



Social Situation Monitor



Determining success factors for personal budgets among people with disabilities - a user perspective

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TABLE OF CONTENTS

Introduction	7
Context	7
Research questions	7
Research scope	8
Methodology	9
Structure of the research note	10
Personal budgets for persons with disabilities in the EU	11
Definition	11
Purpose of personal budgets	12
Practices in four EU member states	13
Netherlands	13
Flanders (Belgium)	15
Germany	18
Ireland	20
Contextual factors	23
Introduction	23
Governmental organisation	23
Success factors	25
Target group	25
Success factors	27
Access and accountability	27
Access and control	27
Waiting lists	28
Success factors	29
Information and communication	29
General information and communication policy	29
Contact person	31
Success factors	32
Adequacy and use of the budget	33
Adequacy	33
Types and (associated) freedom of use	34
Success factors	36
Available care and support	37



Size of the offer	37
Resistance among care/services providers.....	38
Success factors	38
User-related factors	40
Introduction	40
Type of disability	40
Success factors	41
Level and complexity of care/support needs.....	41
Success factors	42
Communication skills and entourage	42
Success factors	44
Living situation	44
Location.....	44
Housing type	45
Success factors	45
Case overview of context and user-related factors.....	47
Conclusion.....	50
References	53
Appendix	60
Methodology expert interviews.....	60
List of interviewed experts.....	60
Questionnaire	60
Practical questions	61
Introduction	61
Purpose and use of the personal budget.....	61
General evaluation of the personal budget from the user perspective	61
Contextual (success) factors	62
User-related (success) factors.....	63
Final questions	63



INTRODUCTION

CONTEXT

The use of personal budgets – whereby people with a certain care need are given monetary benefits that they can use to purchase certain services – is not a recent phenomenon. Since the 1990s, it has been used within the long-term care sector as an alternative to direct provision of services (Da Roit and Le Bihan, 2010). Nevertheless, personal budgets have not been universally applied to policies for persons with disabilities, largely because social protection schemes traditionally viewed people with disabilities as passive actors. They were treated by the authorities as patients with a constant support need, with the focus on either their medical needs (the *medical* model) or their need for social and economic (financial) support (the *charity* model). However, considering people with disabilities as members of society with the ability and right to make their own decisions has gained traction in the last two decades (Al Ghaib, 2017). This *human-rights* based approach is reflected in the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD), adopted in 2006, in which persons with disabilities are seen as actors able to make autonomous choices. The notion of personal budgets was subsequently more closely linked to policy: Article 19 of the Convention states that people with disabilities must have the right to live independently and to be included in the community. In order to safeguard these two rights, Parties to the Convention shall take ‘effective and appropriate measures’ to ensure that persons with disabilities can freely choose where and with whom to live, are not obliged to live in a particular living arrangement, and are provided with support, including in-home, in order to promote their inclusion in the community. This support should be tailored to the individual needs and preferences of persons with disabilities to enable independent living and inclusion in the community (UN, 2006).

In line with the UN CRPD, ratified by the European Union (EU) and all individual Member States, the European Commission’s Strategy for the Rights of Persons with Disabilities 2021-2030 confirms the importance of ‘quality, accessible, person-centred and affordable, community- and family-based services comprising personal assistance, medical care and interventions by social workers’ for achieving ‘independent living and inclusion in the community for persons with disabilities’ (European Commission, 2021). This transition from institutionalised care to more independent living integrated into society has seen personal budgets gain popularity within and outside the EU. Several Member States have also transformed the allocation of subsidies for persons with disabilities towards more personal and individual subsidisation systems.

RESEARCH QUESTIONS

Personal budgets for people with disabilities have been implemented in some Member States for some time, prompting the need to determine critical success factors for successful allocation and implementation of the budget. The focus of this research note is the perspective of the user. Its



purpose is to examine the conditions that personal budgets must meet in order to be used in the best possible way by persons with disabilities.

