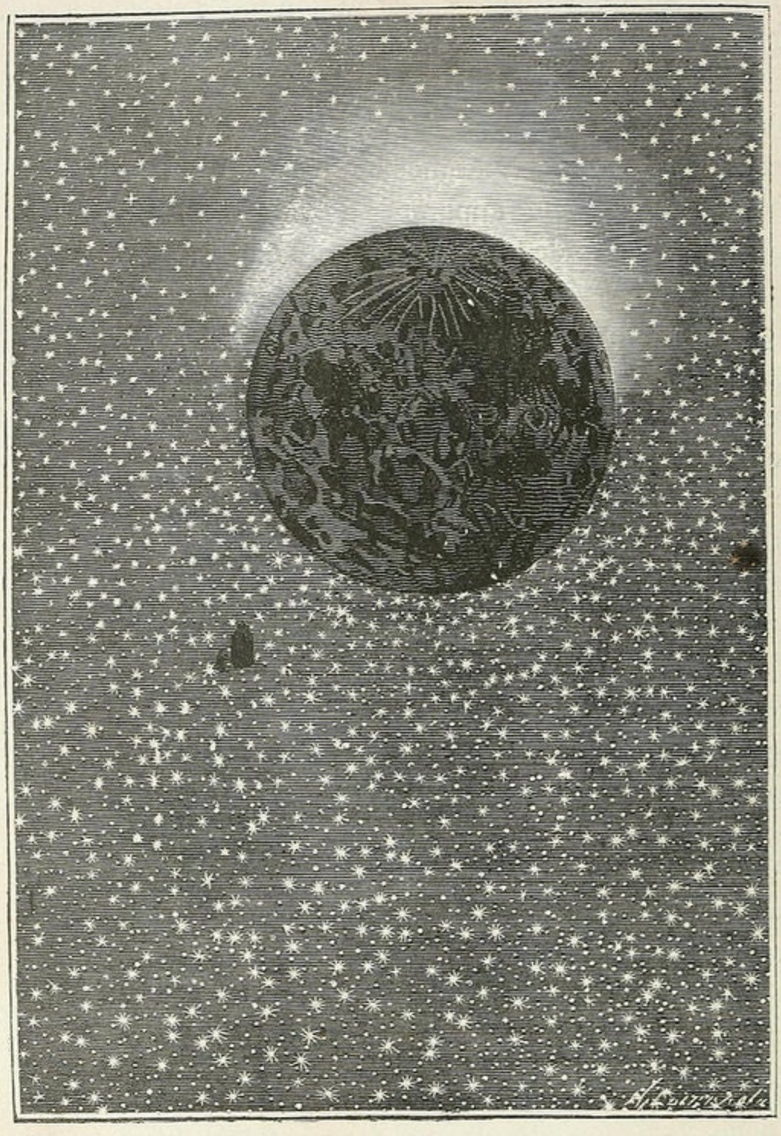
CHAPTER TWO

The Rise of 'the Ideal Client'



Rien ne pouvait égaler la splendeur... (Page 111.)

Abstract

In this chapter we will present the qualitative analysis of semi-structured interviews with 25 social professionals in England and The Netherlands, that was part of a larger exploratory study on personal budget schemes. The aim of this study was to gain insight into the process of translation of the envisaged 'right to social services' under various personal budget policies into practice. We identified commonalities in the way social professionals in different contexts realise the right to social services. Professionals are challenged with new roles and responsibilities, causing them to balance different policy objectives. Within this context, professionals introduce a construct of 'an ideal client' as a condition to access personal budget schemes. Consequently, a practice with unequal and sometimes limited access for disabled people is established, reserved for this 'specific type of user'. We conclude that such a translation of policy in practice actually contributes to the inequality between disabled people in their autonomy and choices concerning meaningful care.

2.1 Introduction

Personalised budget scheme policies are a striking example of the international trend in welfare states towards more individual and personal care for people with disabilities. Since the turn of the millennium, a range of pilot projects has been introduced in several Western European countries, resulting in the implementation of fully-fledged systems that are explicitly modelled on the UN convention on the rights of people with disabilities. With personal budgets, governments attempt to formulate an answer to the continuing opposition to traditional care services and the 'one-size-fits-all' critique (Leadbeater, 2004). This means that in the context of personal budget scheme policies 'social services are designed to fit their users, instead of users having to adapt to the services' interests and decisions of service providers in this traditional care' (Mladenov et al., 2015; 308). However, a diversity of research on Personal Budget schemes has addressed difficulties and opportunities related to implementing these policies into practice (e.g. Baxter and Glendinning, 2011; Ellis, 2007; Fleming et al., 2016), showing that 'law in books' (the rights of people as introduced in the UN Convention of the Rights of people with disabilities (2006)) does not necessarily equal 'law in action' (are rights realised?). More specifically, we need a more nuanced understanding of how professionals make choices in the care pathways of people with disabilities to understand the relation between personal budget schemes as a tool for social justice. We respond to the gap in knowledge concerning the rationales social professionals make use of in the roll-out of these personalisation practices, auxiliary to the law-like formal accounts and logics of social policy (Brodkin, 2003).

By talking to a wide range of practitioners and policymakers in the Netherlands and England about the accessibility of personal budget schemes and the experiences they have with their translation and implementation of policies on personal budgets into practice. The finality lies not in comparison, where similarities and differences become apparent, but in developing an understanding of the translation of the right to social services within contexts of personal budget policies. Of course, the context and the design of these policies are very diverse, and the operational aspects of these schemes differ greatly. However, we wanted to gain insight into how, beyond these differences, social professionals deal with these policies in practice. Therefore, this study sheds light on the application, assessment and allocation phases - the phases distinguished by the decision-making powers of social professionals- in personal budget scheme practice. By doing so we aim to contribute to the knowledge of social policy makers and practitioners concerning the realisation of the right to social services.

Personal Budgets' Policy Context

The promotion and centralisation of choice and control for people with disabilities in the policies on individual funding schemes in Western European countries can be traced back to the UN convention on the rights of people with disabilities (2006). Particular attention is paid in these policies to Article 19, which stipulates that all persons with disabilities, regardless of the type or severity of the disability or the level of support necessary, have the right to live in the community, with choices equal to those of others (Convention on the Rights of People with Disabilities, 2006). According to Harpur (2012), the UNCRPD can be used to drive change to increase the ability of persons with disabilities to exercise their rights by providing clarity on how those rights should be realised.

States that endorse the UNCRPD demonstrate their recognition of the Article 19: Living independently and being included in the community. And thus, need to take steps for their 'full exercise of this right, and to facilitate people with disabilities' full integration and participation in society' (ECCL, 2016, p. 18). This means that Member States must take effective and appropriate measures to enable people with disabilities to exercise their rights in general and the Art. 19 right in particular. The introduction of a range of pilot projects in Western European countries since the turn of the millennium, resulting in the implementation of various personal budget schemes, reflects this commitment. In the course of this evolution, organisations representing the interests of people with disabilities often play an important role (Harpur, 2012).

For example, organisations like 'In Control' in England and 'Per Saldo' in the Netherlands have consistently advocated for self-directed support and person-centeredness. Consequently, the personal budget schemes in this study to a greater or lesser extent adopt or advocate a person-centred approach (Williams, Porter and Marriott, 2014). In partnership with governments, the advocacy groups have been able to use the UNCRPD as a framework for providing more personal care, separately from traditional social care, within the context of a choice of market opportunities (Baxter and Glendinning, 2011; Boyle, 2004; Glendinning et al., 2000; Kendall and Cameron, 2014; Lymbery, 2012). This has led to a policy and resultant practice that must deal with different and sometimes opposing objectives. On the one hand, the development of a care market is an inherent feature of personal budget schemes (Arntz and Thomsen, 2011; Van Den Berg and Hassink, 2008). On the other hand, these market logics may impose constraints on professionals' ability to fully function with a rights-based approach (Pearson, 2000).

Critical academic research has excessively stipulated that tendencies of marketization always stems the social justice agenda in personal budget practices (Mladenov et al., 2015; Needham, 2011). It is argued that, in the face of budget cuts, European governments primarily see merit in the promotion of Personal Budgets as a means to make informal care more attractive to citizens (Grootegoed et al., 2014). Following this, a market logic tends to emphasize a rather individualistic reading of social rights with a framing of clients as customer-citizens (Beresford, 2005). In sum, these important critiques on personal budget schemes from Ferguson (2007), Needham (2011) and Mladenov et al. (2015) centre around the subordination of the social justice aspect of these social policies to a marketization agenda.

Personal budget's implementation in a decision-making context

A wide range of research on the realisation of the demand-driven care and the accessibility of these systems highlights the way in which the 'social just aspect' loses out to the other policy logics. In reconciling the strained matters outlined above, social professionals will have many different and new responsibilities to deal with. Personal budget schemes might bring some substantial improvements over traditional care arrangements from a cost-efficiency perspective (Stainton et al., 2009), yet care managers spent a significantly longer time with individual budget users than traditional service users (Jones et al., 2012). Appropriate information and support services appear to be necessary preconditions for achieving the potentials that PB schemes offer in practice (Baxter and Glendinning, 2011; Rabiee, 2012), especially a higher level of support in the planning phase (Dew et al., 2013; Netten, et al., 2012) and in particular support for all staff to adjust to their new roles in personal budget schemes (Laragy and Ottmann, 2011).

These informational and structural matters are crucial in bringing social professionals and people with disabilities together as allies in their pursuit of choice and control over the care and their struggle for equal citizenship (Stainton, 2002). Mladenov et al. (2015: 309) make clear that hierarchical structures are challenged 'by acknowledging 'lay' forms of knowledge and expertise, as well as by promoting greater autonomy for service users. The promise of social justice in personal budget schemes is then realized through the redistribution of power and the democratisation of choice and decision-making, and service users are transformed from passive recipients to active agents of their wellbeing. Although in practice, resistance to this power shift functions as a barrier in the implementation of a personal budget scheme in Ireland, resulting in an anxiety-based control by professionals (Fleming et al., 2016). All in all, these schemes do entail a risk of increasing inequality on different levels, between system users with or without strong networks or due to limited local service options (Brooks et al., 2017; Dew et al., 2013). Other scholars even state that the ambition to achieve greater equality among citizens seems to be overwhelmed by the use of such systems as a useful tool in times of savings (Grootegoed et al., 2014: 126). More generalist concerns include the observation of a decline in professionalism in favour of managerialism due to far-reaching market forces steering policy and practice (Baxter et al., 2011; Jones and Netten, 2010; Kremer, 2006). In addition, a recent study by Brookes et al. (2015) reports that resource reduction may impede future developments in practice, since personal budget schemes originated in a more comfortable financial climate.

This brief account of the international evidence shows that the studies on Personal Budget schemes have addressed difficulties and opportunities related to implementing these policies into practice.

This ultimately raises the question how social professionals translate these policies and what this means in concrete care practice. A nuanced understanding of how professionals make choices in the care pathways of people with disabilities is of crucial importance for a social policy and a social work practice with the pursuit of social justice. In this case the social just aspect in essence means 'creating choices equal to those of others', the bedrock of Art 19 of the Convention on the Rights of People with Disabilities (2006), as this is the cornerstone of personal budget schemes. Research has in fact rarely reported on the ways in which social professionals working in the junction between personal budget policy and practice make their decisions. This means, as Dickinson's correctly raised the question: '*What is not clear from the literature is whether these are inevitable features of these schemes, or whether these factors relate to the ways in which they have been implemented and the degree to which they have been appropriately supported*' (2017: 11). It thus may not be the funding itself that has the impact on care and support practice, but rather the decision-making in application, assessment and allocation processes. Therefore, the logics that shape the implementation of personal budget policies and steer professionals' actions are crucial in the realisation of the right to social services for all people with disabilities.

2.2 Method

Research Context

Our study focuses on two early adopters of personal budget systems for the care for people with disabilities in western welfare states: the Netherlands and England. We look closely at all legislation relating to personal budgets for people with disabilities, composed of both social care and healthcare. The policies are modelled on the UNCDRP, with similar procedures on the macro level for obtaining and managing a personal budget. In this contribution, we focus on the way in which the right to social services is realised in the application, assessment and allocation practice. The envisioned decentralised implementation of the systems allows practitioners and local policymakers substantial freedom to interpret. In this sense, the decisions of all authorised practitioners in the care trajectories can have considerable consequences for the individual person with a disability and their care network (i.e. carers and care services involved). Despite the great similarities in the policy rationales, there are considerable differences in the context of implementation in the considered cases. Therefore, the organisational aspects of these systems are also very different. These matters include the extent to which the systems are decentralized and fragmented, a context of austerity, a division between medical and social care, the role of public opinion, etc. Notwithstanding this, some concerns and remarkable issues run like a red line through the data and the analysis of the translation of this 'policy on paper' towards 'policy in practice' (i.e. the realisation of the right to social services). As expected from qualitative research, this study does not provide a clear comparative evidence trail showing how and why organisational differences impact on practice, but a description of ways in which practical context factors and affiliated technical systemic characteristics generate interference with the policy objective of delivering personalised and meaningful demand-driven care.

Data Gathering and Analysis

In a first phase an extensive scoping assessment of regulations and policy documents from the English and Dutch systems was carried out in order to gain insight in the functioning of their personal budget schemes. In a second phase 25 key stakeholders participated in 20 interviews, which were carried out between March and October 2017. In each country, macro-actors and central government policymakers were interviewed to test our knowledge of the systems and to clarify possible misinterpretations.

Respondents were carefully selected in order to have an overview of the whole trajectory: from application, through assessment and allocation to support for the client. Meso-actors were selected because of their awareness of both the policy and the practical issues concerning personal budgets. Attention was paid to involve those who both had experience with the implementation of the policy within a local government and also served as a representative in an association of local policy actors (e.g. the Association of Directors of Adult Social Services in England or the Association for Dutch Municipalities in the Netherlands). Finally, based on a snowball sampling method, contact was made with other relevant stakeholders in the system to capture the experience of various key social professionals involved in the process, for example managers of advocacy organisations (Noy, 2008). The table below gives an overview of the different types of actor interviewed per country.

	The Netherlands	England
Intersection Policy-Practice	8	5
Policymaker	5	4
Advocacy organisation	1	2
Total	14	11

Table 3: Participants by country and professional role

To achieve the desired depth and persuasiveness, data was gathered through qualitative in-depth interviews with a relatively small sample size (Crouch and McKenzie, 2006). The topic list was based on elements that identify the extent to which access to care is guaranteed. It refers to the question whether care is 'accessible, available, affordable, understandable and usable' for all stakeholders involved. We used these core concepts as a steppingstone for formulating a series of open questions to guide the semi-structured interviews with the stakeholders. In this way, we provided sufficient margin for the respondents' understanding of the meaning of the concepts (Bogdan and Biklen, 2003; DiCicco-Bloom and Crabtree, 2006). The interviews were conducted under confidential conditions, thereby following the authors' university's research ethics guidelines. All respondents gave their informed consent prior to the interview and accordingly agreed to audio record the interviews and annotated during the transcription. The transcriptions of the interviews were thematically analysed (Floersch et al., 2010) using a data-driven approach to code development (Van Hove and Claes, 2011). The thematic analysis allowed us to identify recurring themes and rationales underpinning the practical implementation of these policies on personal budgets (Gilson, 2012). By focusing on the way in which the right to social services is realised by social professionals across countries, we identified parallel logics. In the findings, we present conditionalisation as a main logic in the implementation of personal budget schemes.

2.3 Findings

A range of technical systemic characteristics inherent to the policy designs create a high degree of distortion in the translation of 'law in books' to 'law in action'. These technical features refer to the procedures to be followed and the organisational design, requiring social professionals to make choices and act upon in the implementation.

Respondents through various legislative authorities let a control logic prevail, as a way of dealing with their new roles and responsibilities. The discussions with key stakeholders in the Netherlands and England reveal that this distortion in the practical implementation occurs in both systems. This main logic follows from the policy and is deepened in practice. Predominantly a specific type of client is granted access to a personal budget and is able to benefit from this shift in social policy. This construction by the social professionals of an 'ideal client' has (1) a simple or straightforward care need and is presented as a determined and independent client and (2) meets specific language skills and literacy-expectations.

The idea of 'an ideal client' is a conceptualisation of the right to social services in terms of a conditionalised right, whereby similar characteristics are attributed to potential beneficiaries. We proceed to explore how social professionals position themselves in their new role as evaluator and gatekeeper.

(1) A simple or straightforward care need and presentation as a determined and independent client

The more complex the demand for care, the more difficult it is to identify the need for care. Where the case is more difficult because answers to the questions are not clear-cut, it is likely that rather than providing support, the application will be rejected or that responsibility for the assessment will simply be shifted to another legislative body. It even happens that no reference is made to the possibility of obtaining care through a personal budget, because this would require more time and support from the authorised institution to assist the person in the application.

Local authorities in England have a duty to inform individuals about the options for independent client support, but they have the freedom to impose criteria on who is subject to this duty. They do not, therefore, point out this possibility to every person.

> *In practice, we have people who say to us, the social worker said: 'It's a daunting experience, you can't have a direct payment, you become an employer, there are a lot of legal obligations, you have to do all this paperwork', etcetera, etcetera. So, of course, if the individual is new to this concept, the social worker's attitude will put them off, immediately.* [*Professional in advocacy organisation B*]

As a result, the policies of local governments and the professionals' judgement are essential elements in the ability of individuals to obtain client support. When the care and support plan states that the person needs support in managing the budget, this must also be paid for by the direct payment. It is often decided not to inform people of their options or even to discourage a DP when significant management support is needed, as this is also a cost for the local authority. Furthermore, the tendency to avoid automatically pointing out the option of support in the process is fuelled by the idea of an independent and autonomous user. Respondents indicate that it is a matter of individual responsibility when the person purchases care from inferior care providers. Proactive support is rarely provided.

> *I: But you can inform or advise?*
> *R: If they ask us, we do, but they are autonomous. I really see things that I think this is not in the interest of the user.* [*Practitioner A*]

As the above extract shows, actions are only taken when there are signals that things are clearly in danger of going wrong or when the personal budget is not used according to the rules.

Based on the idea that this system is for people able to manage the budget and all other aspects themselves, support seems to be subordinate to the responsibilities of the budget holder. However, an example is also given in which a municipality consciously deployed client support in a mediation between the municipality, a care provider and a client. The care provider acted as the representative of the person with a disability and tried to influence the indication in order to obtain the largest possible budget. Grounded in its own financial agenda, the local government appealed to a client support officer who, under the guise of 'the interests of the client', could also look after the government's own interests.

(2) Language skills and literacy

> *We say if they can make a care plan, there is a good chance that they can also manage a personal budget.* [*Practitioner B*]

The allocation of a personal budget is largely based on the ability to draw up a care plan. The substantive and intrinsic motivation is of great importance here: why is the person applying for a personal budget, what does he or she want to do with it and what are the solutions offered? A standard list is seldom used, but professionals are trained in substantiating a decision together with the applicant. In some local authorities throughout the different systems, interdisciplinary teams may help in the creation of the care plan. Nonetheless, the dispensing of the funds procuring care is related to this process. When individuals are not able to draw up their plans as expected, managing a personal budget is discouraged rather than support provided. One respondent [Policymaker F] said that 'a lot of people use their budget for things they can get from us, so we convince them it's easier [not to apply for a personal budget]'.

This illustrates vividly the role of the appreciation of professionals when the budget is to be used to promote community living and independent life in a preferred and convenient way.

> *I get lots of requests about if the money is being spent on things that are not care. And my answer is: 'if it is in the care plan, and it has been discussed in advance, it is part of the care plan, so it is fine'. So, art lessons, horse riding, toenail painting, that is improving the quality of life and is part of the care plan, then that is actually fine.* [*Policymaker G*]

This example shows that being able to negotiate or being supported in drawing up a care plan has far-reaching consequences. If a person finds the space to formulate many things in the plan, beyond the standardised solutions, a great deal can also be achieved in practice. A person who is not literate or able to draw up a care plan in the expected way has fewer chances of being regarded as 'capable' or 'competent'. When such persons can call on a representative or a network of supportive people, this can be stimulating in making a budget available. A client support officer says the following about this:

> *It is subjective, yes, and sometimes it really depends on language. So, if you use certain words, it's approved* [*...*] *in fact, we think that a client should write a plan himself, but we can definitely advocate in this.* [*Practitioner C*]

The literacy of a person, having a network with literate people or having a representative and the ability to draw up a good care plan can all be seen as a cluster of variables. The care plan is considered to be a visible artefact in which these factors all play a role, and together they are significant in the professionals' assessment of a person's competence. In practice, what can or cannot be included in the care plan is in some cases also fleshed out. This defines and limits what care can possibly be organised with a personal budget.

The discretion of the assessor may play an important role in determining what care need in a given situation will be eligible for support and which care tasks will ultimately be indicated. Respondents with an overview of the state of affairs in their local authority report that practitioners who have an adequate grasp of the options and obligations within the systems are more likely to be creative and to take risks and go off the beaten track when approving the preferred care.

2.4 Discussion

We addressed, by citing Dickinson (2017, p.11), that to date it's not clear from the literature what steers the realisation of the right to social services within personal budget policies: the inevitable features of these schemes or the ways in which these policies have been implemented and appropriately supported. It thus is unclear what the professionals' decision-making in application, assessment and allocation processes contributes to the realisation of these policies in practice. Therefore, the analysis of the conceptualisation of these rights-based policies throughout different systems is intended to shed light on the ways in which personal budget policies are realised, and, what logics shape the implementation of personal budget policies and steer professionals' actions. We uncovered two main logics that have limiting consequences for the realization of the right to social services, one inherent to the policies and the other originating in the professionals' actions. A control logic prevails as a way of dealing with technical systemic characteristics that are inherent in the policy designs. Secondly, through a conditionalised conceptualisation of the right to social services, social professionals develop a care logic mainly according to a specific type of user. The identified notion of 'the ideal client' demands reflection on the macro-policy level, the meso-level of translating these policies into a care practice and the micro level of care delivery to all people with disabilities.

Highly debated issues on policy level originate in these social policy designs, such as the financial context of the local authority and a clear emphasis on financial efficiency.

These are important driving forces in the professionals' judgement of competence. Recently, Brookes et al. (2015) stated that it remained to be seen whether the cold financial climate resulted in a top-down prescriptive approach to personalisation or led to local innovation to enable people to make decisions about their needs. Our results show evidence for both, but even the local innovative approaches that encourage creativity are prompted by a focus on efficiency. This often implies a limiting interpretation of the client's options and furthermore entails a subordination of the quality of care and support to the amount of care. A context of austerity thus acts as a catalyst for limiting access to subsidised care and for seeking creative, unfunded solutions.

Several important reflections emerge on a meso-level, regarding the new roles and responsibilities of social professionals responsible for the application, assessment and allocation of personal budgets. Our social professionals appear to see their new role and responsibilities rather as an unsolicited responsibility within which they meet the client when articulating the demand for a personal budget as a well-considered choice. Uncertainty and an absence of clarity about the new role are the driving factors that lead to the introduction of conditionality and a further consolidation of this repertoire of conduct. In this way, the notion of the 'ideal client' does not exist as such. The professionals contribute to this construct by installing a 'judgement of competence'. In comparison with the application, assessment and allocation in traditional care, these processes are characterised with an additional workload in personal budget schemes (Jones et al., 2012). As a result, new barriers are being built in to make use of time in a more targeted way, say for those people 'who really need it'.

This ideal type of client is constructed as an eloquent person with a singular care question who is aiming to lead an independent life in the community. People with disabilities that correspond to this ideal image will therefore be granted a PB more easily in these systems.

One way in which respondents assess the eligibility of applicants is by checking whether the care need corresponds with the predefined care categories. In doing so, they shape the assumptions about the right sort of person for direct payments not through their own professional judgement, but through a check against a predetermined allocation system. According to Ellis (2007), this can be associated with the suspicion of social professionals that they may be held accountable for any incident that occurs, which justifies their adherence to a discourse of control. We too recognise that a discourse in favour of a control logic seems to take precedence over a commitment to support.

In most cases, those people with disabilities that are granted a personal budget are also those who fit into the preconceived idea of the 'ideal user'. This reality then reinforces the idea that eligible people are autonomous and self-reliant citizens. This is at the very opposite of the assumption that personalisation concerns users with all kinds of impairments, which requires the concept of autonomy to be understood in relational terms (i.e. that emerges within and is maintained by appropriate infrastructures of support) rather than purely the ability to make independent decisions (Mladenov, 2012). A logic of control seems to be used to safeguard a minimalist reading of the initial purpose of the personal budget schemes, that is, autonomy and freedom of choice and the trend towards the deinstitutionalisation of care (Harpur, 2012; Leadbeater, 2004). From this perspective, the use of a budget for support and care that can also be obtained in traditional care services is not just discouraged but rather rejected.

In order to be able to formulate a socially just judgement about access to personal budget schemes, whereby support is also considered for those not complying with the construction of the ‘ideal client', social professionals need sufficient time, means and confidence. The fear for a sort of ‘professional misjudgement’ also occurs in the study of the implementation of a personal budget scheme in Ireland by Fleming et al. (2016). They identified an anxiety-based control and a resistance to the power shift that derived from a feeling of responsibility for the protection of the disabled person. This points to the need for information to alleviate fears and confusion that hinders the access to social services (Fleming et al., 2016).

Finally, we learn that the creation of ‘the ideal client’ has important repercussions for the clients themselves. The professionals’ understanding of autonomy as a purely cognitive term rather than a relational has its repercussions for the accessibility of personal budget schemes for all persons with disabilities, including those who need support in making choices. As Mladenov (2012) makes clear, autonomy as a relational term is understood as the ability to make independent decisions in an environment with sufficient opportunities for appropriate support, aiming to include all people with disabilities. Our analysis reveals that irrespective of the repetitive arguments about the pivotal role of support through the care trajectories in personal budget schemes (Rabiee, 2012), the more complex and time-consuming option of a personal budget is often problematised by respondents in this study for those people who are in need of support with the management of their PB. By doing so, professionals act as gatekeepers with regard to the right to social services, thus excluding clients with intensive and complex questions. The retention of an image of autonomy in its cognitive term is an extension of the characterised conditionality.

This conception of the person grounded in an idealised rationality forms a context in which the inequality between users in their options for meaningful care remains unaddressed.

2.5 Concluding Remarks

This article has explored the realisation of the right to service provision within personal budget policies that are often subjected to a distorted implementation in practice. We highlighted the decision-making processes of social professionals in the application, assessment and allocation in practice, since they are authorised with substantial freedom to interpret. Their decisions concerning the realisation of these rights-based schemes can have considerable consequences for the individual person with a disability. Recognizing previous findings concerning the context and technical peculiarities of the personal budget systems that leave social professionals insecure and uncomfortable about their new roles (e. g. Baxter and Glendinning, 2011; Spandler, 2004; Stainton, 2002). Additionally, the article acknowledges that the new roles and responsibilities appear to be the main catalysts for the conditionalisation of the access to obtain a personal budget. Nevertheless, a lack of clear information and insecurity about the translation of these policies in practice are rooted in the difficulties that arise in the reconciliation of the different policy objectives in practice. The practice that this study sheds light on is far from the objective of a social policy on personalisation as social services designed to fit all their users (Mladenov et al., 2015; 308). Contributing to the initial impetus of this policy and coherent practice: a realisation of a social just practice -in terms of the realisation of the right to social services-, requires support. Therefore, we must bend all our efforts to provide support when needed, even if proved costly and irrespective of whether this cost is due to administrative inefficiency entrenched in the policy design or due to professionals' attitude and organisational culture.

Without throwing the baby of personal budget schemes out with the bathwater of the conditionalized practice, it is important to critically address the conceptualisation and relating realisation of the right to social services. In this regard, it is worth mentioning that the facilitating or mediating role of a local service or organisation can be decisive as a counterbalancing element to the dominant control logic. The fragmented landscape therefore also offers opportunities to draw the ‘support card’ and not to adopt a conditional approach. On the other hand, this constitutes a structural confirmation of the 'coincidence character' of this system, insofar as the culture and organisation of the responsible local entity is decisive for the course of care to be followed. Decentralisation and the resulting fragmented landscape in this way ensures the importance of the application, assessment and allocation processes in the pathways possible for beneficiaries towards meaningful care and support (Dew et al., 2013), whilst a reduction of the ‘noise and distortion’ and thus a greater harmonisation may be required in the interest of social justice (Priestley et al., 2010).

The control-logic and ditto conditionalisation offer an account of what an aim to broaden the social just logic would encompass. And serves as a template for reform in these policy schemes. More academic and political work needs to be done to deepen this analysis in a changing policy context. To foreground service user perspectives and the receptiveness of social policy on ‘personalised’ matters and formulate a social policy that responds to the envisaged social justice.

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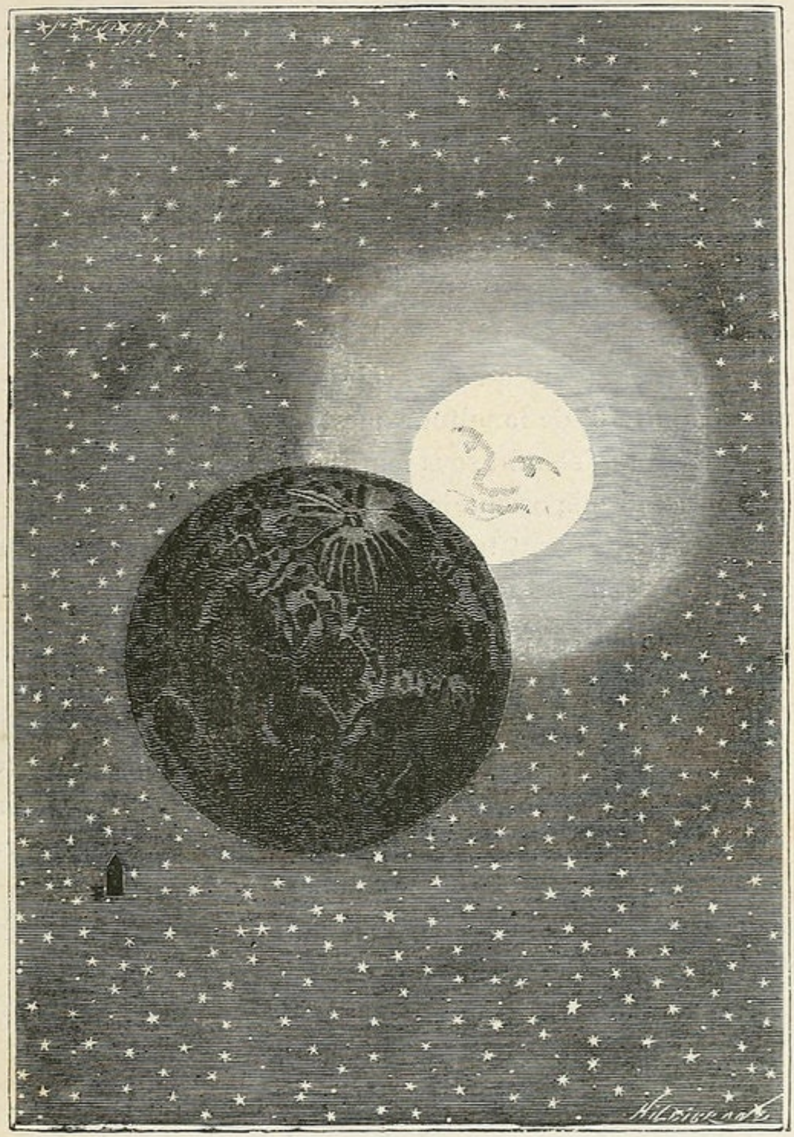
CHAPTER THREE

Contributing to 'a Capable Human Being'



C'est la faute à la lune. (Page 107.)

Abstract

In this chapter, Ricoeur's concept of 'A Capable Human Being' is applied to gain a deeper insight into the translation of a policy on personal finance into practice. We make use of this conceptualisation, which originates in the capabilities approach, to explore the tense relationship between policy and practice in their efforts to promote social justice. Our analysis reveals a major focus on organisational and technical questions in the policy design and the implementation in practice. This results in a practice of personal budgets that enables people with disabilities to speak up about their preferred care and support, and in case they receive a budget, are enabled to act through the use of it. As the 'capability to tell', which encompasses a dialogue and a shared construction of significance, is hard to formalise and standardise, it is above all this aspect that is being overlooked by this formalisation of care processes. This strong formalisation of the application, assessment and allocation practice of personal budgets contributes to an increasing accessibility to the rights of people with disabilities. Yet, the meaning and personal preference of the delivered care does not form the starting point of the intervention, an insight that puts pressure on the intended demand-driven approach. We conclude that a clear commitment in the promotion of this capability to tell, which implies a sharpened focus on the narratives of persons with disabilities, is a necessary commitment to realise the socially just character of this policy.

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3.1 Introduction

An evolution towards personalisation of care as a realisation of disability rights can be noted from the 1990s onward (Brooks, Mitchell and Glendinning 2017; Kremer 2006; Wilberforce et al. 2011). This implies a shift from residential towards individualised care in in deinstitutionalised settings. The introduction of personal budget schemes is the most prominent and essential recent policy that serves this paradigm shift towards the rights of people with disabilities (Needham 2011; Manthorpe et al. 2015). In the search for a clear understanding of the dynamics that shape the translation of this policy into practice, we studied the German, Dutch and English systems of personal budgets (PB). As the realisation of a socially just provision of care for people with disabilities is one of the most important reasons for the introduction of personal budgets, it is of the utmost importance to bring discussion of the meaning of social justice to the fore. In this article, we will make use of a human capabilities-informed understanding of social justice. Within this framework, the realisation of social justice is about creating opportunities for all people with disabilities to function and achieve what they have personal reason to value. From this perspective, we researched personal budget schemes, looking for a deeper understanding of the relationship between the allocation of resources and the creation of opportunities to make choices (Sen 2009; Nussbaum 2009, 2011). The role of social work professionals is crucial as key actors in the application, allocation and assessment phases of personal budget schemes (Benoot et al. 2017).

First, we review the three main principles underlying the policy shift towards personal budget schemes. Subsequently, we focus on the policy frameworks of the three distinct personal budget schemes in England, the Netherlands and Germany, followed by the policies' objective of autonomy and independence, as well as its limitations for the realisation of a socially just practice.

The following sections demonstrate how a capabilities approach provides a framework for critically assessing these personal budget schemes and analysing policy interventions driven by human development and social justice (Otto, Walker and Ziegler, 2018). This framework provides a deeper understanding of the relationship between the allocation of resources and the creation of opportunities to make choices. Based on Ricoeur's (2005) concept of 'a capable human being', the analysis explores the potential in both practice and policy to reconcile the different objectives and to extend the opportunities for all persons receiving care within the personal budget systems. In the final section, points of discussion and the main conclusion are reported. The analysis of personal budget policies in practice through Ricoeur's idea of 'a capable human being' opens up new perspectives on how to understand the inequality between users in their options for meaningful care.

The principles of personal budget schemes

Personal budgets and direct payments embody what Leadbeater (2004) calls 'deep forms' of personalisation of care. Their objectives are the redistribution of public funds from institutionalised care to user-led support in order to 'enhance the autonomy of users and their status within interactions with service providers and professionals and providing the users with the prospect of exercising greater influence in decision-making processes' (Owens, Mladenov and Cribb 2017, 9).

The first major driving force is the ratification of the Convention of the Rights of People with Disabilities (UNCPRD 2006). The states that endorse the UNCRPD are committed to the recognition of the rights of people with disabilities and to taking steps 'to facilitate their full integration and participation in society'.

This means that states must take effective and appropriate measures to contribute to social justice in general and to enable people with disabilities to exercise their rights. The provision of personalised care by means of personal budgets can thus serve as an example of how governments and society as a whole try to find new ways to foster human development and social inclusion for all. The government's responsibilities are to ensure a focus on the needs and goals of the person (with disabilities) concerned.

A second factor in the formation of the personalisation policy agenda is the campaigns of disability movements (Morris 2006) focusing on active citizenship (see for example Oskarsdottir [2007]). Social movements such as the Independent Living movement responded to the restrictions on service users' autonomy and voice. In order to acquire greater choice and control in the care they receive, these movements advocated for the deinstitutionalisation of public services. Through redistributive measures such as personal budgets, in all their variations, they sought the enhancement of service users' autonomy (Owens, Mladenov and Cribb 2017). These campaigns are based on the politics of disability rights and argue for increased choice and control as essential elements of self-determination (Duffy 2003; Shakespeare 2006), putting the notion of 'autonomy' at the centre of the care and support agenda (Baxter and Glendinning 2011; Boyle 2004; Lymbery 2012; Needham 2013; Kendall and Cameron 2014).

The third foundation of these policies is the creation of a 'care market' in which people, as they are seen as autonomous, can select the appropriate care, which should meet individual quality requirements (Van den Berg and Hassink 2008; Arntz and Thomsen 2011). These personal budget schemes create apparent opportunities to give more input into decisions about health and social care services (Baxter and Glendinning 2011).

Besides seeing a developed market for care provision as an essential element in making real use of these opportunities (Brooks, Mitchell and Glendinning 2017), these policy schemes are as well a means to increase efficiency and to lower the cost of services

Outline of personal budget schemes

We selected three personal budget systems through the 'family resemblance' method (Simmons and Rush Smith 2019). This is particularly suitable for studying social policies that have a similar appearance with subtle differences, ambiguities and complexities. Our brief introduction below reveals that apart from their differences in the politico-administrative system, the three cases share attributes to varying degrees (Simmons and Rush Smith 2019), such as differences in the competences of local authorities, in the complexity of the systems and in eligibility criteria, to name a few. Notwithstanding the differences, the systems in this study share many features. As indicated above, they are all instigated by the same principles of personalisation, marketisation and a commitment to social justice. Furthermore, they all comprise similar means of determining entitlements through the assessment of needs and support planning and enable the client to choose between directly contracted care or a cash budget.

The cash for care system for people with disabilities in England is composed of two separate parts: social care and healthcare. The (Department of Health, 2014) constitutes the legal framework for personal budgets in social care and is implemented by local authorities with adult social care responsibilities (Department of Health, 2014). They are responsible for determining the eligibility of the client, based on national eligibility criteria.

However, local authorities are entitled to exercise discretion in calculating the budget and determining whether a direct cash payment (DP) is an adequate tool for an individual with care needs, based on his needs and capacity. When the primary needs are related to continuing healthcare, the Clinical Commission Groups (CCGs) bear the responsibility for assessment and budget allocation. When an individual has both social and healthcare needs, she/he can obtain a joint package of care. The way in which the local authorities and CCG's cooperate with each other depends on local agreements. The main difference between social- and healthcare personal budget systems is that the former is means tested (Department of Health 2016).

In Germany, the Social Codebook IX (SGB IX) promotes social integration and rehabilitation and enables the person with a disability with eligible care needs to receive a cash budget (SGB IX, 2017). The provision of care as a personal budget became a legal right for persons with disabilities throughout Germany on 1 January 2008 (Bundesministerium fur Arbeit und Soziales, 2014). Responsibilities are divided among eight different entities, 'Sozialleistungsträger', each of which is responsible for a different aspect of social integration and support.[1] The entities and their competences are described in SGB IX (Bundesministerium fur Arbeit und Soziales 2017). In this study, the main focus is on the administrative organisation of the personal budget within Sozialhilfe and Pflegeversicherung. The eligibility criteria and budget configurations differ depending on the institutions that are involved. The individual is eligible for support from the social services at the local government level only when support options from the other entities have been exhausted. Access to care and support is, in principle, not income- or wealth-dependent.

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[1] The Health Insurance Fund, the Federal Employment Agency, the Accident Insurance Carrier, Pension Insurance Fund, War Pension Office, Youth Welfare organisations, Social Service organisations, long-term care insurance carriers and Local Integration Offices.

Social care, which is an important component for persons with disabilities, is nevertheless the exception. Only persons who do not exceed the income and wealth limit are eligible for a personal budget. The income and wealth limits were to be gradually raised by 2020 (Bundesministerium fur Arbeit und Soziales 2017).

In the Netherlands, three different laws regulate the cash for care system for people with disabilities: the Social Support Act (WMO); the Long-Term Care Act (WLZ) and the Healthcare Insurance Act (ZVW). The Social Support Act (WMO) is implemented by local authorities with the corresponding competences to determine eligibility criteria, calculate budgets and decide the suitability of a cash budget (PGB) based on the capacity of the client. People with chronic major care needs are eligible for care under the Long-Term Care Act (WLZ). In contrast to the WMO, under the WLZ the assessment is carried out by the national Centre for Needs Assessment (CIZ). Separate local Care Administration Offices allocate the budget and decide, based on an interview with the client, whether a cash personal budget or care services in kind are the best way to address the care needs.

The assessment process and the budget allocation are both more standardised in the WLZ than in the WMO. A combination of support from the WMO and WLZ at the same time is not possible. However, support from the Healthcare Insurance Act (ZVW) can be combined with WMO or WLZ support (Noordhuizen and Langerak 2014). The ZVW introduces the possibility to opt for a personal budget to arrange nursing and personal care at home. The assessment and decision concerning the suitability of a cash budget (PGB) is carried out by the insurance company itself. The rules for obtaining a cash budget can differ from one insurer to another.

When clients obtain a cash budget under the WMO or WLZ, their money is administered by the Social Insurance Bank. This is the biggest contrast with the systems in England and Germany, where the budget is paid directly into a separate bank account of the client (Pike, O'Nolan and Farragher 2016).

The objective of autonomy and independence

The promotion of social justice is undoubtedly an important pillar of these policies. Personalised budget schemes are envisioned as promising vehicles in their potential to address 'misrecognition' (Fraser 2013) by the liberation of service users from institutionalised top-down control mechanisms. Scholars point out the importance of the opportunity personal budgets offer to challenge hierarchical structures in care relationships (Mladenov et al. 2015, 309). However, the development of market opportunities risks suppressing the social justice agenda (Mladenov et al. 2015; Ferguson 2007; Roets et al. 2020).

In this vein, well-founded criticisms of these promises have been formulated. The criticisms most commonly relate to the envisaged deinstitutionalisation and social integration through the promotion of autonomy and independence as an expression of the social justice character of the policies. The concerns about an underlying individualisation through personal budgets stem mainly from the perceived limits on individual consumer choice. Bondi (2005) states that these policy reforms provide an illusion of consumer citizens who fulfil their desires through market opportunities. In this vein, Spandler (2004) asserts that becoming an autonomous consumer-citizen with the opportunity to exercise personal choice is actually an illusion in terms of real empowerment.

And although the policy reforms are rooted in the UNCRPD, with the potential to consider disability as an aspect of social diversity and therefore rights that can be applied to realise true equality (Harpur 2012), several researchers have revealed that this shift towards a more individually controlled service provision can lead to further isolation of traditional service users (Spandler 2004; Baxter and Glendinning 2011). Concerning individuals who are using their budget to organise care outside the walls of an institution, research evidence shows that physical inclusion in society does not necessarily entail that people with intellectual disabilities receive recognition and respect in social interactions (Chowdhury and Benson 2011).