This leads to the following research questions:

- 1) Does the personal budget (partly) meet the demand for care and support of persons with disabilities?
 - What are the (main) objectives of introducing personal budgets?
 - Is the personal budget used for care purposes or is it used for other purposes?
 - What possibilities does the budget offer?
 - What restrictions are experienced?
 - Does the personal budget sufficiently compensate for the additional costs incurred due to the disability?
 - Does the personal budget sufficiently contribute to the independent living of recipients?
- 2) What are the *context factors* for successful implementation of the personal budgets?
- 3) What are the *user-related factors* for successful implementation of the personal budget?
- 4) How do personal budgets compare to traditional types of service delivery?

The determination of success factors is particularly relevant for Member States when reforming their social protection systems and policies. For those that do not yet offer personal budgets for people with disabilities, this study can provide important insights into the elements to consider. The identification of success factors may also be relevant for Member States already offering personal budgets for people with disabilities, allowing to assess and adjust their own policies accordingly.

RESEARCH SCOPE

Personal budgets can take many forms and are applied to different target groups. Outside the EU, they are particularly popular in the United Kingdom (UK), United States (US), Canada and Australia (Fleming, 2016; Crowther, 2019). This research note will focus exclusively on their use for adults with disabilities in the EU Member States.

The European network of academic experts in the field of disability (ANED) synthesis and country reports suggest that several Member States are implementing or experimenting with personal budgets for people with disabilities. In some Member States (Italy, Finland), however, this is limited to a few small-scale pilot projects in certain regions (Griffo and Tarantino, 2019; Katsui et al., 2019). In Luxembourg, there are only tentative plans to introduce personal budgets (Limbach-Reich, 2019). In France, the budget is mainly limited to compensating for additional living costs and aims to provide extra support due to the limitations in daily living (Nicolas and Ebersold, 2019). As such applications



of personal budgets are often at an early stage or developed to a limited extent, they are less useful in this study. Accordingly, this research note focuses on four EU Member States that have rolled out personal budgets for persons with disabilities in a more systematic way: the Netherlands, Belgium (Flanders), Germany and Ireland.

- In the Netherlands, Flanders (Belgium) and Germany, personal budgets have been implemented for some time for all people with disabilities who meet the required conditions. They form an important part of the social policies addressed to persons with disabilities;
- In Ireland, the introduction of personal budgets for persons with disabilities is limited to a number of long-running, large-scale pilot projects that have been comprehensively evaluated. The Irish case is particularly interesting because despite the long existence of the pilot projects, personal budgets have yet to be implemented as a general policy measure. Identifying the obstacles can lead to a better understanding of what is necessary to successfully implement personal budget schemes. It also gives a useful insight into the consequences of failing to introduce personal budgets more widely for the target group.

The use of personal budgets in these four Member States - whether implemented or at pilot stage – have already been the subject of (evaluative) research. This makes them ideal case studies for determining the conditions for successful implementation of personal budgets from the point of view of people with disabilities themselves.

In addition to the four case studies, it should be acknowledged that Sweden was one of the first countries to introduce the system of personal budgets into its national law, in 1993). The personal assistance budget (PAB) is one of the 10 cornerstones of special support and service policy aimed at enabling people with disabilities to live a quality life (European Association of Service Providers for Persons with Disabilities (EASPD), 2021). The Swedish personal budget is calculated based on the number of assistance hours needed by the person. The person can choose to manage the personal assistance themselves, or they can be supported to do this (Westerberg, 2013; Angelova-Mladenova, 2019; Durkin et al., 2021). Although the Swedish case is relevant in the context of this research, recent evaluations focusing on the user perspective are limited compared to the other countries and Sweden was thus excluded as a case study.

METHODOLOGY

A combination of research methods will be used to answer the research questions defined for the study:

- An in-depth literature review, focusing on evaluative studies of personal budgets for persons with disabilities in the four countries. This focuses on the factors that have a direct or indirect impact on the person with a disability. Studies from public/administrative bodies, academics, as well as from organisations supporting persons with disabilities with the



application and use of their budget, and organisations defending the rights of persons with disabilities, are all relevant¹. Evaluations that directly address the views of people with disabilities on personal budgets (testimonies, surveys, etc.) are of particular interest. When discussing results based on surveys or testimonies of personal budget holders, it should be acknowledged that they can be somewhat biased, as people who feel positively about personal budgets may be more likely to participate in such studies;

- Interviews with organisations representing persons with disabilities in each of the four countries, in particular associations representing those who receive a personal budget. These offer a good view of how the personal budget can have a positive (or negative) impact on the person with a disability. The Appendix to this report explains the methodology of the interviews in greater detail, along with providing the list of interviewed experts and the questionnaire used².

STRUCTURE OF THE RESEARCH NOTE

Before examining the (success) factors of a personal budget for people with disabilities, the study spends some time on the correct definition and interpretation of the personal budget. The personal budget is applied in different countries for very different target groups, making a definition of the concept central to the study. Next, the main objectives of the personal budget for persons with disabilities are discussed. At the end of this section, the concrete application of the personal budgets for persons with disabilities is briefly outlined for each of the four countries examined, chiefly addressing the main organisational features and their implementation in the respective countries.

Sections 3 and 4 examine the main characteristics of the personal budget for persons with disabilities. A distinction is drawn between organisational characteristics linked to the regulation and implementation of the budget, and personal characteristics directly linked to the person themselves. This looks specifically at the different approaches to these factors and their impact on the experiences of people with disabilities with the personal budget. These key factors and potential impacts are used to formulate success factors for each subsection. They can therefore serve as important guidelines for countries introducing or adapting personal budgets for people with disabilities.

The report then summarises the context and user-related factors in each of the four case study countries, with two overview tables allowing a quick visual comparison of their similarities and differences.

The report closes with some key overall conclusions.

¹ There is often an important overlap between these two types of organisations – many organisations defending the rights of people with disabilities also provide practical advice and aid.

² As this report is mainly based on the user perspective, direct interviews with persons with disabilities would have contributed significantly, but are unfortunately beyond the scope of the study. Instead, as many large-scale surveys of the target group as possible were considered, combined with interviews with those with good insights into the target group.



PERSONAL BUDGETS FOR PERSONS WITH DISABILITIES IN THE EU

DEFINITION

The use of personal budgets is a relatively recent phenomenon, with a limited scope of application within the EU (see Introduction). In addition, personal budgets for people with disabilities have different modalities in different Member States, and there has been very little international comparative research (Benoot et al., 2017). As a result, no clear-cut definition of the concept of personal budgets for people with disabilities is available. Nevertheless, it is possible to distil some basic common features from the various applications.

In the paradigm shift towards more autonomy and freedom of choice, the general principle of a personal budget scheme is that of demand-driven support, where persons with disabilities take control of the organisation of their own care/support. In practice, this is done by granting persons with disabilities their own budget with which they can choose (purchase) and organise their own care and support (EASPD, 2021; Op de Beeck et al., 2018a). The Irish Expert Reference Group on Disability formulates a number of common essential elements of personal budgets:

- The personal budget enables the person with a disability (or their entourage) to determine and purchase the appropriate support themselves. In other words, it is demand-driven and contrasts with the traditional supply-driven approach where the service provider made decisions for the person with a disability;
- The personal budget is (mainly) provided for the purchase of care and support. Although this can be interpreted very broadly and can, for example, include cleaning activities, the budget is primarily aimed at supporting (daily) care-related activities of the persons concerned;
- The support purchased can be very diverse, accommodating freedom of choice and flexibility of the person with a disability. These services can be offered by traditional service providers or by 'mainstream' service providers that were previously not always available for this target group. The budget can also be used by family members/relatives of the person with a disability or other members of their entourage;
- The personal budget is allocated individually to the person with a disability, and the amount and modality depends on certain characteristics (e.g. level of care/support needed) (Anand et al., 2012).



Persons with a disability can use the personal budget to purchase the necessary support themselves, thus this approach differs from care in kind, where a service provider purchases the care for the person with a disability. Thus, the person with a disability has shifted from a passive 'object' to a 'subject' who can decide their support needs and supply for themselves (Zorgwijzer, 2022). This is also evident from the main objective of the personal budget (see next section below).

For consistency, this research note refers throughout to 'personal budgets' (for people with disabilities). Other frequently used terms for this type of budget are 'individualised budgets' and 'cash for care' schemes (emphasising that the person with a disability receives a budget to purchase the appropriate care and support) (Crowther, 2019; Da Roit and Le Bihan, 2010).