As such, the belief in the idea of 'competent citizen-consumers' (Roets et al. 2020) is problematic for the realisation of a practice that gives all individuals with disabilities more opportunity to live a life they consider valuable. The emphasis on the 'key mantra of choice' (Dean 2015) creates numerous challenges when people with learning disabilities and/or their networks are evidently perceived 'as particular kinds of consumers in a contemporary landscape which privileges competency, capacity and individual independence' (Dowse 2009, 573). Realising personalised and meaningful care for all people with disabilities will require more than the reallocation of resources (Ferguson 2012). In order to ensure a just care system for people with disabilities, Walker (2006) suggests that it is the relationship between the available resources, the ability of each person to convert them into their valued capabilities, and the opportunities to make choices which will inform their outcomes, to which we should turn our attention. Several academics, including Duffy (2010), Ferguson (2012) and Owens, Mladenov and Cribb (2017), have argued that personalisation should be normatively assessed with reference to its impact on social justice.

A capabilities approach – the theory of justice elaborated by Sen (1990) and Nussbaum (2009) – provides a strong theoretical basis for examining the translation of personal budget policies aiming at promoting social justice in practice. We make use of Ricoeur's conceptualisation of a 'capable human being' (2005), a relational conception rooted in the capabilities approach, to understand the policy vision of autonomy and agency of people with disabilities and the practical application of these systems. In this way, we try to gain insight in how a contribution can be made to a socially just practice.

3.2 Ricoeur's concept of a 'capable human being'

Although the capabilities framework has been widely applied in a variety of contexts, to date this powerful theoretical approach has not been used as a means of conceptualising the complexities of access to care for people with disabilities in a personalisation policy agenda (Alkire and Deneulin 2009). The approach is not only about giving rights-based entitlements, but also advocates changing the environment into a supportive setting in order to help people realise their rights (Robeyns 2005).

For social work professionals, this means being aware of the fact that a practice cannot be traced back solely to the implementation of a policy plan. A practice is an intervention that cannot be realised unilaterally but is based on unpredictability due to the interaction and communication between people in different positions (Bouverne-De Bie 2018, 25). The capabilities approach provides a framework in which social, cultural, political and economic constraints that affect or limit wellbeing can be identified (Alkire and Deneulin 2009; Robeyns 2003). The policies of public institutions, as Otto, Walker and Ziegler (2018) observe, 'are often critical in ensuring or impeding people's chances to convert abstract and formal opportunities into genuine capabilities in the sense of "real" and effective powers and freedoms' (301).

In this regard, the policies on personal budgets can be analysed beyond their instrumental objective, since this view allows us to understand and recognise the full range of factors that impact on the personalisation of care for those affected by the policies. In this contribution, a capabilities approach is perceived as a conceptualising framework (see Deneulin 2008) rather than a tool (see Sen 1999) for evaluating an individual's quality of life. We conceptualise the impact of a disability policy based on the idea of more personalised care within a capability-informed framework because this has the potential to contribute to an understanding of the relevance and equity the policy entails.

From a conceptualisation of what a 'capable human being' means, we aim to understand how a contribution can be made to a socially just practice. In line with Jancic (2015), we propose to adopt Paul Ricoeur's concept of a 'Capable Human Being' (see Ricoeur 2005, 2006) as a relational aspect of this capability framework. Jancic's research raised the question how a capabilities approach and Ricoeur's idea of basic human capabilities could be combined to provide a theoretical framework for analysing teachers' understanding of pupils' capabilities in the teaching and learning relationship (Jancic 2015, 44). We establish this link in order to understand social work professionals' informational basis of judgement of justice (Sen 1990) concerning the application, assessment and allocation processes regarding people with disabilities in personal budget schemes. Ricoeur's understanding of capabilities can be understood as a valuable contribution to the thickening of the capabilities approach (Jancic 2014). Ricoeur (2005, 2006) proposes – in line with Nussbaum (2011) – a list of central capabilities. Unlike Nussbaum's list, in which all capabilities are treated equally, he formulates basic capabilities that when realised in hierarchical order result in 'the capacity of imputation' and make the person a 'capable human being'.

According to Ricoeur (2005,2006), a person must be 'capable to speak, to act and to tell' in order to be a capable human being. In line with this reasoning, Ricoeur pairs up the human being with a text, or discourse. For him, there is no direct knowledge of oneself, since one must proceed through a detour into signs, symbols, narrative, stories, poetry, discourse, etc. in order to achieve self-understanding (Ricoeur 2005). This means that 'a capable human being' only arises in interaction, in a relational context. Based on this thinking, 'being capable' cannot be set as a condition, but only emerges through a process of interaction and understanding.

In this vein, a better understanding of the interplay between policy design and real-life situations is of vital importance for detecting potential sources of disadvantage that may prevent individuals from fulfilling their own aspirations (Acconia, Chiappero-Martinetti and Graziano 2018). It is in this light that we will explore the three capabilities that Ricoeur (2005,2006) proposes: the 'Capability to Act' is about being able to make things happen; the 'Capability to Speak' refers to the ability to identify, express and specify oneself; and the 'Capability to Tell' relates to the potentiality to narrate one's identity (Jancic 2014). Active participation in society, as embodied in the 'Capability to Act', is an essential dimension of human life in a capability-inspired perspective. Participation refers to the notion of agency, to play a role in society and have voice in the public sphere, and to take part in decision-making processes. Capability-promoting policies essentially recognise agency as a key feature of policy, with people as active subjects and not passive recipients (see for example Deneulin and Shahani 2009). In line with the 'Capability to Speak', Bonvin (2012) has defined 'the capability for voice' as 'the capability people have to express wishes, expectations and concerns in collective decision-making processes and make them count' (15).

However, for Ricoeur this capability to speak is limited to the potential for expressing aspirations and sharing them with others. When it comes to acknowledging personal expressions and making them count, Ricoeur defines a distinct asset under the heading of the 'Capability to Tell'. This essential aspect is only made possible where people have acquired the capability to speak and to act. Jancic (2014) nicely summarizes the capability to tell as the potentiality to narrate your identity, which implies an opportunity to express yourself and also to have a voice that is heard. This process of knowledge construction and production is primarily a participatory practice. In this vein, Vandekinderen et al. (2016) state that participation should be regarded as a foundation for all knowledge construction, and therefore the voice and aspirations of all should be included, which equates with Ricoeur's definition of 'the capability to tell'.

Although these three aspects have been described separately in the capability literature (see for example Deneulin and Shahani 2009; Bonvin 2012; Vandekinderen et al. 2016), it is Ricoeur who has brought them together in one comprehensive conceptualisation of a capable human being. Ricoeur defines capability as 'the power to cause something to happen, a power that is liable to self-recognition' (2006, 18). Self-esteem is not just established reflexively but is also constituted relationally through our interactions with other people. It is thus an interdependent relationship that constitutes self-esteem and that enables people to become capable human beings with an agency they are confident about using (Davidson 2012). In this light, we see the three pillars of a capable human being (to act, to speak and to tell) as a steppingstone towards deepening understanding of the social justice character of personal budget practices.

3.3 Methodology

The data used in this paper originates from a larger international exploratory study of personal budget policies for people with disabilities in England, Germany and the Netherlands (Benoot et al. 2017). The purpose of the project was to develop an understanding of the implementation of personal budget schemes that have a similar configuration and are adopted early in countries with different welfare traditions. An inventory was made of the various key actors involved in the system of personal budgets for each country. The identification of these key actors formed an initial selection of the respondents. In order to be able to map out the various systems, it was important, on the one hand, to involve actors with insight into the choices and effects at the country level. On the other, it was also important to gain insight into the concrete experiences in the practical operation of personal budgets. A total of 22 interviews with 31 participants were carried out between March and October 2017. A double interview was conducted in nine of the cases, and thirteen interviews were one-on-one. The data we make use of in this paper consist of semi-structured interviews with those actors with insight in the concrete experiences in the practical operation: 15 social work professionals working at the intersection between policy and practice in Germany, England and the Netherlands.

The first wave of interviews in each country was based on a purposive sampling, contributing to the research objective to cover experiences in the application, assessment and allocation phases. Respondents were carefully selected to cover all roles and authorities that are involved in the process. Attempts were made to involve those who both had experience with the implementation of the policy within a local government and also served as a representative in an association of local policy actors (for example the Association of Directors of Adult Social Services in England or the Association for Dutch Municipalities in the Netherlands).

These actors were able to share both their experiences in their own practice and their insights at the macro level. Finally, based on a snowball sampling method, contact was made with other relevant stakeholders in the system to capture the experience of various key social work professionals involved in the process, for example managers of advocacy organisations (Noy 2008).

The conceptual model of accessibility of care, as developed by Hubeau and Parmentier (1991), formed the guideline for the interviews. This model questions and identifies the extent to and ways in which access to care is guaranteed. It refers to five key questions: whether care is 'accessible, available, affordable, understandable and usable' for all stakeholders involved (Hubeau and Parmentier 1991; Roose and De Bie 2003). We developed a topic list that is centred around these five key elements, which identify the extent to which access to care is guaranteed within a personal budgets policy and corresponding practice.

The authors' university's research ethics guidelines were followed, ensuring that the interviews were conducted under condition of confidentiality. All research participants were invited to sign a written informed consent, comprising permission to audio-record the conversations while explaining that all information would be treated anonymously and be used only for the purpose of a general analysis and not to reach conclusions about particular decisions or visions. The interviews were conducted in the respondent's usual setting (office of the respective responsible municipality), with a length ranging from 1.5 to 2.5 h, and were fully transcribed. The anonymised transcriptions were thematically analysed (Floersch et al. 2010) through a qualitative content analysis, based on a directed approach (Van Hove and Claes 2011). This is a respected method for refining and validating a conceptual framework or theory (Hsieh and Shannon 2005).

A directed approach to qualitative data analysis starts with a theory or relevant research findings as guidance for initial codes. In this study, these initial codes were the three core elements of Ricoeur's 'capable human being': being capable to act, to speak and to tell.

3.4 Implications of Ricoeur's conceptualisation for personal budget policy and practice

Capable to speak

The policies on personal budgets in our study are inherently characterised by the capability to speak and the capability to act. These basic capabilities are objectives of these policy designs that strive for more individualised care in deinstitutionalised settings (Brooks, Mitchell and Glendinning 2017). Namely, it is legally specified (for example Department of Health 2016; Bundesministerium fur Arbeit und Soziales 2017; Ministerie van Volksgezondheid Welzijn en Sport 2016) that these personal budget schemes provide arrangements for people to express individual preferences concerning the care they need, contributing to the capability to speak. Although there is a right to client support in all three countries, some social work professionals are unaware of the obligation to provide information, fellow practitioners have no knowledge of the right to a personal budget at all, while others are deliberately silent about these matters. The division between different competent authorities in the German system does not make things any easier: 'The law says 'the Leistungstrager have to inform the people ', they have to. But they know it [the information] usually only for their own areas, their own affairs' [Practitioner 6]. Local authorities in England have a duty to inform individuals about the options for independent client support, but they have the freedom set criteria to whom this applies. They do not, therefore, point out this possibility to every person.

In this light, an English client supporter reported: 'We have people who say to us, the social worker said: 'It's a daunting experience [...], etcetera, etcetera. So, of course, if the individual is new to this concept, the social worker's attitude will put them off, immediately' [Practitioner 13]. Drawing up a care plan has far-reaching consequences. Concerning the capability to speak, an English practitioner stated that 'some people feel completely isolated, have a challenging behaviour [...] have mental issues, for them it's very difficult to address those needs in a straightforward plan. It's quite intense' [Practitioner 5]. Those persons who already know clearly what they want in advance of the process and who are able to put this into words are considered 'capable' in the application procedure and benefit more from these support arrangements. A Dutch practitioner stated that this testifies to the possible 'Personal Budget competence' [Practitioner 1] of the client. Since 'it really depends on language' [Practitioner 4], people who are more capable of clearly defining the care needs will have more influence and authority on the way in which the care and support is tailored to their individual wishes and preferences.

If a person finds the space to formulate many things in the plan, beyond the standardised solutions, a great deal can be achieved in practice. A person who is not literate or able to draw up a care plan in the expected way has fewer chances of being regarded as 'capable' or 'competent'. When such persons can call on a representative or a network of supportive people, this can be stimulating in making a budget available. An English client support officer said: 'If you use certain words, it's approved, and ... in fact, we think that a client should write a plan himself, but we can definitely advocate in this' [Practitioner 3]. The German system also bears this strong focus on the language skills of people with disabilities who apply for a personal budget. The size of the allocated budget depends on the care need that has been identified in the support plan (Hilfeplan) (Bundesministerium fur Arbeit und Soziales 2017).

The indication underpinning the plan is not made using a standardised method but is the result of the conclusions reached during the 'Hilfeplan-Konferenz' (support plan discussion) between the client and the competent authority. This illustrates that the client's language is of vital importance in the procedures for obtaining a personal budget. These illustrations show that the opportunity of obtaining a budget is strongly linked to the capability to speak. In all three systems under scrutiny, the capability to speak is strengthened when a certain degree of skill to specify the type of care they would choose with a personal budget is already present.

Capable to act

Secondly, the three personal budget schemes in the study ensure that resources and mechanisms are available to enable people to act independently and make choices concerning the type of care they prefer or deem valuable. In doing so, the personal budget schemes all contribute to the capability to act of people with disabilities. This aim is at the heart of these policies, intending to facilitate the shift towards more individualised care in deinstitutionalised settings. It comes with the claim that people with disabilities thereby benefit from increased choice and control as essential elements for self-determination (Duffy 2003; Shakespeare 2006) and can flourish as active citizens (Oskarsdottir 2007). Section 3.1. of the English Care Act (Department of Health, 2014) offers a compelling example of how the aim to increase agency and thus the capability to act is reflected in policy:

> Information and advice is fundamental to enabling people, carers and families to take control of, and make well-informed choices about, their care and support and how they fund it. Not only does information and advice help to promote people's wellbeing by increasing their ability to exercise choice and control, it is also a vital component of preventing or delaying people's need for care and support (Department of Health, 2014).

In Germany, the population targeted by the personal budget scheme is very wide, as it includes all people with disabilities or people at risk of acquiring a disability. This legislation ensures the opportunity to take part in decision-making processes and to be active agents for all people, irrespective of the type, severity and cause of disability. Even if the person has to rely on advice and support from a third party to manage the budget (for example family members or legal advisors), the right to a personal budget is guaranteed (Bundesministerium fur Arbeit und Soziales 2014). Respondents indicate that, in practice, guaranteeing this active participation does not happen overnight, mainly due to the fact that it is 'a really complex system which is really difficult to understand' [Practitioner 12]. Contrary to the legislative consolidation of the right to a personal budget, regardless of the individual's capacities, individuals are often denied access to a personal budget on the basis of an assessment of their capacities to manage a budget: 'The administration thinks it is written that somebody can be refused access to a personal budget, because they lack capacity. But that is not written in the law, instead, if you are not able then you have to get an assistant' [Practitioner 11].

This respondent stressed that the intention of the personal budget scheme is to increase the opportunities for people with disabilities to be active agents, although in practice those capacities are most often considered a prerequisite. He continued: 'The answer should not be "you don't get it because you cannot do it", but it should be "we pay you also to help to do it if you really want to do it"'[Practitioner 11]. The same tendency occurs in the Dutch system, where local authorities have a lot of local competences and decide on their own eligibility criteria and have discretion in making the decision whether the individual is able to manage and is thus qualified to obtain a cash budget.

The perception of frontline workers about this 'capacity' ('*pgb vaardigheid*') of the client has a large impact in the system: 'I rather see a slow political tendency towards, it can't be said too loud, but there is a very large group of people that is in practice not able to handle a [cash budget] ... And we will be a bit stricter concerning to whom we give a cash budget. And we want people to be even more aware about "why do I want this"'[Practitioner 8].

Furthermore, in the practices under scrutiny there is little freedom for actions (spending the personal budget) that at first sight do not contribute to the social work professional's expected outcome. Respondents make a demarcation specifying that a personal budget is 'meant for a group that in fact says: "I want to organise it myself completely individually", and that is able to do so properly' [Practitioner 13]. In that vein, another respondent delivered the following message to applicants: 'I also say: "If you are being helped with the standard solution, you shouldn't take it on the neck yourself"' [Practitioner 9]. Persons who wish to purchase care with their budget in an institutional setting are not considered 'capable' by social work professionals in their 'capability to act' as they do not take the actions that are desirable within such a system. The freedom of individuals to act is limited to the freedom that the social work professionals set out.

Capable to tell

Third, the 'capability to tell' is even more challenging and problematic to incorporate into personal budget schemes. To realise this last basic element, Ricoeur (2005) argues that it is necessary to have 'the other' who recognises the narrative identity of the person. This implies that, in the context of personal budgets, the social work professional has a crucial role in supporting that person towards her/his realisation of 'the capacity of imputation' and thus being perceived as 'a capable human being'.

Unlike the ‘capability to speak’ and the ‘capability to act’, this ‘capability to tell’ – or relational aspect of an intervention – has not been explicitly supported by legislation on personal budgets. However, legislative steps are being taken to ensure that individuals are actively involved during the care allocation process. The Care Act (Department of Health, 2014), for example, places a new duty on local authorities to appoint an independent advocate for someone who has substantial difficulty in being involved in decisions about their care and support, if there is no appropriate individual to support them (Department of Health, 2014). Such a measure demonstrates the commitment to involve the individual concerned, while stressing the importance of that involvement in the search for appropriate care and support.

In the practices studied there is but little space for personal narratives and individual valorisation of what meaningful care could be. An English practitioner regretted ‘that we don’t, I couldn’t say we don’t allow, but we don’t really often enable somebody to be really creative and really radical with their direct payment, they are often just buying something quite similar to what we would have done’ [Practitioner 12]. Professionals do have a great deal of discretion in determining what care people can and cannot buy with their personal budget.

However, our respondents do not seem to valorise personal preferences when narrated as matters that are far removed from the professionals’ own conception of ‘good care’. In this respect, a respondent indicated that these matters in essence ‘[go] back to “who best knows the culture”. Is it the individual or the officer of the state that knows best?’ [Practitioner 15]. In addition to the consideration of professionalism, examples are given that briefly illustrate how cost-effectiveness and efficiency are used as ways to evaluate the personal accounts of people with disabilities:

> *I once funded a family to go to 'centre parks' after a gentleman had a very long period of psychoses and long hospital treatment and the family basically lost touch with each other... "How could we pay for them* [*...*] *it was an inappropriate way of spending public money." But in my opinion, it was very well used public money, because it saved us another two years of care and it kept that family together.* [*Practitioner* 9]

In this example, a respondent tries to justify the choice of this specific solution on the basis of efficiency gains, in order to counter negative public perceptions of the use of public resources. The meaningfulness of care was seldom given as a primary argument by respondents in our research. Furthermore, media coverage affects the discretion of social work professionals, in particular the extent to which they approve and endorse creative, unusual and innovative forms of care and support (Benoot et al. 2017). This reduces the willingness of frontline workers to record unconventional interventions in the care and support plan. The following excerpt of an interview with two Dutch practitioners exemplifies this eloquently:

> *R*1: *For example, someone who requests a Personal Budget for the care and guidance of a child, and then saves all of the money to do "swimming with dolphins" with the whole family.*
> *R*2: *Yes dolphin therapy, in Curaçao.*
> *R*1: *Yes, then you think yes, then, that is not our intention.*
> [*Practitioners* 1 *and* 2]

These respondents' argument for fairness justifies giving access for the person with a care need only to the same set of capabilities as other citizens in that community. Thus, through the provision of a personal budget, barriers are removed, and resources provided in order to promote the inclusion of the person.

3.5 Discussion

The research presented here thrashed out what challenges there are for the three aspects (act, speak and tell) of Ricoeur's conception of 'a capable human being' (2005, 2006), given that these policies aim to make people with disabilities 'capable' of exerting choice and control over the care they need. Our understanding was built on an analysis of 15 social work professionals' reflections on the practical implementation of three personalisation policies. In line with earlier contributions (Dowse 2009; Roets et al. 2020), this exploration of Ricoeur's conceptualisation of 'a capable human being' demonstrated that viewing a person with disabilities as a self-evidently rational and independent human being is ill-suited to personal budget practice.

Our analysis revealed that people with disabilities who needed any form of support during the process were granted access to a personal budget much less easily. Providing client support is a possible stepping-stone towards strengthening the capability to speak. Practice teaches us, however, that organisational hurdles often undermine this measure. The complexity of the regulations and the lack of clarity, also for practitioners, in working with personal budgets are given as the main obstacles. In response to the often-ambiguous role of the social work professionals in constructing a practice of accessibility (Grymonprez, Roose and Roets 2017), the analysis demonstrated a tendency simply to revert to the realisation of a formal access to a personal budget. We identified that, in this context, especially the capability to tell and thus the opportunity to create personal narratives was hardly recognised in the process for obtaining a personal budget. These findings illustrate the major role of 'sources of variation' (Acconia, Chiappero-Marinetti and Graziano 2018), such as individual characteristics and the socioeconomic context in generating inequality in the capabilities and functioning of people with disabilities.

We will discuss two key points of attention in policy and practice concerning the role of social work professionals (and social work) in the policies' objective to enlarge social justice amongst people with disabilities, and at large amongst all people.

The first main point we uncovered is that the 'capabilities to tell' of people with disabilities tend to be superseded by a formalisation of the care processes. While through the lens of Ricoeur's capable human being precisely 'interdependency' – embodied in the capability to tell – is a necessity for realising shared decision-making and dignity (Davidson 2012), the exploration of policy in practice exposed the strong focus on 'independency' within these systems (Baxter and Glendinning 2011; Needham 2013; Owens, Mladenov and Cribb 2017). Resulting in an instrumental use of personal budget schemes to increase the equality of persons with disabilities in the pursuit of 'full-fledged citizenship'. Consistently, the 'capability to act' seems to be associated with the idea of 'making good choices'. This teaches us that a strong 'formalisation' of the application, assessment and allocation practice entails the risk that the personal preference for meaningful care no longer forms the starting point of the intervention. As a result, the crucial negotiation of the meaning of the delivered care is reduced to 'being subjected to the procedure'. An emphasis on being capable to act and capable to speak thereby tends to overlook and disrespect crucial information concerning what is valued. And furthermore, this puts pressure on the intended demand-driven approach. Within this formalisation, the right to care is 'limited within the condition of joining a pre-structured process and within the condition of recognising and joining a finality based on social expectations' (Bouverne-De Bie 2018, 24). In other words, a professional intervention that takes place irrespective of the clients' ideas of 'good care' does not contribute to the enlarging of people's capabilities and a fortiori not to their dignity.

For the second point, we turn to the personal budget schemes as the envisaged vehicle for people with disabilities to be(come) capable of choosing the care they themselves deem valuable. This refers to the outcry for self-determination, expressed in the drive for increased choice and control (Shakespeare 2006) and consolidated in personal budget policies by disability movement campaigns and the politics of disability rights. Here, the human rights paradigm functions as a starting point and as an objective of these campaigns and resulting policies. It is clear that personal budgets might be a step towards the dismantling of barriers people with disabilities face, although to be able to find your way in the care landscape demands more than the removal of some major thresholds. In other words, acquiring the opportunity to choose and control your care is but the start in the search for meaningful care and a dignified life. In line with Spandler's (2004) suggestion, our analysis indicates that in terms of real empowerment, this focus on autonomous consumer-citizens exercising personal choice in reality turns out to be an illusion for a substantial number of users. Above all, practices of accessibility reveal the construction of conditions of in- and exclusion (Maeseele 2012). Social work professionals in the three crucial phases of personal budget schemes can dismantle or remove barriers insofar as the person in question can 'independently' and 'autonomously' find her/his preferred care; they can lift the person into the world of demand and supply and be a 'companion du route' in this quest; and so on and so forth. The possible ways of shaping social work practice are infinite.

The analysis clearly teaches us that it requires more than resources alone to achieve a social justice policy in practice. To what extent do we take note of the relationship between the available resources, the ability of each person to convert these into their valued capabilities, and the opportunities to make choices which will inform their outcomes (Walker 2006)?

From the research findings we learn that realising the finality of these policies – namely, ‘integrated living in an independent manner’ – ignores the interpretation of the ‘right to’ from a relational and contextual standpoint. From Ricoeur (2006) we learn that connecting capability and the ‘right to’ shows that interpretations are not predetermined and take shape in an interaction. This contribution acknowledges the importance of ‘management of access’ but also aims to strengthen reflection on the ‘meaning’ of access. Effecting social justice requires practitioners to acknowledge the interplay of economic, cultural and political factors with the status and experiences of people with disabilities (Boone, Roets and Roose 2019). That is why we argue that the concretisation and translation of human rights into personal budget policies should be seen as a starting point and as a frame of reference for weighing up a concrete situation and for realising equal opportunities for a dignified existence.

3.6 Conclusion

Personal budget schemes offer an important opportunity to challenge hierarchical structures in care relationships (Mladenov et al. 2015, 309). Acknowledging people with disabilities’ ‘lay’ forms of knowledge, enhancing their autonomy through the redistribution of resources and power and facilitating shared decision-making could prove fruitful for advancing equity amongst service users. Our findings reflect the critical remark of Otto, Walker and Ziegler (2018, 302) that policies that are more capability-promoting than others do not necessarily mean that they are genuinely capability-promoting and oriented towards creating the conditions in which people can live flourishing lives.

The exploration of Ricoeur's 'capable human being' demonstrates that the promise of the three studied personal budget schemes to make everyone 'capable' of making choices and controlling the care obtained is diluted in practice to 'being capable' as a condition for acquiring more options for meaningful care. This is a contradiction between a policy objective and its actual practice at its sharpest. For social work professionals not to limit themselves solely to increasing legal accessibility and the implementation of rights, persons with disabilities must be recognised and acknowledged as equal actors in the process. From Ricoeur (2005) we learn that 'a capable human being' only arises in interaction, in a relational context.

Based on this thinking, 'being capable' cannot be set as a condition, but only emerges through a process of interaction and understanding. Only in recognising the client as an equal actor, with room for the potential to support her/him in her/his capability to tell, can the person in question be acknowledged and recognised as a capable human being by others and by her/himself. In this case of personal budget policy in practice, the complexity of social work practice is expressed at the cutting edge. It is in this contested setting that space for negotiation and involvement in searching together for the personal as well as the social relevance of the actions, is extremely demanding, but of paramount importance.

3.7 References

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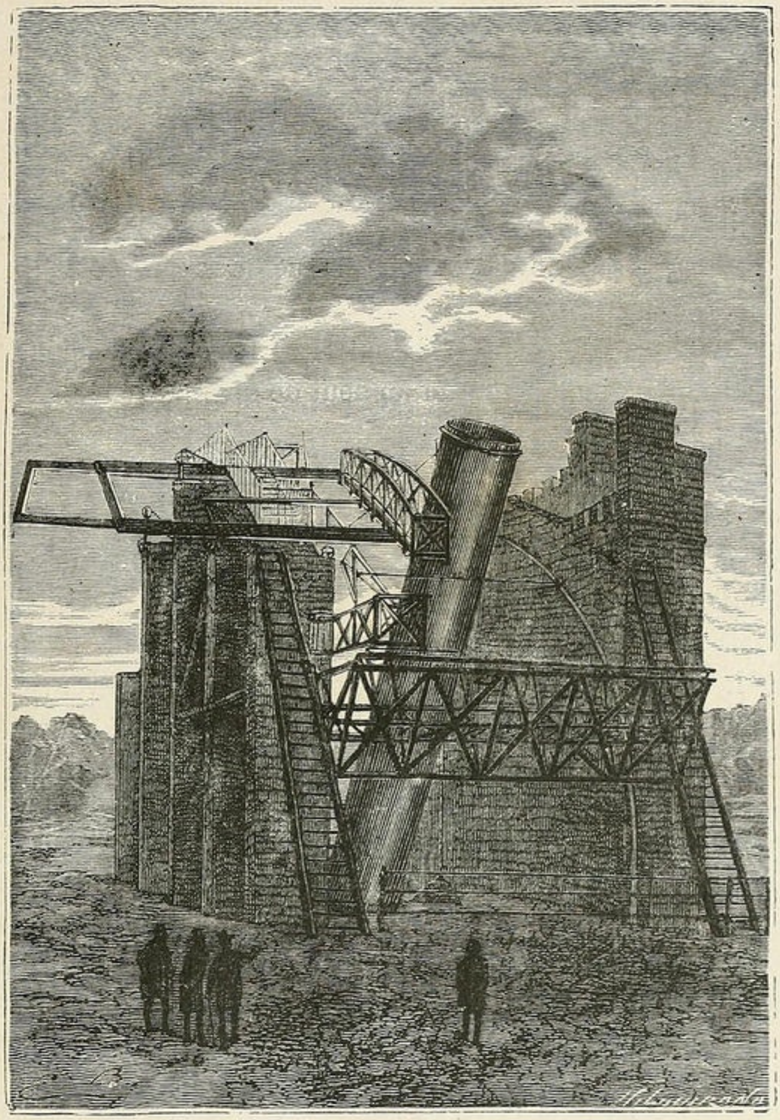
CHAPTER FOUR

The Flemish research context



L'instrument monté. (Page 80.)

Abstract

In this fourth chapter, we provide a brief overview of the profound change that the transition towards demand-driven care caused on the organisation of the Flemish care landscape. We discuss some of the instruments and interventions to achieve the four key objectives of PVF, as well as how the Flemish government and administration (VAPH) intends to further strengthen them in the future.

4.1 From a supply-driven to a demand-driven care landscape in Flanders

The most recent policy shift in the care for people with disabilities in Flanders (the Dutch-speaking part of Belgium), stems from the same three major factors that underly the shift towards personal budgets internationally. The Flemish Government introduced a system of personal budgets in the care for people with disabilities as part of a long-term vision entitled 'Perspective 2020 - [a new support policy for persons with disabilities]', implemented by the Flemish agency for People with Disabilities (VAPH) in January 2017. It enables eligible adults with a disability to obtain a personal budget, in order to be able to buy tailor-made care. The core of this new policy can be summarised as a shift from supply-driven to demand-driven care (Department of Welfare, Public Health and Family Affairs, 2010). This is an evolution that spans over more than two decades, with numerous measures having paved the way towards demand driven care and support. Years of experiments had proceeded with rather limited additions to the existing supply-driven services for people with disabilities.

Twenty years ago, care for persons with disabilities in Flanders was exclusively provided according to a supply-driven system. In this supply-driven system, the government recognises, accredits and subsidises facilities and organisations which, in exchange for the financial resources, develop a range of services and make them available to the targeted group. This is a system in which the care provider is at the centre of the care, without the person with a disability is able to determine what support is offered. Only in the late years of the 1990's, this supply-driven system was cautiously turned down in a first experiment (Breda et al., 2004; Verschuere and Hermans, 2016).

This first experiment with a personal assistance budget (PAB) was carried out in 1997, in which sixteen persons with physical disabilities were allocated a budget. Two years later, the Flemish Government decided to organise a second experiment and tried to respond to criticisms on the small scale and limited representativeness by increasing the budgets, increasing the number of persons and expanding the target group by including all types of disability. On July 17th 2000, the PAB decree was adopted by the Flemish government which made it possible in 2001 for all persons with disabilities or their legal representatives to apply for such a budget and to acquire personal assistance (Looten and Verstraete, 2014; Breda et al., 2004). The PAB enabled persons with disabilities to make choices regarding their care and support and is intended as a more tailor-made approach. An important objective in the introduction of the PAB was to reduce the admission of (the more expensive) residential care. Although that goal was never achieved, the PAB-policy remained in existence because it offered the new possibility for persons with disabilities to employ their own personal assistants (Breda et al., 2006). It meant that the desired care and support could be realised in the person's home environment, with the possibly to combine this with specialised care. This included day care centres and specialised home care, although these options were rather limited.

With the introduction of the Personal Budget (PGB) as early as 2001, the next step was taken towards a demand-driven approach. In 2007, the Flemish sector for persons with disabilities joined forces and drew up 'the Brussels Declaration', in which they called on the government to speed up the implementation of a policy for persons with disabilities based on personal budgets. Only a year later, the PGB decree was finally adopted in practice, by launching yet another experiment. The experiment included a PGB for 133 persons with a physical and/or intellectual disability.

However, a generalisation of the PGB with respect to all persons with disabilities, as happened after the PAB experiments (Breda et al., 2011), was not adopted. However, the PGB created more possibilities for persons with disabilities than a PAB. In addition to the opportunity to employ assistants, it was also possible to obtain support from facilities and services accredited or licensed by the VAPH (VAPH, 2012). Consequently, more so than the PAB, the main goal of the PGB is to offer more choice and control for the care user (Gevers and Breda, 2011). The PGB was distributed via a system of 'Trekkingsrecht', a third payment system, to an accredited service centre of the person with a disability's choice (Gevaert, 2004). At the point of assessment and enrolment, a person has to make a choice between a PAB or a PGT or a combination of both. Provision was also made for individual material assistance, allowing the purchase of equipment and its direct reimbursement to the person with a disability (VAPH, 2012). The PGB thus enabled persons with a disability to organise the support themselves if they wanted to purchase it from the facilities of their choice (Gevaert, 2004).

The decrees concerning PAB and PGB were first steps towards a demand-driven system of care for people with disabilities in Flanders. This movement would take a quantum leap with the adoption of the decree on 'Persoonsvolgende Financiering' (PVF) in 2014.

4.2 Implementation of 'Persoonsvolgende Financiering' (PVF)

The PVF decree of 23 April 2014 is based on a so-called 'gradual' two-stepped system, whereby it is impossible to combine the budget of the first step with the budget of the second (Department of Welfare, Public Health and Family Affairs, 2018).

Step one: *BOB*

The first step is called a 'Basisondersteuningsbudget' (BOB) or Basic Support Budget and consists of a fixed tax-free amount of 300 euros, which is provided on a monthly basis to eligible persons with a disability. The money is available for free use and there is no need to present proof of expenditure. The BOB has not to be applied for as the competent governmental authority itself will contact and disburse this money in case one is eligible. Since 2017, this budget can be allocated to both minors and adults (VAPH, 2019a). Individuals are eligible if they are recognised as having a disability, an established need for support and if no recourse is made to the non-directly accessible help of the VAPH. The BOB as a first step of this gradual system is intended to be accessible for people with a relatively limited demand for support. (VAPH, 2019b). Together with an increase in directly accessible help (less intensive disability-specific help financed by the VAPH), the BOB is an important step towards achieving the advocated guarantee of care and support. Recent figures show that 78 percent of those waiting for a personal budget (step 2) already make use of this form of support (VAPH, 2019a). In a recent evaluation study by Op de Beeck, Schepers and Van Regenmortel (2018) on the implementation of the PDB, the results of a large-scale survey show that the proportion of beneficiaries who consider this budget to be sufficient is more or less equal to that which it considers insufficient.

The authors therefore point to the need for a comprehensive policy in which other policy areas (e.g. poverty reduction, employment, education, transport, housing) contribute as well, in order for the necessary care and support for everyone can be guaranteed. This first exploratory study initiates the debate on the BOB. Yet, as this first step of the PVF system consists only of a link with the directly accessible services and the first-line care, it will not be part of the research focus in the further phases.

Step two: *PVF*

The second stage is intended for persons with a more intensive or more complex demand for care than in the first step. Individuals receive a 'persoonsvolgend budget' (PVB) per year with which care and support can be purchased within one's own network, from voluntary organisations, individual support workers, professional care providers or from care providers licensed by the VAPH. This budget does not involve a lump sum but comprises 24 budget categories, of which one is allocated based on the demand and the extent to which the person needs support (VAPH, 2019b; 2019c). This budget can be combined with the allowances for assistive equipment and adaptations, but a combination with step 1, the BOB and the directly accessible assistance, is not possible (VAPH, 2019a). The application for a PVB, in contrast to the BOB in the first step of the PVF-system, needs to be initiated by the person him/herself and a procedure with several steps needs to be gone through. Therefore, the introduction of 'persoonsvolgende financiering' (PVF) is causing an enormous system shift with consequences for many actors, including the government, care services, formal and informal care providers, the care recipient and its network. To bring the policy into effect, an implementation-system has been designed in which a multitude of actors with specific tasks and roles is involved.

In every step of the care pathway -from application over assessment to the allocation of the budget- clients come into contact with different actors who all have different decision-making competences depending on the step in the procedure (figure 4). This is a completely new procedure that is performed before any care and support is provided.

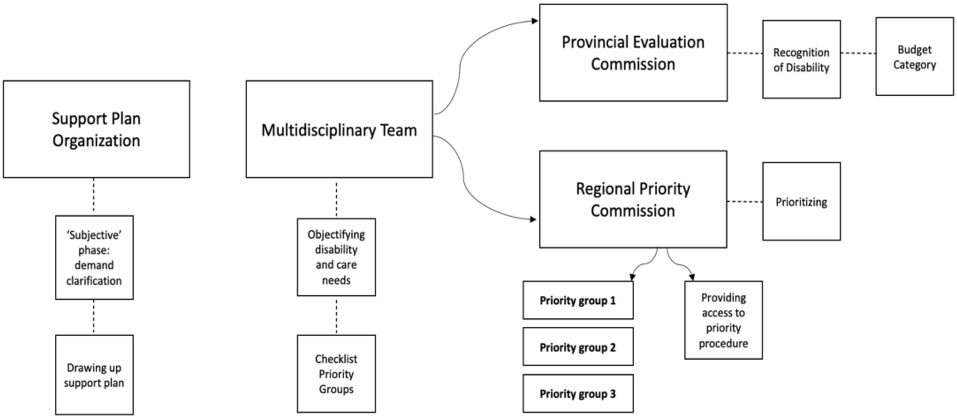


Figure 4: Procedure and actors involved

In order to be eligible for a personal budget, an individual has to become recognised as a person with a disability by the Flemish Agency for People with Disabilities (VAPH) in the first place. Only then, the person can start the procedure of which the first stage consists of determining the level and extent of care and support needed through a needs assessment. This process of 'demand clarification' involves drawing up a care plan. A process that can be done in a diversity of ways. The client can do this independently without any help, or he can be assisted by professional actors such as a service of their health insurance fund (dienst maatschappelijk werk van het ziekenfonds), Multi-Disciplinary Teams (MDT) or the Support Plan Organization (Dienst Ondersteuningsplan) funded by VAPH (VAPH, 2019a, 2019c).

Furthermore, clients can use the support planning tool launched by the VAPH or they can be assisted by a user organisation. In the support plan, the applicant maps all his or her possibilities and those of the environment in a comprehensive plan with information about this person, his current situation and his demand for care and support. The plan should also describe exactly how the process of demand clarification went. The result of this first step is called the subjective demand for care. In case the person is in need of intensive and frequent disability-specific support, a personal budget can be requested to the VAPH to organize and finance this support (VAPH, 2019b).

The second step of the procedure is the assessment of the clients support plan and the urgency of the care needs by a Multi-Disciplinary Team (MDT). Each team is authorised and funded by the VAPH to perform these assessments. In practice they are part of a larger organisation such as e.g. a health insurance fund or a rehabilitation centre. The MDT comprises different professional branches such as doctors, social workers, nurses, psychologists and pedagogues. Based on their professional expertise and supported by a standardised assessment tool they can evaluate the application and objectify the support needs. Additionally, the MDT will complete a checklist to assess the urgency of the support needs. The multidisciplinary report is the specific result of this step.

Thirdly, two commissions compiled by the VAPH will make the decisions concerning the allocation of the budget. The Provincial Evaluation Commission (PEC) will determine, based on the information provided by the client and the MDT, the level of the budget that will be allocated. In addition, the Regional Priority Commission (RPC) will decide on the priority of the support needs based on an intersubjective appraisal using legal criteria (VAPH, 2019b).

Based on this decision, the client will be assigned to one of the three priority groups. People assigned to the first priority group, should obtain their budget in a shorter term than those on group two and three. Clients in a situation of neglect and abuse and with an immediate need for support can appeal for a ‘priority budget’ based on their precarious situation, enabling them to make use of a fast-track procedure to bypass the three priority groups (VAPH, 2019b, 2019c). Ultimately, it is up to the budget holder himself to choose where and how he wants to use the personal budget. There are two combinable options to spend the budget: in cash and in the form of a voucher (VAPH, 2012, 2019b, 2019c). With the 'in cash' option the VAPH transfers the budget to the person with a disability. He or she is fully responsible for the administrative and financial processing of their own budget. It can be used to pay for (non-)-licensed providers and/or individual assistants. In the case of a voucher, the person with a disability arranges his care and support (or part of it) via an agreement with a care provider licensed by the VAPH. With this option, the administrative and financial aspects of the agreement are settled directly between the VAPH and the licensed care provider. A combination of both methods of spending is permitted (VAPH, 2019b, 2019c). In 2018, 92.1% of the total PVB budgets were spent via the voucher option. Only 7.9% was deployed via cash, which was predominantly spent on non-licensed care providers (VAPH, 2019a).

Recent figures of the VAPH (2019b) show the wide range of possibilities to spend the cash budget in practice: ranging from family members, employment contracts or temporary employment agencies, transport and volunteers and even initiatives recognised by the Department of Welfare, Public Health and Family Affairs (outside the disability sector). The combination of the use of the budget in voucher with the cash variant is an element to realise the expected and foreseen demand-driven support.

As such, cash is taken as an option when the care and support is purchased from a non-licensed care provider, contributing to the intended 'vermaatschappelijking'. This brings us to a deeper exploration of the four objectives of the new demand driven PVF system and how social policy intends to address these objectives and to further enhance this in the future.

4.3 Objectives of PVF

Two concept notes lay at the basis of the final decree on PVF. The first is the long-term vision entitled 'Perspective 2020 - a new support policy for persons with disabilities' (Department of Welfare, Public Health and Family Affairs, 2010) paired with the concept note for direct payments for people with disabilities (Department of Welfare, Public Health and Family Affairs, 2013). From these documents the four main objectives of the PVF policy were specified: (1) To Guarantee Care and Support; (2) Well Informed 'users'; (3) Tailor-made care and support; (4) Inclusion and 'Vermaatschappelijking van de zorg'.

1. To guarantee care and support

The policy plan in Flanders mentions that disabled people who experience the most severe need for care and support are guaranteed "adequate, appropriate, and high-quality support at socially acceptable and justified cost" (Department of Welfare, Public Health and Family Affairs, 2010, p. 22). With regard to care continuity of all former users of non-direct accessible services, the personal budget scheme established an automatic transfer to the new system (Department of Welfare, Public Health and Family Affairs, 2013). In other words, all of the persons receiving care under the former care system were allocated a budget, calculated on the basis of their current care and support need (VAPH, 2012, 2019a).

The Flemish personal budget is not means-tested and covers the full costs for care and support (Excluding the costs for daily living [e.g. rent, food]). In practice, the government's ability to allocate a personal budget to all eligible clients in the short term is limited, given the macro-budgetary constraints. Consequently, the Flemish disability sector has been dealing with extensive waiting lists for many years. Back in 2013, 56% of all persons that were registered with a care need received no form of VAPH-support. This number has dropped, mainly due to the introduction of the first step of the PVF-system, the fixed Basic Support Budget for people with limited support need (Department of Welfare, Public Health and Family Affairs, 2013; VAPH, 2019b). At the end of 2018, 15.000 persons were waiting for a PVB, the second step in the care system. From those waiting for a PVB, 47% were issued a BOB, and 22% were not supported at all (VAPH, 2019a). Hence, from a policy perspective, an objective procedure to prioritise access to care and support is paramount (Dursin et al., in Press). One measure that seeks to address this is the expansion of automatic allocation groups (VAPH, 2019a). Persons with a specific profile, such as persons with a rapidly degenerative disorder, and persons in an emergency situation can immediately be allocated a personal budget, without having to go through the objectification and assessment procedure. In particular, as the government has explicitly included access to personalised care and support for people with the most serious support needs as one of the top policy priorities (Roets et al. 2020). According to Ferket et al. (2019), the most important preconditions for personal financing to promote quality of life and to guarantee quality care tailored to the individual are a sufficiently high overall budget for persons with disabilities in Flanders to enable quality of life and the removal of waiting lists for care and support.

2. Well Informed ‘users’

People with disabilities have also been reframed in Flemish social policy rhetoric as competent stakeholders and citizen consumers who can buy their own care rather than as service users. Perspective 2020 strongly accentuates that disabled people should be able to fully develop their own potential and to rule over their own lives. Therefore, it is argued that “initiatives that contribute to the strengthening of personal autonomy and selfdetermination should accordingly be developed” (Department of Welfare, Public Health and Family Affairs, 2010, p. 4). The focus on personal autonomy is one of the major roots for the shift from supply-oriented provisions to demand-driven services. The personal budgets allow people with disabilities to behave as autonomous consumers and likewise buy their care and support (Department of Welfare, Public Health and Family Affairs, 2010, 2018). In this respect, the VAPH is committed to 'informing users adequately so that they can apply for and obtain the necessary care and support' (VAPH, 2019a, p.8).

To this end, the VAPH recognises and subsidises various organisations (see: DOP, MDT, user organizations, ...) to assist individuals in the process of demand clarification and the creation of a support plan. Many people with disabilities appear to be unaware of their rights throughout the application procedure. A large-scale survey by Ferket et al. (2019) shows that the possibility of making use of an independent service to help draw up the support plan is not known by one third of the population. In fact, one in five indicate that they did not perceive the choice to draw up the support plan in cooperation with an independent service as a free choice. In this line, results of a mid-term evaluation of PVF (VAPH, 2019a) show that the support plans are mainly drawn up with the help of a professional: 47,50% with the help of a service of the health insurance fund, 30,50% by a Support Plan Organization, 9,90% with help from other organizations and 12,10% without any professional help.

This shows that the move to an increasingly personalised choice in a free and flexible market of service delivery creates a number of challenges when disabled people, and specifically people with intellectual disabilities and/or mental health problems, are perceived as consumers who are expected to be competent in guaranteeing that care and support will take place with enough professional expertise (Roets et al., 2020). During the policy implementation process, necessary revisions are already captured in the Decree of 2018 which shows that surplus legal protection and quality control is necessary and will be pursued to guarantee this (see also VAPH, 2019a, 2019b). The Decree of 2018 also stresses the major concerns about the shift to self-determination, stating that "many service users today are not capable in managing their own budget, both in terms of costs for care, housing and living conditions. The shift to self-determination requires specific competences of service users which causes major concerns, both on the side of disabled people and their families, and providers of care and support". Therefore, the VAPH subsidises five assistance organisations[2]. They can assist budget holders in starting up, spending and managing their budget. For particularly complex cases, on top of intensive assistance, mediation services can also be provided. The Decree stresses the need for further revisions during a period of transition until 2021, during which service users will be receiving better support in managing their budget and providers of care will be controlled by the Flemish Government, issuing rules that should guarantee fair and transparent costs.

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[2] Absoluut vzw, Alin vzw, MyAssist vzw, Onafhankelijk Leven vzw en ZOOM vzw

3. Tailor-made care and support

The third objective of PVF holds that people with disabilities and their families should always be able to tailor their care and support to specific demands, needs and circumstances (Department of Welfare, Public Health and Family Affairs, 2010, VAPH, 2019a). To this end, the height of the individual budget is objectively determined by the MDT, based on the demand as formulated in the support plan. In this vein, the process of demand clarification and the subsequent support plan is of fundamental importance for the extent to which tailor-made care and support can be provided. The support plan document is structured in such a way that it helps the client to identify ways of meeting needs by focusing both on potential solutions that can be offered by the client's network or regular services and equally by specialised care providers (VAPH, 2019c). In that sense, an integral and dynamic model of "concentric circles" has been based on a notion of the American Association of Intellectual and Developmental Disability (AAIDD) that introduces a novel conceptualization of support needs and resources (Department of Welfare, Public Health and Family Affairs, 2013). The AAIDD conceptualisation of support resources is framed as a strengths-based approach that puts the person with a disability in the middle of a set of concentric circles (Buntinx, 2013). Actors in the first three circles are considered as natural resources that are available in the general community environment, whereas actors in the fourth and last circle concern specialised services-based resources (Buntinx, 2013). The concept of 'concentric circles' should encourage individuals to think about the various possibilities for organising care and support, whereby the person's network comes first, and specialist care should only be addressed in the very last instance (Department of Welfare, Public Health and Family Affairs, 2013).

The capacities of all the persons involved together with the choices of the person with a disability determine which circle needs to be addressed where and when.

The various layers of this circle are described as follows (Department of Welfare, Public Health and Family Affairs, 2013; VAPH, 2019b, 2019d):

1. Self-management of care: What is the person with a disability able or willing to do?
2. Usual care: What support can and will the nuclear family of the person with a disability offer?
3. Care and support offered by family, friends and informal contacts with volunteer community members.

Figure 5: Concentric Circles – (VAPH, 2019d).

4. Formal care offered by professionals in public services accessible for all citizens: In order to strengthen the self-care and support by family members and friends and to offer additional support, the regular care and support comes into the picture. This may involve services and facilities such as domestic care or family support.
5. Formal care provided by professionals in specialized public services: the person can appeal to care and services that are specifically suited for that disability. These complement other forms of support and/or offer extra support.

Rather than adopting the broad definition of supports as material as well as immaterial resources from the AAIDD model, support is mainly captured in terms of support offered by persons (Roets et al., 2020). In the original model, it is argued that the support resources in the first three circles are inclusive to persons with disabilities. It is argued that the shift in thinking reveals a historical turning point, as "the tide turned, and persons with disabilities began to make use of their natural support resources" whereas previously specialised services separated them from the same functions and organisation in the community at large (Buntinx, 2013, p. 14). The AAIDD conceptualization, however, might be problematic in the suggestion that an inclusive society already exists, which is—as research recently uncovers—not the case in Flanders (see Vandekinderen and Roets, 2016). Furthermore, a large-scale survey of Vermeulen, Van Der Niet, Demaerschalk, Van Audenhove and Hermans (2012) shows that 37,3% of the people with disabilities involved in the study do not have enough money to be able to make their own choices. This confirms the link between a lack of financial resources and tailor-made care and self-determination and inclusion (Vermeulen et al., 2012; Ferket et al., 2019).

4. Inclusion and 'Vermaatschappelijking van de zorg'

This fourth objective entails "the promotion of support of the social network (volunteer aid) in the direct environment of disabled people" (Department of Welfare, Public Health and Family Affairs, 2010, p. 5, our translation). The policy rationale of 'vermaatschappelijking van de zorg' embodies the connotation of organising care and support with/in the community and society:

> "a paradigm shift in pursuit of an inclusive approach towards disabled people (…), allowing them to acquire their own meaningful and particular place in society while embracing both their vulnerabilities and strengths, supporting them in this venture where necessary, and organising care and support with, and integrated in, society as far as possible" (Department of Welfare, Public Health and Family Affairs, 2013, p. 4).

This promotion of support in the direct environment is striking example of a shift towards 'welfare pluralism' (see Dean, 2015; Williams, 2001) that rests on the idea that an increasingly significant level of provision should also come from the 'informal sector', meaning from families and communities (Roets et al., 2020). Although there is supposedly no hierarchy but complementarity between informal and formal care, this development of 'vermaatschappelijking' also squares with the idea that the public responsibility for the welfare of citizens should be rebalanced with, and even returned to, the private responsibility of the individual, his/her natural social networks (such as family members) and the community/civil society (Dean, 2015).

The use of the personal budget allows individuals to make use of non-direct accessible and highly professional care, but within the reasoning of concentric circles this is only desirable "after the settlement of the other available sources of support in the natural and social network, and in directly accessible care" (Department of Welfare, Public Health and Family Affairs, 2013, p. 10). Important is that the recent survey by Ferket et al. (2019) identifies the loneliness of a group of persons with disabilities in our society. When we know that the Flemish Government addresses the network of persons with disabilities as a primary source of support and a way to promote inclusion, we need to address the lack of such a social network among a significant group of persons with disabilities (Department of Welfare, Public Health and Family Affairs, 2013).

Furthermore, people with disabilities are at considerable risk to end up in poverty (see Hermans, 2019). A study by Vermeulen, Van Der Niet, Demaerschalk, Van Audenhove and Hermans (2012) showed that the poverty risk among persons with disabilities is much higher than among the general population (39% versus 15%). Poverty will therefore have an impact on this inclusion objective. We can conclude from these studies that it is priority to pay attention to the construction of social networks around persons with disabilities and to accessibility as preconditions to promote the inclusion of persons with disabilities in society.

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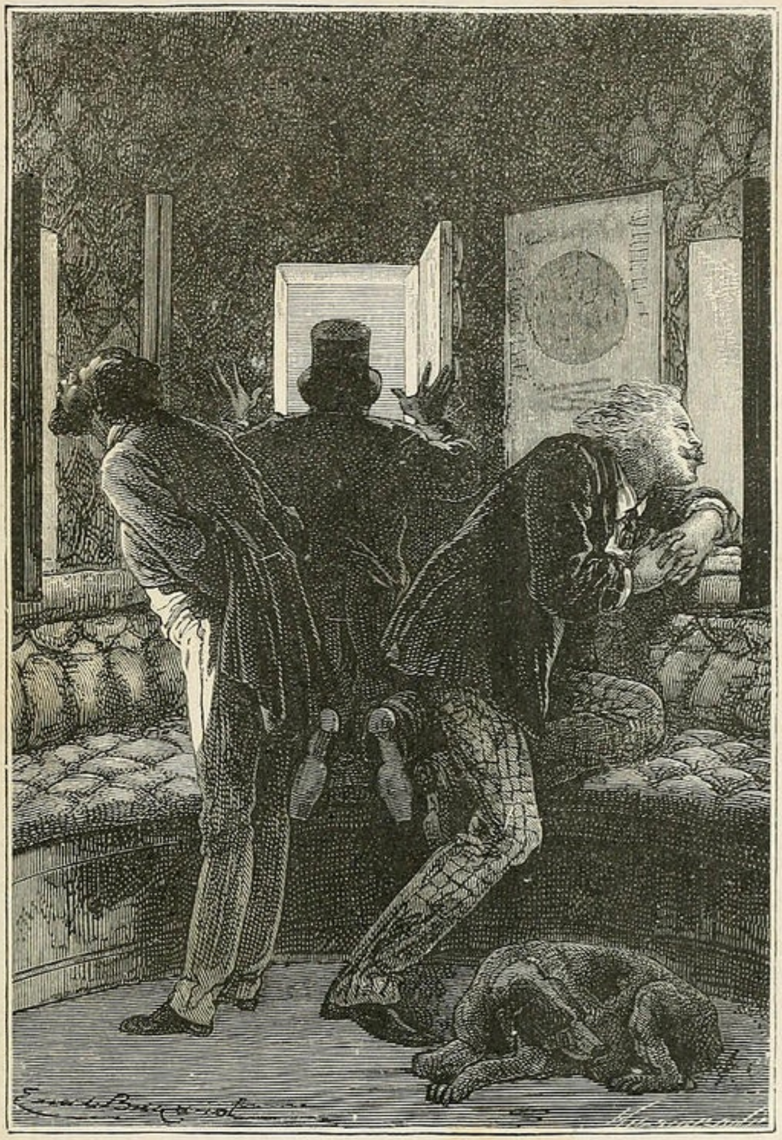
CHAPTER FIVE

The Pedagogical Project of Care Institutions in Flanders



Le soleil... (Page 127.)

Abstract

The care for disabled people in Flanders is currently undergoing a major social policy reform under the introduction of a personal budget scheme. Disability services in Flanders are explicitly expected to develop a demand driven provision of care services. This transition stems from the urge for autonomy and self-determination of disabled people and is aimed to deinstitutionalise the care for people with disabilities. The central question addressed is the way in which the introduction of personal budgets influences the ability of Flemish care institutions to shape their practice. Our findings depict that care institutions emphasise the importance of a dialogical process, in which different views of 'good care' can be discussed. However, in policy implementation, a particular focus on 'a self-aware and autonomous individual' as an objective would make this process more challenging. Our analysis identifies how a far-reaching focus on autonomy and self-determination does not guarantee high-quality care. Nor would the opposite: major autonomy for care institutions. Rather than balancing the negotiating positions, the Flemish personal budget scheme tends to push disability services into an executive role in which the possibilities of a pedagogy as an emancipatory project shrink.

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5.1 Introduction

Following the example of other welfare states, such as, amongst others, The Netherlands (WMO 2015), Germany (Bundesministerium für Arbeit und Soziales, 2017) and England (Care Act, 2014), a recent policy-shift in Flanders (the Dutch-speaking part of Belgium), called 'Perspective 2020', paved the way towards a personal budget system as a realisation of the right to social care for people with disabilities. Drawing on the Belgian ratification in 2009 of the UN Convention on the rights of persons with disabilities (UNCRPD), this plan asserts that the implementation of the convention '*should lead to a comprehensive inclusion policy and a deepened inclusion practice*', and should be realised '*through initiatives that strengthen personal autonomy and increase self-direction*' (Department of Welfare, Public Health and Family Affairs, 2010, p.8.). The UNCRPD recommended that in Belgium a policy of de-institutionalisation should be pursued, reducing investment in collective infrastructures and giving greater consideration to personal choices. This recommendation is in line with an international trend towards deinstitutionalisation in many Western Welfare States since the 1960's, albeit at different pace, argued for by policy makers and citizens organised in self-advocacy groups (see for example: Goffman, 1961; Johnson and Traustadòttir, 2005).

In this vein, Flemish institutionalised care settings have been under attack from self-advocacy groups, such as the regional division of the Independent Living Movement (*Onafhankelijk Leven*), claiming disabled people should get more autonomy and control over the care they receive. This development puts 'the person as an individual' at heart of any discussion on the care trajectory of disabled persons and prioritises the wellbeing and preferences of the individual as key measures of quality of care.

The international quest for deinstitutionalisation advocates the individual's expertise, rather than professional knowledge, congruences more with everyday lives and thus secures a better use of public resources (Needham, 2011). According to this, the position of the government changes from organiser of care through direct subsidies to licenced care institutions, to organiser of the market of care (De Vos, 2014, p. 169). The role of the government has shifted to guaranteeing first and above all the freedom of choice of the individual. In practice, this means that people can choose to use their allocated budget for care and support from non-licenced care providers, family members, temporary workers, etc. The government still monitors and conducts audits in order to guarantee the quality of care provided by licensed care institutions. The licensed care provider has to provide and clarify relevant data for a set of indicators on an annual basis and are required to develop a business plan (Vlaams Minister van Welzijn, Gezondheid en Gezin, 2016). In this context, Flemish social policy has reframed disabled people from users of services to citizen-consumers and competent stakeholders. This shift in terminology reflects the clear choice for self-directed support and expects individuals to ideally behave as consumers (Clarke, 2005; Owens, Mladenov and Cribb, 2017). In addition, disability services are expected to develop their practice according to a market logic. This means care services are supposed to shape their practice based on the individual's care questions instead of providing a predefined care service (Roulstone and Morgan, 2009). This shift from a supply-oriented provision towards a demand-driven service, has been translated by the Flemish government in a new financing system: 'Persoonsvolgende Financiering' (PVF) [Personalised Financing], which enables disabled people to choose and purchase their care and support through vouchers and personal cash budgets (Department of Welfare, Public Health and Family Affairs, 2010, 2018).

Since the Flemish PVF system was introduced two years ago, the vast majority of people with disabilities continued to choose to receive their care from a licenced care provider in a residential setting (VAPH, 2019). Once eligible for a personal budget, the physical and/or intellectual disabled individual (or his/her network) can choose between a cash and a voucher-variant. A cash budget allows the individual to manage all resources at his or her disposal to discharge the need for care. A voucher entitles the person only to choose a licenced care institution. The licensed care provider(s) are then responsible for negotiation with the user, the administrative management and will invoice directly to the Flemish Government. The cash variant provides more flexibility and an even greater degree of autonomy, as all management is in one's own hands (or his/her network). After all, the voucher variant often works with a 'care package' offered by the licensed providers. As 82,73% of all persons eligible for a personal budget (taken together people with physical and intellectual disabilities) opt for the voucher system, the Flemish Agency for Persons with Disabilities (VAPH, 2019) notes in its annual report of the first half of 2019 that: 'For the time being, however, the shifts in the mode of expenditure compared to the old financing system remains rather limited'.

Following this idea of deinstitutionalisation, the Flemish system of Personal Budgets is in effect conceived as an instrument for the creation of a different care landscape in which autonomy and self-development are key, putting the service user in the driver's seat. This reconfiguration is supposed to lead to a dialogue between the newly defined service user and service provider about the quality of care and service delivery. As outlined above, recent numbers learn that care institutions continue to make up a large part of the 'care market'. It is in this context that residential care institutions have to develop a demand-driven service based on freedom of choice and expression of autonomy and self-determination of the client.

The question is how discussions about care and support are conducted within the renewed relationship as a user and service provider in the context of demand-driven care and in what practices this results. This article addresses the perspective of residential care institutions. Based on 12 interviews and one focus-group, we explore the meaning of this new reality of personal budgets for their care practice and pedagogical project.

5.2 Demand Driven Care

A shift in power

The stake of personal budget schemes is more than economic redistribution. It is part of the demand of cultural recognition (see Fraser, 1997) and of shifting the power balance between the various stakeholders being part of the care practice, in order to restore the independence of disabled people (see Williams, 2001). Aligning the critiques on the totalitarian character of care institutions (Johnson and Traustadòttir, 2005) and their subversion of people's individual preferences, the personal budget schemes are a means to achieve a greater influence and involvement and let disabled subjects move from passive and dependent to active and independent agents (Clarke, 2005). In that respect, the provision of resources directly to the recipients of care is a formal recognition of their knowledge and experiences in everyday life. Personal budget schemes contain the potential to involve the 'experientially based knowledge' (Beresford, 2000, p. 493) of service users into the discussion on care practices within care institutions. At the core is the idea that people with disabilities are experts on the hurdles they encounter in their daily lives and should therefore be able to make their own decisions according the matters that require care. As such, the expertise of the individual, which is presumably more in accordance with daily life (Beresford, 2000), is regarded as of the utmost importance for realising qualitative care (Needham, 2011).

The ambition to strengthen personal autonomy goes hand in hand with a shift in the role of the government as the organiser and funder of care-institutions towards guaranteeing the user's freedom of choice. The relocation of welfare resources from institutional and professional care directly to the users is welcomed as an essential condition for the promotion of disabled people's freedom and independence (Author's own, 2017; Dowse, 2009; Mladenov, 2012). In addition, this refers to what is known under the shift from a supply-driven to a demand-driven care landscape, valuing market competition, efficiency and responsiveness to individual needs (Kremer, 2006; Roulstone and Morgan, 2009). Imposing market-based principles and managerial values on government-funded social services are intentions to foster the effectiveness of these services (Otto, Polutta and Ziegler, 2009; Hood, 2014). In addition to organisational gains, personal budgets are considered to be more cost-efficient (Slasberg, Beresford and Schofield, 2012).

In essence, the key objectives are as follows: higher quality driven by competition in a market-environment; enhancing demand-driven care; resulting in more creative and flexible answers whereby personal choice and control over care are central (Dean, 2015; Authors own, 2017). Personal budget policies force service providers to take more account of the needs and wishes of the individual (Needham, 2011; Dickinson, 2017), since the scarce resources are in the user's hands. Service providers are expected to provide more creative and better care to respond to the demand (the care need). The Flemish PVF-system introduces and encourages market mechanisms (Department of Welfare, Public Health and Family Affairs, 2010, 2018) as a means to enhance the more responsive attitude on the part of the institutions. This should furthermore result in the expected demand-driven care practice.

Care and the Pedagogical Project

The policy under scrutiny is intended as an empowering policy (Department of Welfare, Public Health and Family Affairs, 2010, 2018). It is a funding system that aims for the realisation of a care practice where individuals are self-confident and able to make well informed choices to actively shape their own life course. However, the notion of independency defined as an ideal of rational autonomy in the discussed social policies, aligns with a criticised notion of empowerment as an individual responsibility (e.g. Baistow, 1994). This has been argued by scholars to be deeply problematic for a care practice (see Dean, 2015; Dowse, 2009; Owens et al., 2017).

Mladenov (2012; 258) points to 'the possibility to reflexively engage with the world of one's being' as an important condition for independence, underpinning this position with the statement that 'if one is not free to adjust the limits of freedom, citizenship is a trap and one can be considered to be free in prison' (Schecter, 2010; 227). In this vein, the desired shift in power (articulated in the criticism on institutional care) emphasises the recognition of 'lived' knowledge and expertise. However, it is not guaranteed that this will actually lead to an improved quality of support (Dean, 2015), as it is not clear how the notion of quality would be discussed within the care relationship.

5.3 Methodology

We did research on the perspectives of a group of managers of care institutions in a learning community called KWAITO. This is a network organisation of 12 care institutions for people with intellectual and physical disabilities that gathered around the aim to realise qualitative care in the context of the personal budget system. Notions of solidarity and inclusive citizenship form the basis of their practices which they believe are under pressure due to the transition in the Flemish care landscape (www.kwaito.be).

Their primary goal is to establish a common position in discussions regarding institutional care services and the marketisation of the care sector. In this way, the managers gathered in KWAITO offer an interesting case for exploring the perspectives of institutions on this recent policy shift towards personal budgets.

We conducted in depth semi-structured interviews with the managers of the care institutions gathered in this network-organisation (n=12). In three cases, members of the pedagogical staff (n=4) participated out of interest alongside the directors, resulting in 'double-interviews'. They provided valuable input with more tangible stories from the support practice, on which they have a better understanding from their coordinating or supervisory role. The interviews lasted between 1.5 and 3.5 hours. All of the interviews were anonymously transcribed, as indicated in the previously discussed and consequently signed informed consent. Ethical approval for this study was gained through following the authors' university's research ethics guidelines. The conversations are built around the attempt to shed light on the director's decision-making process in the implementation of these policies in practice. We probed with such questions as: "What choices were made in the transition-period towards personal budget schemes?" "How is 'a demand-driven approach' defined within the organisation? Is this a new given?" "How do you reconcile customer-oriented and market-oriented working with social justice issues?" The results depict how these decisions are related to the pedagogical project of the institution.

All the data were entered in MAXQDA, a well-established software program for analysing qualitative data. The coding and categorisations occurred in two phases. As a first step, the major overarching themes were defined by thoroughly reading all the conversations several times.

We began with initial codes such as: “organisational aspects”, “pedagogical matters” and “financial implications” amongst others. As a second step, sub-themes were further developed during the coding process. Through this iterative process, we revised and refined the broader initial codes. Given the focus of the study, we paid particular attention to the relations between “what is changing and what is constant or unalterable in the transition towards personalised care” and “the quality of care”. Whilst analysing the conversations, we became more aware of the attention paid in the interviews to the recognition given within such a system to the 'lived knowledge' of the person with a disability and their network. Consequently, we shifted the focus of analysis towards understanding how the respondents shape the pedagogical practice, given this alteration of knowledge and power.

We collected additional data through conducting a focus group with all directors after the first two phases of analysis. This focus group was mainly aimed at testing the recognisability of this analysis and gathering a deeper insight into their view on the debate about knowledge and the status of professional power. Respondents came up with more practical examples, providing insight into how they relate to the ‘empowered’ person with a disability and her/his’s network, thus shaping the care relationship.

5.4 Results

We find that the respondents, show two distinct visions on how to shape their practice under the introduction of the personal budget scheme. On the one hand, they highlight elements that are appreciated because they facilitate the realisation of a 'good practice' as well as issues that may jeopardize this. It is noteworthy that the things that are put forward as facilitating, are precisely continuations in the care institutions' practice. In other words, things that are not specific to the newly introduced personal budget scheme but are rather the core of what we can call 'their pedagogical project'. For example: *"We still apply the principles we used to apply in the past, and that is to work as much as possible in shared control"* [*R*7]. When stressing the continuity, respondents thus mainly refer to what they see as a 'good practice' and what in their opinion is care of high quality.

The other view on the impact of the transition towards a system of personal budgets highlights the fact that it challenges a number of issues that were previously considered to be self-evident. Respondents indicated in different ways that they question evidences our routines and have to consider changes: *"In the past, it didn't occur..."* [R12]; *"So in that respect, we had somewhat of a need to organise ourselves differently"* [R6]; *"This entire process is a whole new process for the staff, isn't it? That's very new."* [R4]. This includes matters such as payroll expenses, fundraising, efficiency and effectiveness of managerial staff, advantages or disadvantages of scale, which expenditures are passed on to the residents and which others are included in the organisation-related expenditures, etc. The reflection on what formerly were evidences in the Flemish care system (by and large government-funded), cause the respondents to change the organisational and financial aspects of their daily practice.

> *“So, there it is that the market logic of course crept in, as in, look okay now it has to be that way if people are not satisfied now, they are gone. But that also means, gone with their money. That generates a different pressure, doesn't it?”* [*R*6]

The introduction of the system of Personal Budgets therefore also brings to the surface issues that encourage reflection and ensure that the practice that used to be commonplace will have to be changed. The fact that this makes it necessary to consider the organisational and financial 'health' of the care institution is widely welcomed: "*Because it is also important to work efficiently within an organisation*" [R4]. The directors consequently see dealing with these new elements as the main responsibility and challenge in the emerging ‘care market’. Participants emphasised during the focus group that they experience the most pressure when it comes to organisational changes due to the transition. Questioning these evidences is seen as a legitimate consequence of being part of the market of care. When, on the other hand, aspects of the pedagogical project become subject of reflection, this (questioning of evidences) is rather perceived as undesirable and potentially undermining for the pedagogical project.

As a respondent stated it bluntly: *“...but now that each individual is in full-fledged control of his or her own affairs but does not have an up-to-date view on the quality care and wellbeing, yes, but then you are going to take a serious step backwards...”* [R7]. Therefore, we look more closely to three interrelated shifts that are taking place, and in the experience of the respondents, seem to be obstacles in the realisation of a 'qualitative care practice'. These matters were widely discussed in the interviews, and more extensively commented during the focus group. The three shifts that deserve an elaborated exploration are: [1] the shifting care discussions, [2] the shifting knowledge status, and [3] the shifting quality of care conception.

Shifting care discussions

a. Starting point

An inextricable part of the introduction of the new system is the shift in starting point for negotiations on the modalities and details of the care provision. This is a logical consequence of the introduction of the personalisation-policy. Transferring the resources towards the users of these care facilities, also aims to bring about a shift in their possibilities to make decisions and being active participants in shaping the care practice. This brings about a clear shift in practice, "*because*", says respondent 11, "*you feel that customer-perspective is seeping through, especially in the case of new clients, from those clients, from the context, from parents who manage or co-manage the budget and take care of it*". The directors of the care services we spoke to, clearly perceive the shift in resources as a shift in power. Since "*Power is money and money is power [...] the money is currently in the user's hands, not in our hands anymore, is it?*" [*R*13]

Respondents notice a clear distinction in the conversations they have with the people and their network who have been receiving care for a long time and the new influx of people solely familiar with the new system. "*If they have built up a trust over the years, this means that they simply continue from the point of view of trust*" [R9]. In addition, examples are given in which those in need of care have become acquainted with the roles of 'user' and 'customer'. It is stated that "*those customer relations, that's new*" [R3], where through this other approach to the relationship "*a number of clients are much stricter with regard to the care they receive. That, as a consumer, they are more critical so to say*" [R12]. This is not necessarily perceived as a negative evolution, rather as "*a noticeable difference*" [R12]. At the same time, some reservations have been expressed about '*whether it is a budget of the user himself, or a budget that the family needs?*' [R3].

Different interests come to the fore in the usage of the resources from the personal budget, other than merely caring for the person in need of care. This possible conflict of interest highlights the importance of another starting point of the discussion in shaping a pedagogical practice. After all, who is 'in a position' to determine what happens is much more a point of discussion than before. In this way, a respondent was keen to note that: *"well, such a context decides for you, doesn't it? And the loyalty lies there then, hey. We don't think there's much to be done about that"* [*R*1].

b. Content

The discussed shift in power involves an awareness of the 'gained' control over the manner in which care is provided. According to the respondents, this awareness focuses mainly on having the proper resources at their disposal and on the ways in which these can be deployed. *"Especially people with autism spectrum monitor this very closely*: *'How many times have you come, how many points is that, how much do I have left', and so on"* [*R*6]. An important thread that runs through the interviews, concerning the questioning of self-evidences through the introduction of personal budgets, is that *a number of other things are much more important than a good pedagogical vision"* [*R*13]. The conversations with disabled people and their network tend to focus more on the financial aspects, and *"a good vision of the way in which you deal with people with disabilities, that's the last thing one asks the moment a person comes here..."* [*R*13].

Matters that do come to the fore in the discussions that are held in the care institutions concern very specific questions, such as: "*Should the laundry be done here, and should we pay for the laundry? How much does that food cost?* [R13]. Another issue is the comparison of arrangements offered by different care institutions:

> *"There are people who have been in three or four places and who do say 'look there it is two euros cheaper so to speak for your meal, or 'there it is much cheaper to rent a room'"* [*R*2]. But just as much, respondents indicate that some people are so focused on the financial picture, that they forget the core: *"And when you ask them, okay, and what kind of assistance, that sometimes people just don't even know about it"*[*R*4].

Shifting knowledge status

The second shift directors elaborate on further is the shifting status of knowledge. In particular, the status of professional knowledge is being dented, as do several respondents experience. In practice, this shift in the balance of knowledge goes beyond a 'peaceful convergence of different perspectives' but turns out to be '*more in opposition to each other as being complementary*'[*R*13]. Ample examples are given by respondents, wherein often the network of the person with a disability questions the professional expertise, based on their own lived-experience regarding care, thereby revealing that "*the clash between the professional expertise and the expertise gained by experience, that that clash has grown...*"[R13]. The reason for this clash has been described as the pressure of parents claiming that they 'know it better': "*because that's what's going on, that's what makes the discussion difficult, the 'we know better than you'."* [*R*5]. Respondents have a vision on setting up a 'good practice' based on shared knowledge construction, as one expressed their role as '*making our knowledge available and to say look, we are on the road together*' [R4]. This shared knowledge construction is also referred to as a '*complementary notion*' [R13].

In the interviewees' experience, it is precisely such conversations that take place less frequently, and if they do, with more restraint. It indicates that particularly the self-determination that is intended with this financing system-shift is explicitly increased and is exercised to the full by the recipients and their network.

The shift of resources to the beneficiaries of care, thus brings along an upward appreciation of the status of their knowledge: *'...parents who say "yes, they've given us a budget now, we're allowed to decide, we're allowed to manage it." So, in other words "they recognise us in our parenting, and in our expertise by experience."'* [R11]. The emphasis on the 'shared knowledge construction' is not based on a desire for validity, but it is indicated that it is so important that the organisations in their early years were '*in the same situation as those non-profit organisations now*' [R5]. After all, established organisations also emerged 30-35 years ago from a few parents and initiators. Comments as *'I'm like, please don't make the same mistakes again'* [R5] and *'I really dare to say I could write a 'blunder book' of my own care institution'* [R3] relate to the insights that the care facilities have built up through their many years of experience with regard to regulations, organisation, coordination of various interests, etc.

Shifting quality of care conception

A changing status of knowledge brings about a new relationship in which the respondents can no longer simply refer to their professionalism. Of the many examples that illustrate this, we present one of the most revealing:

> *"We have experienced this a few times in our facility, so we know what we are talking about. And yet we see that the father refuses to apply it [a protocol for dealing with problems of swallowing] at home and still goes to a restaurant with his daughter. And we know that this man is a huge danger to his daughter at that moment. So, at some point I would dare to preach that I know better."* [*R2*]

While provisions have been convinced of their 'strong and good pedagogical project' before this transition, this is often up for discussion in this new context. The most common argument is that not all care questions formulated by budget holders can be answered without further do:

> "*We always have to make sure that it can be organised, that it can be safe, that it can be comfortable for everyone. We don't want to lose that, absolutely not.*" [R7].

In addition to the organisational objections, respondents also raised another major concern about the quality of care. One nicely sums up what others acknowledge as he says: *"I am very pro [PVF] because the care and support had been directed way too much, but going to that co-direction is important, not to one's self-direction'*[R7]. At the one hand, this shift in approach is welcomed, as '*people can write their own stories now*' [R8]. Respondents consider it to be '*a healthy process that we are no longer in the vanguard role, but that we sit at the table as a partner among the others*' [R7]. However, this enthusiasm exists to the extent that it raises questions about in whose interest the decisions are actually made. For example, when parents who manage a budget indicate that '*being able to sleep at night knowing that my child is safe*' [R14] is the most important thing.

Respondents indicate that they have problems when the enhanced 'autonomy' that this financing system brings with it means that each individual takes full control of his or her own affairs. Since '*they often do not have the up-to-date view of care and support and quality of life*' [R7], meaning that '*they are going to take a serious step backwards*' [R2]. Put more sharply, it is stated that '*the very strong demand-driven or self-directed thinking is not always so sanctifying but can be criminal at some point in the future*'[R3]. Especially when it comes to highly specialized care, the different conception of quality of care becomes clear, the more so because '*it used to be rarely based on a specific question*'[R3].

When in such cases a demand-driven approach is now introduced and adopted by the service users (and the network), this often creates a tension with what the professionals consider to be 'quality and good care'.

Because, when a specific question is formulated in such situations, these questions are based on the things that people themselves know and want. And as respondents admit, they '*do sometimes let people make decisions, which we think, we would decide differently*' [R10]. But this attitude does not apply to those issues that require a case-specific and specialist response, such as wearing a '*protective helmet*' [R3] or adhere to a 'swallowing protocol' [R8]. When in such situations the service user or his/her network believes that the formulated interventions or actions are 'not necessary', the discussion on the pedagogical project seem to come to a standstill. It is expected that a conversation will take place in which people can reconcile different views, avoiding a so-called 'you ask, and we deliver' approach.

> "*We don't think that, and that may be the limit of paternalism* [...] *but if the person has a trajectory in mind that we don't believe in, and if he says "yes then I'll be gone", then you shouldn't get involved in that trajectory in order to want to absolutely keep him*" [R5].

The dialogical aspect of pedagogical practice is seen by the respondents as a much greater challenge. This is aptly described as "*the cocktail of thinking from the point of view of diversity, the added value in diversity, it is the cocktail of different actors who put their thinking together that ensures that your direction will indeed be right and nothing else and it is precisely that interaction with a very diverse number of actors*" [*R*7]. The distinction between client-centred and 'client-centred in relation to its environment'[R3; R7; R11; R13] is made repeatedly, with preference being expressed for the latter.

5.5 Discussion

In this paper we focused on care institutions within the transition towards the Flemish personal budget scheme for people with disabilities. Within this changing care landscape, care institutions are expected to develop a practice of demand-driven care. Our research question focused on the way in which care facilities give shape to their pedagogical project within a context of personalised and demand-driven care. Our research data identified some changes that facilitate the possibility of what they see as a 'good pedagogical practice' as well as issues that may jeopardize this. The reflection on what formerly were evidences in the Flemish care system (by and large government-funded), cause the respondents to change the organisational and financial aspects of their daily practice. The policy objective to foster the effectiveness of former government-funded services by imposing managerial values and market-based principles (Otto, Polutta and Ziegler, 2009; Hood, 2014) is not being dismissed by these services. On the contrary, it seems that this thinking is gaining ground in practice, albeit with a few reservations. A more managerial response to organisational and financial matters is generally accepted as part of the need for increased efficiency efforts. After all, resources are scarce and no longer run directly from the government to the institutions. This new, more managerial attitude is therefore inevitable in order to guarantee the continuity of the service (Needham, 2011).

Regarding the pedagogical project of care institutions within the context of the (re)positioning in a market logic, we identified several bottlenecks and difficulties. It is clear from our analysis that shaping the pedagogical project within the context of PVF is influenced by three interrelated shifts: [1] the shifting care discussions, [2] the shifting knowledge status, and [3] the shifting quality of care conception.

The pedagogical project has been described by the respondents as a joint project, 'client-centred in relation to its environment', wherein a ‘dialogical process’ is of central importance. Their characterisation of a pedagogical project echoes Mollenhauer's model of an emancipatory practice (Theorien zum Erziehungsprozess, 1972). Mollenhauer suggests that an emancipatory practice implies a 'self-reflection in dialogue' that must lead to the formation of self-aware and autonomous subjects, and thus to emancipation. This conceptualisation refers to a practice that makes possible to “see the reality within the light of the potential” (Mollenhauer, 1972). In this vein, emancipation is confronting the reality with other readings of that reality, and people are willing and able to hold their ground in that confrontation (De Bie, 2016).

Our analysis comes across the very fact that this ‘confrontation’ and the ‘dialogical endeavour’ that is at the heart of our respondents' pedagogical project is being challenged within the policy transition. It gives levers to disabled people to have a formal voice in the conversations on their care trajectory and provides choice. One could argue that this is an emancipatory practice in Mollenhauer’s idea, as espoused by the respondents, since the finality is 'the formation of self-aware and autonomous subjects'. However, as indicated in the focus group, the practical implementation of PVF seems to be "*a means that had gotten lost as a target*" [R14]. The policy’s emphasis, whether implicit or not, on the individual’s self-determination, risks to silence the pedagogical project as a 'dialogical endeavour' (a relational pedagogical project) before it has even been initiated. As the results of our study depict, the strong focus on the autonomous subject in the design of this social policy is being adopted by the people to whom it applies. The policy therefore does what it intends to do: to empower people with disabilities.

But as argued by several scholars (see Dean, 2015; Dowse, 2009; Owens et al., 2017) the notion of empowerment as a profound individual responsibility is deeply problematic for a care practice. Because this focus on the autonomous individual from a means of realising a more personal care, to an end, institutions are encountering obstacles in realising their pedagogical project as an emancipatory practice. This ambiguity is at heart of social work practices, at the same time supporting people on an individual level, whilst opening up discussion on the democratic character of the problem constructions (Roose et al., 2012).

First of all, the recognition of 'lived' knowledge and expertise has led to a different starting point and content of the dialogue about the quality of care and service delivery. Equally, this sometimes means that there is no longer any discussion, as the market logic creates a context in which de facto people no longer have to listen to each other. It is possible to go to another care provider without further ado, or the care provider itself could say that it does not want to respond to a care need or a specific question. Especially when disabled people adopt a hardline market logic in which it is expected that a care institution offers a service that fits the demand, people 'get empowered' in the way they make their own decisions, but in turn does not leave much opportunity for 'self-reflection in dialogue' (Mollenhauer, 1972). At this point, such conduct is more exception than rule, but according to our respondents it results in a practice that can be far from emancipatory.

Another important matter that occurs in the analysis, across the three shifts described, is the shifting role for professionals from 'confronter' to 'confronted' subject. The experienced pressure on professional knowledge can be situated within two finalities of the Flemish Personal Budget System. On the one hand, the intended self-determination of persons with a disability.

On the other hand, the shift that care facilities need to go through towards a strong focus on the demand of 'the potential user'. The desired shift of power that these two policy-goals reflect, are being translated in the care practices of our participants. As the discussions are steered by the disabled person or his/her network and the status of their knowledge has shifted through the recognition of everyday life experiences, professional knowledge devalues in strength. Professional knowledge can still be a ‘confronting’ matter (De Bie, 2016) albeit with less evidential value. Care institutions and professionals simply can no longer just invoke their professional knowledge when they claim to ‘know better’. As previously emphasized (Needham, 2011; Dickinson, 2017), personal budget policies force care institutions to take more account of the needs and wishes of the individual, because they have the resources in their hands. As a consequence, respondents indicated to feel the urge to be more careful in confronting another vision on ‘good care’. Hence, presenting another option or withholding a response to a specific question can make the client wanting to leave the institution and thus take with him the resources. These are consequences that lead to a more careful, considered approach for professionals in the ‘dialogical endeavour’.

Additionally, numerous examples in the analysis outline how a far-reaching focus on autonomy and self-determination offers no more guarantee of high-quality care than a unilateral trust in institutions. In this vein, Pols (2004) notes in her research on washing regimes of chronic patients that reference to an individual’s autonomy can end in neglect. It is argued that care practices are forged in the interaction between caregiver and patient/client. In this respect, our findings align with Pols’ (2004) understanding of self-determinacy and autonomy as a relational happening, and not as an essential characteristic of humans.

5.6 Concluding Remarks

New levers are being given to care institutions to reshape their organisation according to a care market, yet these levers seem to be lacking for the pedagogical project. It is important for policy not to forget the actual care practice when reshaping the care landscape towards more personalised care. Guaranteeing qualitative and good care cannot be a privilege (or possibly defined as a burden) that only rests on the client's shoulders. According to our respondents, a personalised care and a demand-driven approach can only be realised successfully in a dialogical relationship. The radical approach of 'a self-aware and autonomous individual' as the policy objective is, implies that this pedagogical project is 'dead on arrival'. With the quality no longer being guaranteed by the government, and the facilities themselves no longer always have the means to block choices that are not in the client's interest, we emphasise the importance of a dialogical process, in which different views of 'good care' can be discussed. Given that this study highlights one perspective within this proclaimed dialogical relationship, further research needs to draw attention to the experiences and perspectives of the other parties involved in the support practice, such as family members and volunteers, as well as, of course, the persons with disabilities themselves. However, this perspective on the professional support relationship teaches us about the challenges that care institutions face regarding a dialogical and relational based pedagogy, and that care institution's "light of the potential" is rather dimmed than brightened through the Flemish personal budget scheme.

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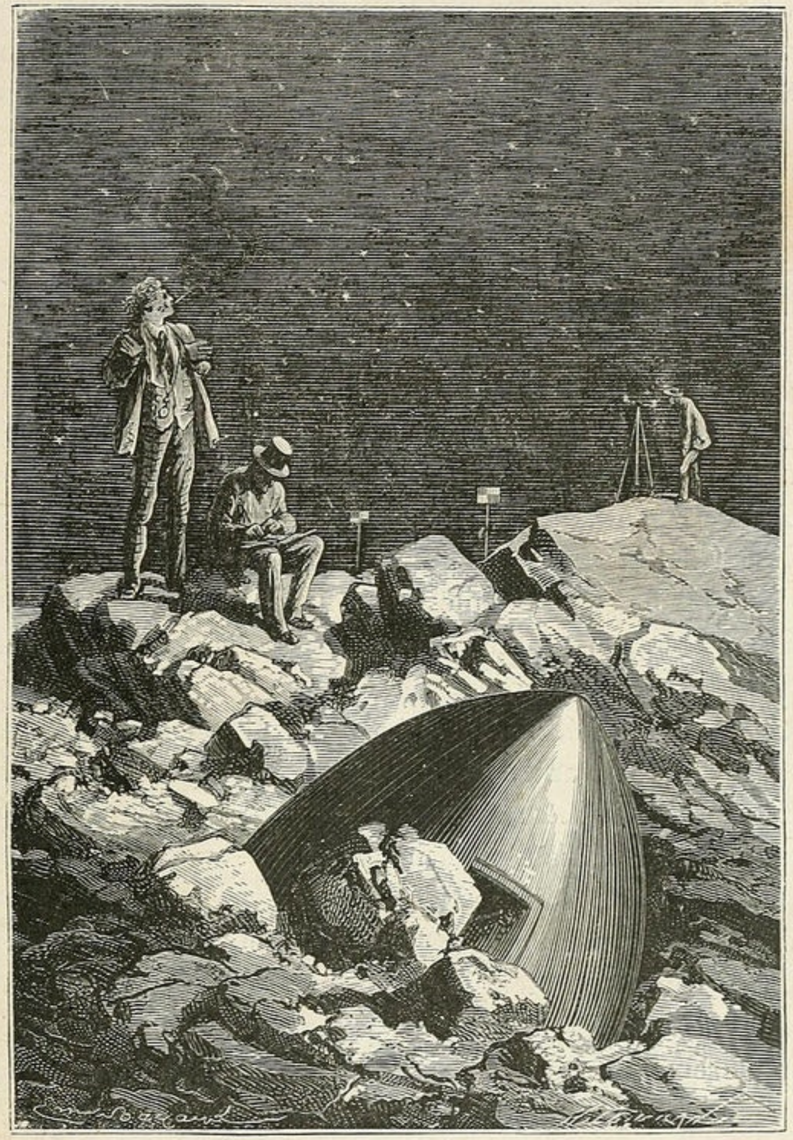
CHAPTER SIX

A Visual Report of what is of Value for People with Intellectual Disabilities in a Care Organisation



« Il me semble que je les vois. » (Page 158.)