PURPOSE OF PERSONAL BUDGETS

The genesis of personal budgets for persons with disabilities is closely linked to the main objective of the UN CRPD – the empowerment of persons with disabilities to become persons able to enjoy their rights and more decision-making freedom. Personal budgets were used to meet this objective from a financial point of view (National Disability Authority, 2020). By providing a personal budget, people with disabilities can decide the care and support that is best for them, as well as the service or person that should provide this service, and when (Bundesministerium für Arbeit und Soziales, 2020; Fleming, 2016). The central aim of personal budgets for people with disabilities is to enable them to participate in society despite physical or mental limitations, without always having to depend on others to make choices about care and support. It increases their self-reliance and their influence on the way services are provided (Franken, 2022; Kromhout et al., 2018). They recognise that each person's situation is unique and provide the necessary flexibility. Instead of a top-down approach where everything is decided for them, personal budgets provide a bottom-up approach (Martinez and Pritchard, 2019), in line with both the UN CRPD and the advocacy tagline 'Nothing About Us Without Us', reflecting the active involvement and participation of persons with disabilities in the planning of strategies and policies that affect their lives (UN Department of Economic and Social Affairs (DESA), 2022). This research note examines the extent to which personal budgets in the four case study countries meet this central objective, and the factors determining their success.

According to Da Roit and Le Bihan (2010), personal budgets can have additional objectives. One closely related objective is to use personal budgets to financially reimburse informal caregivers, including relatives, for their services. Being able to financially compensate informal caregivers recognises their role in supporting a person with a disability. An international study of five Member States³ found that this type of policy achieves its objective. However, the allowance has little impact on the decision on whether or not to provide care, given that is mostly perceived as recognition for a role the carer would take on anyway (Belgian Health Care Knowledge Centre, 2014).

³ BE, DE, FR, LU, NL.



A third objective focuses on potential budgetary benefits for policymakers, stating that personal budgets can be economically advantageous compared to traditional supply-driven policies (Da Roit and Le Bihan, 2010). One recent Dutch study suggests that the introduction of the personal budget for people with disabilities could generate cost savings due to lower overheads compared to the traditional supply-driven model. As the person with a disability has far more freedom of choice, the traditional supply model (e.g. large-scale residential units) is challenged, opening the way for new initiatives. These new players improve competition in the market, with a positive effect on the cost-efficiency of certain providers (Van den Eeckhout et al., 2021).

In focusing on user perspectives, this research note examines the extent to which the application of personal budgets fulfils the central objective, i.e. the empowerment of persons with disabilities in line with the human rights approach of the UN CRPD. An extensive study of the impact of the introduction of the personal budget on the public budget or on innovative practices is not included but may be discussed indirectly where it has an impact on the experiences of people with disabilities.

PRACTICES IN FOUR EU MEMBER STATES

This section explains the main characteristics of the application of personal budgets in the four case study Member States: the Netherlands, Belgium (Flanders), Germany and Ireland. The next section then examines specific characteristics and possible differences in greater detail.

Netherlands

Policy

In the Netherlands, the personal budget (*persoonsgebonden budget* - PGB) is a subsidy (budget) from the government with which people can purchase the care they need themselves. It is considered an alternative to care in kind, where the care office, the municipality, or a health insurance company purchases the care for the person with a disability (Zorgwijzer, 2022). After monitoring foreign experiments in the 1970s and 1980s, several motions were submitted in the Dutch parliament to implement a personal budget in the Netherlands itself. In the 1990s, the first national experiments followed in two cities (Drenthe and Eindhoven). Evaluation of these experiments showed that the personal budget provided the desired freedom of choice and that the costs were lower than in-kind care, and the personal budget was subsequently introduced in 1995 (Van den Eeckhout et al., 2022). This early adoption means that implementation cannot be directly linked to adoption of the UN CRPD a decade later. However, as a result of the ratification of the UN CRPD (in 2016), the Dutch government amended two laws to be fully compliant with its provisions (Rijksoverheid, 2021)⁴.

⁴ The UN recently announced that it will evaluate the Netherlands' implementation of the UN CRPD, following a 2019 report showing that in many areas, the position of people with disabilities had deteriorated since the introduction of the Convention in 2016 (Per Saldo, 2022a).