Abstract

This paper presents the findings from a qualitative research project which explored what ten people with intellectual disabilities who receive care and support in a residential care facility deem valuable for living a good life and what the opportunity to manage resources for care and support themselves means to them. With the use of photovoice, the ten participants documented their care and support and by extension their own lives. We describe how the project was carried out and the facilitating and obstructing factors we encountered. The collected images and related personal stories teach us about the central importance of significant others to the lives of the participants and their vital role as 'necessary others' who nurture a multitude of possibilities. The increasing policy focus on independence and self-sufficiency is opposed to the vital role of relationships in the participants' view of a good life.

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***"It is your telling of your tales that best reveals how you really make sense of your world - which stories you choose to tell about your life and to whom you tell your tales"* -Ferguson et al. 1992, p. 2.**

6.1 Introduction

A recent policy shift in Flanders (the Dutch-speaking part of Belgium) called "Persoonsvolgende Financiering" (PVF) relocates welfare resources from insti- tutional and professional care to persons with a disability themselves (Department of Welfare, Public Health and Family Affairs, 2018). Leadbeater (2004) refers to personal budget schemes as "deep forms" of personalisation of care for people with disabilities. These policies imply the redistribution of public funds from care organisations to user-led support and more individualised care in deinstitutionalised settings. With the prospect of enabling users to exer- cise greater autonomy and more influence in decisionmaking processes (Owens et al., 2017), these policies are welcomed as an essential condition for the pro- motion of disabled people's freedom and independence (Dowse, 2009). The main characteristic of the personal budget policy is that people with intellectual disabilities themselves are given a choice in the arrangement of their care and support in practice (Department of Welfare, Public Health and Family Affairs, 2018). This is expected to change the practice of care to one in which the person with a disability plays a more active role and has the opportunity to make decisions about the care practice.

The movement towards "less government intervention, more contractual arrangements in services and a stronger focus on the responsibilities of individuals for their own lives" (Johnson & Traustadòttir, 2005, p. 17) echoes the demands of the deinstitutionalisation movement.

The pursuit of deinstitutionalisation, along with an emphasis on freedom of choice, autonomy and self-determination of the individual, lay at the basis of the transformation towards PVF in Flanders. In light of this policy transition, care and support – and therefore care organisations – are required to promote the individual freedom and self-determination of people with disabilities, reflecting “a challenge to the assumed, all-encompassing dependency of the “cared-for” in care relations and practices” (Williams, 2001, p. 470). This is completely in line with the assumption in contemporary welfare state arrangements that people with disabilities are no longer passive and dependent, but should be active and independent (Clarke, 2005). The ideal of rational autonomy being equated with independency as a dominant policy discourse is contested amongst scholars. Mladenov (2015) argues that when people for whom making choices and exercising control is not obvious can be assisted by third parties in this process, this is not a problematic issue. Other have argued that this discourse is deeply problematic (see Dowse, 2009; Goodley et al., 2019; Lister, 1997; Williams, 2001) because these assumptions might have profound implications for people with intellectual disabilities, who have differentiated and heterogeneous needs (Man- sell, 2006).

The main critique in earlier research (Dean, 2015; Ferguson, 2007; Roets et al., 2020) support these con- cerns as they demonstrate that realising the ultimate objective of personalisation policies – namely, “integrated living in an independent manner” – neglects the interpretation of personalised care from a relational and contextual standpoint. The particular interpretation of freedom and autonomy as a consumer in a care landscape where competence, capacity and individual welfare independence are paramount (Dean, 2015; Dowse, 2009) is an explicit challenge for people with intellectual disabilities. This downgrades the promise to make everyone “capable” of making choices and controlling the care obtained to “being capable” as a condition for acquiring more options for meaningful care.

Furthermore, this dominant ableist rhetoric (Goodley, 2014; Williams, 2001) might paradoxically mark people with intellectual disabilities as different and disabled (Dermaut et al., 2020). According to Ricœur (2005), "being capable" cannot be set as a condition; rather, it only emerges through a process of interaction and understanding. The importance of interaction and understanding also applies, following Nussbaum (1988), to the concept of choice; hence it is only in a context that "choice" can be materialised and acquired meaning. The things that a person would like to see accomplished – internal capabilities – when the right situation arises can only be achieved "if the appropriate circumstances present themselves" (Nussbaum, 1988, p. 160). In the case of choosing, this means that the person has the opportunity to choose functions, but a per- son may be prevented from functioning in accordance with their choices if the appropriate circumstances do not present themselves (Nussbaum, 2000). Similarly, critical disability studies emphasise that all people are dependent on infrastructures and relations of support (Mladenov, 2015), while able-bodied people are also interdependent and need others to nurture their human potentialities (Goodley & Roets, 2008).

Embedded in the theoretical framework of the Capabilities approach (Nussbaum, 2000; Sen, 1999, 2009) this research aims to address the question of the expansion of "human capability" and real freedoms (Robeyns, 2003). In this way, the focus is on the ability of people with disabilities to lead lives they have reason to value and to enhance the substantive choices they have regarding their care and support. Through emphasising the creation of opportunities, the Flemish personal budget policy may be considered capability-promoting (Bonvin, 2011; Otto et al., 2018). Hence it is well in line with Bonvin's (2011) argument that in a capability-friendly policy model, the beneficiary is regarded as an active citizen and invited to take part in the definition of their care and support and the modalities of implementation.

The primary focus of capability promoting policies is to strengthen democratic social power (Wright, 2010) and thereby "to subordinate or at least make former powers accountable to this social power" (Otto et al., 2018, p. 303).

The capability-promoting potential of personal budget schemes can only be studied in terms of their contribution to the real opportunities and freedoms of people with disabilities (Walker, 2006). The provision of per- sonal budgets does not in itself create suitable conditions and appropriate circumstances – the favourable external conditions – for all people with dis- abilities to make decisions about their care and support and live a life they deem valuable (Benoot et al., 2020; Dowse, 2009; Gridley et al., 2014). Especially not for those persons who do not align with the normative ideal of an autonomous and selfdetermining individual (Mansell, 2006), such as people with intellectual disabilities in residential care. This group has often been neg- lected and underresearched in the context of the logic of personal budgets. In this article we shed light on the things that ten people with intellectual disabilities who receive care and support in a residential care facility deem valuable for living a good life and what the opportunity to manage resources for care and support themselves means to them. While exploring the elements that are of importance for the participants to live a valued life, we make use of a capability-friendly research method: through the use of photovoice, we give people who sometimes lack a "capability to voice" the opportunity to share their story (Akkerman et al., 2014). The rich data enables us to analyse and discuss the importance, consequences and potentiality of "independence" and "autonomy" for the ten people with intellectual disabilities that participated.

6.2 Methods

To find out what people with intellectual disabilities who receive care and support in a residential care facility deem valuable for living a good life and what the opportunity to manage resources for care and support themselves means to them, we made use of the photovoice method. Photovoice, as first developed by Wang and Burris (1994) is a process by which people can identify, represent and enhance their community through a specific photographic technique. This research tool pro- vides participants with an avenue for expressing themselves through the action of photographing (Jurkowski, 2008, p. 3), enabling persons with low literacy to share their views (Wang & Burris, 1997). The photographs then become the input for an interview. The photovoice method offers a way of engaging with persons with intellectual disabilities, one that enables the participants to define themselves in terms of the things they most valued in their lives (Booth & Booth, 2003).

We make use of photovoice as a tool to "facilitate the expression and documentation of the views and needs of people with intellectual disabilities" (Jurkowski, 2008, p. 3). There is a small but increasing interest in the use of photovoice as a method to engage people with disabilities (Shumba & Moodley, 2018). Especially the involvement of people with intellectual disabilities remains rare, although there has been a growing engagement in recent studies. Some examples are studies by Jurkowski and Paul-Ward (2007) on health perceptions of people with intellectual disabilities, a project of Booth and Booth (2003) involving mothers with learning disabilities, Akkerman et al. (2014) applied photovoice to study job satisfatcion of people with intellectual disabilities and van Heumen and Schippers (2016) used photovoice in an evaluation of the long-term impact of individual family support for young adults with intellectual disability and their families in the transition to adulthood.

Our study was conducted in collaboration with an accredited Flemish care organisation dedicated to the support of adults with mainly intellectual disabilities. The care organisation has various entities located throughout Evergem, a suburban municipality in the vicinity of the city of Ghent with a village-like atmosphere. It serves approximately 120 adults with intellectual disabilities and offers a wide range of types of support, such as intensive support, residential housing, independent living with flexible (residential) support, independent living with permanent support and various forms of day care and supported employment, and individual support by appointment.

More than half of the participants are supported in a form of independent living with permanent support. In order to make this variety of housing support possible, the facility offers various forms of housing. The intensity of support differs in all housing types, depending on the care needs and preferences of the residents. We will outline our photovoice project using the stages Overmars- Marx et al. (2018) distinguished in their study of different photovoice research processes with people with intellectual disabilities. These four stages are (1) preparation, (2) taking photographs, (3) interview, (4) post-interview. After described our research process, we will elaborate on some ethical and methodological issues we encountered.

1. Preparation: Recruitment and Selection

Participant	**Alias**	**Gender**	**Age**	**Living condition**
P1	Oliver	Male	51	Independent living with permanent support
P2	Amelia	Female	29	Independent living with permanent support
P3	Jack	Male	55	Independent living with permanent support
P4	Harry	Male	23	Independent living with flexible support
P5	Olivia	Female	69	Independent living with permanent support
P6	Emily	Female	58	Independent living with flexible support
P7	Jessy	Female	51	Independent living with flexible support
P8	Jacob	Male	30	Independent living with flexible support
P9	Charlie	Male	49	Independent living with flexible support
P10	Thomas	Male	50	Care-intensive living

Table 4: Overview of participants

The selection of participants took place in several consultations with the general directors and the pedagogical coordinator. Due to the nature of the photovoice method, all residents were eligible to participate, including individuals with limited verbal abilities. An initial selection of possible participants was made in an intake conversation with the general directors of the organisation. The main criterion used was the presence of "a distinctive pedagogical question", which means a need for care or support that does not fit within the predefined responses of the care organisation, along with a variation of types of disability among the residents and a variation in living conditions. This initial selection was discussed with the pedagogical director. We made adjustments based on his assessment of the current situation in which these persons found themselves, based on his close involvement with the residents and the support workers. Following these steps, 10 participants with intellectual disabilities were included in our study. Table 4 provides an overview of descriptive data of the participants, showing the diversity in gender, age and living conditions.

The purpose of the study was explained to the selected adults by pedagogical staff members, followed by the question whether they wanted to participate. The researcher then visited the persons who agreed to participate in a one-to-one setting. This could be at the participant's home or in the care facility. In this meeting, the structure of the research was again explained, this time by means of an information letter written in basic terms. Subsequently, the informed consent was discussed orally. The information letter and the consent and assent forms were carefully adapted for people with a limited understanding (Povee et al., 2014) and were approved by the Ethical Commission of the researcher's university. A witness (support worker) was present when participants were known by the care facility staff to be illiterate or inarticulate. If the participant was under the supervision of a guardian, the latter was asked to sign an assent form. The researcher introduced the participants individually to the method of photovoice. Each participant received a disposable camera with a capacity of 39 shots. As a first shot, the participant and the researcher often took a selfie, which enables the participant to master the act of taking a picture. We consulted the pedagogical coordinator and the general director on how to tackle the abstract nature of the question "what elements are important to live a life that is deemed valuable?". As a result, the main question posed in the introductory conversation with the participant, as written down in the information letter, reads:

> We want to talk to you about how the care and support in the care facility is going and what you think of it. That is why we ask you to use your camera to take pictures of things, people, activities, and so on that are important to you. Once those photos are printed, we will discuss together why those things appear on the photographs. We also find it important to know how your personal budget plays a role in this. Have things changed since you have had a personal budget, or not at all? And has this affected the things you think are important to have a "good life"?

2. Taking the photographs

Photovoice, amongst other participatory research methods, emphasises the unique and valuable insider perspective on the lives of participants (Jurkowski, 2008). In a typical photovoice procedure, participants take photo- graphs that are later used to facilitate reflection on their feelings, ideas and experiences (Mitchel, 2011). This insider perspective is important for the understanding of policy and programmes that aim to improve the health and wellbeing of people with intellectual disabilities.

Photovoice is a technique that challenges the established politics of representation by putting people in charge of how they document their own lives (Booth & Booth, 2003). This research method lessens dominant views or outsider bias because people take their own pictures (Jurkowski, 2008). Providing cameras to people who may not be able to participate in the dominant dialogue opens doors for them to participate in a process that can ultimately lead to social action (Wang & Burris, 1997). Within the outline of this study, photovoice offers a most suitable way to gather data that leads to an understanding of the elements that are of importance for the participants to live a flourishing life, what the opportunity to manage resources for care and support themselves means to them, and bring to the fore those issues we might overlook in policy and practice.

There is great variety in the forms of assistance provided in photovoice projects with people with intellectual disabilities (Overmars-Marx et al., 2018), ranging from technical support to more fundamental issues of content. Studies also have various restrictions regarding the time frame within which photographs can be taken and the number of images. Some studies provide their participants with no guidance (see Akkerman et al., 2014; Booth & Booth, 2003), while others restrict the total amount of pictures (Povee et al., 2014) or the time available (Jurkowski & Paul-Ward, 2007).

We asked participants of our study to take the photographs within a timeframe of two to three weeks in the month of February 2020. We opted for the "more advanced" disposable camera with a flash and with the option to take a maximum of 39 pictures. Some finished within a day, whilst it took others more than three weeks to fulfil the assignment. We did not oblige the participants to reach this maximum number. Many indicated after taking a dozen photographs that they were "ready". Some expressed doubts during the follow-up as to whether they had photographed the "right" things and whether they were allowed to capture certain things on film. Each time again, the researcher communicated that they were in control of the content of the photos, namely: "photograph what is important to you and use the number of images that you think are appropriate to do so". Some participants drew on carer assistance to take the photographs, due to physical impairments (Thomas) or lack of confidence (Olivia). The 10 participants returned the films for processing and took a total of 181 photographs. The number of pictures taken per person ranged from only one picture up to 46 pictures. Leaving these two extremes aside, the other participants delivered an average of up to 18 images per person.

Shumba and Moodley (2018, p. 6) listed "obsessive tendencies in taking photographs of one item or taking very few photographs resulting in limited pictures" as one of ten methodological challenges that photovoice as a data collection method in research with people with disabilities bring. We recognise this challenge and deal with this consideration by including the pictures of Jack and Harry in our study, as these are the elements they choose to photograph. The subsequent interviews covered more than those elements photographed. In this vein, the photovoice method was used as one of multiple ways of giving a voice to the participants. We combined this intensive research process with an ethnographic stance (Goodley, 1996).

The researcher visited the participants multiple times during the course of the study, some up to seven times. They did activities together, such as going to the local store, feeding the chickens, doing a walk or just having a coffee together. From each encounter with the participants, a personal report, or fieldnotes, were documented, which present critical ethnographic moments during the research process.

3. The interview

The central question we posed during our study was "what is important to have a "good life", and in particular, what are important things related to the support you receive?" Following the participants' responses to this question, an individual interview took place. Like other photovoice studies involving people with intellectual disabilities (Booth & Booth, 2003; Jurkowski, 2008; Ott- man & Crosbie, 2013), no questions were specified during the interview stage. We started each conversation by looking at the photo series, with the participants being in charge of selecting the photos that they wanted to discuss. The interviews were conducted in Dutch and were held individually between the researcher and the participants, sometimes accompanied by an assistant whenever necessary or desired. In order to capture the meaning of their story in more depth, we opted to include the personal assistant with whom the non-verbal participants (Charlie and Thomas) had developed a distinct way of communicating. In addition, whenever a participant was willing to let a support worker or assistant be around (Jacob and Oliver), we agreed to this.

As the collections of photographs did not serve as an end in themselves but were the instigators of a conversation about the meaningful elements in life (Jurkowski, 2008), open-ended questions were used during the conversation and provided participants with the openness to tell their story at their own pace and in their own words.

The stories of the participants further unfolded by bringing up issues that were discussed at previous meetings. During the course of the interviews, the field notes we had collected over the previous visits offered important input (Overmars-Marx et al., 2018). The field notes supported the stories to unfold and helped in learning to understand the significance of the photographs and those issues that had not been captured, but nevertheless discussed.

4. Post-interview

All conversations were recorded and transcribed orthographically (DiCicco-Bloom & Crabtree, 2006). The content of the series of photographs was analysed in the context of the personal stories (Booth & Booth, 2003), drawing on the logbook and transcripts. To conduct this content analysis, we made use of the MAXQDA software. In a first stage, we used open coding (Glaser & Strauss, 1967) to synthesise the material (DiCicco-Bloom & Crabtree, 2006). Subsequently, the codes were categorised into themes and subthemes in an iterative process that led to adjustments of the categories during the process of analysis. These codes or categories were not predefined but emerged from the data, using an inductive or data-led approach. Table 5 shows the distribution of photos by subject for each person. Eleven themes emerge from the participants' collection of images that reveal the things they value in their lives. About eight points come up that appear in the photovoice project of Booth and Booth (2003) as a way of mapping out meaningful elements in the lives of mothers with learning difficulties. Three more themes occurred in our data: mobility, work and leisure activities. The series of photographs answer the research question "what do you think is important to have a good life?", and mainly cover these themes:

	P1	**P2**	**P3**	**P4**	**P5**	**P6**	**P7**	**P8**	**P9**	**P10.**	**TOTAL pictures**	**TOTAL participants**
Self	9	10		1	7	8	5	3	7	17	67	**9**
Partner	7					3	1				11	**3**
Support workers		8			8	1		1	5	3	26	**6**
Extended family		2					1				3	**2**
Friends/colleagues		1			5	12			1		18	**3**
Pets		2			6	5	3				16	**4**
House/garden		2		17	4	1					24	**4**
Significant location	1	6	1	6			1		6	5	26	7
Work						22	1				23	**2**
Transport/mobility		3				3				2	8	**3**
Leisure activities	1	1		25			2	2		9	40	**6**
No. of photos	**12**	**16**	**1**	**46**	**16**	**39**	**18**[3]	**12**[4]	7	**19**	**181**	

Table 5: Distribution of photos by subject for each person

While the photographs illuminate the participants' lives in context, Booth and Booth (2003) have pointed to the importance of the individual lived experience in order to grasp the biographical significance of the photographs of each participant. The reason why something is considered meaningful often emerged during the conversations with the participants.

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[3] only 8 printed

[4] only 7 printed

In what follows, we will elaborate on the subjects covered in the photo reports and illustrate this with some remarkable photos, amplified with information provided during the discussions of the images. Hence, the significance of the images often could not be deduced from the photographs alone (Overmars-Marx et al., 2018).

5. Ethical and methodological issues

At the start of this research project, we faced some ethical and methodological issues that we addressed in an ethical application plan which was approved by the ethical committee of the researcher's university. For example, ethical issues arise with regard to visual approaches in intellectual disability research (Akkerman et al., 2014), such as questions of property rights and possible issues of privacy. In our case, no additional measurements were required to be in line with the GDPR regulations.

The care facility itself took precautions by asking each resident whether photographs are permitted to be taken and, if they are depicted in any photographs, whether they may be used for research purposes. The informed consent, describing different scenarios on how and by whom consent would be granted was discussed orally with all participants. Not only at the beginning of the research process but throughout the research process, the willingness to participate was discussed repeatedly with each participant. Furthermore, the consent made clear that our participants under any condition remain the owners of the pictures they took. The prints, including the negatives, were given back to them and only a digital copy is still available to the researchers. When it comes to storage of the digital copies on the researcher's device, we overcame ethical mishaps by blurring all pictures with recognisable features. For this reason, there are no problems with individuals being portrayed in the photographs of the participants within the framework of this study.

In our research venture, the involvement of seldomly heard voices within research projects was considered to be an important, complex, but above all a necessary condition. The ethnographic point of view during this research process gave the participants a level of freedom to shape the course of the research themselves, and the way in which the participant wished to communicate could be constantly evaluated and adjusted. In this sense, we complemented the necessary procedural research ethics with diligent attention to the 'ethics of doing research' (De Wilde, Roets and Vanobbergen, 2019). Adopting a situational research ethics stance, for example was meaningful when dealing with the limitation that photovoice implies the expectation that what a person values is visual or present. Many participants informed the researcher during the process of photographing what they had shot, what they would like to photograph but had not yet the opportunity to do so, and what they would like to capture but what was not within their possibilities, for example the dog of an aunt who lives far away. By making clear their intentions, the participants indicated how they understood this research venture. On occasions when participants indicated that they were not sure about the process, like Jessy who said that her husband would not like it if she took a photo of him, the researcher and the participant agreed on a compromise in which the participant felt comfortable. These situational research ethics prompted the researchers to be aware of the limitations of their methodological approach while focussing on overcoming the barriers that impede the involvement of people with disabilities (Vandekinderen, Roets and Van Hove, 2013).

It is important to mention that focussing on the numbers of pictures for each theme that is covered in the photographs could generate a distorted view of what the participants value in their care and support and their life in general. As shown in table 5, some participants took only one picture of a subject, and others did so in abundance.

For example, Harry took 25 pictures of his game console and television, while Jacob captured his favourite game on camera only twice. We therefore take the number of participants that address a particular theme as a benchmark in the presentation of our results. Jack is not taken into account here because he took no pictures, apart from the one picture we took together. However, we continue to regard him as a participant in this research, as we also had several conversations and an interview with him.

6.3 Results

The major thing that stands out and is therefore our focus in the presentation of the results is that nine participants had themselves portrayed in more than one third of all photos (67 out of 181 pictures). As such, 'the self' is a constant in the photo series of all participants, covering the ten other themes. These are clustered into three large groups that include photographs (1) depicting important activities, such as work, leisure activities and transportation (mainly commuting); (2) posing with a significant other, including a partner, a support worker, friends and colleagues, family and pets; and (3) at a significant location or in their house and garden.

(1) Depicting important activities

Seven of the participants chose to make pictures of leisure and work activities. However, it should be noted that this is a narrow reading of what the theme 'activities' can entail. For Olivia, hosting people over coffee is an important daytime activity, and Charlie does not perceive his job as work. We met him one time when he was working at the local Oxfam shop. When we asked him about his work, he said that he ‘doesn’t have a job’. Most remarkable is that they all have themselves photographed whilst doing the activity. Jacob had his supervisor take a picture of him rolling cigarettes: ‘for *cigarettes, because I like it*’.

The photo series of Thomas contains nine pictures of his favourite activity: painting and drawing. The supporter who is his primary companion in daytime activities took these photos. In the conversation, it appears that this person is of vital importance in his life by means of facilitating the daytime activities he likes. Together with Thomas, this person went looking for another activity when his favourite activity, helping on the farm, could not be continued. We learn from these portraits that others are an important part of the daily life of the participants. In principle, many of these pictures could be taken by the participants themselves. In this vein, the photos tell us something about the way in which these persons want to be represented.

The participants are portrayed doing something they themselves find important. This concerns not only daytime activities, such as work and leisure, but sometimes what appear to be more trivial activities as well. Consider, for instance, the importance of rolling cigarettes for Jacob. Another telling image is how Emily had herself photographed near a car of the facility that is packed with groceries.

Picture 1: Emily posing with errands.

When Emily was asked why she found it important to go for groceries, she answered: '*because she is a good support worker*'. During the conversation it soon appeared that in addition to the importance attached to shopping as an activity in itself, the learning process associated with it was of great importance to Emily. Whilst shopping together, the supervisor would teach Emily how to use and manage money. ‘*I can already cope with* 10 *euros*', she says. This picture tells a lot more than what it depicts. Not only does it show a car full of groceries, for Emily this picture reveals that she is able - together with the support worker - to do errands.

Picture 2: Amelia posing on the way to her workplace.

In line with this is the meaning of the photograph on which Amelia is to be seen on her bicycle (picture 2). The bike as an object in itself is important to Amelia because it broadens her opportunities to go places: *‘I'm happy if I have to take the bus for an hour, and it's nice weather, I say ‘hup’ I go by bike and then I'll be there quicker too’.*

Another important aspect is the meaning of the support relationship that is captured in this picture: *'I wanted her [support worker] to take a picture of me on my bike, I thought that was important because I am also very happy that they have taught me how to ride a bike so far. Actually, that's because of that.'*

(2) Posing with a significant other

The photographs of eight of the nine participants who used the camera pictured 'others', including their partner, friends and colleagues, support workers, family and pets. All participants that have a pet took a picture of it. Harry had a dog when he was little. His mother moved to an apartment and gave the dog to her sister, Harry's aunt. He wants to see the dog way more often. Since that did not happen during the research period, he could not capture it on camera. If we take his intention to photograph the dog into account, all participants that took photographs deem 'others' important enough to photograph. All three participants that have a partner took a photo of her/him. And two of the three did not picture any of the support staff.

Support workers were portrayed by people living in more residential settings with permanent support as well as by people in the 'independent living with flexible support' setting. The series of photos from Charlie catches the eye, consisting of seven photos depicting himself and others, five of which were taken with someone from the support staff. All his photos were taken in the central office, next to where he lives and which he visits several times a day to drink a coffee and have a chat.

Picture 3: Jessy posing with a family member at a bar.

Only two participants, Jessy and Amelia, took photographs of family members. It appeared throughout the conversations that most participants are in isolated situations and have a contested relationship with family members and with their parents in particular. Jessy had herself and her uncle photographed (picture 3) and explained: '*You know why I had that [picture] made? That's the only one who's a little high up with me.*' Later she stated: '*He gives me good advice [...] he says to me, like for example that [raise glass of Coke] is not good for you [...] If one of my family or friends comes, I will listen to them more than to another.*' We had this conversation in the cafe of the facility, where Jessy drank a Coke. Later a support worker came to pick her up, and Jessy was addressed on the fact that she was drinking a Coke. It appears that Jessy has an understanding with the supporters that she should moderate the consumption of soft drinks for the sake of her health. That goes some way towards explaining the statement on '*listening more to family than others*' that Jessy made before.

(3) At a significant location

Additionally, the photographs taken to display an important place or location for the most part feature a posing participant. One photograph that stands out is of Oliver in his room. There are numerous elements in this picture that are significant for him. It almost seems like a staged image of all the things that are important for his well-being. The painting is one of the things he could buy for very little at a flea market, one of his favourite getaways. He explained why he found the painting very beautiful: *‘I bought that. And not, not much money.’* The loudspeakers standing on the desk next to the bed continuously generate a white noise. *‘I sleep, with that, rest*! *Yeah, yeah, interference when I sleep’*, he says. Oliver goes to the store twice a week with a support worker and usually buys Coke, chips and cigarettes. The bottle of Coke placed on the bedside table is one of the things that indicates that this is his place. It is what he calls '*his place*', because he is at ease and can be alone with his girlfriend. *‘We just are’*, he said, *‘and we're not ashamed’*. *‘I'm comfortable here. You've got music. You've got music. I'm at ease and K. loves me.’* The person who captured this image on photo was his girlfriend, living in the very same care facility.

Picture 4: Oliver posing in 'his place'.

In addition to having themselves portrayed by and with others, we notice that some participants relied on others to take photographs that they would not have been able to take without them. For example, the picture of Thomas showing a tiny house requires further comment. Thomas has an intellectual and a physical disability, and therefore experiences limited mobility. His physical health condition is decreasing systematically, which means that the things he likes to do are no longer all possible. For example, some of his pictures provide a glimpse into his past, into what he finds important, but can no longer do. One of these things is the farm, as shown in picture 5 below, where he helped for many years. Thomas decided to stop his activities on the farm after a fall out of his wheelchair. Because he attaches great importance to this farm and the activities associated with it, he asked to go there with a care worker to have this picture taken.

He might not be portrayed in this particular image, but Thomas actively engaged with a support worker to go to a place that is filled with meaningful memories. The two pictures that Thomas took of the farm are the only pictures of his album that do not feature himself.

Picture 5: Thomas's former favourite place: 'the farm'.

6.4 Discussion

The aim of this research was to gain a better understanding of the perspective of people with intellectual disabilities on a valuable life in a care organisation within the context of the Flemish personal budget scheme. Using photovoice, participants addressed 11 themes of content in 181 photos: self, partner, support workers, extended family, friends/colleagues, pets, house/garden, significant locations, transport and mobility, work and leisure activities. These themes emerge as issues that persons with intellectual disabilities who participated in this research find important to living the life they consider valuable to live. The identified themes largely correspond with the themes emerging in the research of Booth and Booth (2003), showing that mothers with intellectual disabilities did value the things that most people value, namely family, a home and friends, but that they often lacked the supports that sustain these things — partners, relatives and services. In the same way, the people with intellectual disabilities that participated in our study pointed to relationships as being of utmost value in their lives. The relationships were presented not only as a value in themselves, but also as a vital resource for living a flourishing life (Nussbaum, 2009).

The analysis showed that three large groups of topics come to the fore, focussing on activities, significant others and significant places. Significant others are presented as central to the lives of the participants, showing that many of the things that are considered important are social phenomena. In this way, the participants in our study subscribe to a notion of relational autonomy, a concept that Lister (1997, p.114) refers to as an autonomous self that ‘is only made possible by the human relationships that nourish it and the social infrastructure that supports it’.

Given that the participants all receive care and support in a care organisation (with a variety in independent living conditions), it should come as no surprise that these human relationships and social infrastructures are at the heart of what these people value in their lives. Their photo albums demonstrate in a striking way that their autonomy only takes shape in and through the human interactions (Lister, 1997; Goodley and Roets, 2008). In addition to the appreciation of the people involved in the social interactions, participants also marked the appreciation and importance of 'the other' as an enabler or an opportunity-creating factor. To the participants, 'the other' signifies a bridging to more possibilities, serving as a lever to meaningful activities. Throughout the conversations with the participants, these significant others were presented as ‘necessary others’.

The stories clearly tell us that these relationships are to a large extent characterised by an interdependency that is acknowledged by all participants, but also questioned and challenged through the presentation of the practice of care and support as a value-laden, contested and complex issue that invokes what Williams (2001, p.468) calls ‘multiple relations of power’. Participants do not merely receive the care and support, they actively shape the ‘how, what and where’. This active role in shaping the support practice is not expressed in a 'detachment' or an attempt to shape an autonomous life as independent and self-determined. People with complex needs continue to value professional expertise and expert knowledge, particularly in the organisation, co-ordination and purchasing of services (Gridley et al., 2014). More precisely, the focus of our participants is on themselves giving shape to the relationship and implying something in this relationship with the 'necessary other'. Our participants by no means use their personal budget to give shape to the care practice. In this way, their stories give us the opposite impression of what advocates for personal budgets tell us.

Namely that this new financing system is an essential condition for the promotion of disabled people's freedom and independence (Dowse, 2009). The understanding of relational autonomy that is presented in the stories of our participants allows us to distinguish various expressions of interdependence for all people as an essential feature of human life and the human condition (Dean, 2004; Lister, 1997; Williams, 2001). Human relationships and social infrastructure (see Lister, 1997; Sen, 1999) are indeed important means of achieving a life they deem valuable and might be of greater importance than to other people, such as people with physical disabilities (Nussbaum, 2006). Their photo series and related stories point to the central importance of significant others to the lives of the participants, and their vital role as ‘necessary others’ that nurture a multitude of possibilities and human potentialities (Goodley and Roets, 2008). In order to increase the capabilities of these persons with intellectual disabilities, a social policy should guarantee and enhance the potential to create a care and support practice in partnership and with due regard for interdependence between carer and cared for (Dean, 2015; Dermaut et al., 2019). The material resources that a personal budget offers to shift choice and control over care to the user are not used by our participants. Instead, together with 'necessary others', 'appropriate circumstances' (Nussbaum 1988) are being used to the full to make choices to achieve a flourishing life. The Flemish personal budget policy in this vein seems to have disregarded the care and support practice as a possible open space that constitutes power relationships that work both ways.

Capability-promoting policies also emphasise that people should, at the same time, be equally empowered to contribute to the collective control of the conditions and decisions that affect their common fate (Otto, Walker and Ziegler, 2018, p.303).

This research project has provided resources that made a contribution to the capabilities of people with intellectual disabilities to relate their stories, experiences and views and make them a relevant part of the public political discourse (Wright, 2010). This research demonstrates the importance and the urgency to equip people with intellectual disabilities with the resources to take an active part in shaping public policy and remove unwanted and subtle obstacles to their doing so. For the PVF system to become a capability-promoting policy for all persons with disabilities, in addition to freedom of choice and financial strength, it should guarantee access to social services and opportunities for everyone to share their experiences and wishes on what is required to be able to live a flourishing life.

6.5 Conclusion

This article sought to inform policy and practice by exploring the understanding of valuable elements in the care of people with intellectual disabilities, and whether and how their capabilities to choose may support a flourishing life. In the light of the Flemish PVF policy and practice, this study, focusing on the value of choice by people with intellectual disabilities, is a small but timely contribution to our understanding of the impact of and need for a redistribution of resources. Significant and necessary others are presented as the resources that broaden the participants' opportunities, without mentioning the personal budget and financial independence as issues that matter. The findings highlight tensions between the participants' need for relational support and the increasing policy focus on independence and self-sufficiency (Ferguson, 2007; Goodley et al., 2019; Roets et al., 2020). The voices of people with intellectual disabilities in this research teach us that if the care and support practice in Flanders wants to promote disabled people's freedom and independence, then in addition to the question of redistribution, it is necessary to have an eye for recognition of relationships and interactions as a vital resource for living a flourishing life.

6.6 References

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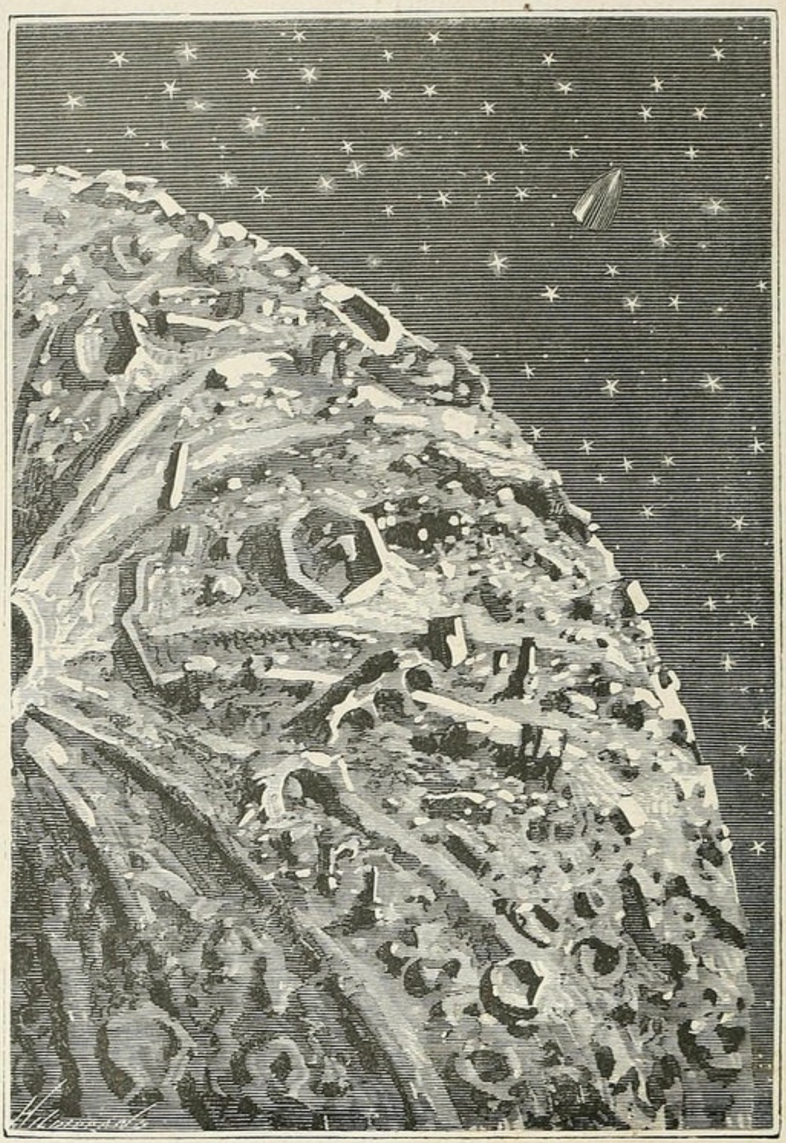
CHAPTER SEVEN

Aspirations of People with Intellectual Disabilities as Opportunities



Il distinguait tout cela. (Page 133.)

Abstract

This paper presents the results of a research project involving ten people with intellectual disabilities concerning their idea of 'a good life' in a residential care setting, within a context of personal budgets. We introduce the capability approach as a framework for focusing on the opportunities personal budgets offer for people with intellectual disabilities. We make use of qualitative interviews following a photovoice project in which people with intellectual disabilities documented their lives in order to research what they deem valuable and aspire to. In the analysis section, we present the elements which the participants identified as limiting and enhancing for imagining their future. From their stories we learn that their aspirations are nourished by the encounters and social bonds that they engage in within a residential care context. The results make clear that the use of pocket money offers opportunities to elaborate on what is already known and enables the realisation of aspirations, while interactions with significant others more often than not encourage participants to explore and try out changes and thus further develop people's set of aspirations. In drawing the discussion to a close, we explore the implications these stories might have for understanding the role of aspirations in the practice of care and support for people with intellectual disabilities. The findings encourage us to think about the pedagogy of recognition and to address this in the practices of personal budgets.

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'Aspirations are never simply individual
(as the language of wants and choice inclines us to think).
They are always formed in interaction and in the thick of
social life.' - **Appadurai, 2004, p. 67**

7.1 Introduction

Traditionally, welfare state delivery of social care for people with disabilities has tended to consist of services in an institutionalised or home setting (Walmsley, 2005). Social movements representing the interests of disabled people were responding to the restrictions on service users' autonomy and voice (Harpur, 2012), critiquing that traditional service delivery provides little opportunity for disabled people to take control of their lives and make decisions (Arksey and Kemp, 2008). Through redistributive measures such as personal budgets, in all their variations, governments sought the enhancement of service users' autonomy (Owens, Mladenov and Cribb, 2017), enabling people with disabilities to plan, purchase and control their own care and support arrangements (Stainton, 2002).

The Flemish variation of personal budget schemes, 'Persoonsvolgende Financiering' (PVF), follows this growing international focus in disability policy on providing social services that "are designed to fit their users, instead of users having to adapt to the services interests and decisions of service providers in this traditional care" (Mladenov et al., 2015, p.308). The Flemish PVF system introduces and encourages market mechanisms (Department of Welfare, Public Health and Family Affairs, 2010, 2018) as a means of enhancing a more responsive attitude on the part of suppliers and establishing a demand-driven care landscape.

Designed to increase influence in decision-making processes (Owens et al., 2017), these schemes are intended to empower people with disabilities to become active agents with opportunities to make decisions about the care practice (Clarke, 2005). In this vein, personal budgets in the care sector for persons with disabilities can be seen as an example of a capabilities-promoting policy (Authors own, 2020a; Otto, Walker, & Ziegler, 2018). Such a capabilities-promoting policy refers to the capabilities approach as a theory of justice that focuses on the creation of opportunities for people so that they are able to develop freely according to personal standards (Sen, 1999; Nussbaum, 2000).

Alongside the premise that personal budget schemes can contribute to a socially just care and support practice for people with disabilities, scholars such as Dowse (2009), Dean (2015) and Garett (2018) point to the challenges that the focus on choice and control might create for people with intellectual disabilities. Because personal budgets define individuals as consumers in a care landscape that privileges competency, capacity and individual welfare independence, this ableist rhetoric (Goodley, 2014) might paradoxically mark people with intellectual disabilities as different and disabled (Dermaut et al., 2019). In accordance with this critical observation, Nussbaum (2006) argues that due to the subordination of individuals due to enduring inequalities in society relating, for example, to disability, individuals adapt their preferences because they see the world in a restricted way. Nussbaum (2006, p. 114) argues that "habit, fear, low expectations and unjust background conditions deform people's choices and even their wishes for their own lives". Therefore, we turn our attention to the matter of providing people with intellectual disabilities with a budget that aims to enable them to make choices about the care and support they need, and how this might relate to or impact on their preferences concerning care and support.

The capabilities approach as a theory of justice (see Sen, 1999, 2002; Nussbaum, 2000; Robeyns, 2006, 2017) enables us to think about personal budgets for people with disabilities as a capabilities-promoting policy in terms of expanding people's real opportunities to shape the care and support of their choice. In order to strengthen the reflection on the meaning of care and support and of social work practice for people with intellectual disabilities within the context the Flemish personal budget scheme, we set up a photovoice project that focuses on the effective opportunities of people with intellectual disabilities who receive care and support in a care organisation with a residential character and who spend much of their lives there.

In qualitative interviews following the visual data from the photovoice project, we asked the participants about the things they would like to do/be in the future, their aspirations, and about the meaning of a personal budget in respect to the things they consider valuable. In addition, we asked questions to learn about the opportunities they had to talk explicitly about the future. Knowing their vision of what access to the use of a personal budget means and their concerns, expectations and aspirations for the future contributes towards both researchers and professionals developing a better understanding of the pedagogics of care.

Before we present the applied method in this study, followed by the main results, we start with a brief exploration of the different concepts of the capabilities approach that we make use of in this paper.

7.2 Connecting aspirations, capabilities and conversion factors

In a previous published paper (see author's own, 2020), we focussed on the matters that the participants portrayed in the photovoice project, elements reflecting what they themselves value in the care and support they receive in the care organisation. In this paper, we turn our gaze to the future, to the aspirations of the participating people with intellectual disabilities, more precisely to their 'capability to aspire' and what, in their view, possibly impacts this capability and therefore other capabilities to emerge (Figure 6).

Appadurai (2004, 2013) conceives aspirations as a navigational capability, which is the real freedom of individuals to imagine a future different and better than one's current condition. It is an ability to project oneself into the future and view it as an open space of possibilities (Cuzzocrea & Mandich, 2016). It is a useful concept for understanding the cultural and normative dimensions of the capabilities of people, as capabilities are constructed in a particular social, economic and political context (Walker, 2006). Aware of this situatedness, Appadurai (2004, p. 75) refers to the capability to aspire (C) as a precondition for capabilities and therefore calls them "local horizons of hope and desire". In this line, Hart (2016) considers the functioning of aspiring (E) to sit between the freedom to aspire (C) and the capability to achieve the particular aspiration (F). Thus Hart (2016, p. 329) argues that "aspirations are powerfully situated as the forerunners to many capabilities". Capabilities (A) are the genuine opportunities each person has to achieve the things that they have reason to value (Sen, 2002).

Capabilities are what Robeyns (2006) calls the real opportunities to realise functionings: one's actual achievements. Considering aspirations as the forerunners to many capabilities has important implications for our understanding of an individual's opportunities and freedom, by virtue of combining their degrees of freedom to aspire (C) with their options to transform (F) this aspiration into a capability (A), a genuine opportunity (Robeyns, 2007).

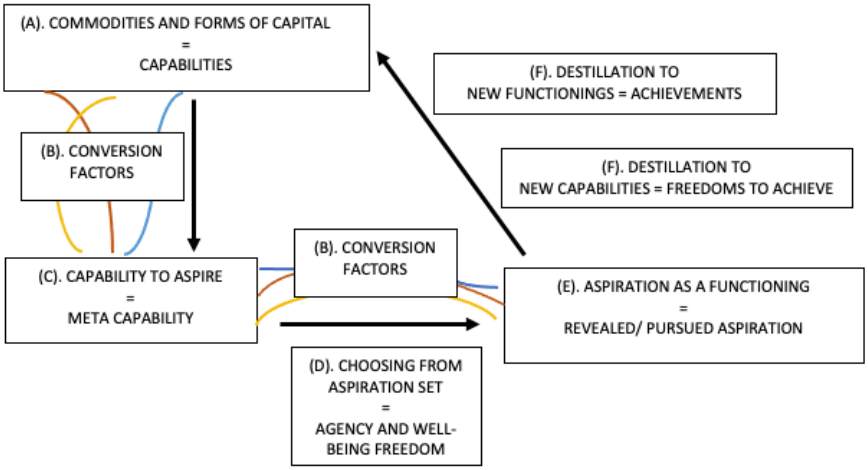

Figure 6: Iterative process of aspirations as meta capabilities. Based on Hart (2016, p. 330)

Sen's (2002) conceptualisation of capabilities does not assume that a capability will necessarily become a functioning (E). This means that people can have aspirations they do not necessarily want to see realised (D). An individual's capability to aspire is a freedom in its own right (Hart, 2012) and has a value in itself without necessarily enabling possible future capabilities and functionings. For example, a person with an intellectual disability may have developed the aspiration of living in an apartment without support from caregivers, without necessarily wanting to pursue and realise this aspiration.

But even so, a person with an intellectual disability may experience limited opportunities and agency (D) to develop their aspirations freely due to material or social constraints, such as a strong parental involvement, to name one. In this sense, Hart (2004, 2012) points to the layered and complex manifestation of aspirations. Some aspirations may prevail while other less conventional aspirations never have the opportunity to emerge. An individual's revealed aspirations therefore only give a partial view of their 'aspiration set' (Hart, 2012). The capabilities approach acknowledges interpersonal variations in the conversion of resources into functionings, recognising the complex ways in which various factors intersect, interrelate and influence the lives of people (Sen, 1992; Robeyns, 2017; Walker, 2019). These variations are understood in the concept of conversion factors (B), material and social conditions (Walker, 2006) which, in interaction, convert resources and commodities of different kinds into capabilities and capabilities into functionings, in both facilitating and limiting ways (Sen, 2002; Robeyns, 2017).

In general, conversion factors are classified into three groups: personal factors (reading skills, physical condition), social factors (public policies, social norms) and environmental factors (infrastructure, public goods) (Robeyns, 2017; Hart, 2012). A distillation process (F) occurs both from aspiration to capabilities and capabilities to functioning. Whilst a large bundle of aspirations may be converted into capabilities for a given individual, it will not necessarily be the case that all of these aspirations can be realised. Hart (2016, p.331) therefore notes that "an aspiration set will include some but not all of the precursors to the capabilities an individual enjoys".

The impact of various conversion factors on an individual's capacity to aspire will result in high levels of freedom to aspire for some but low levels for others. A personal budget for people with disabilities can give one person more opportunities and stifle another, for example when considering the financial management. This is an important point in the sense that the capability to aspire is referred to as a meta capability (Hart, 2012) and a precondition for capabilities (Appadurai, 2004), and therefore the aspiration set of an individual is in itself an important conversion factor for developing many capabilities. On the basis of this conceptual argument, this article addresses conversion factors, namely those elements that affect the participants' capability to aspire.

7.3 Method

The data presented in the next section draw on qualitative interviews following a photovoice project with ten people with intellectual disabilities (see Author's own, in press). Photovoice was first developed by Wang and Burris (1997) as a means to collect data, enabling participants to highlight their perspectives and reflect on their lives, foregrounding the unique and valuable insider perspective of participants (Jurkowski, 2008). In a typical photovoice procedure, participants take photographs which are later used to facilitate reflection on their feelings, ideas and experiences (Mitchel, 2011). Photovoice has the potential to include people in research who experience difficulties with direct communication (Jurkowski, 2008) and is therefore very well suited to involving people with intellectual disabilities in research (Booth & Booth, 2003). This study was conducted in collaboration with an accredited Flemish care organisation dedicated to the support of adults with intellectual disabilities. We made use of a purposive sampling method (DiCicco-Bloom and Crabtree, 2006), meaning that the participating care organisation was selected on the basis of its characteristics and the purpose of the study.

The particular care organisation is part of a learning network ‘KWAITO’, which aims to develop a clear vision on quality of care which they want to integrate into their practice in the context of the personal budget system. In various entities throughout a village-like municipality, this care organisation offers a wide range of types of support to about 120 adults with intellectual disabilities. The intensity of support differs markedly across the different housing types, depending on the care needs and preferences of the residents. In consultation with the general manager and the care manager, potential participants were selected. The main criterion used was the presence of 'a distinctive pedagogical question', which means a need for care or support that does not fit within the predefined responses of the care organisation, along with a variation of types of disability among the residents and a variation in living conditions. Five participants live independently with flexible support in houses throughout the village that are rented by the care organisation. Four participants live in studios with permanent support in a larger homelike building of the care organisation. One participant lives in the care-intensive residential accommodation of the care organisation.

Table 6 shows an overview of the participants, identified by the pseudonyms that will be used throughout this contribution. The purpose of the study was explained to the selected adults by pedagogical staff members, followed by the question whether they wanted to participate. The researcher then visited the persons who agreed to participate in a one-to-one setting, in which the structure of the research was explained by reading to the participant an information letter written in basic terms. Subsequently, the informed consent was discussed orally. A witness was present when participants were known by the care facility staff to be illiterate or inarticulate. In those cases where the participant was under the supervision of a guardian, the latter was asked to sign the form if agreeing.

The information letter and the consent and assent forms were carefully adapted for people with a limited understanding (Povee et al., 2014). This method is in line with the research ethic guidelines and was accordingly approved by the Ethical Commission of the researcher's university.

Participant	Alias	Gender	Age	Living condition
P1	Oliver	Male	51	Independent living with permanent support
P2	Amelia	Female	29	Independent living with permanent support
P3	Jack	Male	55	Independent living with permanent support
P4	Harry	Male	23	Independent living with flexible support
P5	Olivia	Female	69	Independent living with permanent support
P6	Emily	Female	58	Independent living with flexible support
P7	Jessy	Female	51	Independent living with flexible support
P8	Jacob	Male	30	Independent living with flexible support
P9	Charlie	Male	49	Independent living with flexible support
P10	Thomas	Male	50	Care-intensive living

Table 6: Overview of Participants

The first author of this article introduced the participants individually to the method of photovoice. Each participant received a disposable camera with a flash and with the option to take a maximum of 39 pictures. We asked participants of our study to take the photographs within a timeframe of two to three weeks. The visual material our participants produced during the photovoice project depicts the elements they valued concerning their care and support at the time of the project (see Author's own, in press). The participants revealed what they deemed valuable in their care and support in the present. Their photo series and related stories point to the importance of significant others in the lives of the participants (see Author's own, in press) and of their vital role as necessary others in the promotion of a multitude of opportunities and human potentialities (Goodley & Roets, 2008).

The photovoice method was used as one of multiple ways of giving a voice to the participants and did not serve as an end in itself, but rather as a starting point for a conversation about the meaningful elements in life (Jurkowski, 2008). To complement data about their appreciation of the present, reflected in the photographs, the first author of this article conducted qualitative interviews with open questions in which the focus lies on their possible futures and on their idea of the personal budget, thus allowing more topics to be addressed than those elements photographed. Through these conversations, the participants provided insight into their capabilities, the genuine opportunities available to them to take on the freedom to choose (Robeyns, 2006), as assumed under a personal budget scheme, and their 'capacity to aspire' (Appadurai, 2004, 2013; Hart, 2012).

During the conversations, we paid particular attention to conversion factors, elements that helped support or, rather, hindered our participants in developing or realising their capacity to aspire. In considering the capacity to aspire as a forerunner of opportunities, defined as a meta-capability by Hart (2012), these conversion factors are important for our understanding of the development of aspirations and the expansion of an individual's capability set. Once the data had been collected, the interviews were transcribed orthographically. Field notes were recorded during the photovoice project (Overmars-Marx et al., 2018), which entailed three to seven meetings with each participant. Subsequently, all interview data and field notes from the photovoice project were read multiple times and complemented with memos and with notes taken during or immediately after the interviews. In the next phase, the transcriptions were thematically coded using qualitative data analysis software (MAXQDA). This provided a firm basis for determining the factors that convert the development of participants' capacity to aspire, but also provided a structure for communicating our results.

7.4 Results

Plenty of different kinds of aspiration were touched upon during the discussions of the photographic material they produced in the photovoice project and the following interviews. The variety of aspirations expressed by the participants support the premise that aspiration is a dynamic and multi-dimensional concept (Hart, 2014). Moreover, the aspirations that participants shared give only a partial view of their individual 'aspiration sets' (Hart, 2012), since some aspirations can remain hidden, and people can also express aspirations they do not necessarily want to see realised (Sen, 2002). While not listing the nature of the participants' aspirations, we draw attention to those elements that the participants put forward as influencing the development of their aspirations. Given that aspirations are defined as preconditions for capabilities (Appadurai, 2004; Hart, 2016), it is essential to gain insight into the conversion factors that enable and obstruct the capacity to aspire.

Enabling and obstructing elements in the capacity to aspire

Our participants identified two elements that acted as conversion factors in developing or realising their capacity to aspire: (1) 'interactions with significant others' and (2) 'the use of pocket money'. From those two elements, both enabling and obstructing ways will be highlighted and discussed, drawing on examples provided by participants.

Interactions with significant others

The potential of interactions with significant others was demonstrated by Emily in the joint search with a support worker for a meaningful and suitable job. Emily worked two days a week at a school for blind children. She explained that she was able to find out what she would like to do through interactions with the support worker:

> *"She came by one day, to find out if I can do that or that or that or that.* [...] *And she checked if I could do that. And I could then continue to do that".*

Charlie was proudly taking dancing lessons, resulting from a joint exploration process with his personal assistant after she saw him dancing multiple times in his living room. Jacob illustrated this enabling potential eloquently when he talked about his ambition to work at the municipality's green service. He had informed his personal assistant about this aspiration after he himself had made contact with the green service. Through involving the assistant, Jacob tried to increase the prospects of achieving his goal. The municipality took Jacob's question seriously but was unable to address it, stating that they had sufficient workers for the moment. This did not prevent Jacob from further developing this aspiration together with his personal assistant, who had Jacob alternatively mowing the lawn at her home. This encouraged him and, in the presence of the researcher, he dreamt aloud, with another caregiver present at the time of the interview, about working at the green service and what a potential day of work might look like:

> *I would work for the municipality, and then I'll come to your house.* [Jacob]
> *And then you can take a break at my house and come and have coffee, that would be a thought.* [Caregiver]
> *Yeah. And drive off your grass. And have a cookie with you.* [Jacob]
> *You'd like that.* [Caregiver]
> *And have a chat with my colleagues.* [Jacob]
> *Yeah.* [Caregiver]
> *You'd take more breaks than you'd work.* [Researcher]
> *That would be good.* [Jacob]

Participants pointed to ample examples of an emerging awareness of ‘being different’ through interactions with others. For Harry, this became apparent when we talked about his housing situation. He lived independently in a housing project with permanently available assistance, but especially experienced 'being different' when the person for the night shift arrived: *“when they come in, I just feel like I'm in jail”*. For a long time, Oliver lived independently in a social housing tower.

When considering whether he might want to live alone again, he resolutely said no: *“I don't want that anymore. I don't anymore. No, you won't. It's too difficult for me, no I can't”*. Later, he said that he was being taken advantage of a lot and that he had been the victim of multiple burglaries as well. Interactions with others left Amelia with a feeling of “being an outsider” and therefore thinking about herself as not able to aspire, let alone being in a position to express aspirations. A large part of the conversation we had following the photovoice project focused on a picture she made of her three sisters. Amelia said that she was different from her sisters because she was born with a disability. When asked what she had the hardest time with, she answered: *“Yes, I have a disability, I wanted to study like my sisters. I'm hurt about that”*. Throughout the different encounters we had, Amelia presented herself as an outsider to the possibility of making opportunities work. She said “I’d like to have studies like my sisters did”. When asked if she had any idea what she would like to have become, she answered:

> [*sighs*] *I can't say that right now.* [*...*] *I can't explain that, you're not going to, you're not going to ask me questions like that, you can't do that, I can't even explain why.* [*...*] *Because I have no idea what it could be. Do you understand me?* [Amelia]

The potential for an aspiration to be developed or attained was not in her experience within her reach, because of her ‘otherness’. In addition to a sense of otherness, the continuous dependence on others also formed an obstacle to the participants' potential to aspire. This ‘dependency fatigue’ came to the fore when Harry talked about his aspiration to become a forklift driver. We talked about this idea and how he might be able to put this plan into action. His mother had already figured out whether he was eligible to get a driving licence with his disability. When asked if he had any idea what else would be needed to be able to do that job, Harry answered with resignation: *“That I don't really know. Because I've never done it before, so yeah. Unfortunately, I can't tell you that”.* Harry did know what he would like to do, but in further developing his aspiration he needed significant others. He did not seem to be taking any further steps to explore or realise this aspiration. The continuous dialogue and interaction with others appeared to be an obstacle. This was also the case for Jessy, who often expressed her aspiration about changing jobs and phasing out support, yet repeatedly indicated that she had not yet discussed this with any of the support workers “because they might not approve”.

The use of pocket money

The second reoccurring element in the discussions with the participants about the things that impacted their aspirations was the use of pocket money. The personal budget of the participants, designated for their care and support, was in all cases managed by a family member, a lawyer or a legal guardian. In the case of Jessy, her older brother and an attorney managed her personal budget. Jessy had to ask permission when she wanted to go out, for example to a drag queen show that would cost her 65 euros. When Jessy was asked whether she then saved her pocket money for two weeks or asked her brother's permission, she replied:

> *"I'm not going to tell him everything. Then I'll ask my attorney first* [...] *then I'll send an email to my attorney, see that's so much for each person and everything, and I'm sure it will be okay"*.

Jessy was the only participant who endorsed the idea of managing her personal budget herself in order to be able to make choices about her care and support. All the other participants indicated that they would like to keep the care and support as it was right now. The only thing Jessy would change was the frequency of assistance and counselling, as she believed that support staff were visiting her house more than she liked. Continuing with this thought about how she would use the money for her support in a different way, Jessy reacted reluctantly: *"No no, if I had that, then there would be no more money. Then I would go to the cafe many times a month ... If I ran out of meat or beverages, I would buy drinks and meat for putting in the freezer, sure"*. Eventually she concluded that *"it's easy the way it is now"*. In this way also Jessy joined all participants in the idea that they did not want to manage the personal budget allocated for their care and support themselves. What all participants did receive was pocket money, which they could use as a resource to achieve the things they liked. Pocket money is not related to their care and support and is not part of their personal budget. This concerns for example the money Jessy would ask for to go to the drag queen show. These were often small amounts, varying between 5 and 50 euros per week. When respondents talked about money, they were referring to their pocket money. All respondents indicated that they found it difficult to manage this on their own, some even stating they could not work with it. Yet, most participants were prompted by significant others to save up, although Oliver and Jacob said that saving was "too difficult", and Olivia identified "saving money in the present" as meaning that she would be unable to spend the money in the future.

Furthermore, participants did not have much experience in managing money, mainly because they did not have a paid job. In addition, as outlined above, significant others managed the personal budget, leaving the participants with very limited financial responsibilities apart from the things they could buy with their pocket money.

The (un)availability of pocket money does contribute to the capacity to aspire of participants, insofar as it makes them reflect on their ability to manage money and to save. Emily, for example, said that she was not able to handle money on her own. The receipts from the food she ordered during lunchtime at her job were therefore being sent to the central administration of the care organisation. Emily explained that she did not want to arrange this herself, because, as she said, she *"is not able to handle it"*. On the other hand, she was eager to learn how to use money step by step and she was proud to say that she could *"already deal with 10 euros"*. Jacob had a hard time making ends meet with his 70 euros of pocket money a week. He had tried out several approaches to cope with this, such as spreading his budget over several days of the week. Jacob had no goal for saving, and when he had some of this pocket money left at the end of the week, he wanted to use it to buy cookies and tobacco. *"I spend it all",* he said with a smile. As Jenny was unable to manage the personal budget and her pocket money herself, her brother and attorney managed it for her and fulfilled most of her wishes and needs. Jenny had a stomach reduction several years ago, but she had to continue to be aware of her health needs. For that reason, she said she was inspired to get a watch that counted her steps and measured her heart rate. The availability of money, and the certainty that significant others would agree with her requests, provided Jessy with opportunities to develop her aspirations. It enabled her to think about things she appreciated and would like to achieve, such as reflections on how to stay healthy.

Above all, pocket money, and by extension money in general, was presented as an obstructing element. Harry said that when it came to spending, he *"knows no limit"*. Emily stated that she *"can't get away with it yet"* and Jessy said that she would like to have a final say over her money but acknowledged that she *"would only buy food with it"*. Talking with Amelia about matters associated with money resulted in disquiet with her, claiming that she *"don't know about stuff like that"*. Oliver always used all his pocket money at once, although he had the intention to save up money for a bike and therefore created a savings account at the local bike store. But when he ran out of money to buy his daily cigarettes and coke, he collected his savings time and time again. When Oliver was asked about his aspiration to ride a bike, he explained that it was still on his mind. On the question what kind of bike he would like to ride, Oliver answered: *"I don't know about that, it's expensive"*.

The very fact that a bike was expensive thus meant for Oliver that he had no idea what bike he could get. Yet, this process of saving and collecting money at the local bike store has continued to this day. Money as a factual resource has not helped in the realisation of Oliver's aspirations, because there is not enough both to save up for a bike and to meet his need for cigarettes and coke. But the idea of the opportunities that money creates has provided levers for him to imagine things he would like to do.

There are also interesting examples of ways in which participants were able to achieve the things they deemed valuable, although with little money to do so. We present the case of Jack, who used his three euros pocket money a week to have a drink at a café.

It would be way more costly were Jack to go to the bar himself and thus have to arrange transportation, such as taking the bus or ordering a taxi, or were he to go to another bar, not the one opened by the care institution and mainly run by volunteers. But since carers would bring Jack to the café and pick him up, let him be there as long as he wanted and have staff looking after him, it was possible to make this happen with his three euros. Yet, in Jack's perception the little pocket money he had allowed him to do this activity. Another example is Olivia's request to keep chickens, which was granted by the director of the facility years ago. Asking why she wanted to have chickens, Olivia said the following:

> *For an egg! To have an egg. Before I was in the clinic, before that, hey, I went peddling the neighbours' houses with those eggs. That was 10 euros, that was just right for those chickens to buy their food. And now I'm not going to peddle them anymore. And now we eat them all ourselves.* [Olivia]

When Olivia was in better physical health, she went around the streets in the neighbourhood to sell the eggs. She said that selling the eggs to the neighbours provided sufficient money to provide for the food and maintenance of the chickens. Her physical health had declined and she was unable to go on the street to sell the eggs, so the residents of the care institution ate them themselves. With what money the food for the chickens was being bought now, Olivia could not answer. Obviously, it was the care institution that had provided for the chickens all along, built a fence to keep foxes out, made a cute cottage for the chickens, bought hay, etc.

7.5 Discussion

Participants shared stories in which they were projecting themselves into the future while viewing it as an open space of possibilities (Cuzzocrea & Mandich, 2016), emphasising 'interactions with significant others' and 'using pocket money' as conversion factors. These two elements impact on the specific opportunities people with intellectual disabilities are given to learn about and appraise different options for the future (Baillergeau & Duyvendak, 2019).

Although the pocket money is in itself a resource, it was also presented by our participants as a conversion factor in the development and realisation of their aspirations. It was mostly cited as an obstacle to realising aspirations: on the one hand, the financial resources they managed, the pocket money, were rather limited, while on the other, participants had little financial responsibility, did not earn any money, and most had all resources apart from the pocket money managed by a guardian. A personal budget, therefore, did not act as an opportunity-enhancing element for our participants (Robeyns, 2017), contradicting the expectation that personal budgets in the care sector for persons with disabilities have a potential for capabilities-promoting policy (Authors own, 2020a). We continued, however, to explore with the participants what opportunities a personal budget might create. On this point, participants indicated that they did not want to change much in terms of their care and support. The results reported that only two participants were considering possible changes: Jessy would like to be supported less, because she felt that the personal assistant was making too many visits to her home, while Emily felt that the personal assistant should visit her more often. The nature of the support, apart from the quantity, was not questioned by any participant.

Pocket money was for the participants in our study necessary for realising the things they valued, for example, to be able to go to a drag queen show, to have a drink in the café or to be able to buy a bike, although they considered their inability to manage it to be a reason not to imagine other possible outcomes. Hence, why think about it if it is not within your capacity to pay for it. Money in general and pocket money in particular were therefore presented as a limiting factor that mainly hindered their capacity to aspire. The presence or lack of money also nourished reflection by multiple participants on the opportunities that being able to manage or acquire money might open up. In this vein, their capability to aspire enables more capabilities to be generated, and acts as a meta capability (Hart, 2012).

This line of thinking prompted participants to aspire to be able to manage money and use it for valued purposes, even if it meant providing for basic and trivial needs, such as tobacco and cookies. The examples provided by Jack and Olivia illustrate how their aspiration set was broadened by what they perceived as money, but in reality, comprised interactions with significant others. In these cases, money acted as a substitute for the whole underlying platform of solidarity within the care institution, giving the participants a sense of self-sufficiency and independence but covering up the (inter)dependent nature of the care relationships, in which necessary others played a vital role in the promotion of opportunities (Goodley & Roets, 2008).

This brings us to a discussion of the various ways in which interactions with significant others influence the capacity to aspire. Our results give plenty of examples in which the attentiveness, proximity and responsivity of significant others enabled our participants to discover possible ways of being and doing. The participants indicated that it was in their contacts with significant others that opportunities were discussed and that both parties became able to contemplate a wider set of options for the future, for instance searching for a job they would like to do.

The crucial role of interactions in the development of aspirations has already been described by Sen (2004), Hart (2016) and Appadurai (2013). According to Sen (2004) talks and discussions are of vital importance so as to "practice the arts of aspiration, lending immediacy and materiality to abstract wishes and desires, and struggling to reconcile the demands of the moment against the disciplines of patience" (p. 76). In this way, aspirations are related to people's capacity to give voice, their options to share their story and have their story taken seriously (Ricoeur, 2005; Author's own, 2020a). In line with Sen's argument that "value formation is an interactive process" (2004, p. 42), Hart (2016, p. 322) emphasises that "aspiration formation is an interactive process". As an active and relational engagement, the process of aspiring, sometimes in abstract thinking, can be further developed through verbal, written or other forms of creative and physical expression (Hart, 2012). Significant others and the ability to share and construct a story made an essential contribution to the capacity to aspire of these ten people with intellectual disabilities. It is in the proximity and attentiveness that are inherent in a pedagogical relationship that the 'light of the potential' is broadened (See Author's own, 2020b; Mollenhauer, 1972).

However, interactions are not always conducive to a more developed capacity to aspire (Baillergeau & Duyvendak 2019). As the data reveal, loyalty to significant others frequently contrasted with other issues that participants themselves considered important. In this line Hart (2016) notes that "significant others' engagement in judgements regarding the feasibility of aspirations" (p. 331) is pivotal in the development of capabilities. Our participants acknowledged that significant others are often necessary others (Author's own, in press; Lister, 1997), whose ideas are sometimes at odds with their own plans or what they considered an important and meaningful use of time.

In the meaningful interactions that participants have, areas of tension and competing aspirations can emerge that undermine the development of the capacity to aspire (Baillergeau & Duyvendak, 2019), and cause aspirations to wither away. For example, some participants stopped talking about their aspirations with significant others. Interactions sometimes contributed to an emerging sense of being different, which obstructed the formation of aspirations. The formation of aspirations was therefore presented as something that was beyond their capabilities, something they were not meant to take an interest in. Furthermore, the continuous dialogue and interaction with others so as to be able to develop and realise their own aspirations in some cases resulted in dependency fatigue. This in turn resulted in aspirations to remain hidden or concealed (Hart, 2014), and therefore prevented further development.

Supporting people with disabilities in the management and use of personal budgets is presented as being of pivotal importance for people's care trajectories (Rabiee, 2012; Newbronner et al., 2011). Whereas this can contribute to the 'good use' of such a budget, our results show that supporting the management of a personal budget does not in itself contribute to the development of aspirations and opportunities on which the budget can be used. The stake of personal budget schemes is more than economic redistribution, as the provision of resources directly to the recipients of care is a formal recognition of their knowledge and experience of everyday life (Beresford, 2000). It is part of the demand for cultural recognition (see Fraser, 1997) and for shifting the power balance between the various stakeholders in the care practice. A personal budget does not provide a tool for the participants to actively look for new knowledge, other possible forms of support, other useful daytime activities, etc. It is through engaging in interactions with significant others that ideas can be discussed or that new ones may emerge.

A personal budget and, by extension, money are indeed meaningful for our participants in realising what they already know and appreciate.

But this is of little significance in the expansion of their set of aspirations and thus the creation of opportunities. A social work and social care practice should be a two-way traffic between service workers and users, each learning from the other (Beresford & Croft, 2001). From the stories of these ten people with intellectual disabilities we learn that creating opportunities and aspirations is for them a question of recognition and not so much a redistributive issue. Through recognition by and discussions with significant others, such as social workers and social care practitioners, service users become able to learn and to aspire. The primacy of relationships and care do not have to pose a threat to the autonomy or independency of these individuals with a care and support need, instead confirming autonomy as a fundamental social concept stemming from intersubjective mutual recognition (see Honneth, 2011). Relational processes of recognition and discussion form the bedrock of the capability to aspire of the participants in this study; without it, we can expect practice to disempower, damage and wither (Beresford & Croft, 2001). This should prompt us to think about the pedagogy of recognition and how to address this in the practices of personal budgets.

7.6 Conclusion

This study contributes to a strengthening of our understanding of the aspirations of people with intellectual disabilities receiving care and support in a care organisation with residential character. Our results imply that meaningful interactions with significant others, such as family members and social professionals, and the resultant ability to share and construct a story make a vital contribution to their capability to aspire. The most important tool for acquiring new knowledge and new insights for the participants is the involvement of significant others, their recognition of what is of value and their participation in conversations that people want to enter into. If social workers and care workers fail to recognise what is of importance to people with intellectual disabilities, the most effective tool for gaining relevant knowledge is no longer in place and the aspirations may turn into fantasy or despair. A personal budget for people with intellectual disabilities contributes to what is already known and offers no further perspective on imagining a possible future. And without aspiration, there is no pressure to know more (Appadurai, 2013). With the compelling testimony of Sophie: "how can I know what I want", the participants in this study remind us of the importance of a relational pedagogy for the development and realisation of aspirations.

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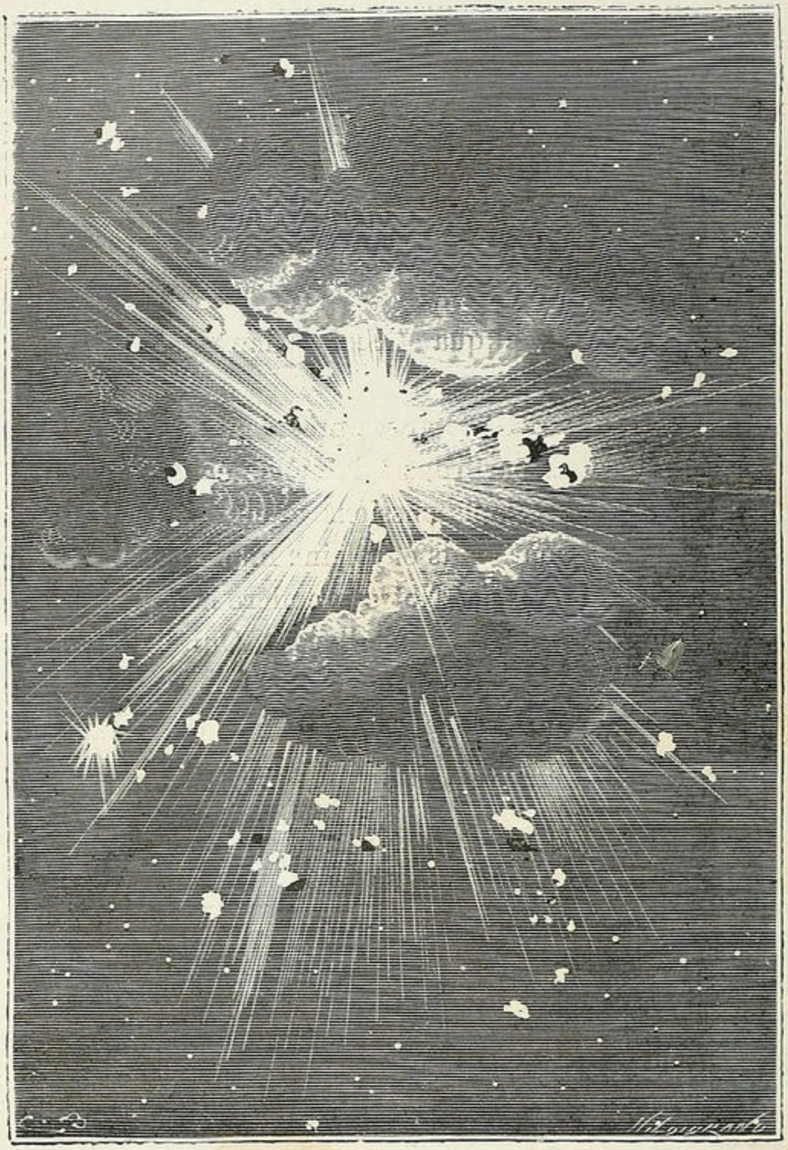
CHAPTER EIGHT

General discussion and conclusion



Quel spectacle! (Page 124.)

Personal budgets have been criticised for becoming practices which encourage a particular idea of empowerment as a private responsibility and which propagates an idea of autonomy in terms of consumerism and rationality (see Ferguson, 2007; Lymbery, 2012; Roets et al. 2020). These evolutions are considered to be deeply problematic for the potential of developing a care practice that is concerned with social justice. In particular, the focus on the primacy of the individual calls for a greater commitment from social work to put social justice issues on the agenda. This dissertation aims to make a contribution to the reflection on the engagement of social work with social justice for people with disabilities, by building on how social work practitioners, managers of care institutions and people with intellectual disabilities receiving care and support relate to the concepts of autonomy and choice and to the promise of social justice and social change as embedded in personalisation and personal budget policies. The rich experiences that professionals in neighbouring countries shared with us with regard to personal budget schemes, as well as the experiences of directors of Flemish care institutions and the stories of the participants in the photovoice project, provided us with a multitude of insights, each of which sparked significant discussion. For the purposes of this dissertation, we highlight those elements that focus on the meaning of the introduction of a system based on market mechanisms and personalisation for the pedagogical project in social work and the opportunities that care and support services have to develop a pedagogic project, the pedagogical relationship between 'carer' and 'cared for' and an understanding of what 'autonomy' and 'a good life' might entail. The five different research questions we posed were grounded and discussed in the existing international literature and contemporary debates. We examined and addressed these questions in the previous chapters. The first part of this general conclusion provides a reflection on the methodological and ethical choices that were made during this research.

In the second part, we summarise the main findings reached in the previous chapters. In the third part, the findings of our research will be viewed in relation to our quest to deepen the pedagogical perspective on social work. We will start the concluding reflection by exploring two distinct notions of autonomy that came to the fore in our research findings, which we critically examine. We then elaborate on the question why it is fruitful to make use of a capability-informed framework to examine the real impact of personal budget policies on care and support practice. Additionally, we explore the capability-promoting potential of the personal budget policies for social work practice. We conclude by exploring the significance of 'a pedagogy of personalisation' as a socially just pedagogy in the social work practice of personalised care and support.

8.1 Reflection on Methodological and Ethical Choices

In formulating an answer to our central research question 'how can a socially just pedagogy be conceptualised in relation to a system based on marketisation and personalisation', we believe there is much to gain by adopting a multi-dimensional point of view, especially from an understanding of the different stakeholders' perspectives on the central features of autonomy in a context of personal budgets: choice and control over one's care and support. The methodological strength of this research is therefore that it combines in-depth interviews with social professionals and directors of care institutions with ethnographic accounts of people with intellectual disability through the means of a photovoice project. The combination with in-depth data from a range of stakeholders is an added value, as it is one of the first examples of research on personal budget schemes to collect data from a multi-perspective approach. In particular, our decision to include an ethnographic element in the photovoice project, which contributed to our understanding and analysis of what the photos represent, is quite innovative.

Our argument that people with intellectual disability in residential care are a neglected group in research gives the research some originality in the use of photovoice to explore what is important for them in their lives.

Although we can now endorse or critically assess the choices we did or did not make, this PhD trajectory could not escape the conventional 'coincidence' either. It became clear very quickly that this research project would go in other directions than we could have imagined at the start. Due to the opportunity to carry out a study commissioned by the Policy Research Centre for Welfare, Public Health and Family of the Flemish Government in early 2017, the proposed literature study to investigate experiences with personal budgets in countries with a longer tradition of such systems, the so-called 'early adopters', was redirected into a one-year intensive exploration of the experiences with systems of personal financing in the Netherlands, Germany and England. Looking back, this was a most welcome development for our research project, given that the rollout of PVF in 2017 was all the more interesting to our research sometime after its implementation. Our search for a pedagogy in care facilities under PVF brought us to the group of facilities that gathered in the learning network 'KWAITO'. It is from this collaboration that we explored the possibility of including in our story the voices of people with intellectual disability in one of these facilities.

It is within the confines of coincidences and fortuitous encounters that we have made somewhat creative or even innovative choices within this research. In the following sections we will elaborate on the implications of these choices and how valuable these have proved to be in the light of the general research project. Needless to say, however, there are a number of reservations to be addressed with regard to the methodology used in this study.

As a result of conducting our research from a social work perspective, throughout this dissertation our focus moved from policy analysis to scrutinising concrete practices. Precisely because we approach the issues of personal budgets, autonomy and social justice from the perspective of social work, it is imperative to look beyond the implementation of policy. After all, social work "does not start from predefined problem definitions, but from a critical awareness of the diversity of possible meanings about the same situation" (Bouverne-de Bie, Coussée, Roose and Bradt, 2019). For this purpose, we aimed to capture a diversity of perspectives on the practice of personal budgets in the care of people with disabilities by documenting the voices of both professionals and clients. In what follows, we will discuss some of the choices, strengths and limitations of our research in this regard, focussing on the use of a social work perspective that resulted in the selection of the KWAITO network as a specific group of care institutions and in employing an ethnographic stance.

Selecting a specific group of care institutions

Adopting a social work perspective on a social issue means that the researcher takes an active place and is present in the field of practice (Roose et al., 2016). Rather than questions about technicalities and 'what works', a social work perspective is about revealing ambiguity and complexity in social work practice. This social work perspective encourages the researcher to ask questions about the 'why' of actions and the meaning they have for practice. In this vein, the first study of this research, which encompassed the English, Dutch and German systems of personal budgets, focussed on the social professional's experience and perspectives on the application, assessment and allocation phases. These are very important phases in the pathway towards obtaining a personal budget and largely determine what the care and support that can be purchased with a personal budget will look like.

For this reason, we chose to focus our international exploratory study on these three crucial phases while looking for the complexity in practice. These three personal budget schemes did show a different outset than the Flemish PVF system. The Flemish personal budget policy places more emphasis on the relationship between care supplier and person with a care need than on the application, assessment and allocation phases. That is why, for our second study, we focused on care institutions in Flanders. In order to gain insight into the questions that arise from Flemish PVF practice, we chose to include the experiences and perspectives of directors of care institutions in our research. More specifically, we aimed to gain an understanding of the meaning of PVF for care practice from the perspectives of directors of care facilities that are specifically orientated towards engaging in a pedagogical project. This brought us to the group of facilities that joined the learning network 'KWAITO' and that are engaging specifically in the debate on the pedagogical project in the context of personal budgets and social entrepreneurship, as foregrounded by the Flemish Government (Department of Welfare, Public Health and Family Affairs, 2010, 2018).

The researcher's choice to give this group of facilities a central place in the debate on the significance of PVF in Flanders is certainly not without challenges, and therefore needs to be well reasoned. First, our third research question concerning the meaning of personal budgets for the pedagogical project of care institutions makes it especially relevant to focus on the experience and perspective of these facilities, which themselves indicate that they are motivated to put the pedagogical project at the heart of their actions. The complexities they identify regarding the realisation of a pedagogical project within the context of PVF raises the question of complexities in those organisations that do not have a clear commitment to this question.

We consider the choice to limit ourselves to the experiences of the 12 members of this learning network to be a strength in our efforts to gain insight into the impact of PVF on the practice of care services.

Secondly, our focus on this learning network does not allow a comparison to be made between different types of care facility. After all, we were not looking to map out various ways of dealing with the personal budget scheme in practice. On the contrary, what was central to this research process with the members of this learning network was the exploration of how a system of personal budgets affected their ability to shape a pedagogical project. Lastly, the selection of this group of care institutions is also grounded in our aim to contribute to the central research question of how a socially just pedagogy can be conceptualised in relation to a system of personal budgets based on marketisation and personalisation.

Addressing this question should also contribute towards our main objective to deepen the pedagogical perspective on social work (see Bouverne-De Bie et al., 2014; Lorenz, 2016), as the mandate of social work is seen as a pedagogical one that consists of sustaining the premise that there are always alternatives and that alternatives must be based on joint negotiations between all participants (Lorenz, 2013). The accounts of the members of the KWAITO group provided us with valuable insights for addressing our central research question. Nonetheless, they are only a part of the complex puzzle of the diversity of perspectives that make up a pedagogical project.

Employing an Ethnographic Stance

An essential element in the choice to involve in this research venture those primarily concerned – ten people with intellectual disability – was the radical belief that the lived experiences of people with intellectual disability can provide seldom recognised, yet valuable sources of knowledge (Beresford, 2010; Vandekinderen and Roets, 2016). In this section, we attempt to outline how we responded to and negotiated in hegemonic power arrangements (Baez, 2002) and how we aimed to revalue knowledge that risks being disqualified in current social sciences (Lyotard, 1979).

We are strongly convinced that there is much potential in our application of photovoice, combined with an ethnographic stance, as our research method, foremost because the visual voices of the participants provided thick, rich data that emerged at the forefront of the findings. By making use of this research method, we aimed at telling their story from their own words. We opted for this unconventional method of data collection and analysis as the voices of these people with intellectual disability risk not being captured and understood by conventional research methods. In our attempt to provide a suitable stage for participants to share their experiences and thoughts, the researcher was repeatedly reminded of the shortcomings of this endeavour. An example was the continuous reflection on how, as a researcher, to avoid (re)producing an othering discourse (Vandekinderen, Roets and Van Hove, 2013) or maintaining an image of "alienation, objectification and exclusion of individuals with disabilities" (Petersen, 2011, p. 294). Petersen (2011, p.293) argues that "much of the research on disability has been critiqued as oppressive because of its failure to include individuals with disabilities in the research process".

We are convinced that, without adopting an ethnographic stance, we would – unwillingly – have contributed to the 'alienation and objectification' that is inherent in traditional disability research (Petersen, 2011). This ethnographic research stance has helped us not to allow ourselves to lapse into objectification of the participants in this research, because the seemingly odd and irrational things became meaningful during the course of the research.

Throughout the research process, we paid particular attention to the ways in which our research ventures could function as sites for the production of knowledge and power (Denzin and Lincoln, 2003), and we were constantly reminded of communicative challenges. For some participants, verbal communication was particularly difficult. For others, it was quite a challenge to talk about themselves. This meant that it was not always straightforward or easy to have a conversation, making it necessary to listen carefully and attentively, not only in terms of content, but also to the way things were told (Ferguson and Ferguson, 2000). The choice to use photovoice was one way of addressing these challenges. Including only people who were eloquent as participants would in itself have invalidated the aim of this study: to find out what people with intellectual disabilities value as a meaningful concept of autonomy. Denzin and Lincoln (2003) argue that researchers tend to make a claim to scientific authority in writing about the realities of others. In translating the realities of our participants to a wider audience and into public issues, we bear a huge responsibility. We reflected critically on this issue of representing the voices and perspectives of people with intellectual disabilities in a residential care setting, which led to great uncertainty concerning our forthcoming production of knowledge and power. Ellis et al. (2008) refer to this uncertainty about describing and representing social realities to a wider audience as a 'crisis of representation', as these translations are always the result of interpretative accounts that cannot completely capture the lived experiences of research participants.

With our commitment to listening and to making the voices of our participants heard in a variety of ways, (Booth and Booth, 2006), we wanted to tackle these challenges in terms of representation and power. The participants in our research gave shape to the research in a variety of ways. We believe this was partly due to the responsive and reflexive attitude of the researcher (De Belie and Van Hove, 2013), who facilitated the participants to share their story whenever they wished, or equally to keep it to themselves. The research makes it clear that the participants are not 'passive research objects' who generate answers to the research questions of the researcher. They all became active participants in the research, who also co-shaped the project.
The researcher therefore allowed, on the basis of sensitive responsiveness (De Belie and Van Hove, 2013), that the participants actually participated in the research project as well as acquiring a meaningful experience themselves.

The plurality of ways of collecting data – by creating opportunities for participants to express their stories visually, verbally and even through actions – proved to be fruitful in capturing this plurality of stories and in giving participants the opportunity to make their own decisions in the research process. This research process was an exercise in constantly reassessing the participant’s way of interacting and communicating: by doing an activity together such as shopping, feeding chickens, or going to a favourite café together, by making extensive use of the opportunities offered by the photographic material, by having many short conversations, by involving the supervisors, and so on. The position of the researcher as an ‘outsider’ may sometimes have been a privileged one in gathering information, allowing the collection of data that is complementary to the social professional’s insights (see Roose et al., 2016).