The initial target group was limited to chronically ill people and people with physical disabilities, and later expanded to include people with intellectual disabilities and people with (life-long) mental illnesses. Much has since changed with regard to its legal basis, implementation and supervision.

The exact provisions of the personal budget are based on the care demand, i.e. the care and support the person with a disability needs. This indication then determines the personal budget. The legal basis for obtaining a personal budget is spread across four different laws and the application differs per form (Van den Eeckhout et al., 2021):

1. The Law on Long-Term Care (*Wet Langdurige Zorg* - PGB-WLZ) covers people who need long-term intensive care in the vicinity. It must be applied for from the national Care Assessment Centre (*Centrum Indicatiestelling Zorg* – CIZ), which maps out the care entitlement for the person and sends that indication to a regional care office.
2. The Law on Societal Support (*Wet Maatschappelijke Ondersteuning* - PGB-WMO) focuses on people who need material help and support in and around the house. The municipality is responsible for this subgroup.
3. The Care Insurance Act (*Zorgverzekeringswet* - PGB-ZVW) determines the personal budget for personal nursing and/or care. The point of contact is the healthcare insurer⁵.
4. The Youth Law (*Jeugdwet PGB*) regulates the personal budget for minors. Again, the municipality is the central point of contact (Zorgwijzer, 2022).

The regulations that eventually cover a person with a disability seeking care depend on the basis, the type of care and support needed, and the degree of severity. Access to care and support in the form of a personal budget takes place in two stages, irrespective of the sub-law. The first step is to determine whether the person is eligible for care and support within the relevant law, while the second step examines the extent to which the person can obtain their care in the form of a personal budget (Van den Eeckhout et al., 2021; Benoot et al., 2017).

A person with a disability can appoint an authorised representative (*gemachtigde vertegenwoordiger*) to handle matters related to their personal budget. A legal representative (*wettelijke vertegenwoordiger*) can also be appointed, but cannot be designated by the person themselves. These include parents or guardians of a child under 18, or a person appointed by a judge. The representative can request information, sign care agreements and arrange other practical matters for the person with a disability (Sociale Verzekeringbank, 2022).

Recent figures

Government statistics publish the number of users per law, giving an indication of the total number of users of a personal budget. As these figures date from different years, this section presents an overview of the most recent figures per individual law, as well as a total figure for the most recent year for which figures for all (sub-)laws are available:

⁵ Everyone who lives or works in the Netherlands must have basic health insurance (Rijksoverheid, 2022b).



- Based on the most recent figures per law for 2022, there are 55 436 users under the PGB-WLZ and 45 385 users under PGB-WMO. For the other two laws, the most recent figures are based on 2019 data (Ministerie van Volksgezondheid, Welzijn en Sport, 2022a).
- The most recent figures for the total number of users of personal budgets based on the four laws date from 2019, with 49 522 users under the PGB-WMO; 45 225 users under the PGB-WLZ; 19 043 users under the PGB-ZVW; and 15 514 under *Jeugdwet PGB*. In 2019, a total of 132 203 persons with a disability used the personal budget (Van den Eeckhout et al., 2021).

In addition to a personal budget, a person with a disability can also opt for care in kind, where the municipality or health insurer determines which care organisation or supplier will provide the care. This is supply-driven support, in which the user's freedom of decision is limited (Per Saldo, 2022a). The person with a disability can also opt for a combination of the personal budget and care in kind. In 2020, 12 440 of the 48 800 personal budget users (25 %) based on the PGB-WLZ law used both types of support (Ministerie van Volksgezondheid, Welzijn en Sport, 2022b). The use of this combination makes it difficult to ascertain the ratio between the two groups, and exact figures are not available.

Understanding the total take-up of the personal budget requires knowing the numbers of potential beneficiaries. Molenaar states that, in principle, everyone who uses one of the four laws is entitled to a personal budget (Molenaar, 2022). However, because the local authorities have a lot of room for manoeuvre with the municipal laws and can determine who is eligible for the personal budget (see Target group section), the exact number of those entitled to a personal budget is unclear. It is certainly not the case that every person with a disability needs a personal budget: a large proportion of the approximately two million people with some form of disability do not need extra support (Rijksoverheid, 2022a).