A last point that deserves reflection, is the expectation that what a person values is visual and present. Indeed, as shown earlier in this reflection, the pictures 'as such' do not speak for themselves. The ethnographic stance and the related fieldnotes have proven to be essential in making the photographic data 'useful' in the course of this research. For the participants, it was important to 'get something in return'. They were all very curious to see the result and to hold the pictures in their hands. Amelia, for example, immediately put the picture of her and her sisters on her wall, saying: "They are very important to me". We are convinced that in this way the research also contributed insight into what our participants themselves valued in their lives. Maybe this could also spark their aspirations and initiate the development of new capabilities (see chapter seven). In this vein, our research project was not the merely instrumental use of a participatory approach as a 'box ticking' exercise (Beresford, 2002). The question about 'how' to involve people in vulnerable situations should not dominate the more ethical consideration of 'why' methodological choices are made to involve them (Roose et al., 2016). In our research venture, the involvement of seldomly heard voices within research projects was considered to be an important, complex and above all a necessary condition. This brings us to a reflection on the meaning of employing an 'ethics of doing research' in addition to the necessary procedural research ethics.

Employing an Ethics of Doing Research

At the start of each of the three studies for this doctoral research, we faced ethical and methodological issues that we addressed in a procedure which was approved by the ethical committee of the researcher's university. Yet, not all ethical questions can be resolved at the start of the research process, as new questions emerge during the process itself (Roberts, 2002).

This was especially the case in our third study, in which we purposely enabled our participants to jointly and continuously (re)shape the research project at any time that was deemed necessary. For example, ethical issues arise when it comes to visual approaches in intellectual disability research (Akkerman et al., 2014). This concerns questions such as whether we should seek consent as a single step or at multiple times. Whose consent should be sought also played a role: does it concern only the person taking part in the study or should the person's legal guardian also give consent? Is oral consent sufficient or should written consent be given by everyone, including those who are not capable of writing? It is common for qualitative research to pay attention to such issues of procedural ethics (see Roberts, 2002; Goodwin et al., 2003), but in addition we adhere to the call of De Wilde, Roets and Vanobbergen (2019) that researchers should pay more attention to the 'ethics of doing research'. Boxal and Ralph (2009) argue that involving people with intellectual disabilities in research by using accessible research methods is an ethical issue in itself, especially as it concerns people who have been under-represented in research. It is in this spirit that we have chosen to complement our procedural ethics with a particular emphasis on situational research ethics.

Situational research ethics are described by Guillemin and Gillam (2004, p. 262) as "the difficult, often subtle, and usually unpredictable situations that arise in the practice of doing research". During our research process, struggles with ethical dilemmas came regularly to the fore. These issues prompted us to raise questions about the legitimacy of our positionality and reflexivity as a researcher (Ellis, 2007; Inckle, 2015). Considering questions of procedural ethics, such as those presented in the previous paragraph, is always part of an attempt to establish a practice of transparency (see Roose at al., 2016).

Rather than stressing the individual researcher's responsibility for adhering to procedural ethics, the pursuit of an 'ethics of doing research' is more than a practice of transparency and refers to the importance of the creation of a reflexive space in which to embrace and discuss the complexities of social work research (Roose et al., 2016). We accepted these situational research ethics as an almost obligatory feature of doing ethnographic research in a complex and dynamic research setting.

For example, the photovoice method worked particularly well for a participant who, in addition to having an intellectual disability, also has a degenerative muscular disease. His physical condition makes it very difficult for him to express himself verbally. Taking pictures on the basis of which he could have a conversation was a great help to him. During the conversation about the pictures, it became clear on several occasions that these pictures were also valuable material for communication between him and his personal assistant, with whom he has a particularly strong bond. The participant had made images of many things that were new to the assistant and that also impressed him, things that also facilitated conversation between the two. These examples show that the participants actively shaped the way in which the research was carried out and what data was produced. A sensitive responsiveness (De Belie and Van Hove, 2013) and reflexive attitude on the part of the researcher is of paramount importance for the participants to be able to participate actively in the process of knowledge construction.

The researcher could often be found in the care facility, at times drinking coffee with one participant, on other occasions taking a walk with another participant. Consequently, the participants knew of each other's participation in the project, which led them to question the position of the researcher.

For example, more than once the researcher was asked what was discussed with other people, what things others had photographed and whether the others were also being visited as often as they were. This was mainly the case for the four participants living in the same residential unit. The researcher had to make his position explicit each time again, as well as continually emphasise that information was treated with confidentiality. Moreover, after a few visits many of the participants appeared to become attached to the researcher, resulting in questions such as: “Will you go swimming with me next week?”, and: “Can you take me to the shop, the support worker never has time for me”. In addition, in this kind of intensive research project it was essential that a single researcher was involved in the entire process with the participants: from getting to know each other, to taking photographs (whether or not with assistance), to having conversations about the content of the photographs. Because the researcher and the participants walked ten unique trajectories over a period of two months, the interaction between researcher and participant and the resulting relationship was essential to fully understanding the meaning of the generated data in its social, political and historical context (Vandekinderen, Roets and Van Hove, 2013).

Only in the interaction between the researcher, the participants and – eventually – the audience do meanings come alive (De Wilde, Roets and Vanobbergen, 2019). It is for this reason that our interactive way of shaping and reshaping the methodology in this study is of great importance. By applying an ethics of doing research, we tried to cultivate a reflexive attitude throughout the research process. In addition to the procedural questions about ‘how to conduct research well', this provided us with questions about 'how to conduct good research', and what 'good research' might look like.

8.2 Main Findings

In the **introductory chapter** of this dissertation, we gave an overview of the development towards 'personalisation' and 'marketisation' within social work, which paved the way for the introduction of personal budget schemes as a means to adopting a demand-driven approach to the care and support of persons with disabilities. Research on existing personal budget schemes revealed a strained relationship between the various grounds on which personal budgets are based. From the observed ambiguities and contradictions in the practices of personal budgets, we formulated the need to deepen the pedagogical perspective on social work (see Bouverne-De Bie et al., 2014; Lorenz, 2016) in order to reconnect engagement with the individual wellbeing of people with disabilities with the commitment to social justice and societal change. This pedagogical perspective implies a quest to establish how to relate the right to individual freedom and autonomy, as foregrounded in personal budgets, to principles of justice and equality (Houston, 2010).

As was clarified in the introduction, we divided this research into three studies, each aimed at gaining insight into a distinct part of personal budget practice. The first study focussed on the implementation of personal budget schemes internationally, namely what role professionals play in their implementation and how the socially just pillar of these systems is conceived and shaped in practice. The second study aimed to discern the meaning of the introduction of a system based on market mechanisms and personalisation for the pedagogical project of care facilities and the opportunities that facilities have to develop a pedagogical project. In the third study, we turned our attention to the voice of people with intellectual disabilities concerning their care and support, their understanding of the notion of autonomy and what elements create opportunities for them to be able to do and be what they value.

In **chapter two**, we devoted ourselves to the research question how professionals deal with the implementation of personal budget policies in practice in three different personal budget systems. We highlighted the conclusion that the systems under scrutiny have been designed mainly according to a specific type of user. This 'ideal client' is constructed as an eloquent person with a singular care question who is aiming to lead an independent life in the community.

We argue that this construction is embedded in the design of these systems and was further modelled by professionals in the implementation of the personal budget schemes. The notion of the 'ideal client' therefore does not exist as such but is a construct that functions for professionals as a way to deal with unclear new roles, responsibilities and assignments. Compared to the application, assessment and allocation in more traditional supply-driven care systems, these processes in demand-driven personal budget schemes tend to be burdened by an additional workload (see Jones et al., 2012). As a reaction to the rapid changes in social professionals' work, this notion of 'an ideal client' is welcomed as a new limitation enabling them to make use of time in a more targeted way. The installation of a 'judgement of competence' throughout the phases of application, assessment and allocation of a personal budget brings about a strong conditionality in which meeting the requirements of this construction of 'the ideal client' equals the entitlement and access to a personal budget. Our findings highlight that due to the way personal budget schemes are implemented, it is likely that more educated and articulate service users, people with disabilities who correspond to the ideal image, will be enabled to realise their preferences concerning care and support more easily than others. This draws attention to a widening inequality in opportunities for individuals to make use of personal budgets, as exposed in earlier research (see Brooks et al., 2017; Dew et al., 2013).

Given that many of those people in need of care and support have to deal with physical and cognitive vulnerabilities, they will fail to pass the 'judgement of competence' introduced by professionals. This is because there are clear limitations on their ability both to make a choice and to use that choice in the desired way. For social work, which ought primarily to be concerned with those people who have the lowest levels of capacity to act as self-sufficient clients (Lymbery, 2010), this is deeply problematic.

Personal budget schemes' application, assessment and allocation phases are permeated by a conception of people as independent and rational individuals. The policy objective to enlarge people's capacity to live a life of equal opportunities with others in an inclusive society contradicts the premise of an assumed capacity of cognitive rationality. This leads to our argument that the rampant belief in the idea of 'competent citizen-consumers' (Roets et al., 2020) is problematic for the realisation of a practice that gives all individuals more opportunities to live a life they consider valuable.

In **the third chapter** we therefore turned to the question of what the implementation of personal budget schemes, in which autonomy and control are central, means for our understanding of social justice in practice. In our aim to gain a deeper understanding of the interplay of policies on personal budgets for people with disabilities and social work practice, we made use of Ricoeur's notion of a 'capable human being' (2005, 2006) to scrutinise how social professionals contribute to the notion of social justice in the application, assessment and allocation procedures in personal budget schemes. We explored how personal budget policies and practices contribute to the distinct elements of 'a capable human being': 'the capability to speak', 'the capability to act', and 'the capability to tell'.

This exploration asserted that the appeal to the government to achieve greater equality in opportunities to live a life people themselves value was being formalised and standardised, for example through the construct of an 'ideal client'. This results in a practice of personal budgets that enables people with disabilities to speak up about their preferred care and support, and if they receive a budget, to act through using it. As the 'capability to tell', which encompasses a dialogue and a shared construction of significance, is hard to formalise and standardise, it is above all this aspect that is being overlooked by this formalisation of care processes. The analysis taught us that in a strong formalisation of the application, assessment and allocation practice, the meaning and personal preference of the delivered care does not form the starting point of the intervention, an insight that puts pressure on the intended demand-driven approach. Both in policy and in practice, few moments are built in when an exploration of other interpretations of, for example, the right to choose and the notion of autonomy can take place. In this way, social professionals limit their intervention to increasing legal accessibility and implementing the rights of people with disabilities. The finality of these policies is namely 'integrated living in an independent manner' and ignores the interpretation of rights and what is socially just from a relational and contextual vision. We choose to contrast this with connecting people's rights and entitlements to people's capabilities and genuine opportunities, a relational approach in which awareness of multiple interpretations of what is important, good and just takes shape in an interaction. We concluded this chapter with arguments in favour of seeing the concretisation and translation of human rights in personal budget policies as a starting point and as a frame of reference for weighing up a concrete situation, for realising equal opportunities for a dignified existence.

Chapters two and three revealed that recognition of an individual's understanding of 'good care and support' and 'autonomy' should be something different than making it meet the predetermined notion of the ideal client. This international exploration has taught us that the social work practice of personal budgets is one of formalised and standardised procedures. This leaves very little space for negotiation, disagreement and alternative opinions and recognition of multiple and ambiguous understandings of the envisaged autonomy. Therefore, in chapter five we tackled the question what the Flemish personal budget scheme means for the pedagogical project, more specifically, the pedagogical project in care institutions. Before that, **chapter four** provided a brief overview of the Flemish system of personal budgets, highlighting its main policy objectives. The systems of personal budgets that were scrutinised in the first study showed a different starting point from the Flemish PVF system. In order to get a grip on the complexity of the new roles, social workers in these three foreign systems indicated that they strengthened their dominant position. The Flemish personal budget policy places more emphasis on the relationship between care supplier and person with a care need than on the application, assessment and allocation phases. That is why, in the second study, we focussed on care facilities in Flanders.

In the process of discerning the meaning of the Flemish PVF policy for the care practice of care facilities, and more specifically the pedagogical project, we conducted interviews with the directors of care institutions, accompanied by pedagogical staff, that are part of the learning network KWAITO. We discussed in **chapter five** how the Flemish PVF system, in line with personal budget systems internationally, introduces and encourages market mechanisms (Department of Welfare, Public Health and Family Affairs, 2010, 2018) as a means of enhancing a more responsive attitude on the part of the institutions towards what people with disabilities themselves find important concerning their care and support.

This responsive attitude should result in a demand-driven care practice. As a first major point, the participants indicated the new levers that PVF gives them to reshape their organisation according to the paradigm of 'social entrepreneurship' (Department of Welfare, Public Health and Family Affairs, 2010) that is expected of them in the newly introduced care market. Overall, these suppliers of care and support deem this to be a positive evolution, as it motivates them to rethink their organisational structure for the better and prompts them to start new collaborations and go beyond deep-rooted conventions.

The second point on the impact of the Flemish personal budget scheme on their practice concerned their pedagogical project, through three major changes: (1) a shifting care discussion, (2) a shifting status of knowledge and (3) a shifting quality of care conception. Concerning the first shift, discussions are often shaped by the modalities of the care and support provided, rather than what this support would entail. Second, the allocation of resources to the person in need of care implies a recognition of that person's knowledge of the requirements to achieve well-being. This changing status of knowledge brings with it a new relationship in which respondents can no longer simply invoke their professionalism. And third, because professional knowledge has less evidential value, respondents also indicate that many individuals say they know best, as they are the experts concerning their everyday life experiences. These shifts have resulted in a more considered approach by professionals in the dialogues on the delivered care and support. The ability to confront another vision of the way to address a question remains, but professionals indicate that they feel a pressure to be careful since that confrontation might upset 'the client' and make him or her search for another supplier.

We have learned that more and more professionals and care facilities are being requested to formulate a specific, predetermined and desired response to a care need. This reduces care and support to an ‘executive practice’, which raises questions about the value of the mantra of a demand-driven practice for the pedagogy of care and support. The need for a pedagogical perspective on social work was strongly emphasised in this chapter, as these directors are convinced that a qualitative care practice can only take shape in dialogue. Their stories make clear that within the contours of personal budgets it is more difficult to realise a pedagogical project centred on a dialogue about possible ways to address a need.

Reflecting on the first and second studies, we have noted that the dominant position is shifting in a different way in the Flemish system than in the three foreign systems. Whereas in the Netherlands, England and Germany social professionals indicated that they were trying to highlight their professionalism by introducing a 'judgement of competence' as a criterion for access to a personal budget, we do not see this happening in Flanders. As we have set out in chapter four, the Flemish system grants a personal budget to every person who obtains recognition from the VAPH. As a result, issues of access, apart from the issue of waiting lists or priority groups, have not been considered in this dissertation. Due to the way in which the Flemish system is conceived, shifting of the dominant position takes place between care provider and person with a demand for care.

Our focus in the further course of this research was therefore on pedagogical issues, on the relationship between care providers and people with disabilities and the meaning of personal budgets, rather than on questions concerning the accessibility of personal budgets.

Following this, we turned our attention in the third study to the voice of people with intellectual disabilities concerning their care and support in a residential setting, which we set out in chapters six and seven. Through photographic material and in-depth conversations, we were able to gain an insight into their understanding of the notion of autonomy, what they valued with regard to the current care and support and what elements created opportunities to be able to do and be what they value. In **chapter six**, the participants in this study revealed that financial independence and a personal budget were not means that promoted their wellbeing and their freedom to choose valued support and care. Significant and necessary others were the resources that broadened these people's opportunities. This chapter reveals the tension between the policy objective of independence and self-sufficiency as contributing to wellbeing and our participants' need for relational support to live a flourishing life.

Chapter seven explored the creation of opportunities for people with intellectual disabilities to be able to do and be what they value, to develop freely according to their own standards. In doing so, we focused on the question what elements function as capability-promoting, in other words, what elements are conversion factors to broaden people's opportunities to choose from. More specifically, we turned our focus on what enables the 'capacity to aspire' to blossom, a capacity that enables individuals to imagine a future different and better than their current condition, and therefore called 'local horizons of hope and desire' (Appadurai, 2004) and perceived as the forerunners of many capabilities (Hart, 2016). As the participants revealed, money mainly functions as an obstructing factor for the development of aspirations, as the idea of taking responsibility for the management of money deters them. It turned out that a personal budget does not provide a tool for our participants to look actively for new knowledge and other possible forms of support.

The stories of our participants revealed that creating opportunities and aspirations is more a matter of recognition than a matter of redistribution. They referred to interactions with meaningful others from which relevant new knowledge was gained and from which aspirations could be developed. We concluded that a commitment to a relational notion of autonomy is paramount for people with intellectual disabilities to be able to develop and realise their aspirations.

Hence, we argued that people with intellectual disabilities are too often expected to commit to or brought to the norm of a rational and self-sufficient citizen. We have to be aware of the divergent interpretations and provisions of notions such as autonomy and wellbeing. All this challenged us to think about what kind of pedagogy we should pursue. Above all, the findings from these three studies lead us to suggest that a pedagogy of personalisation should be one in which recognition finds a central place.

8.3 Concluding Reflections

This research aimed at the outset to contribute to our understanding of 'autonomy' in social work, through examining the case of personal budgets in the care for people with disabilities. The Flemish 'Persoonsvolgende financiering', in line with the personal budget schemes in other European countries, is intended as an 'empowering policy' (Department of Welfare, Public Health and Family Affairs, 2010, 2018). In the sense that it aims, through the redistribution of public means from formerly subsidised care institutions to the people with a care need, to contribute to a practice where individuals gain a sense of autonomy and are or become able to make choices to actively shape their own life course.

On autonomy as an 'ableist' notion

> *I find it helpful to think of us all living with the "dis/ability complex". This is a bifurcated reality where just as disability is diagnosed so ability is further expanded. And just as society holds more sway in the promises of self-sufficient, autonomous, and able citizens so those that fail to meet up to the ableist zeitgeist are rendered disabled. And there are winners and losers here as different values, social groupings, and individual human qualities are placed on either side of the dis/ability complex.*
>
> (Goodley, 2018, p.7)

One of our main research findings was the essentialist implementation of personal budgets as a way of achieving greater rational autonomy. For example, the practitioners in the international study (chapters two and three) made clear that it is common practice to use a 'judgement of competence' in the application, assessment and allocation of a personal budget.

This implies granting a personal budget when, in their professional judgement, the respective person would be able to manage the resources in an appropriate way; he or she would then be able to make choices and use this freedom to become 'more autonomous'. This 'ideal type of user' consists of someone who is articulate and can therefore formulate a clear care question, in response to which support can contribute to that person's independence. Tonkens (2003) stresses that the focus on this ideal of the articulate/researching citizen as an inherent characteristic of demand-driven care obscures our view of all those people who can never become articulate and who, above all, need good care and support. Our exploration of Ricoeur's 'capable human being' in chapter three revealed that the promise of the three studied personal budget schemes to make everyone 'capable' of making choices and controlling the care obtained is diluted in practice to 'being capable' as a condition for acquiring more options for meaningful care. This strong focus on the ideal of rational autonomy in this way results in a widening gap in -formal- opportunities for people with intellectual disabilities, who a priori do not meet this ideal.

So, where does this emphasis on the rational and autonomous individual in personal budget policy and practice actually stem from? On the one hand, it is an inherent characteristic of the market-based principles that underpin personal budget schemes (see Owens, Mladenov and Cribb, 2017), as discussed in the introductory chapter. The 'demand-driven' approach is in fact built on the premise of an ability to formulate a specific demand. On the other hand, what Goodley, Lawthom and Runswick-Cole (2014) name 'the utopian human ideal' is grounded in what we have called the 'social justice pillar' of personal budgets. The universality of human rights and of the United Nations Convention on the Rights of People with Disabilities (United Nations, 2006) in particular is grounded in a common understanding of what it is to be human and what a person is entitled to by the very fact of their humanity (Sen, 2004).

This notion of what it is to be human "is portrayed as a timeless entity that is based upon appeals to reason and absolute truth" (McKenzie and Macleod, 2012, p. 17). As argued throughout this dissertation, personal budget schemes, as a means of adopting the UNCRPD in policy and practice, imply an understanding of the individual from a humanistic perspective. Humanism, as summarised by Braidotti (2013, p. 29), is hallmarked with the notions of autonomy, responsibility, self-determination, solidarity, community-bonding, social justice and principles of equality. This vision of what it is to be human is above all perceived as a legacy of the enlightenment, embodied in "a rational animal endowed with language" (2013, p. 141).

The phenomenon of humanism is found to be problematic, especially due to that universal claim (Braidotti, 2013; Goodley, Lawthom, Liddiard and Runswick-Cole, 2020; McKenzie and Macleod, 2012; Mignolo, 2009; Otto, 1999; Wynter, 2003). As such, it minimises diversity and draws on what are deemed to be common or universal values. Mignolo (2009) writes on this matter that the humanist man is a particular kind of human being, and that those striving for humanism to be deployed universally were those whom it applied to. It is in this vein that Stammers (1999) argues for a critical view of human rights that balances the usefulness of an appeal to human rights against a careful consideration of what is being achieved through such an appeal. As this rational citizen, presented as a neutral description of the state of the human (Wynter, 2003), becomes the centre of rights, this might raise questions for those people who lack the physical and/or intellectual capacities. The inability of many people – and especially of people who do not fit into this humanist ideal – to relate to this norm becomes apparent in the definition of the World Health Organization of what it entails to be a person with an intellectual disability:

> *Intellectual disability means a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence). This results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development.* (World Health Organization, 2020)

The assumption that a person with an intellectual disability is not competent to understand complex information and to cope independently implies that they can only make weak claims to the aforementioned 'humanist' and 'ableist' norm (see Goodley, 2018) and consequently to these rights. This debate raises questions about how people with intellectual disabilities may be served by a personal budget system, given that they are categorised specifically in terms of their inability to make informed decisions for themselves (McKenzie and Macleod, 2012). To address these issues, Rabiee (2012) and Newbronner et al. (2011) point to the pivotal role of support through the care trajectories in personal budget schemes. On that note, Brookes et al. (2015) advocate for the funding of voluntary organisations to partner with service users to develop their support plans. These interventions do indeed contribute to making personal budget systems more accessible, aiming at including those who do not meet the ideal image of the autonomous consumer-citizen (Dean, 2015; Roets et al., 2020), and thus contribute to making these systems ‘work for all’. The Flemish policy also attempts to contribute to this objective by recognising and subsidising five 'assistance organisations' (see chapter four). In cases in which it is difficult for a person to clearly formulate a care and support question or to find a suitable service to meet that specific demand, one of these five organisations, out of which not surprisingly the individual has to choose one, can provide assistance.

While we do acknowledge the importance of 'management of access' as a way of ensuring equal opportunities to shape the care and support practice for all people, we note that such mechanisms deepen the erosion of the ambiguity that is essential in social work (Parton, 1998; Grymonprez, Roose and Roets, 2017; Roose et al., 2012). In 'making the system work for all', social work becomes an integral part of the logic of the system and does not critically engage in its position as an intermediary body between 'the private' and 'the public' (Bouverne-De Bie, 2015) and as 'agents of social change' (Craig, 2002). As we discussed the multitude of building blocks and underlying logics of personal budget schemes, it became apparent that they are characterised by an ambiguity between the realisation of individual well-being and the pursuit of social change. We have observed that, more than putting the person in the centre of decision making and discovering what possible interpretations of autonomy might contribute to their wellbeing and could in their way inform the public on which barriers prevent this from being, in the practice of personal budget schemes the humanist 'ableist' ideal comes to the fore. The key question of social work, as formulated by Bouverne-De Bie et al. (2004) – "Is it the ambition of social work to integrate people in a particular order, or is it (also) the ambition to make political subjectivity possible?"(p.47) – has in this case been answered for us. We therefore argue that these policies, presented as policies of inclusion, driven by the dominance of the universality of self-sufficient, autonomous and able citizens, result in practices of normalisation. In this way, social work misses out on a great opportunity to make private issues public. Considering that gaining an understanding of the opportunities for individuals to shape their lives and society implies in fact an evaluation of that society itself (Sen, 2009).

On autonomy as a diversity of notions of ‘a good life’

Divisions do not run between the mad and the sane,
the private and the public, the patient and the citizen,
the autonomous and the dependent, the clean and the dirty,
but between situations with specific characteristics.
(Pols, 2006, p. 100)

We have drawn attention to the observation that the thirst for a rational and humanist understanding of autonomy is argued from the universality of human rights and is being expressed in relation to a group of people with intellectual disabilities that has been characterised precisely by a huge heterogeneity of needs (Mansel, 2006). This instrumental use of personal budget schemes focussing on people’s independency (Needham, 2013; Owens et al., 2017) entails the risk that conversations about what the notion ‘autonomy’ can mean for a person, in what way the care and support can contribute to this and what elements are deemed valuable or impeding, are no longer part of a social work practice. In order for social work practice not to limit itself solely to increasing accessibility and the implementation of rights, we have argued in chapter three of this dissertation that persons with disabilities must be recognised and acknowledged as equal actors in policy and research processes.

In order to strengthen this reflection, we explored in the third study, together with ten people with intellectual disabilities, what the concept of 'autonomy' means to them. In retrospect, this study was a shared exploration of their present and a projection of their future. It became clear that the normative interpretation of autonomy as anchored in PVF is different from their interpretation of autonomy.

An important note to bear in mind is that stories not only present the subjective definition of a situation, as accounted for by their tellers, but also highlight the social constraints upon each individual (Goodley, 1996). This relates to the situatedness of the participant's stories in a concrete time and space. Through this awareness, the stories are a clear reflection of how they understand their personal condition in that specific time and place (Guillemin and Gillam, 2004).

The place, an institutional care setting, is presented by our respondents as a given that offers them opportunities but also limitations. The central elements in their lives, as presented in their stories, teach us about what makes their life 'a good life' in the present, from which we explored together how they project their future. These joint explorations, as described in chapters six and seven, have taught us that a personal budget and an interest in managing resources for their care and support play no part in this. They did show an interest in pocket money and above all in managing a greater amount to carry out the activities they like to do. A lesson we learn from this finding is that 'care and support', for which a personal budget should be used, is interpreted too narrowly, as many leisure activities, the things for which participants have to use their pocket money, also involve a form of support, increase their wellbeing and contribute to living a flourishing life. For example, having a pet and going on a summer camp, matters that greatly contribute to those individual's notion of 'a good life', cannot be paid for by the personal budget for care and support. This observation emphasises once more that the ideal of rational autonomy being equated with independence (see Mladenov, 2012) is the dominant policy discourse. If the personal budget policies genuinely aim to contribute to the emancipatory aspect of personalisation (Lymbery, 2012; Ferguson, 2007) – the realisation of individual notions of what a 'good life' might entail – no distinction should be made between 'care and support' and other activities.

We make this argument because freedom of choice regarding care and support, as provided by a personal budget, is of little value to our participants. Firstly, they do shape the care and support practice they find themselves in at the moment. Secondly, they do not see their care and support as elements that should contribute to an idea of autonomy as independence. The assumption of rational autonomy and independence, as embedded in the logic of personal budgets, does not do justice to what it means for them to live a good life. This requires a reconsideration of interdependence as the basis for all human interaction and as a universal feature of the human subject (see Mansell, 2006; Watson et al., 2004).

As a manifestation of interdependence, the participants overturned the assumption of intellectual disabled persons as one-sided recipients of care and support by making clear that they shape the ‘what and how’ of the care practice in their relationships with professionals and other important persons in their lives. That these (caring) relationships are to a large extent characterised by interdependence is recognised by all participants but questioned at the same time. This struggle and ambiguity are not expressed in a 'detachment' or an attempt to gain independence. Rather, it is fuelled by an urge to mean something and take a stance in the relationship with the 'necessary other'. This involves small gestures; however, they do imply that the person has equal standing in the relationship with the other. An example follows that we could not include in the previous chapters but would nonetheless like to highlight here:

> Olivia (female, 69 years) seems to comply with the cliché image of a lady in a nursing home as she spends her time listening to music (the Beatles and Rod Stewart), hosting other residents and caretakers for coffee, and having her daily work with reading the newspaper, the advertising magazines and talking to the cat called Diego.

> Caregivers and other residents come by to make coffee after she has finished eating, they drink a cup themselves and stay for a while. Olivia told during the interview that she can actually make her own coffee, but that the others are not allowed to know. She says that if ‘they’ knew, nothing would be done for her at all, and then she would be alone for a long time after she has finished eating.

This exemplifies that care and support practice is always a contested and complex issue that invokes “multiple relations of power” (Williams, 2001, p. 468). Above all, the stories of our participants are full of acknowledgements of the (need for) connection with and dependence on others. Not only their evaluation of the present but also their aspirations and thus projections of their possible future consist of things that can be achieved by and with others, not things where independence and individuality take precedence. The recognition that these persons display with regard to their limitations and their opportunities, and what others mean to them in realising these opportunities, is very strong. We could not discern an appreciation of the personal budget policy, which is aimed at a normative outcome that is very different from their reality and image of the future. After all, it does not start from a recognition of multiple possible interpretations of what a 'good life' means. This interdependent notion of autonomy contributes to the awareness of a multiplicity of perspectives on what autonomy might mean in situations with specific characteristics, in a given context of place and time (Pols, 2006). Acknowledging the reciprocity and interconnectedness in human interactions holds an acknowledgement of each person’s agency and impact on other people’s actions. This relational understanding of autonomy refers to an autonomous self that “is only made possible by the human relationships that nourish it and the social infrastructure that supports it” (Lister, 1997, p. 114).

In this vein, Pols (2006, p. 69) states that “it is not of central importance to be autonomous; instead, the citizen has to establish and maintain relations with other people [...] To be citizen, to be connected to other people”.

We argue that this recognition of interconnectedness is in itself a recognition of the autonomy of each person as a given, and as a central feature of each human being (Fyson and Kitson, 2007; Mansell, 2006). From this recognition, there is no need for social work to bring people towards another normative notion of autonomy, such as the notion of ‘the ideal client’ and the humanist notion of autonomy that underpins the personal budget systems under scrutiny. The story of humankind for Honneth (1995) is as much a continuous struggle for recognition as it is one for freedom. And as a matter of fact, this points precisely to people’s shared quest for personal autonomy (Turner, 2006), one that acquires significance in interactions.

On a pedagogy of personalisation

> *Ubuntu does not ask that we erase differences and become the same.*
> *It asks that we interpret others positively,*
> *recognising that whatever our differences, our humanity is equal.*
> *It is an invitation to dialogue, to understanding,*
> *even without agreement.*
> - Michael Onyebuchi Eze

The word for a human being in many African bantu languages is closely related to the word Ubuntu or Botho. The concept of ubuntu is bound up with the very idea of what it is to be a human and to be a member of society. The concept forms the core of a humanist ideology which is centred around the idea that 'a person is a person through other people'. In fact, Ubuntu induces an ideal of shared human subjectivity that promotes a community's good through an unconditional recognition and appreciation of individual uniqueness and difference (Eze, 2008). The premises of Ubuntu resonate in the argument that the recognition of interconnectedness is in itself a recognition of the autonomy of each and every person, that the individual can only exist through and with others (Ricoeur, 2005; Tronto, 1994), and that interconnectedness is a central element of what it is to be human (Fyson and Kitson, 2007; Mansell, 2006).

Before we go any further into this issue of recognition, it is good to take a step back to the very beginning of this dissertation. This research considered the search for social justice in the contemporary focus in social work on autonomy through personalisation. In an attempt to address the multifaced and systemic challenges intrinsic to social justice (Davies et al., 2014), we made used of a capabilities-informed framework.

This normative framework reflects the dual role of social work (see Roose et al., 2012; Bouverne-De Bie, 2014) as it aims on the one hand to promote well-being at the individual level and on the other the socially just character of a society by reducing and eventually eliminating freedom-depriving obstacles that hinder the freedom to live a life that is reasonably considered worth living (Sen, 2009). The capabilities approach, as repeatedly indicated in this dissertation, provides a process-oriented instead of an outcome-based approach to social welfare, by measuring more than only outcomes as indicators of justice and equality (Saito, 2003; Nussbaum, 2006). The normative aspect of what autonomy and 'a good life' entail within a capabilities approach is people's capabilities: the substantive freedom of the individual to do or to be that which he or she values (Sen, 1999).

In this dissertation, we have put forward several arguments on why we use the normative concept of capabilities as a stepping stone to scrutinising social justice in practice. We used this approach as a counterweight to the value judgements that personal budget schemes have adopted, such as the proposed ideal of 'vermaatschappelijking van de zorg', conforming to the ideal of being an 'informed citizen-consumer' and that the use of the personal budget should ultimately contribute to the realisation of the universalist idea of being a rationally autonomous citizen. By focusing on the substantive freedom of the individual to do or to be that which he or she values, the capabilities approach accommodates the diversity of human beings and the complexity of their circumstances (see Burchardt, 2006). The aim of a capability-promoting policy is to increase people's real freedoms in order to give shape to the things they value. In this sense, we have argued (see chapters three, five, six and seven) that personal budgets in the care and support for people with disabilities can be seen as an example of a capability-promoting policy (see Otto, Walker and Ziegler, 2018).

These personal budget policies hold the promise of focussing on creating opportunities or removing barriers in order to explore and ultimately give shape to the personal interpretation of the notion of 'autonomy'. The capabilities approach acknowledges that people's available opportunities are affected by one's resources and the way one's personal, socio-economic and environmental conditions affect the extent and type of real opportunities available (Acconcia et al., 2018; Robeyns, 2003). Increasing a person's capabilities to shape 'autonomy' is a way of challenging the deliberative nature of the pedagogical project in care and support and of maintaining a reflexive stance. In this way, social work would be able to do justice to its mandate of practising a two-way relationship between care workers and users, each learning from the other (Beresford and Croft, 2001). A capacity-enhancing policy, with its multidimensional perspective on human well-being and its focus on creating institutional conditions for people to flourish as human beings, will not put a specific functioning (such as an ideal of rational autonomy) first. However, this is how personal budget arrangements are often deployed in practice. Social professionals who are directing a person towards achieving an objective and persons with a care need who are formulating a specific demand from which no derogations are permitted are both focussing on a 'functioning'. This pushes the pedagogy away from its dialogical core and results in a practice that is stiffened into a contract that needs to be carried out.

The white paper 'Perspective 2020' that forms the bedrock of the Flemish personal budget scheme stresses that disabled people should be able to fully develop their own potential and to rule over their own lives, in this way reflecting the objectives of a capability-promoting policy. Further, it is argued that "initiatives that contribute to the strengthening of personal autonomy and self-determination should accordingly be developed" (Department of Welfare, Public Health and Family Affairs, 2010, p. 4).

The focus on personal autonomy has been translated as a shift from supply-oriented provision to demand-driven services, resulting in a new system of vouchers and personal cash payment budgets which allow disabled people – as consumers – to purchase their care and support (Department of Welfare, Public Health and Family Affairs, 2010, 2018). This policy and subsequent practice indeed have the potential to contribute to the strengthening of the personal autonomy of people with a disability. Moreover, the debate about recognising different interpretations of what autonomy can mean is actually present in the PVF policy. In that sense, this system is not intended to direct towards a particular idea of autonomy. The main findings of our studies nevertheless showed that the policy also has a strong impact on those normative elements of the choices made by people with disabilities. Through the focus on a demand-driven organisation of care, it mainly orientates to the ableist notion of autonomy and therefore risks falling short of the ambition to contribute to social justice. In the following paragraphs, we will reflect on the premises of a demand-driven approach and the ableist notion of autonomy. From these reflections, we will formulate our appeal to recognition and a 'pedagogy of personalisation'.

A demand-driven approach to care and support assumes a linear practice, one based on detecting and understanding the needs on the side of the person with a disability and an attitude of 'delivering' on the side of care and support services. The stories of people with intellectual disabilities and the directors of care institutions taught us that the care relationship is anything but straightforward and linear. The elements that are important to people fluctuate and change according to time and place. Given that, as Sen (2004, p. 76) reminds us, "value formation is an interactive process", jointly contemplating and reasoning on these continuous shifting preferences and needs will be productive in gaining an understanding.

Through the exploration of what is possible in the joint search, discovery, planning, performing, and adaptation of ideas, the significance of the act of care and support emerges.

In this vein, a demand-driven care practice, in which the power relations are assumed to be the opposite as those in a supply-driven context (Mladenov, 2012) and in which the interaction consists of articulating a need and offering an appropriate service (Dean, 2015), will not be fruitful for the development of aspirations and real freedoms to choose from (see Appadurai, 2004). The findings of our third study revealed that being able to talk about a different future is important in itself. The participants in our research all expressed their need for care and support but formulated possible futures that would mean doing things on their own as a way of escaping from this reality, without really wanting to do so. PVF and extensive demand-driven care entail the danger that expressing and talking through one's dreams also means that they must be realised. But that is not what our participants aim for by sharing and talking through possible other futures. Aspirations can contribute to the joint exploration of possible other futures, which can then serve as a foundation for people's actual capabilities (see Hart, 2016). Formulating aspirations and thinking about a possible different future is an 'escape' from the reality that is fixed, a reality they appreciate and value. From here, the present becomes interesting and together with 'necessary others' they explore what can be meaningful. A demand-driven practice would mean that, over time, people would run out of aspirations, as these are actually created in a process of dialogue with meaningful others (Appadurai, 2004). In this vein, Biesta (2015) offers an interesting criticism of a demand-driven approach when he states that a pedagogical practice does not embrace the unlimited development of all people's talents and qualities.

It is rather a process in which the individual is also confronted with the question “whether what I wish for is indeed desirable and preferable for my own life and my life with others (democracy) on this planet (ecology)” (p. 60). As discussed in chapter five, a demand-driven approach to a care relationship serves only the demanded outcome and entails the risk of not including any process-oriented pedagogical endeavour.

Furthermore, the ableist notion (Goodley, 2018) of ‘a self-aware and autonomous individual’, as entrenched in the PVF policy, might reduce the care and support relationship in the social work practice to a transaction and generate the impression that a person is autonomous solely through his or her consumerist stance. This reflects an idea of citizenship as that of a 'consumer citizen' (see Dean, 2015; Mladenov, 2012), who shares his or her values and ideas of well-being through the choices he or she makes and the products he or she purchases.

Fraser (2003) describes this particular view of the citizen thus: “A subject of (market) choice and a consumer of services, this individual is obligated to enhance her quality of life through her own decisions. In this new ‘care of self,’ everyone is an expert on herself, responsible for managing her own human capital to maximal effect” (p. 168). The Flemish PVF system is also committed to this idea of citizenship, as it aims to produce a 'well-informed' user (see Department of Welfare, Public Health and Family Affairs, 2010, 2018) who makes conscious choices and formulates a question with which he/she can contact service providers. From our application of the capabilities approach throughout our research, we have argued that this view of individuals ignores the 'possible freedoms' that people have to value and eventually make their choices. We will sketch the problematic nature of the focus on choices with an example very different from that of personal budgets for people with disabilities.

Take the case of people living in suburbs in Flanders, a highly contested issue nowadays, as this standard of housing contributes to traffic congestion, flooding and deforestation, to name but a few problems. A large proportion of the Flemish people live in this type of residential housing suburb and their number continues to grow year after year. However, the figures do not permit us to deduce that all those living there want to contribute to the problems listed. That would be the case if we were to assume that the choices these people make reflect their idea of well-being. We think it is of greater value to find out the significance of choices by engaging in conversations, taking contextual factors into account and looking at the real options that people have. We would then see that a large proportion of people living in a suburban area do not consider this to be a 'choice' and have differing justifications for this outcome. Things like 'it's cheap', 'the piece of land belonged to my parents' and 'I don't know where else to live' would certainly play a role. This exemplifies why the idea that people are communicating on the basis of their consumption behaviour is too short-sighted. The outcome of a behaviour or an action does not reveal anything about the intention and the justification people give for this outcome.

In the above reflections, it was argued that in a strong focus on this 'ideal-typical' rationale of autonomy and citizenship, social work’s ‘dual mandate’ of care and control (Hauss, 2008) is only deployed unilaterally. Social work then inscribes itself in the reproduction of the norm of a self-sufficient rational individual as a universal feature of what it is to be human. Moreover, we sketched that there are ambiguous and layered forms of autonomy, all of which can contribute to what it means to live a good life. At this point it is appropriate to formulate our appeal to recognition as a central aspect of a ‘pedagogy of personalisation’.

We thereby join a long list of scholars and critical thinkers who have drawn on theories of recognition to examine democracy and social justice (see Bourdieu, 1998; Fraser, 1995, 2000; Honneth, 1995, 2004; Houston, 2010; Lorenz, 2013; Turner, 2006, to name a few).

Whilst there is an ongoing debate between the two most influential thinkers, Fraser and Honneth, as to how recognition should be theorised (Fraser and Honneth, 2003), they both point to recognition as a means for the realisation of more socially just societies. The overvaluation of the universalist ideal of autonomy and self-sufficiency (Mladenov, 2016) holds a misrecognition of autonomy as a diversity of notions of 'a good life'. This over-accentuation might force people with disabilities "to embolden the ability side of the dis/ability complex in order to survive, hopefully thrive, but definitely make do and mend" (Goodley, Lawthom and Runswick-Cole, 2014, p. 981). Mladenov (2016) has therefore proposed a transformative strategy of recognition that holds the potential to deconstruct the ideal of self-sufficiency "by exposing self-sufficiency as rooted in relations of interdependence" (p. 7). Critical disability studies emphasise that all humans rely on infrastructures and relations of support (Mladenov 2015), as individuals are merely temporarily able-bodied (Braidotti, 2013; Goodley, Lawthom and Runswick-Cole, 2014) and always interdependent (Fyson and Kitson, 2007; Lister, 1997). The reason why these matters are being overlooked, Mladenov (2006) argues, is because "the infrastructures of support and care that we depend on remain invisible or unrecognised, receding in the background […] hidden in the realm of the 'private'" (p. 9). Social work practices involved in a pedagogy of personalisation should engage in the stimulation of societal change in such a way that the perspectives of unheard and marginalised groups in society are brought into public debate (Dean, 2013), so as to make possible transformation towards a more just society.

To contribute to public debate is quintessential; as Blonk, Huijben, Bredewold and Tonkens (2020) describe in a very balanced way, recognition of the capabilities of people with disabilities is an important element, but cannot overcome structural problems, in their example in the labour market, which is also bound to ableist notions of productivity. It is in this vein that we propose a 'pedagogy of personalisation' that connects the ambiguous and layered interpretations of personalisation and autonomy to questions of social change and social justice, through recognising unrecognised interpretations that are hidden in the private sphere and bridging these matters to 'the public'.

In every act of intervention, social workers do not therefore address just 'private troubles' but treat them in relation to public issues and hence are engaged in an act of 'social policy making' (Lorenz, 2016). By a 'pedagogy of personalisation' we refer to a continuous deliberation and reflection on what autonomy can mean in social work practices and to an awareness of different notions of human dignity and 'a good life'. It refers to a cultivation of the 'possible freedom' to consider issues of autonomy and personalisation. We thereby subscribe to De Vos's (2015) call to "build a theory in which social problem definition, socialisation and subjectivation in their interrelationship provide the formulation of the pedagogical telos of social work practices" (p. 505). 'Going public' with these divergent ideas and conceptions of autonomy and human dignity, through what Fraser (2008) calls 'representation' or in Sen's (1999, 2009) words 'public reasoning', might open up a debate on which freedoms and capabilities are considered important and socially just in a specific context or society. In this view, it is not sufficient to determine from a conceptual or theoretical perspective which prioritised capabilities and possible freedoms are important to every human being. Instead, a democratic process should enable people to express their own preferences (Sen, 2009). And it is exactly in this process that social work should take up its intermediary place between the private and the public (Bouverne-De Bie, 2015).

This intermediary position requires social work to employ other forms of public accountability than what van der Tier, Hermans and Potting (2020) refer to as legal and organisational accountability. Such public accountability we detected in our first study, where accounting for 'access' and 'making the system work' prevailed. In this vein, we appeal for a more deliberative accountability strategy for social work practice, one with a relational perspective at its heart, enabling different actors to discuss their views on practice (van der Tier, Hermans and Potting, 2020).

Furthermore, we argue that, in order to bring the recognition of interdependence and of support as an inherent element of what it is to be human into the public debate, social work practice should take up its role to inform policy and citizens. As social work is not only subject to policy, but also shapes it (Evans & Harris, 2004), an inherent part of social work as a policy practice entails keeping problems and ambiguities in view (Roose, 2017). Vandekinderen, Roose, Raeymaeckers and Hermans (2020, p. 881) argue that "social work as a human rights practice brings social processes, patterns and rules into the picture to question them and change the situation in the direction of greater respect for human dignity". The politicising role thus goes beyond strengthening the social position and well-being of people to striving for a more socially just society (Jansson, 2014; Vandekinderen et al. 2020), by bridging the public sphere and the diversity of concrete private matters (Schiettecat, Roets and Vandenbroeck, 2018). De Corte and Roose (2018) propose formulating and defending policy demands that are informed by the day-to-day experiences of social workers who work with service users on an individual basis as one of the ways in which social work can realise its social justice agenda.

It is in this vein that we propose ‘going public’ with divergent ideas and conceptions of autonomy and human dignity with which social work can influence the development, implementation and evaluation of social policies (Jansson, 2014), such as the personal budget policies for people with disabilities, and in so doing open up a debate on which freedoms and capabilities are considered important and socially just in a specific context or society.

Through a politicising stance we argue that social work can contribute to shifting the policy focus from the objective of contributing to ‘well-informed citizens’ towards ‘informing citizens well’. The argument for shifting the focus towards ‘informing citizens well’ is twofold: firstly, it confirms the ‘act of social policy making’ (Lorenz, 2016) for social work; and, secondly, it recognises divergent ideas and conceptions of autonomy and human dignity. Letting unheard voices speak is not solely a matter of enhancing well-being, but also a way of promoting the democratic project within society (Bouverne-De Bie, Roets and Roose, 2013) by considering issues for broader public debate (De Corte and Roose, 2018). ‘Informing citizens well’ holds the ambition to make people’s voices heard in the public forum and to name social obstacles, to dare to question dominant thought patterns (Vandekinderen et al., 2020). Focussing on the development of 'well-informed citizens' creates the expectation that individuals will gather information themselves and develop a clear understanding of what care and support they consider to be 'good' and wish to obtain, as well as the idea that individuals are capable of doing so. On the other hand, focusing on 'informing citizens well' implies maintaining a dialogue through ‘public reasoning’ (Sen, 1999, 2009), as well as a shared responsibility to keep that dialogue and conversation ongoing. Moreover, this implies an appeal to policy makers, social work professionals and researchers to take an active role in this assignment to 'inform well'.

Exactly by focussing on individual unrecognised stories and by sharing those stories as a way to inform citizens, social work can provide alternative interpretations that question the existing norms and can hold the opportunity to contribute to a debate, and to the development of a pedagogical project that is concerned with social justice.

Based on these reflections, and inspired by the notion of Ubuntu (see Eze, 2008), that we are people only through our interconnectedness with other people, we propose a *pedagogy of personalisation* as the socially just pedagogy which our central research question addressed: *How can a socially just pedagogy be conceptualised, aware of the ambiguous and deliberative character of autonomy, in relation to a system based on marketisation and personalisation*? We are far from arguing for this pedagogy of personalisation to be 'the' pedagogy or to consist of 'the' strategies for social work practice to deploy.

With the elements of reflection, we have touched upon during this research, we want to stimulate further reflection and debate on how social work can embrace the ambiguous nature of the notion of autonomy and relate to specific needs, concerns and aspirations, whilst connecting them to the broader socio-political level so that they can no longer be ignored. All these aforementioned issues underpin the argument of Leibetseder (2014) that social policies are being redesigned to emphasise personal autonomy and choice to such an extent that they become an obligation. This consumerist view of citizens within an "enterprise culture" (Honneth, 2004) dictates self-realisation as the one and only reality. We observed that the practice of personal budgets is characterised by questions of access to the system as an important attempt to achieve 'equal rights'. In doing so, social work engages in the realisation of the logic of the system, that is, the achievement of rational autonomy, self-sufficiency, ableism and self-realisation for every individual.

This is at odds with the ambiguity that is defined as the essence of social work (Bouverne-De Bie, 2015; Hauss, 2008; Parton, 1998), or what Lorenz (2013) called the real mandate of social work: to uphold at the personal and political levels equally the premise that there are always alternatives, and that alternatives which enhance a sense of belonging and solidarity need to be based on shared negotiations between all participants.

8.4 References

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APPENDIX I

Methodological Approach

In-depth overview of the research process: three studies

Bearing in mind the aims of this research and the research questions, adopting a qualitative research stance is the logical consequence. As a matter of fact, we seek to capture different perspectives on and experiences with personal budgets, from social professionals who make decisions about the allocation and use of a budget, over managers in care facilities, to people with intellectual disabilities who receive care and support within this system. As a consequence, we applied qualitative methods of data collection and analysis throughout the three distinct studies, which we will explain extensively in the following section.

Study one: International exploratory study on autonomy and social Justice

To gain a better understanding of the relationship between the different rationales for introducing personal budget schemes in practice, our focus was on previously implemented systems in neighbouring countries. At the moment our research project started, at the end of 2016, the system of personal budgets was in the process of being gradually introduced in Flanders. At that time, the Policy Research Centre for Welfare, Public Health and Family of the Flemish Government had us carry out an exploratory study into the experiences with the implementation of personal budget regulations in three neighbouring countries (see final report: Benoot, Dursin, Verschuere and Roose, 2018). This study was commissioned to learn from the difficulties and opportunities experienced in personal budget schemes in the Netherlands, England and Germany with regard to the realisation of the right to accessibility of care.

The motivation for the selection of these countries is grounded in a multitude of considerations, as first they all are early adopters of personal budget systems in Western welfare states. Second, their policies are all explicitly modelled on the UNCDRP. And third, they have similar procedures on the macro level for obtaining and managing a personal budget.

This procedure consists of seven phases: (1) the application, (2) assessing and indicating the care need, (3) defining, (4) providing and (5) allocating the budget, (6) accountability and (7) support during the process. In the light of this dissertation, we focus on the way in which the right to social services is realised in the application, assessment and allocation practice of personal budgets.

Ultimately, this first study aims to contribute to the first two research questions, namely (1) how social professionals deal with the implementation of personal budget policies in practice and (2) what we can learn from the way these systems are implemented for our understanding of social justice in practice.

Data collection

In a first phase an extensive scoping assessment of regulations and policy documents from the English, German and Dutch systems was carried out in order to gain insight in the functioning of their personal budget schemes. In a second phase, between March and October 2017, we conducted 22 qualitative semi-structured interviews with 31 key stakeholders with the objective of obtaining in-depth insights into their experiences with the implementation of the personal budget scheme, their specific role in the process and how this influenced shaping their work. The relatively small sample size serves to achieve the desired depth and persuasiveness of the data (Crouch and McKenzie, 2006, Mortelmans, 2007). Furthermore, the semi-structured nature of the interviews enabled the exploration of the relationship between the different rationales for introducing personal budget schemes in practice to be deployed in greater depth, while allowing sufficient space to address issues that emerge during the course of the interview (DiCicco-Bloom and Crabtree, 2006).

Respondents were carefully selected in order to have an overview of the whole trajectory: from application, through assessment and allocation to support for the client. We paid special attention to involve those who both had experience with the implementation of the policy within a local government and also served as a representative in an association of local policy actors (e.g. the Association of Directors of Adult Social Services in England or the Association for Dutch Municipalities in the Netherlands). Finally, based on a snowball sampling method (Lewis-Beck, Bryman and Liao, 2004), contact was made with other relevant stakeholders in the system to capture the experience of various key social professionals involved in the process, for example managers of advocacy organisations (Noy, 2008). Table 1 gives an overview of the different types of actor interviewed per country.

	The Netherlands	England	Germany
Intersection Policy-Practice	8	5	2
Policymaker	5	4	3
Advocacy organisation	1	2	1
Total	14	11	6

Table 1: Participants by country and profession

Two researchers conducted all the interviews together, of which 13 were double-interviews, and 9 interviews were held with one participant. The participants in the double interviews were always colleagues who complemented each other in knowledge or experience. In the view of DiCicco-Bloom and Crabtree (2006), an element that does not form a problem at all. Most of the interviews took place at the workplace of the participants and two interviews were conducted at a restaurant. The interviews lasted between one and two hours, with exceptions up to longer than two hours and a half.

We started the interviews with a handful of questions about the particular systems of personal budgets, focused on the specific role that the respondents fulfilled. This served a twofold purpose: on the one hand to gain a deeper insight into the functioning of legislation and practices, and on the other hand to correct any misinterpretations from our study of the literature.

The topic list that formed the guideline for the interviews was based on the analytical framework for policy and practice, as developed by Hubeau and Parmentier (1991), that identifies the extent to which access to care for the client is guaranteed. It refers to the question whether care is 'accessible, available, affordable, understandable and usable' for all stakeholders involved (Hubeau and Parmentier, 1991; Roose and De Bie, 2003). We used these core concepts as a steppingstone for formulating a series of open questions to guide the qualitative semi-structured interviews with the stakeholders. In this way, we aim to provide sufficient margin for the respondents' understanding of the meaning of the concepts to come to the fore. In addition, the use of open-ended questions encouraged the participants to come up with topics they found important ass well, rather than being steered in a particular direction (DiCicco-Bloom and Crabtree, 2006; Van Hove and Claes, 2011). Depending on the core mission, role and responsibility of the respondents within their own organisation and within the system of personal budgets, this list of guiding questions was slightly modified according to the relevance of certain topics (Bogdan and Biklen, 2003; DiCicco-Bloom and Crabtree, 2006).

Data analysis

The interviews were conducted under confidential conditions, thereby following the researchers' university research ethics guidelines. All respondents gave their informed consent prior to the interview and accordingly agreed to audio record the interviews and fully transcribe them.

The transcriptions of the interviews were thematically analysed (Floersch, Longhoffer, Kranke and Townsend, 2010; Mortelmans, 2007; Van Hove and Claes, 2011) using the software NVivo 11. We used both deductive as inductive coding (Hsieh and Shannon, 2005). The deductive codes were used in the initial coding stage and were based on the analytical framework on which we based the topic list we used during the interviews: whether the participant's practice is 'accessible, available, affordable, understandable and usable' (Hubeau and Parmentier, 1991). The inductive codes emerged as part of the data-driven approach (Van Hove and Claes, 2011) to thematically analyse our data. These inductive codes were a deepening of the deductive codes, that are more or less the central themes. In this way, we were able to identify the mechanisms and rationales underpinning the practical implementation of these policies on personal budgets across the three studied countries (Gilson, 2012). Two researchers each analysed independently half of the interview data, enhancing the credibility of the data and findings but also allowed the researchers to re-interpret important issues and patterns (Floersch et al., 2010). This made the analysis more consistent and reliable.

Study two: Personalisation, marketisation and the pedagogical project

For this study, we obtained data from a qualitative study with directors of a group of care facilities that gathered in an interest group called KWAITO. In contrast with systems of personal budgets for people with disabilities in neighbouring countries, the technical specificity of the Flemish Personal Budget system results in less far-reaching influence of the application-indication-allocation phases. As a result, care institutions remain important centres of the decision-making processes and negotiation and reasoning about what 'meaningful care' is and how the notion of autonomy is shaped in the personal budget practice in Flanders.

Therefore, this study focusses on the spaces (places and time) where processes of discussing care and support for people with disabilities takes place in Flanders: the care institutions. We will outline how we selected the participants, how the interviews were conducted, and the analysis of the data was carried out.

Selection of participants and data collection

The care initiatives were selected through a purposive sampling method (DiCicco-Bloom and Crabtree, 2006), meaning that the participants are selected based on their characteristics and the purpose of the study. In this way we aim to enhance the richness of the collected data by including facilities within a Flemish context which adopt for themselves an approach of social entrepreneurship with a focus on solidarity, inclusive citizenship and guarantee of quality of care.

This group, gathered in the learning network 'KWAITO', focusses on 'Qualitive, Innovative Entrepreneurship' and position themselves in the discussions regarding institutional care services, the introduction of social entrepreneurship and 'a good pedagogical practice'. They aim to develop a clear vision on quality of care which they want to integrate into their practice in the context of the personal budget system. Social entrepreneurs, for this group of organisations, are 'enterprises that operate actively, professionally, innovatively and creatively in a healthcare market, with the aim to dynamically match the support needs with the support offered'. The twelve facilities have been distributed throughout the entire Flemish region, with four members located in the province of West Flanders and four in East Flanders. Two members are located in Flemish Brabant and one in Antwerp and Limburg respectively.

Conducting the interviews

Between February and May 2019, 13 semi-structured interviews were conducted with all 12 directors and 4 pedagogical staff members of the involved care institutions. Of the 16 respondents, 14 had a background in the social sector and a related degree. Only 2 respondents had a former experience in the profit-sector. The objective of the interviews was to shed light upon the way in which personal budgets in Flanders are conceptualised through the implementation on service-level, on the one hand, and how directors see their practices contributing towards the reconciliation of a care logic and a market logic, on the other hand. The interviews were guided by the third research question concerning the meaning of personal budget scheme for the pedagogical project in care institutions. The semi-structured conversations were conducted on the basis of a topic list that schematically presented the various points for discussion (DiCicco-Bloom and Crabtree, 2006; Mortelmans, 2007) and was placed in the middle of the table during the discussion. This scheme includes the four objectives that shape the PVF-policy and are expected to be strengthened by PVF: primarily this concerns marketisation, but more specifically 'well-informed users' and the expected shift in power; 'tailor made care and support', 'to guarantee care and support' and 'inclusion and vermaatschappelijking'. In addition, the premises of the policy overlap with the existing tensions and the central points of discussion in the literature. It is in these areas of tension that the pedagogy takes form. They comprise the following elements: autonomy and demand-driven care, systemic aspects of personal budget systems, disadvantaged groups, individualisation versus solidarity, and the expectation of creativity and competition due to social entrepreneurship.

These tensions impact on three different levels: Pedagogical (care logic), Financial (market logic) and Organisational (as a link between the two, and a way in which the management shapes policy). This brings us to the following schedule (Figure 2) that led the interviews:

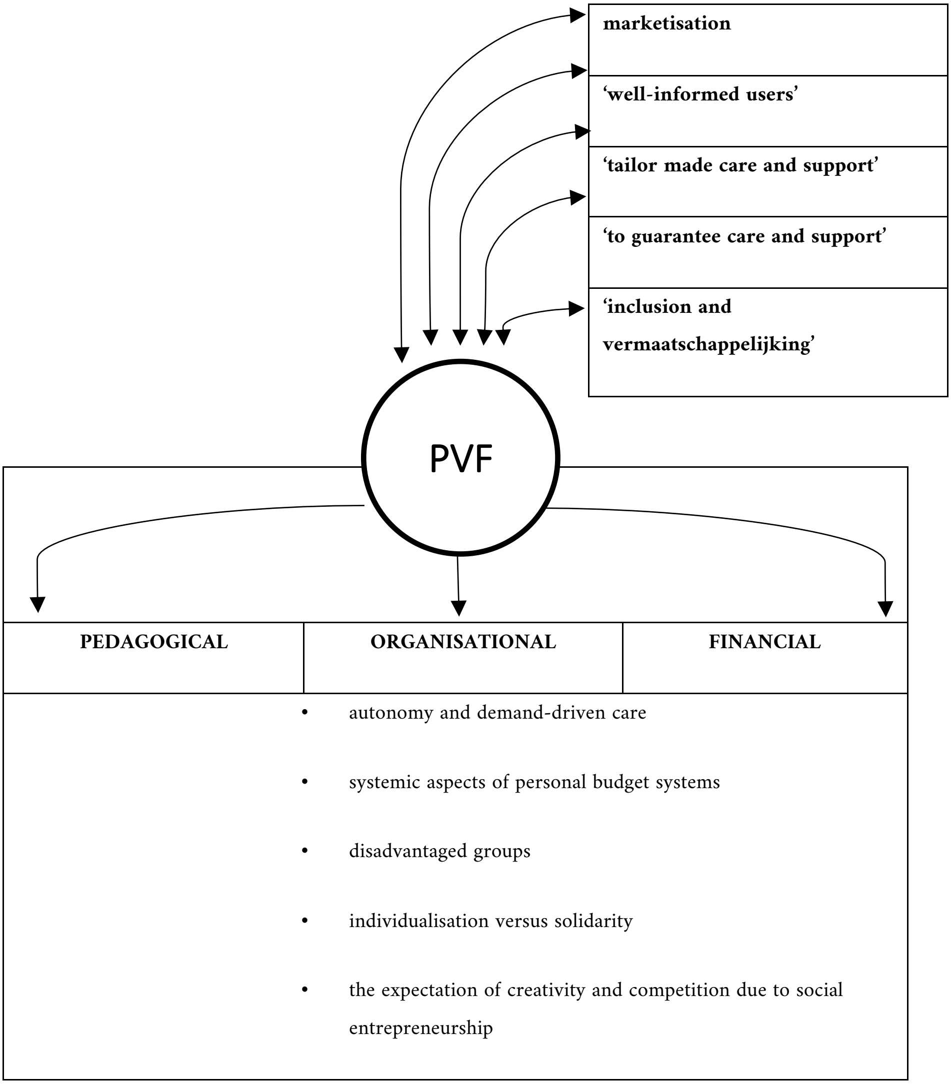

Figure 2: Interview scheme for directors of Flemish care institutions

With this interview schedule we aimed to maintain a balance between the thematic structure and the possibility for the participants to elaborate on topics that are specific to their area of interest and on which they wanted to share their views. In this vein, the conversations were built around the attempt to shed light on the director's decision-making process in the implementation of these policies in practice. We asked with such questions as: "What choices were made in the transition-period towards personal budget schemes?" "How is 'a demand-driven approach' defined within the organisation? Is this a new given?" "How do you reconcile customer-oriented and market-oriented working with social justice issues?" These interviews lasted between 1.5 and 3.5 hours and all took place at the care institutions the participants run. All of the interviews were digitally recorded and anonymously transcribed, as indicated in the previously discussed and consequently signed informed consent approved by the Ethical committee of Ghent University.

Analysis of the interviews

All interviews and the focus group were audiotaped and transcribed verbatim (DiCicco-Bloom and Crabtree, 2006). The qualitative data collected from these open-ended questions were entered in MAXQDA, a well-established software program for analysing qualitative data (Mortelmans, 2007). We made use of this software to analyse the rich data using a thematic approach (Bogdan and Biklen, 1998; Floersch, Longhoffer, Kranke and Townsend, 2010). The coding and categorisations occurred in two phases. As a first step, the major overarching themes were defined by thoroughly reading all the conversations several times (DiCicco-Bloom and Crabtree, 2006). We began with initial codes such as: "social entrepreneurship", "solidarity", "organisational aspects", amongst others. These codes are closely linked to the issues addressed in the interviews. As a second step, sub-themes were further developed during the coding process.

Through this iterative process, we revised and refined the broader initial codes (Mortelmans, 2007; Van Hove and Claes, 2011). We thus applied a conventional content analysis (Hsieh and Shannon, 2005) to analyse the transcripts, in which the coding was largely inductive as we allowed the themes to arise from the data using a coding tree (Hsieh and Shannon, 2005). The coding tree allowed us to organise the data into a hierarchical structure, existing of categories, for example 'pedagogy' and 'financial matters', subcategories, for example 'solidarity' and themes, for example 'relationship with the network' (Hsieh and Shannon, 2005). We considered this predominantly data-led approach (Van Hove and Claes, 2011) to be appropriate, given we had no theoretical framework that steered our analysis. Given the focus of the study on the pedagogical project, we paid particular attention to the relations between "what is changing and what is constant or unalterable in the transition towards personalised care" and "the quality of care". Whilst analysing the conversations, we became more aware of the attention paid in the interviews to the recognition given within such a system to the 'lived knowledge' of the person with a disability and their network. Consequently, we shifted the focus of analysis towards understanding how the respondents shape the pedagogical practice, given this alteration of knowledge and power. Following this, we collected additional data through conducting a focus group with all directors (n=12) after the first two phases of analysis. We found it necessary to organise focus groups about some of the preliminary findings and to elaborate on these topics with the respondents (Mortelmans, 2007; Van Hove and Claes, 2011) This focus group was mainly aimed at testing the recognisability of this analysis and gathering a deeper insight into their view on the debate about knowledge and the status of professional power. Respondents came up with more practical examples, providing insight into how they relate to the 'empowered' person with a disability and her/his's network, thus shaping the pedagogical relationship.

Study three: Autonomy and 'a good life' as pedagogical question

In order to address the research questions 'What do people with intellectual disabilities value with regard to their care in support' and 'What elements create opportunities for people with intellectual disabilities to be able to do and be what they value', we have chosen to apply a participatory research design. The objective of this third study was twofold. First, we wanted to complement the previous study, on the perspective of directors of care institutions, with an in-depth understanding of the personal budget scheme in practice through eliciting the experiences of persons with disabilities in the residential care context. Second, we present these experiences in relation to the policy-objective to guarantee a better quality of care through autonomy and independence, contributing to the knowledge of the pedagogical meaning of autonomy. A scoping review was conducted on the use of photovoice as a disability research method and its potential use in eliciting the experiences of persons with intellectual disabilities in care institutions in Flanders. We then made use of photovoice as a participatory research tool, to foreground what people with Intellectual Disabilities deem valuable to live a 'good life'. From this visual data, we engaged in conversations with people with intellectual Disabilities about the meaning of a personal budget in respect to the things they consider valuable. Through bringing the experiences of persons with disabilities to the fore and relate these experiences to the policy-objective to guarantee a better quality of care through autonomy and independence, we ultimately aim to gain insight in the pedagogical meaning of autonomy.

To this end, this study documents the lives of 10 people with intellectual disabilities who live in an institutionalised setting and who spend much of their lives there. It is of utmost importance in this dissertation to capture the point of view of the people with disabilities themselves, because they have their own stories to tell (Goodley, 1997).

Photovoice offered a meaningful way of engaging with persons with learning disabilities, one that enabled the participants to define themselves in terms of the things they most valued in their lives (Booth and Booth, 2003). Particularly for these people who have less verbal capacity, this approach offers opportunities to share their ideas and perspectives. Photovoice, as first developed by Wang and Burris (1997) has the potential to include persons with disabilities as central part of qualitative research, as it is suited for persons with low literacy. The photovoice methodology is a participatory action research tool that provides participants with an avenue for expressing themselves through the action of photographing (Jurkowski, 2008, p. 3). Photovoice is a celebrated research method in the light of its possible contributions towards empowerment of the participants (Wang and Burris, 1997; Jurkowski, 2008). Although we recognise the merits regarding the empowerment of people with (intellectual) disabilities, that will not be the intention of this study. We make use of photovoice as a tool to 'facilitate the expression and documentation of the views and needs of people with intellectual disabilities' (see Jurkowski, 2008, p. 3). In this vein, Photovoice is used as a way of giving voice to people with intellectual disabilities within an institutional setting. The use of photovoice as a disability research method, bears the potential to be used in eliciting the experience of persons with disabilities in a residential care setting. While making use of a capability-informed framework (see Sen, 1999, 2002; Nussbaum, 2000; Robeyns, 2006, 2017), this study focuses on the aspirations and the effective opportunities that people with disabilities have to lead the lives they have reason to value within the context of a personal budget scheme. Under the aegis of Article 32 of the UNCRPD, persons with disabilities should be consulted in services in which they are involved (UN, 2006). Research therefore should include persons with disabilities and their community and network as a central part of the process (Boyce and Ballantyne, 2000).

Since the initial conceptualisation of photovoice as a community-based health promotion tool, it has evolved and used in many other settings. In a scoping of photovoice as a disability research method, Shumba and Moodley (2018) distinguish three main uses of this research method: as a participatory evaluation tool (Wang and Burris, 1997), a retrospective evaluation method (Kramer et al., 2010) and a needs assessment tool (Findholt, Michael and Davis, 2011). In eliciting the meaning of the pedagogical relation for disabled people within a residential care setting, all three of the above-mentioned uses of photovoice will be combined. Both mapping participation possibilities and needs assessment, complemented by retrospective notes, are matters that are addressed in the context of the pedagogical relations within residential care. Shumba and Moodley (2018) listed ten methodological challenges that photovoice as a data collection method in research with people with disabilities bring. We concisely formulated how we dealt with these considerations in our research in the table 2, presented below.

METHODOLOGICAL CHALLENGES	**CONSIDERATIONS IN OUR STUDY**
1. Need for assistive technology or assistants for those with more severe disabilities	- Researcher and personal assistant could assist with photographing if needed. - Supervisors or buddies could be present during conversations with those participants with more severe disabilities, if necessary. -Informed consents were adapted to the target group. This was drawn up in clear language and without the use of any specialist jargon.
2. Visual images are explanatory, but we are still required to provide a written explanation thus challenging on articulation skills	- Discussions on the photographs were recorded and transcribed. - If needed, personal assistants were present during conversations and could assist in the conversations.
3. Ethics of taking photographs of human subjects (procedures for informed consent) proved to be difficult to execute for some participants.	- The informed consents were adapted to the target group. This was drawn up in clear language and without the use of any specialist jargon. - The ethical guidelines of the university were followed, and in addition, the ethics committee of the university gave its permission to conduct this research.
4. Limitation in advocacy skills	- The direction and the pedagogical staff compiled a list of possible participants, taking into account the resilience of the users. - The informed consent contained elements that explicitly state that participants can stop participating in the research at any time, without the need to give a reason. - The Board of Users of the care institution was involved prior to the study.
5. Although photovoice is suitable for individuals with low literacy in writing, interpreters are needed in the case of deaf participants	-If needed, personal assistants or family members were present during conversations

6.Photographic censorship applied by parents if employed with children with disabilities or amongst family members	-The care institution has its own policy on photographic material in accordance with the GDPR rules. Parents and representatives have been consulted during that process. These regulations also applied to this research. -If photographs portray people who have not given permission, these photographs will be adequately anonymised in publications. - The participants are the owners of the photographic material. They received the photos including the negatives. The researcher only has a digital copy of the photos.
7. Some aspects can be absent at the time of photography assignment	-Photos were supposed to be the starting point of the conversations we had afterwards. The conversations were not limited to the elements depicted on the photographic material. -Furthermore, the researcher will take fieldnotes during the photovoice project, which will contain things that were not captured on the photos.
8. Obsessive tendencies in taking photographs of one item or taking very few photographs resulting in limited pictures	-As photos were the starting point of the conversations, these were not limited to the elements depicted on the photographs. We also opted to include those participants who only took one picture and who photographed his hobby more than 20 times, as these are the elements they choose to photograph. The conversations covered more than those elements photographed. In this vein, the photovoice method was used as one of multiple ways of giving a voice to the participants.

9. Some abstract aspects like attitude can be difficult to capture or photograph	-Therefore, we asked a very straightforward question: 'what is important in your life?'. And in addition: 'in your life in the institution'. -Things that could not be captured on photographs might have occurred in the conversations and the participatory observation phases of the study.
10. Persons with disabilities can shun away from photo gallery for fear of public scrutiny	-All participants were asked what photos can and cannot be used, assuring appropriate anonymisation or not displaying any pictured when desired.

Table 2: Modifications with regard to ten methodological challenges as listed by Shumba and Moodley (2018).

Research setting and environment

The study was conducted in collaboration with an accredited Flemish care institution dedicated to the support of adults with mainly intellectual disabilities. In the course of the second study of this research, contacts were made with this facility, as it is one of the members of the KWAITO learning network. The care institution has various entities located throughout Evergem, a suburban municipality in the vicinity of the city of Ghent with a village-like atmosphere. It serves approximately 120 adults with intellectual disabilities and offers a wide range of types of support such as: intensive support, residential housing, independent living with flexible (residential) support, independent living with permanent support and various forms of day care and supported employment, individual support by appointment, etc. More than half of the participants are supported within a form of independent living with permanent support. In order to make this variety of housing support possible, the facility offers various forms of housing. The intensity of support is very different in all these housing types, depending on the care needs and preferences of the residents. Figure 3 illustrates the place of residence of the participants and the various sites of the institution. The symbols are explained in the legend.

●	R1
●	R2
●	R3
●	R4
●	R5
●	R6
●	R7
●	R8
●	R9
●	R10
●	Entities of the care institution
●	Daytime activities

Figure 3: Housing and support

1. Independent living with permanent support

Three different types of housing are provided, spread over a radius of 7 km. A first type of housing offers space to adults with a mild to moderate mental disability and additional psychical vulnerability. Individual counselling and support are provided in accordance with the personal needs of the residents. Based on these individual needs and possibilities, there are four rooms and six studios available in this type of housing. At this location participant 1 and participant 3 stay in a room, and participant 2 and participant 5 reside in a studio. In addition, the facility rents four connected houses in the middle of a residential area where 10 residents live independently.

Daytime and leisure time can be organized with the individual support wherever this is desirable or necessary. The focus is on living and experiencing together with and in the neighbourhood. Participant 4 lives at this location. Thirdly, independent living in the centre of the town is made possible. There are apartments and houses available for one to four persons. Participant 9 lives in one of these houses. The small scale and central location make it possible for the facility to give shape to its emancipatory idea. The support team, and in particular the personal caretaker, visits the houses at least once a day, but often several times a day. For practical support in the three independent living support units, regular services such as cleaning, family help, nursing, etc. are used.

2. Independent living with flexible support

The mobile teams offer flexible housing support to these persons who live largely independently. The nature and frequency of this support can vary greatly. Some people visit the facility daily and the support is quite intensive, for others one visit a week, or even less, is sufficient.

In addition, "the office" is the permanent place where residents can drop by without an appointment with their questions and needs. The office is located in the centre of the town. Many of the apartments and houses offered by the care facility are located in the immediate vicinity of this location. Participant 6 and participant 9 live close to 'the office'. Participant 7 and participant 8 live within walking distance.

3. Care-intensive living

This residential entity is located in the same town and offers a home for people with high care needs. This site is located in a residential area close to the centre of the community, and within walking distance of 'the office'. There are six houses where eight to ten people live together in a living group.

These houses are situated around a large inner garden, and each has its own little garden. Each resident is supported individually, depending on his or her needs and independent functioning. Respondent 10 lives in ‘Huis B’ on this site. Everyone gets a personal caregiver who keeps a close eye on the well-being, comfort and happiness of the resident. This person is the confidant for the resident and his family/network. There are quite a few group places, such as the café 'the empty cup' and the courtyard garden, enabling group moments as well. Yet everyone also has their own space and the freedom to make a place their own. The independence of each resident is stimulated, in the way in which they give shape to these wishes.

Selection of participants

The selection of respondents took place in several consultations with the general director and pedagogical coordinator. Due to the nature of the method of photovoice, all residents were eligible to participate, even so individuals with limited verbal abilities. The purpose of the study was explained by pedagogical staff members, followed by the question whether they wanted to participate. The researcher then visited the persons who agreed to participate in a one-to-one setting. This could be at the participant’s home or in the care facility. In this meeting, the structure of the research was again explained, this time by means of an information letter written in basic terms. Subsequently, the informed consent was discussed orally. The information letter, consent and assent forms were carefully adapted for people with a limited understanding and were approved by the Ethical Commission of the Researcher’s University. A witness (pedagogical staff, support staff) was present when participants were known by the care facility staff as to be illiterate or non-articulate. If the participant is under the supervision of a guardian, the latter was asked to sign an assent form. Guardians obtained the letter of consent, which they then returned to the care facility.

The researcher introduced the participants individually to the method of photovoice. Each participant received a disposable camera with a capacity of 39 shots. As a first shot, the participant and the researcher often took a selfie. On the one hand, this will enable the participant to master the act of taking a picture. On the other hand, it does ensure which participant is the photographer of the pictures on this camera.

No additional measures were required to be in line with the GDPR regulations. The facility itself took measures by asking each resident whether photographs are permitted to be taken, and if they are depicted on this photograph, whether they may be used for public distribution. If other individuals are portrayed in the photographs of the participants, this does not raise a problem for the analysis within the framework of this study. However, the publication of this photographic material will be checked in consultation with the participant and the director and pedagogical staff of the care institution. Furthermore, all persons who are portrayed in a photograph that is considered for use in a publication, will be approached by the researcher and asked for written permission for use. This procedure was approved by the ethics committee of the researcher's university. We consulted the pedagogical coordinator and the general director on how to tackle the abstract nature of the question of 'what elements are important to live a life that is deemed valuable'. In their opinion, the selected participants are all able to think about this and start working with this question. As a result, the main question posed in the introductory conversation with the participant, as written down in the information letter, reads:

> “We want to talk to you about how the care and support in the care facility is going and what you think of it. First and foremost, we want to find out what you think is important to have a 'good life'. That is why we ask you to use your camera to take pictures of things, people, activities, and so on that are important to you. Once those photos are printed, we will discuss together why those things appear on the photographs. We also find it important to know how your personal budget plays a role in this. Have things changed since you have a personal budget, or not at all? And has this affected the things you think are important to have a 'good life'?”

Taking the photographs

Participants were encouraged to identify activities, people, objects and aspects of their daily life, in the community and within the residential setting, that affected their conception of ‘a good life’ and thus their wellbeing. We asked participants to take the photographs within a timeframe of two up to three weeks. The use of disposable camera’s brought with it the limited number of possible pictures. We opted for the ‘more advanced’ camera with a flash and with the option of taking a maximum of 39 pictures. Some finished within a day, whilst it took others more than three weeks to fulfil the assignment. We did not oblige the participants to reach this maximum number. Many indicated after taking a dozen of photographs that they were ‘ready’. Some expressed doubts during the follow-up as to whether they had photographed 'the right' things and whether they were allowed to capture certain things on film. Each time again, the researcher communicated that they were in control of the content of the photos, namely: ‘photograph what is important to you and use the number of images that you think are appropriate to do so’.

All respondents involved other people in the process of taking the pictures, by means of asking them to take a picture of themselves with a significant person or location. Also, the researcher got involved in this way.

We offered the possibility to go along together with the respondents. But none of them really wanted to take the photo's together. The option for a 'guided approach' (Overmars-Marx et al., 2018) did not overcome barriers in our study, but in fact seemed to be a barrier in itself. Respondents however did ask themselves sometimes to take a picture of them in front of an important location, or together with another person. We combined this intensive research process with an ethnographic stance (Goodley et al., 2004). The researcher visited the participants multiple times during the course of the study, some up to seven times. They did activities together, such as going to the local store, feeding the chickens, doing a walk or just having a coffee together. From each encounter with the participants, a personal report, or fieldnotes, were documented. These fieldnotes present critical ethnographic moments during the research process.

Conducting the interviews

The central question we pose during our study is "*what things are important to have a 'good life', and more in particular, what are important things for you related to the support you receive*". This question is closely related to the question Booth and Booth (2003) asked to photograph people, places and things 'that are important'.

Following the participants' responses to this question through engaging in the photovoice-project, an individual interview took place. These interviews lasted between one and three hours (with one exception of approximately 30 minutes) and almost all of them took place in the participants' home environment or in their room or studio in the care institution. One interview took place in the café of the care institution, also a familiar environment for that particular participant.

We started each conversation by looking at the photo series of the participant in question. The 10 persons returned the films for processing and took a total of 182 photographs, with an average of up to 18 images per person. The photographs were often reviewed one by one and clarification was given as to what the photograph depicts. In this way, the conversation about what is valuable for the person in question started immediately. In other cases, the participants were highly enthusiastic about the photographic material, which they had first gone through entirely before discussing its content and meaning in detail. In those cases, the researcher asked which photos the participant wanted to talk about first, going through all the pictures in this way.

Like other photovoice studies (Jurkowski, 2008; Booth and Booth, 2003; Ottman and Horsfall, 2013), no questions were specified during the interview stage. As stated before, every conversation started different, putting the participants in the lead. The interviews were held individually between the researcher and the participants, sometimes accompanied by an assistant whenever necessary or desired. The photovoice project of Povee et al. (2014) also included non-verbal participants that pointed at photographs and used gestures to tell their story. In order to capture the meaning of their story with more depth, we opted to include the personal assistant with whom two non-verbal participants developed a distinct way of communication. In addition, whenever a participant was willing to let a support worker or assistant be around, we agreed on this. Open ended questions were used during the conversation and provided participants with the openness to tell their story on their own pace and with their own words. During the course of the interviews, our fieldnotes offered important input (Overmars-Marx et al., 2018). We had collected fieldnotes from the several meetings with the participants during the project, ranging from three meetings up to seven visits.

The stories of the participants further unfolded by bringing up issues that were discussed at previous meetings. The fieldnotes also helped to learn to understand the significance of the photographs and those issues that were not captured yet discussed.

Data analysis of the photo series, fieldnotes and interviews

While the photographs illuminate the participants' lives in context, Booth and Booth (2003) have pointed to the importance of the individual lived experience in order to grasp the biographical significance of the photographs of each participant. The reason why something is considered meaningful often emerged during the multiple visits (captured in the fieldnotes) and during the discussion of the series of photos with the participants. All conversations were, as communicated in the informed consents which each participant approved (either verbally or written), recorded and transcribed orthographically (DiCicco-Bloom and Crabtree, 2006).

In a first step, all interview data and field notes from the photovoice project were read multiple times and complemented with memos and with notes taken during or immediately after the interviews. The content of the series of photographs were analysed in the context of the personal stories (Booth and Booth, 2003), drawing on the fieldnotes and transcripts. To conduct this content analysis of the qualitative data, we made use of the MAXQDA software (Blaikie, 2010; Floersch et al., 2010; Mortelmans, 2007). We used open coding (Glaser and Strauss, 1967) in order to synthesise the material. Subsequently, the codes were categorised in themes and subthemes in an iterative process that led to adjustments of the categories during the process of analysis. These codes or categories were not predefined but emerged from the data, using an inductive (Hsieh and Shannon, 2005) or data-led approach (Van Hove and Claes, 2011).

We considered this predominantly data-led approach (Van Hove and Claes, 2011) to be appropriate, given we had no theoretical framework that steered this first analysis. In a second analysis, we used both deductive as well as inductive coding (Hsieh and Shannon, 2005). The deductive codes were based on some key concepts of the Capability approach, such as Conversion factors (e.g. Nussbaum, 2006; 2011; Robeyns, 2003; Sen, 1992; Walker, 2019) and 'the capacity to aspire' (e.g. Appadurai, 2004, 2013; Hart, 2012, 2016). The inductive codes emerged as part of the data-driven approach (Van Hove and Claes, 2011) to thematically analyse our data. Making use of this capability-informed framework (see Sen, 1999, 2002; Nussbaum, 2000; Robeyns, 2006, 2017), we were able to identify what effective opportunities and aspirations people with disabilities have to lead the lives they have reason to value, and what elements help or hinder them in the development of these effective freedoms and aspirations.

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APPENDIX II

English Summary

The development towards 'personalisation' and 'marketisation' within social work is the starting point of this dissertation. These dynamics paved the way for the introduction of personal budget schemes as a means to adopt a demand-driven approach in the care and support of persons with disabilities. Existing research revealed a tense relationship between the various grounds on which personal budgets are based. These grounds are threefold and consist of: firstly, the demand for equal citizenship from self-advocacy groups and organisations that represent the interests of people with disabilities; secondly, a commitment to a socially just organisation of care and support that stems from the ratification of the UN Convention on the Rights of Persons with Disabilities; and thirdly, the introduction of market mechanisms in the sector of care and support following a trend towards greater efficiency and effectiveness in the use of public resources. From the observed ambiguities and contradictions in the practices of personal budgets, we formulated the need to deepen the pedagogical perspective on social work (see Bouverne-De Bie et al., 2014; Lorenz, 2016) in order to reconnect the engagement with individual wellbeing of people with disabilities with the commitment to social justice and societal change. This pedagogical perspective implies a quest of how to relate the right to individual freedom and autonomy, as foregrounded in personal budgets, to principles of justice and equality (Houston, 2010). The question at the heart of this research is that of autonomy in relation to social justice. It is in this vein that this research aims to explore how theoretical insights of the capabilities approach as a theory of justice can contribute to our understanding of personalised care and support for people with disabilities as part of a social justice agenda. And last but not least, we aim to gain insight in what people with disabilities themselves consider to be a 'good life' and what personalisation and personal budgets mean to them in the pursuit of living the life they deem valuable.

Accordingly, this aligns with the aspiration to stimulate academic and public discussion of the understanding of what a social just policy and practice of care and support for people with -intellectual- disabilities might entail. These broad research aims are specified into the main question this dissertation will tackle:

> ***How can a socially just pedagogy, aware of the ambiguous and deliberative character of autonomy, be conceptualised in relation to a system based on marketisation and personalisation***?

We divide this question into five sub-questions that are dealt with in three studies, each of which were extensively explained in various chapters. The three studies each focus on a particular component of the interplay between the elements of marketisation, personalisation and social justice, associated with the paradigm shift towards personal budget schemes, each involving multiple practices and stakeholders:

STUDY	**RESEARCH QUESTIONS**	**METHODOLOGY**	**CHAPTER**
Study 1 International exploratory study of social justice in the implementation of personalisation and marketisation principles	1.How do professionals deal with the implementation of personal budget policies in practice? 2.What does the implementation of personal budget schemes, in which autonomy and control are central, mean for our understanding of social justice in practice?	Semi-structured qualitative interviews with 31 social professionals	2 & 3
Study 2 Personalisation, marketisation and the pedagogical project	3.What is the meaning of the Flemish personal budget scheme for the pedagogical project in care institutions?	Semi-structured qualitative interviews with 15 managers of care institutions, followed by a focus group.	5
Study 3 Personalisation and 'a good life' as pedagogical and social justice questions	4.What do people with intellectual disabilities value with regard to their care and support in a Flemish care organisation? 5. What elements create opportunities for people with intellectual disabilities to be able to do and be what they value?	Ethnographic data collection through a participatory research project (photovoice) and qualitative interviews with 10 persons with intellectual disabilities.	6 & 7

In chapter two, we devote ourselves to the research question how professionals deal with the implementation of personal budget policies in practice in three different personal budget systems. We highlight that the systems under scrutiny have been designed mainly according to a specific type of user. This ‘ideal client’ is constructed as an eloquent person with a singular care question who is aiming to lead an independent life in the community. We argue that this construction is imbedded in the design of these systems and was further modelled by professionals in the implementation of the personal budget schemes.