A 2021 survey of more than 3 000 budget holders found that the personal budget is generally well received. Almost three quarters (74 %) of respondents indicated that they would still opt for a personal budget if care in kind offered the same care. Most explained that the personal budget gives them the freedom to plan their day and choose their care provider. The freedom of choice is much greater than in-kind care. Despite these predominantly positive experiences, a considerable number of respondents were not satisfied with certain aspects of the budget. For example, one-third of respondents (29 %) experienced the allocation of the budget as negative, citing a laborious process that caused a great deal of stress, took a very long time, or was otherwise unsatisfactory. Another one-third (31 %) reported experiencing policy changes that limited the (free) use of their personal budget (Van den Eeckhout et al., 2021).

Flanders (Belgium)

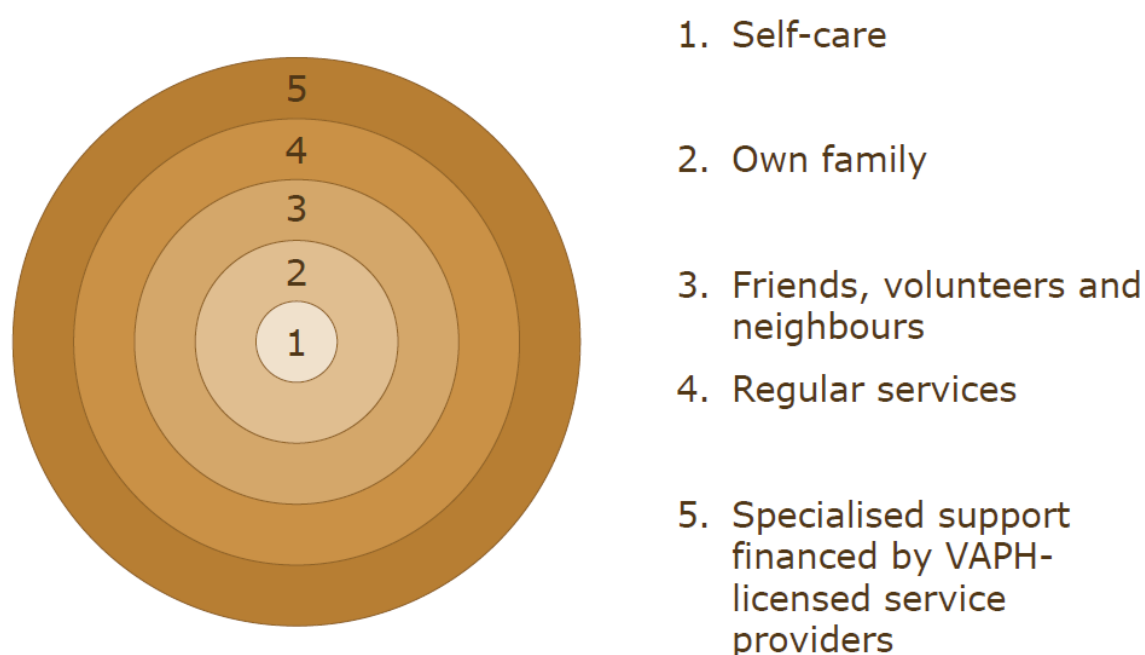
Policy



In Belgium, the Communities⁶ are responsible for personal matters, including welfare services for persons with disabilities (FPS Social Security, 2013). In Flanders, the Flemish Agency for Persons with Disabilities (*Vlaams Agentschap voor Personen met een Handicap – VAPH*) is responsible for developing and evaluating the policy for persons with disabilities in the area of care and support. It is also responsible for providing the personal budgets and supervising their use (VAPH, 2022a).

After a small-scale pilot project (*Experiment Persoonsgebonden Budget*) in 2001 (Breda et al., 2011), the Flemish Minister of Welfare, Public Health and Family launched the policy note 'Perspective 2020 - New support policy for persons with disabilities' in 2010 (Vandeurzen, 2010). This policy note gave rise to important changes in the disability care sector in the Flemish Community (Flanders), centering shared care and support, inclusion, demand-driven and self-management. Care and support for people with disabilities is considered a shared responsibility, visualised by five concentric circles (Figure 1). The circles represent the different possible sources of support for the person with a disability. They can be used interchangeably and independently from each other to meet the specific individual need. The person with a disability forms the centre of the circles (VAPH, 2022b). The policy note explicitly links the personal budget to the broader social evolution embodied by the UN CRPD (particularly Article 19), referring to the concentric circles as the operationalisation of the UN guidelines (Vandeurzen, 2010).

Figure 1: Sources of support for persons with disabilities



Source: VAPH (2022b).

The personal budget makes it possible for a person with a disability to decide how and where to buy the necessary care and support, thereby forming an important link in the policy. Depending on their

⁶ Belgium has three language-based communities - Flemish, French-speaking and German-speaking.



needs, the person has several options where the personal budget can serve as a support (VAPH, 2022b). Introduced in 2017, this system of personal budgets for people with disabilities (*persoonsvolgende financiering*) is a relatively recent policy initiative. The system of personal budgets for people with disabilities is structured into two different types of budgets:

- A care budget for people with disabilities with a light support need that enables the person to organise care and support in an accessible way (*Zorgbudget*). A fixed amount (EUR 300) is paid by the care fund (i.e. an institution affiliated with the health insurance funds; the Flemish government also has one) and can be spent freely by the person with a disability⁷ (Op de Beeck et al., 2018b; Flemish Government, 2022a);
- A second type of personal budget targets persons with disabilities with more intensive support needs for whom the care budget is not sufficient (*Persoonsvolgend budget*). The amount reflects the person's individual need: 24 budget categories are distinguished, with the amounts varying between EUR 10 000 and EUR 90 000 per year (Flemish Government, 2022b). The budget is intended to pay for care, support, and assistance. Only a limited part of the budget can be spent freely, and the largest part must be accounted for by the person. The personal budget can be obtained as a cash budget, as a voucher to pay licensed care providers, or as a combination of the two. Applications for this type of personal budget must be made via the VAPH (Op de Beeck et al., 2018a). It is limited to persons with disabilities between the age of 17 and 65 years old (VAPH, 2021)⁸.

A person with a disability can obtain only one of the two budgets (if the conditions are met).

The VAPH licences and funds assistance organisations to provide accessible and quality assistance in using the personal budget. For help with the start-up and management of the personal budget, persons with a disability can turn to an assistance organisation (e.g. questions related to concluding contracts, how to use the budget without incurring significant administration themselves, how to choose the right support, etc.) (VAPH, 2022c).

Other forms of care and support for people with disabilities are also available, such as directly accessible help and allowances for aids and adaptations:

- Directly accessible assistance (*Rechtstreeks Toegankelijke Hulp* – RTH) is limited, disability-specific support in the form of counselling, daycare or accommodation for those who need occasional help. This type of support is granted automatically;
- Allowances for aids and adaptations (*Tegemoetkomingen voor hulpmiddelen en aanpassingen*) can help to carry out activities in which a person has difficulties. Where granted, such an allowance can usually be combined with a personal budget (VAPH, 2021).

Recent figures

⁷ Negotiations are taking place within the Flemish government to reform the care budget for people with a light support need, but it is not yet clear what that reform might look like (Ceule, 2022).

⁸ A separate budget is provided for elderly people with disabilities (from 65 years of age – the care budget for elderly people with care needs (*Zorgbudget voor ouderen met een zorgnood*). However, this is beyond the scope of this study, as evaluative studies are mainly limited to the other two budgets.



Information in the VAPH annual report allows for the total number of users of a personal budget (light support need; more intensive support need) to be determined. In 2021, 15 413 users received a budget for persons with a light support need and 27 266 a budget for persons with a more intensive support need. In total, 42 679 people with a disability received a personal budget in 2021.

The fact that the actual demand for a personal budget in Flanders is much greater than the number of people who currently have a budget is demonstrated by the large waiting lists. In 2021, 15 918 people were waiting for (more) support. Those waiting for a personal budget for people with an intensive support need often already receive a form of VAPH support, such as directly accessible assistance and/or allowances for aids and adaptations. In total, 102 438 people had some form of assistance in the form of a personal budget or another form of financial support in 2021. The large waiting lists show that this is not the most appropriate support for a significant proportion of people with an identified need (VAPH, 2022d).