The notion of the ‘ideal client’ therefore does not exist as such but is a construct that functions for professionals as a way to deal with unclear new roles, responsibilities and assignments. Compared to the application, assessment and allocation in more traditional supply-driven care systems, these processes in demand-driven personal budget schemes tend to be burdened by an additional workload (see Jones et al., 2012). As a reaction to the rapid changes in social professionals their work, this notion of ‘an ideal client’ is welcomed as a new barrier to make use of time in a more targeted way. The installation of a 'judgement of competence' throughout the phases of application, assessment and allocation of a personal budget brings about a strong conditionality in which meeting the requirements of this construction of ‘the ideal client’ equals the entitlement and access to a personal budget. Our findings highlight that due to the way personal budget schemes are implemented, it is likely that more educated and articulate service users, people with disabilities that correspond to the ideal image, will more easily be enabled to realise their preferences concerning care and support than others. This draws attention to an increased inequality in possibilities of individuals to make use of personal budgets, as exposed in earlier research (see Brooks et al., 2017; Dew et al., 2013).

Given that many of those people in need of care and support have to deal with physical and cognitive vulnerabilities, they will fail to pass the 'judgement of competence' introduced by professionals. This is because there are clear limitations to their ability both to make a choice or to use that choice in the desired way. For social work, which is ought primarily to be concerned with those people who have the lowest levels of capacity to act as self-sufficient clients (Lymbery, 2010), this is deeply problematic.

Personal budget schemes' application, assessment and allocation phases are permeated by a conception of people as independent and rational individuals. The policy objective to enlarge people's capacity to live a life with equal opportunities as others in an inclusive society contradicts with the premise of an assumed capacity of cognitive rationality. This leads to our argument that the rampant belief in the idea of 'competent citizen-consumers' (Roets et al., 2020) is problematic for the realisation of a practice that gives all individuals more possibilities to live a life they consider valuable. Therefore, in the third chapter we turn to the question what the implementation of personal budget schemes, in which autonomy and control are central, does mean for our understanding of social justice in practice. In our aim to gain a deeper understanding of the interplay of policies on personal budgets for people with disabilities and the social work practice, we make use of Ricoeur's notion of 'capable human being' (2005, 2006) to scrutinise how social professionals contribute to the notion of social justice in the application, assessment and allocation-procedures in personal budget schemes. We explore how personal budget policies and practices contribute to the distinct elements of 'a capable human being': the capability to speak, the capability to act, and the capability to tell.

This exploration asserts that the appeal to the government to achieve greater equality in opportunities to live a life people themselves value is being formalised and standardised, for example through the construct of an 'ideal client'. This results in a practice of personal budgets that enables people with disabilities to speak up about their preferred care and support, and in case they receive a budget, are enabled to act through the use of it. As the 'capability to tell', which encompasses a dialogue and a shared construction of significance, is hard to formalise and standardise, it is above all this aspect that is being overlooked by this formalisation of care processes. The analysis teaches us that in a strong formalisation of the application, assessment and allocation practice the meaning and personal preference of the delivered care does not form the starting point of the intervention, an insight that puts pressure on the intended demand-driven approach. Both in policy and in practice, few moments are built in in which an exploration of other interpretations of, for example, the right to choose and of the notion of autonomy can take place. In this way, social professionals limit their intervention to increasing legal accessibility and the implementation of rights of people with disabilities. The finality of these policies is namely: 'integrated living in an independent manner' and ignores the interpretation of rights and what is social just from a relational and contextual vision. We choose to contrast this with connecting people's rights and entitlements with people's capabilities and genuine opportunities, which is a relational approach in which the awareness of multiple interpretations of what is important, good and just takes shape in an interaction.

We conclude this chapter with arguments in favour of seeing the concretisation and translation of human rights in personal budget policies as a starting point and as a frame of reference for weighing up a concrete situation, for realising equal opportunities for a dignified existence.

Chapter two and three reveal that recognition of an individual's understanding of 'good care and support' and 'autonomy' should be something different than making it meet the predetermined notion of the ideal client. This international exploration teaches us that the social work practice of personal budgets is one of formalised and standardised procedures. This leaves very little space for negotiation and recognition of multiple and ambiguous understandings of the envisaged autonomy. Therefore, in chapter five we tackle the question what the Flemish personal budget scheme means for the pedagogical project. More specific the pedagogical project in care institutions. Before that, chapter four provides a brief overview of the Flemish system of personal budgets, highlighting its main policy objectives. In the process of discerning the meaning of the Flemish PVF policy for the care practice of care facilities, and more specifically the pedagogical project, we conduct interviews with the directors of care institutions, accompanied with pedagogical staff, that are part of the learning network KWAITO. We discuss in chapter five how the Flemish PVF-system, in line with personal budget systems internationally, introduces and encourages market mechanisms (Department of Welfare, Public Health and Family Affairs, 2010, 2018) as a means to enhance the more responsive attitude on the part of the institutions for what people with disabilities themselves find important concerning their care and support. This responsive attitude should result in a demand-driven care practice. As a first major point, the participants point to the new levers that PVF gives them to reshape their organisation according to the paradigm of 'social entrepreneurship' (Department of Welfare, Public Health and Family Affairs, 2010) that is expected of them in the newly introduced care market. Overall, these suppliers of care and support deem this to be a positive evolution, as it motivates them to rethink their organisational structure for the better and prompts them to start new collaborations and go beyond deep-rooted conventions.

The second point on the impact of the Flemish personal budget scheme on their practice concerns their pedagogical project, through three major shifts: (1) a shifting care discussion, (2) a shifting status of knowledge and (3) a shifting quality of care conception.

Concerning the first shift, discussions often are shaped on the modalities of the care and support provided, rather than wat this support would entail. Second, the allocation of resources to the person in need of care implies a recognition of that person's knowledge of the requirements to achieve well-being. This changing status of knowledge brings with it a new relationship in which respondents can no longer simply invoke their professionalism. And third, because professional knowledge has less evidential value, respondents also indicate that many individuals say they know best, as they are the experts concerning their everyday life experiences. These shifts have resulted in a more considered approach of professionals in the dialogues on the delivered care and support. The ability to confront another vision the way to address a question remains, but professionals indicate to feel a pressure to be careful since that confrontation might upset 'the client' and make him or her search for another supplier. We learn that more and more professionals and care facilities are being requested to formulate a specific, predetermined and desired response to a care need. This reduces care and support to an 'executive practice', which raises questions about the value of the mantra of a demand-driven practice for the pedagogy of care and support. The need for a pedagogical perspective on social work is strongly emphasised in this chapter, as these directors are convinced that a qualitative care practice can only take shape in dialogue. Their stories make clear that within the contours of personal budgets it is more difficult to realise a pedagogical project centred around the dialogue on possible ways to address a need.

Following this, we turn our attention in the third study to the voice of people with intellectual disabilities concerning their care and support in a residential setting, set out in chapter six and seven. Through photographic material and in-depth conversations, we gain an insight into their understanding of the notion of autonomy, what they value with regard to the current care and support and what elements create opportunities to be able to do and be what they value. In chapter six, the participants to this study reveal that financial independence and a personal budget are no means that promote their wellbeing and their freedom to choose valued support and care. Significant and necessary others are the resources that broaden these people's opportunities. This chapter reveals the tension between the policy objective of independence and self-sufficiency as contributing to wellbeing and our participant's need for relational support to live a flourishing life.

Chapter seven explores the creation of opportunities for people with intellectual disabilities to be able to do and be what they value, to develop freely according to their own standards. In doing so, we focus on the question what elements function as capability promoting, in other words, what elements are conversion factors to broaden people's opportunities to choose from. More specifically, we turn our focus on what enables the 'capacity to aspire' to blossom, a capacity that enables individuals to imagine a future different and better than one's current condition, therefore called 'local horizons of hope and desire' (Appadurai, 2004), and perceived as the forerunners to many capabilities (Hart, 2016). As the participants reveal, money mainly functions as an obstructing factor for the development of aspirations, as the idea of taking responsibility for the management of money deters them. It turns out that a personal budget does not provide a tool for our participants to actively look for new knowledge and other possible forms of support.

The stories of our participants reveal that creating opportunities and aspirations is more a matter of recognition than a matter of redistribution. They refer to interactions with meaningful others from which relevant new knowledge was gained and from which aspirations could be developed. We conclude that a commitment to a relational notion of autonomy is paramount for people with intellectual disabilities to develop and realise their aspirations. Hence, we argue that people with intellectual disabilities are too often expected to commit to or brought to a norm of a rational and self-sufficient citizen. We have to be aware of the divergent interpretations and provisions of notions such as autonomy and wellbeing.

All the above challenges us to think about what kind of pedagogy we should pursue. Above all, the findings from these three studies lead us to suggest that a pedagogy of personalisation should be one in which recognition finds a central place.

The whitepaper 'Perspective 2020' that forms the bedrock of the Flemish personal budget scheme strongly accentuates that disabled people should be able to fully develop their own potential and to rule over their own lives, in this way reflecting the objectives of a capability promoting policy. The focus on personal autonomy has been translated as a shift from supply-oriented provisions to demand-driven services, resulting in a new system of vouchers and personal cash payment budgets which allow disabled people – as consumers – to buy their care and support (Department of Welfare, Public Health and Family Affairs, 2010, 2018). This policy and subsequent practice have indeed the potential to contribute to the strengthening of the personal autonomy, albeit through the focus on a demand-driven organisation of care, mainly to the ableist notion of autonomy.

We argue that in a strong focus on the 'ideal-typical' rationale of autonomy and citizenship, social work's 'dual mandate' of care and control (Hauss, 2008) is only deployed unilaterally. Social work then inscribes itself in the reproduction of the norm of a self-sufficient rational individual as a universal feature of what it is to be human. Moreover, we sketch throughout the three studies that there are ambiguous and layered forms of autonomy, all of which can contribute to what it means to live a good life. It is in that vein that we formulate our appeal to recognition as a central aspect of 'a pedagogy of personalisation' that can connect autonomy and social justice as the core mandates of social work.

This 'pedagogy of personalisation' should connect the ambiguous and layered interpretations of personalisation and autonomy to questions of social change and social justice, through recognising unrecognised interpretations that were hidden in the private sphere and bridging these matters to 'the public'. This is about allowing the ambiguous interpretations of what a good life is. Sharing this wide range of possible interpretations of what is meaningful in individual well-being can contribute to a broader understanding of what the notion of autonomy can encompass. The debate about the layered nature of what autonomy can mean is embedded in the conceptual framework of the Flemish system of PVF. Nevertheless, it is assumed all too easily that the system contributes to the creation of opportunities for people with disabilities to shape their lives in a way that they themselves consider valuable. With a 'pedagogy of personalisation' we refer to a continuous deliberation and reflection on what autonomy can mean in social work practices and to an awareness of different notions of human dignity and 'a good life'. It refers to a cultivation of the 'possible freedom' to consider issues of autonomy and personalisation.

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APPENDIX III

Nederlandstalige Samenvatting

De ontwikkeling naar 'verpersoonlijking' en 'vermarkting' binnen het sociaal werk vormt het vertrekpunt van dit proefschrift. Deze dynamieken maakten de weg vrij voor de invoering van persoonlijke budgetregelingen, een middel om een vraaggestuurde aanpak te hanteren in de zorg en ondersteuning voor mensen met een beperking. Bestaand onderzoek bracht een gespannen relatie aan het licht tussen de verschillende gronden waarop systemen van persoonsgebonden budgetten zijn gebaseerd. Deze gronden zijn drieledig en bestaan uit: ten eerste de vraag naar een gelijkwaardig burgerschap vanuit organisaties die de belangen van personen met een beperking behartigen; ten tweede een streven naar een sociaal rechtvaardige organisatie van zorg en ondersteuning die voorstemt uit de ratificatie van het VN-verdrag inzake de rechten van personen met een handicap; en ten derde de introductie van marktmechanismen in de zorgsector vanuit een gang naar meer efficiëntie en effectiviteit van de besteding van overheidsmiddelen.

Vanuit de vaststelling dat de systemen van persoonlijke budgetten in de praktijk moeite blijken te hebben met de verscheidene fundamenten met elkaar te verzoenen, formuleerden wij de noodzaak om het pedagogisch perspectief op sociaal werk te verdiepen (zie Bouverne-De Bie et al., 2014; Lorenz, 2016). Dit pedagogisch perspectief impliceert een zoektocht naar hoe het recht op individuele vrijheid en autonomie, zoals vooropgesteld in de persoonlijke budgetten, gelinkt kan worden aan principes van rechtvaardigheid en gelijkheid (Houston, 2010). In dit proefschrift gaan we dus op zoek naar elementen die waardevol kunnen zijn om het engagement voor het individuele welzijn van mensen met een handicap te verbinden met het engagement voor sociale rechtvaardigheid en maatschappelijke verandering.

De kwestie die centraal staat in dit onderzoek is hoe autonomie en sociale rechtvaardigheid zich tot elkaar verhouden. Het is in deze geest dat dit onderzoek verkent hoe de theoretische inzichten van de ‘capabilities approach’ als rechtvaardigheidstheorie kunnen bijdragen aan ons begrip van ‘verpersoonlijking’ van de zorg en ondersteuning voor mensen met een handicap als onderdeel van een agenda gericht op sociale rechtvaardigheid. Daarenboven pogen we inzicht te verwerven in wat mensen met een handicap zelf als een 'goed leven' beschouwen en wat persoonlijke budgetregelingen betekenen in het realiseren van die elementen die zij waardevol achten. Deze brede onderzoeksdoelen worden gevat in de hoofdvraag waar dit proefschrift zich over buigt:

> ***Hoe kan een sociaal rechtvaardige pedagogiek, zich bewust van het ambigue en deliberatieve karakter van autonomie, worden geconceptualiseerd in relatie tot een systeem dat gebaseerd is op vermarkting en personalisering***?

Vanuit deze onderzoeksvraag formuleren we vijf deelvragen die in drie studies behandeld worden. De drie studies richten zich elk op een aspect van het samenspel van vermarkting, verpersoonlijking en sociale rechtvaardigheid, elementen die verband houden met de paradigmaverschuiving naar persoonlijke budgetregelingen. Bij de verschillende studies zijn telkens meerdere praktijken en stakeholders betrokken:

STUDIE	ONDERZOEKSVRAGEN	METHODOLOGIE	HOOFDSTUK
Studie 1 Internationale verkennende studie over sociale rechtvaardigheid in de implementatie van principes van verpersoonlijking en vermarkting.	1.Hoe gaan professionals om met de implementatie van persoonlijke budgetregelingen in de praktijk? 2.Wat is de betekenis van persoonlijke budgetregelingen, waarin autonomie en controle centraal staan, voor ons begrip van sociale rechtvaardigheid in de praktijk?	Semigestructureerde kwalitatieve interviews met 31 sociale professionals	2 & 3
Studie 2 Verpersoonlijking, vermarkting en het pedagogisch project.	3.Wat is de betekenis van het Vlaamse persoonlijke financieringssysteem voor het pedagogisch project in zorgvoorzieningen?	Semigestructureerde kwalitatieve interviews met 15 directieleden van zorgvoorzieningen, gevolgd door een focusgroep.	5
Studie 3 Verpersoonlijking en 'een goed leven' als pedagogische en sociale rechtvaardigheids-vraagstukken.	4.Wat waarderen personen met een verstandelijke beperking in hun zorg en ondersteuning in een Vlaamse zorgvoorziening? 5. Welke elementen creëren mogelijkheden voor personen met een verstandelijke beperking om te doen en zijn wat zij waardevol vinden?	Etnografische dataverzameling door middel van een participatief onderzoeksproject (photovoice) en kwalitatieve interviews met 10 personen met een verstandelijke beperking.	6 & 7

In hoofdstuk twee leggen we ons toe op de onderzoeksvraag hoe professionals in de praktijk omgaan met de uitvoering van persoonlijke budgetregelingen. We trachten hier antwoorden op te formuleren op basis van gesprekken met professionals in Nederland en Engeland die ervaring hebben met de implementatie van persoonlijke budgetten. Hierbij merken we op dat deze systemen vooral in dienst staan van een specifiek type gebruiker. Deze 'ideale cliënt' wordt geconstrueerd als een welbespraakt persoon met een duidelijke zorgvraag die streeft naar een zelfstandig leven in de gemeenschap. Deze studie leert ons dat deze constructie voor een deel is ingebed in het ontwerp van de persoonlijke budgetregelingen, maar ook verder wordt vormgegeven door professionals in de implementatie van de systemen. Het begrip 'ideale cliënt' bestaat dus niet als zodanig, maar is een constructie die door professionals wordt verwelkomd als een manier om met onduidelijke nieuwe rollen, verantwoordelijkheden en opdrachten om te gaan. In vergelijking met de aanvraag, beoordeling en toewijzing van zorg en ondersteuning in de traditionele aanbodsgestuurde zorgsystemen gaan deze processen in de vraaggestuurde persoonsgebonden budgetregelingen vaak gepaard met een extra werkdruk (zie Jones et al., 2012). Als reactie op de grote veranderingen in het takenpakket van de sociale professionals wordt deze notie van 'een ideale cliënt' door hen verwelkomd als een handige drempel om gerichter om te gaan met aanvragen. Met deze notie van een 'ideale cliënt' gaat een 'competentie oordeel' gepaard, waarbij het voldoen aan de eisen van deze constructie van 'de ideale cliënt' gelijk staat aan het recht op en de toegang tot een persoonlijk budget. Onze bevindingen benadrukken dat door de manier waarop persoonlijke budgetregelingen worden geïmplementeerd, het waarschijnlijk is dat meer opgeleide en welbespraakte gebruikers -deze mensen met een handicap die voldoen aan het ideaalbeeld- gemakkelijker in staat zullen worden gesteld om hun voorkeuren op het gebied van zorg en ondersteuning te realiseren.

Gezien het feit dat veel mensen die zorg en ondersteuning nodig hebben ook fysieke en cognitieve kwetsbaarheden hebben, zullen deze het geïntroduceerde 'competentie oordeel' niet halen. Dit komt omdat er duidelijke beperkingen zijn aan hun vermogen om een keuze te maken alsook om deze keuze op de gewenste manier aan te wenden. Voor sociaal werk, dat zich in de eerste plaats ten dienste hoort te stellen voor deze mensen die het minste in staat zijn om als zelfstandige cliënten naar voor te treden (Lymbery, 2010), is dit uiterst problematisch.

De aanvraag-, beoordelings- en toewijzingsfasen van de persoonlijke budgetregelingen die we in deze studie onder de loep nemen, steunen op een opvatting van individuen als onafhankelijk en rationeel. De beleidsdoelstelling om het vermogen van mensen te vergroten om een leven met gelijke kansen te leiden in een inclusieve samenleving, staat haaks op het uitgangspunt dat deze personen over het vermogen dienen te beschikken om rationeel keuzes te maken. Van hieruit argumenteren we dat het geloof in het idee van 'competente consumentenburgers' (Roets et al., 2020) problematisch is voor de realisatie van een praktijk die alle individuen meer mogelijkheden wenst te geven om een leven te leiden dat zij als waardevol beschouwen.Daarom buigen we ons in het derde hoofdstuk over de vraag wat de uitrol van persoonlijke begrotingsregelingen, waarin autonomie en controle centraal staan, kan betekenen voor ons begrip van sociale rechtvaardigheid in de praktijk. Om meer inzicht te krijgen in de wisselwerking tussen het beleid inzake persoonlijke budgetten voor mensen met een handicap en de sociaal werk praktijk, maken we gebruik van Ricoeur's notie van een 'capable human being' (2005, 2006). Vanuit een verkenning van deze conceptualisering gaan we na hoe sociale professionals bijdragen aan de notie van sociale rechtvaardigheid in de aanvraag-, beoordelings- en toewijzingsprocedures van persoonlijke budgetteringsregelingen.

We onderzoeken hoe persoonlijk budgetbeleid en -praktijk bijdragen aan de verschillende elementen van 'een capabel mens': het vermogen om te spreken, het vermogen om te handelen, en het vermogen om te vertellen (Ricoeur, 2005). In deze verkenning wordt duidelijk dat de doelstelling om meer gelijkheid te bereiken in de kansen die mensen hebben om een leven te leiden waar deze zelf waarde aan hechten, wordt geformaliseerd en gestandaardiseerd, bijvoorbeeld door het construeren van een 'ideale klant'. Dit resulteert in een praktijk van persoonlijke budgetten die mensen met een handicap in staat stelt zich uit te spreken over de zorg en ondersteuning die hun voorkeur geniet, en in het geval ze een budget krijgen in staat te stelt te handelen door middel van het gebruik ervan. Het 'kunnen vertellen', dat een dialoog en een gedeelde constructie van betekenis omvat, is daarentegen moeilijk te formaliseren en te standaardiseren. Het is dan ook deze bouwsteen van wat het betekent om ‘een capabel mens’ te zijn, dat door deze formalisering van zorgprocessen over het hoofd wordt gezien.

Deze analyse leert ons dat bij een sterke formalisering van de aanvraag-, beoordelings- en toewijzingspraktijk de betekenis en persoonlijke voorkeur van de geleverde zorg niet het uitgangspunt van de interventie vormt. Dit inzicht plaatst de beoogde vraaggestuurde aanpak onder druk. Want, zowel in de beleidskaders als in de praktijk van de betreffende persoonlijke budgetregelingen wordt weinig tot geen aandacht gevestigd aan de verkenning van verschillende mogelijke interpretaties van wat keuze en autonomie kunnen betekenen voor een individu. Hierdoor blijft de interventie van sociale professionals eerder beperkt tot het vergroten van de toegang tot persoonlijke budgetten en tot de implementatie van de rechten van mensen met een handicap. Het einddoel van deze regelingen is namelijk: “inclusief leven op een onafhankelijke manier” en gaat voorbij aan de mogelijke meervoudige interpretatie van rechten en van wat sociaal rechtvaardig is.

We kiezen ervoor om dit mensbeeld te contrasteren met een relationele benadering: een benadering waarbij centraal het bewustzijn staat dat er in en door interacties meervoudige interpretaties naar voor komen van wat belangrijk, goed en rechtvaardig is. We sluiten dit hoofdstuk af met argumenten om de vertaling van mensenrechten in persoonlijke budgetregelingen als uitgangspunt en als referentiekader te hanteren voor het realiseren van gelijke kansen op een waardig bestaan.

De internationale verkennende studie, die een antwoord biedt op de eerste twee onderzoekvragen, leert ons dat de praktijk van persoonlijke budgetten er een is van geformaliseerde en gestandaardiseerde procedures. Dit laat zeer weinig ruimte voor onderhandeling, tegenspraak en erkenning van meervoudige en dubbelzinnige opvattingen over de beoogde 'autonomie'. Daarom gaan we in de tweede studie in op de vraag wat de Vlaamse persoonsgebonden budgetregeling betekent voor het pedagogische project, meer specifiek het pedagogisch project in zorginstellingen. Hieraan voorafgaand wordt in hoofdstuk vier een kort overzicht geschetst van het Vlaamse systeem van persoonlijke budgetten en de daarbij horende beleidsdoelstellingen. In hoofdstuk vijf bespreken we hoe ook het Vlaamse PVF-systeem marktmechanismen introduceert en stimuleert (Departement Welzijn, Volksgezondheid en Gezin, 2010, 2018) als een middel om zorginstellingen responsiever te maken voor wat mensen met een handicap zelf belangrijk vinden inzake hun zorg en ondersteuning. Deze responsieve houding dient een vraaggestuurde zorgpraktijk te garanderen. Om de betekenis van dit Vlaamse PVF-beleid voor de zorgpraktijk en het pedagogische project te onderzoeken, voeren we interviews uit met de directeurs van zorginstellingen die deel uitmaken van het lerend netwerk KWAITO.

Als eerste belangrijke punt wijzen de deelnemers op de nieuwe hefbomen die het Vlaamse PVF-beleid hen biedt om hun organisatie vorm te geven in lijn met de verwachting van 'sociaal ondernemerschap' (Departement Welzijn, Volksgezondheid en Gezin, 2010) in de nieuw geïntroduceerde zorgmarkt. Over het geheel genomen ervaren deze zorgaanbieders de transitie naar sociaal ondernemerschap als een positieve ontwikkeling die hen motiveert om hun organisatiestructuur om te vormen, hen ertoe aanzet om nieuwe samenwerkingsverbanden aan te gaan, en voorbij diepgewortelde conventies te denken. Ten tweede beïnvloedt de introductie van het PVF-systeem in grote mate het pedagogisch project, en dit via drie grote verschuivingen: (1) een verschuiving van de discussies omtrent zorg en ondersteuning, (2) een verschuiving betreffende het statuut van kennis en (3) een verschuivende opvatting van kwaliteit van zorg.

De eerste shift omhelst het verschuiven van discussies over inhoud van zorg en ondersteuning naar discussies over de modaliteiten van de geleverde zorg en ondersteuning. De tweede verschuiving verwijst naar de toewijzing van middelen aan de persoon met een zorgnood die een erkenning inhoudt van diens kennis omtrent de eigen situatie. De persoon in kwestie wordt namelijk geacht zelf het best te weten hoe de zorg en ondersteuningsvraag beantwoord kan worden. Deze veranderende status van kennis brengt een nieuwe relatie met zich mee waarin de respondenten zich niet langer simpelweg kunnen beroepen op hun professionaliteit. En ten derde, omdat professionele kennis een minder doorslaggevend karakter heeft, geven de respondenten ook aan dat er een andere maatstaf geldt voor kwaliteit. Een maatstaf gebaseerd op de kennis van de personen met een hulpvraag, gezien hun vooronderstelde expertise met betrekking tot hun noden. Deze drie verschuivingen brengen een meer onzekere en afwachtende houding van professionals teweeg in de dialogen over de geleverde zorg en ondersteuning.

Professionals geven aan een druk te voelen om voorzichtig te zijn in het aanvoeren van andere mogelijke benaderingen van een situatie, omdat die confrontatie 'de klant' zou kunnen storen en hem/haar zou kunnen aanzetten om op zoek te gaan naar een andere ‘leverancier’.

Deze studie leert ons dat professionals en zorginstellingen steeds vaker gevraagd worden om een specifiek, vooraf bepaald en gewenst antwoord op een zorgbehoefte te formuleren. Zorg en ondersteuning wordt op die wijze herleidt tot een 'uitvoeringspraktijk', wat vragen oproept over de waarde van het mantra van een vraaggestuurde praktijk voor de pedagogie van zorg en ondersteuning. De noodzaak van een pedagogisch perspectief op sociaal werk wordt in dit hoofdstuk sterk benadrukt. De directieleden geven overtuigend aan dat een kwalitatieve zorgpraktijk alleen in dialoog vorm kan krijgen. Hun verhalen maken duidelijk dat het binnen de contouren van de Vlaamse persoonlijke budgetregeling voor hen moeilijker wordt om een pedagogisch project te realiseren dat een centrale plek biedt aan dialoog over verschillende mogelijke wijzen van zorg en ondersteuning.

Vervolgens richten we in de derde studie onze aandacht op de stem van mensen met een verstandelijke beperking. In hoofdstuk zes en zeven brengen we de stem van tien personen met een verstandelijke beperking naar voor met betrekking tot hun zorg en ondersteuning in een residentiële omgeving. Door middel van fotomateriaal en diepgaande gesprekken verschaffen de participanten ons inzicht in hun conceptualisatie van ‘autonomie’, in de elementen die zij waarderen in hun huidige zorg en ondersteuning en in de elementen die mogelijkheden creëren om te kunnen doen en te zijn wat zij waarderen.

In hoofdstuk zes laten de deelnemers aan dit onderzoek zien dat financiële onafhankelijkheid en een persoonlijk budget geen elementen zijn ter bevordering van hun individueel welzijn en hun vrijheid om te kiezen voor de zorg ondersteuning die zij waarderen. Wel zijn 'significante en noodzakelijke anderen' middelen die de kansen en mogelijkheden van deze mensen verbreden. Dit hoofdstuk duidt bovenal op de spanning tussen de verwachting dat onafhankelijkheid en zelfredzaamheid een bijdrage zal leveren aan het individuele welzijn van personen met een beperking.

Hoofdstuk zeven werpt een licht op die elementen die mogelijkheden creëren voor mensen met een verstandelijke beperking om te kunnen doen en te zijn wat zij waarderen en om zich vrij te ontwikkelen volgens hun eigen normen. Daarbij richten we ons op de vraag welke elementen als capabiliteitsbevorderend worden beschouwd. Met andere woorden: welke elementen zijn 'conversiefactoren' die de keuzemogelijkheden van mensen verbreden. Meer specifiek richten we onze aandacht op die zaken die de 'capacity to aspire' tot bloei brengen, een vermogen dat individuen in staat stelt zich een andere en betere toekomst voor te stellen dan de huidige toestand. Daarom wordt deze 'capacity to aspire' ook wel 'lokale horizonten van hoop en verlangen' genoemd (Appadurai, 2004) en gezien als de voorlopers en basiselementen van vele capabilities (Hart, 2016). Zoals aangegeven in hoofdstuk zes fungeert geld voor de participanten vooral als een belemmerende factor in de ontwikkeling van aspiraties, net omdat het idee van verantwoordelijkheid voor het beheer van geld hen afschrikt. Verder blijkt dat een persoonlijk budget geen instrument is voor onze participanten om actief op zoek te gaan naar nieuwe kennis en naar andere mogelijke vormen van ondersteuning die zij zouden kunnen waarderen.

Uit de verhalen van onze deelnemers blijkt dat het creëren van kansen en aspiraties meer een kwestie van erkenning is dan een kwestie van herverdeling van financiële middelen. Het zijn net de interacties met 'significante en betekenisvolle anderen' waaruit relevante nieuwe kennis ontspruit en waaruit aspiraties kunnen worden vormgegeven. We concluderen dit hoofdstuk met het beargumenteren dat een engagement van sociaal werkpraktijken voor een relationeel begrip van autonomie van het grootste belang is voor mensen met een verstandelijke beperking om aspiraties te kunnen ontwikkelen en realiseren. Van mensen met een verstandelijke beperking wordt al te vaak verwacht dat ze -al dan niet met hulp en ondersteuning- de norm van een rationele en zelfredzame burger nastreven. Deze studie leert ons echter een bewustzijn van het bestaan van uiteenlopende interpretaties van begrippen zoals autonomie en persoonlijk welzijn.

Dit alles daagt ons uit om na te denken wat voor pedagogiek waardevol kan zijn in de praktijken van persoonlijke budgetregelingen. De bevindingen van deze drie studies brengen ons ertoe te suggereren dat een 'pedagogiek van personalisering' er een dient te zijn waarin erkenning een centrale plaats inneemt. Het document 'Perspectief 2020' dat de basis vormt van de Vlaamse persoonsgebonden budgetregeling, benadrukt sterk dat mensen met een handicap hun eigen potentieel ten volle moeten kunnen ontplooien en over hun eigen leven moeten kunnen beslissen, en weerspiegelt zo de doelstellingen van een capabiliteiten-bevorderend beleid. De focus op persoonlijke autonomie heeft zich vertaald in een verschuiving van aanbodgerichte voorzieningen naar vraaggestuurde diensten, met als resultaat een nieuw systeem van vouchers en cash betaalbudgetten die personen met een beperking - als consument - in staat stellen hun zorg en ondersteuning zelf in te kopen (Departement van Welzijn, Volksgezondheid en Gezin, 2010, 2018).

Dit beleid en de daaropvolgende praktijk kunnen, zo blijkt, inderdaad bijdragen tot de versterking van de persoonlijke autonomie van mensen met een handicap. Zij het echter dat door de focus op een vraaggestuurde organisatie van de zorg voornamelijk aan de 'ableistische' notie van autonomie wordt bijgedragen. In de concluderende reflecties beargumenteren we dat net binnen die focus op de ideaaltypische 'ableist' conceptualisaring van autonomie en burgerschap het 'tweeledige mandaat' van het sociaal slechts eenzijdig wordt aangewend. Het sociaal werk plaatst namelijk zo ten dienste van de reproductie van de norm van een zelfvoorzienend rationeel individu als universeel kenmerk van wat het is om mens te zijn.

Bovendien schetsen we in de drie studies dat er dubbelzinnige en gelaagde vormen van autonomie bestaan, die stuk voor stuk kunnen bijdragen aan wat het betekent om een goed leven te leiden. Het is in die geest dat we ons appèl op erkenning formuleren als een centraal aspect van 'een pedagogiek van verpersoonlijking' die autonomie en sociale rechtvaardigheid als centrale mandaten van het sociaal werk met elkaar kan verbinden.

Deze 'pedagogiek van verpersoonlijking' dient de dubbelzinnige en gelaagde interpretaties van verpersoonlijking en autonomie te verbinden met vraagstukken van sociale verandering en sociale rechtvaardigheid. Het is hier dat wij een plaats weggelegd zien voor het erkennen van niet eerder erkende interpretaties die tot nu in de private sfeer verborgen bleven, en voor het overbrengen van deze zaken naar 'het publieke'. Dit gaat over een plaats geven aan de meerduidige interpretaties van wat een goed leven inhoudt. Waarbij het delen van deze brede waaier aan mogelijke invullingen van wat betekenisvol is in het individueel welbevinden, kan bijdragen aan een breder begrip van wat de notie autonomie kan omhelzen.

Het debat over de gelaagdheid van wat autonomie kan betekenen zit vervat in het denken van het Vlaamse systeem van PVF. Maar desalniettemin wordt er te gratuit van uitgegaan dat het systeem bijdraagt aan de creatie van mogelijkheden van personen met een beperking om hun leven vorm te geven op een wijze die zij zelf waardevol achten. Met een 'pedagogiek van verpersoonlijking' verwijzen we naar een voortdurende reflectie en overweging over wat autonomie kan betekenen in de praktijk van het sociaal werk en naar een bewustzijn van verschillende begrippen van menselijke waardigheid en 'een goed leven'. Het verwijst naar een cultivering van de 'mogelijke vrijheid' om zich te buigen over vraagstukken omtrent autonomie en verpersoonlijking.

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APPENDIX IV

Data Storage Fact Sheets

Data Storage Fact Sheet (No.1)

Name/identifier study: **International exploratory study on social justice in the implementation of personalisation and marketisation principles**
Author: Toon Benoot
Date: 27 October 2020

1\. Contact details
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1a. Main researcher

- name: Toon Benoot
- address: Henri Dunantlaan 2, 9000 Gent
- e-mail: toon.benoot@ugent.be

1b. Responsible Staff Member (ZAP)

- name: Prof. dr. Rudi Roose
- address: Henri Dunantlaan 2, 9000 Gent
- e-mail: rudi.roose@ugent.be

If a response is not received when using the above contact details, please send an email to data.pp@ugent.be or contact Data Management, Faculty of Psychology and Educational Sciences, Henri Dunantlaan 2, 9000 Ghent, Belgium.

2. Information about the datasets to which this sheet applies

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* Reference of the publication in which the datasets are reported:

Benoot, T., Dursin, W., Verschuere, B. and Roose, R. (2020). Lessons from Ricoeur's 'Capable Human Being' for Practices of Personalisation in Three European Countries. Disability & Society. DOI: 10.1080/09687599.2020.1769561

Benoot, T. (2020). Autonomy in Social Work: A Search for Social Justice. The Case of Personal Budgets in the Care for People with Intellectual Disabilities. (Doctoral dissertation)

* Which datasets in that publication does this sheet apply to?:
the sheet applies to all the data used in the publication

3. Information about the files that have been stored

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3a. Raw data

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* Have the raw data been stored by the main researcher? [X] YES / [ ] NO
If NO, please justify:
* On which platform are the raw data stored?
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  - [X] research group file server
  - [ ] other (specify): ...

* Who has direct access to the raw data (i.e., without intervention of another person)?

- [X] main researcher
- [X] responsible ZAP (as the data is stored on the research group file server, the data is available for both the main researcher and its supervisor)
- [ ] all members of the research group
- [ ] all members of UGent
- [X] other (specify): co-researcher

3b. Other files

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* Which other files have been stored?

- [X] file(s) describing the transition from raw data to reported results. Specify: see methodology section of the article
- [X] file(s) containing processed data. Specify: All interviews were transcribed and saved as word files on my pc and on the on the research group file server.
- [X] file(s) containing analyses. Specify: see findings section in the article. Also, a file with the preliminary results is available on my PC, as well as on the research group file server.
- [X] files(s) containing information about informed consent: a blank copy is saved on my PC. All signed informed consents were scanned and are on my pc, as well as on the research group file server.
- [X] a file specifying legal and ethical provisions. Specify: The documents that were submitted to the Ethical Commission are on my PC, along with the approval of the Ethical Commission. The adapted and translated versions of the informed consents are also available on my PC.

- [X] file(s) that describe the content of the stored files and how this content should be interpreted. Specify: A word document contains an overview of all the raw data that was collected.
- [ ] other files. Specify:

* On which platform are these other files stored?
  - [X] individual PC
  - [X] research group file server
  - [ ] other: ...

* Who has direct access to these other files (i.e., without intervention of another person)?
  - [X] main researcher
  - [X] responsible ZAP
  - [ ] all members of the research group
  - [ ] all members of UGent
  - [X] other (specify): co-researcher

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   - address:
   - affiliation:
   - e-mail:

Data Storage Fact Sheet (No.2)

Name/identifier study: **Personalisation, marketisation and the pedagogical project**
Author: Toon Benoot
Date: 27 October 2020

1. Contact details

==

=

1a. Main researcher

- name: Toon Benoot
- address: Henri Dunantlaan 2, 9000 Gent
- e-mail: toon.benoot@ugent.be

1b. Responsible Staff Member (ZAP)

- name: Prof. dr. Rudi Roose
- address: Henri Dunantlaan 2, 9000 Gent
- e-mail: rudi.roose@ugent.be

If a response is not received when using the above contact details, please send an email to data.pp@ugent.be or contact Data Management, Faculty of Psychology and Educational Sciences, Henri Dunantlaan 2, 9000 Ghent, Belgium.

2. Information about the datasets to which this sheet applies

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* Reference of the publication in which the datasets are reported:

Benoot, T., Dursin, W., Verschuere, B. and Roose, R. (2020). Personal Budgets and the Pedagogical Project of Care Institutions in Flanders. European Journal of Social Work. Doi: 10.1080/13691457.2020.1815656

Benoot, T. (2020). Autonomy in Social Work: A Search for Social Justice. The Case of Personal Budgets in the Care for People with Intellectual Disabilities. (Doctoral dissertation)

* Which datasets in that publication does this sheet apply to?: the sheet applies to all the data used in the publication

3. Information about the files that have been stored

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3a. Raw data

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* Have the raw data been stored by the main researcher? [X] YES / [ ] NO
If NO, please justify:

* On which platform are the raw data stored?
  - [X] researcher PC
  - [X] research group file server
  - [ ] other (specify): ...

* Who has direct access to the raw data (i.e., without intervention of another person)?

- [X] main researcher
- [X] responsible ZAP
- [ ] all members of the research group
- [ ] all members of UGent
- [ ] other (specify):

3b. Other files

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* Which other files have been stored?

- [X] file(s) describing the transition from raw data to reported results. Specify: See methodology section of the article
- [X] file(s) containing processed data. Specify: All interviews were transcribed and saved as word files on my pc and on the on the research group file server.
- [X] file(s) containing analyses. Specify: See findings section in the article. Also, a word file and a MAXQDA-file with the preliminary results is available on my PC, as well as on the research group file server.
- [X] files(s) containing information about informed consent: a blank copy is saved on my PC. All signed informed consent were scanned and are on my pc, as well as on the research group file server.
- [X] a file specifying legal and ethical provisions: The documents that were submitted to the Ethical Commission are on my PC and on the research group file server, along with the approval of the Ethical Commission.
- [X] file(s) that describe the content of the stored files and how this content should be interpreted. Specify: a word document contains an overview of all the raw data that was collected.
- [ ] other files. Specify: ...

* On which platform are these other files stored?
  - [X] individual PC
  - [X] research group file server
  - [ ] other: ...

* Who has direct access to these other files (i.e., without intervention of another person)?
  - [X] main researcher
  - [X] responsible ZAP
  - [ ] all members of the research group
  - [ ] all members of UGent
  - [ ] other (specify): ...

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  - address:
  - affiliation:
  - e-mail:

Data Storage Fact Sheet (No.3)

Name/identifier study: **Personalisation and ‘a good life’ as pedagogical and social justice question**

Author: Toon Benoot

Date: 27 October 2020

1. Contact details

===
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1a. Main researcher

- name: Toon Benoot
- address: Henri Dunantlaan 2, 9000 Gent
- e-mail: toon.benoot@ugent.be

1b. Responsible Staff Member (ZAP)

- name: Prof. dr. Rudi Roose
- address: Henri Dunantlaan 2, 9000 Gent
- e-mail: rudi.roose@ugent.be

If a response is not received when using the above contact details, please send an email to data.pp@ugent.be or contact Data Management, Faculty of Psychology and Educational Sciences, Henri Dunantlaan 2, 9000 Ghent, Belgium.

2. Information about the datasets to which this sheet applies

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* Reference of the publication in which the datasets are reported:

Benoot, T., Dursin, W., McKenzie, J., Verschuere, B. and Roose, R. (Submitted for peer review). 'I don't know a thing about that, it's expensive': Accounts of Aspirations of People with Intellectual Disabilities in a Flemish Care Institution. Journal of Social Work.

Benoot, T., Dursin, W., Verschuere, B. and Roose, R. (Submitted after minor revision). A Visual Report on what is of Value for People with Intellectual Disabilities in a Flemish Care Institution. Journal of Intellectual & Developmental Disability.

Benoot, T. (2020). Autonomy in Social Work: A Search for Social Justice. The Case of Personal Budgets in the Care for People with Intellectual Disabilities. (Doctoral dissertation)

* Which datasets in that publication does this sheet apply to?: the sheet applies to all the data used in the publications

3. Information about the files that have been stored

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3a. Raw data

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* Have the raw data been stored by the main researcher? [X] YES / [ ] NO
If NO, please justify:

* On which platform are the raw data stored?
  - [X] researcher PC
  - [X] research group file server
  - [ ] other (specify): ...

* Who has direct access to the raw data (i.e., without intervention of another person)?
  - [X] main researcher
  - [X] responsible ZAP
  - [ ] all members of the research group
  - [ ] all members of UGent
  - [ ] other (specify):

3b. Other files

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* Which other files have been stored?
  - [X] file(s) describing the transition from raw data to reported results. Specify:
    See methodology section of the article and the dissertation.

- [X] file(s) containing processed data. Specify: All interviews were transcribed and saved as word files on my pc and on the on the research group file server. All the photographic material has been suitably anonymised.
- [X] file(s) containing analyses. Specify: See findings section in the article. Also, a word file and a MAXQDA-file with the preliminary results is available on my PC, as well as on the research group file server.
- [X] files(s) containing information about informed consent: a blank copy of the different types of consent are saved on my PC. All signed informed consent were scanned and are on my pc, as well as on the research group file server.
- [X] a file specifying legal and ethical provisions: The documents that were submitted to the Ethical Commission are on my PC and on the research group file server, along with the approval of the Ethical Commission.
- [X] file(s) that describe the content of the stored files and how this content should be interpreted. Specify: a word document contains an overview of all the raw data that was collected.
- [ ] other files. Specify: ...

* On which platform are these other files stored?
  - [X] individual PC
  - [X] research group file server
  - [ ] other: ...
* Who has direct access to these other files (i.e., without intervention of another person)?
  - [X] main researcher
  - [X] responsible ZAP
  - [ ] all members of the research group
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  - [ ] other (specify): ...

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