Possible uses of the personal budget depend on the type of budget. While the personal budget for light support need is only paid as a cash budget (Op de Beeck et al, 2018b), persons with a more intensive support need can use the personal budget with a cash system or with a system with vouchers, or a combination of both. 2021 data suggest that:

- 72 % of budget holders of a personal budget for people with a more intensive support need spend their budget solely in vouchers;
- 10 % of budget holders only use the cash system;
- 18 % opt for a combination of cash and vouchers.

The figures also show that new budget holders are quicker to opt for cash expenditure or a combination of cash and voucher expenditure (VAPH, 2022d).

In a large-scale evaluation of the personal budget for persons with disabilities with light support needs, the need for the budget was confirmed by all results (2018 surveys; personal testimonies of the beneficiaries). The vast majority of budget holders who participated in the survey stated that they (very much) need the personal budget (survey 1: 90 %; survey 2: 86 %) (Op de Beeck et al., 2018b). In a general 2018 survey on the impact of personal budgets on quality of life among the two subgroups with light and intensive support needs, the personal budget generally rated well compared to traditional care funding: 63 % of persons with disabilities stated that the personal budget gives them more control over their care compared to other types of financing (Van Puyenbroeck et al., 2019).

Germany

Policy

In Germany, the benefit type of the personal budget for persons with disabilities (*persönliches Budget*) was introduced in 2001 in the ninth book of the Social Code (SGB IX). The UN CRPD became legally binding with the ratification of the CRPD and its optional protocol through national legislation. Since



January 2018, the definition of disability in the SGB is adapted to the definition⁹ of the CRPD (Grieser, 2018).

In 2008, the personal budget was introduced in Germany as a legal right for persons with disabilities. The regulatory framework is set out within the SGB. This means that the right of choice of potential budget recipients is fully respected and, if the legal requirements are fulfilled, all applications for approval of personal budgets must be approved (Bundesministerium für Arbeit und Soziales, 2020).

The introduction of the personal budget ensured that a person with a disability had the choice to receive the budget for care and support in two ways. In addition to the traditional supply-driven financial support based on in-kind payments, an application could also be made for a personal budget (Franken, 2022). Applications for a personal budget can be submitted to different types of service providers, such as contact points of rehabilitation centres, health insurance companies, youth welfare institutions, social welfare institutions, integration offices and the Federal Employment Office (Bundesministerium für Arbeit und Soziales, 2020). A special feature of the German implementation of personal budgets is that, until 2018, the person had one central contact point from the time of application to the time of receiving the budget. The authority first contacted with a care request was thus assigned the coordinating role for the entire application process. This approach was abolished at the end of 2018, however (Benoot et al., 2017).

Social services and care offices are the most important bodies in the context of support for adult persons with disabilities. The social service will initiate a 'care and support needs assessment' to identify the needs of the person seeking care, the impact on their well-being and the outcomes they seek. While the social services are chiefly organised on a (supra)local level, care offices are more bound to national rules in determining care needs and rates (Benoot et al., 2017).

The amount of the personal budget is based on the costs of the necessary services and can vary from very small amounts to more than EUR 10 000 per month. However, most amounts vary between EUR 200 and EUR 800 per month (Bundesministerium für Arbeit und Soziales, 2020). Personal budgets can be provided for a variety of services, such as basic care, medical rehabilitation, and occupational participation, as well as services such as housekeeping, home care and study assistance (Grieser, 2018).

Recent figures

In theory, every person with a disability, or at risk of disability, can apply for a personal budget, no matter the severity of their case (Bundesministerium für Arbeit und Soziales, 2020). Determining how many persons with disabilities actually receive a personal budget is complicated by the considerable variety of possible service providers and significant regional autonomy. The authority that is responsible for implementing the personal budget depends on the particular need for care. In practice, it is

⁹ 'Persons with disabilities are persons who have a physical, psychological, mental or sensory impairment, which in interaction with attitudinal or environmental barriers may hinder their equal participation in society very probably longer than six months' (§ 2 SGB IX).



possible that a request for care and support for a person with a disability is answered by several authorities at the same time (see Governmental organisation).

The largest providers of personal budgets are those based on social assistance legislation (*Sozialhilfe*) or long-term care legislation (*Pflegeversicherung*). On the website of the Federal Employment Office, the monitoring section of personal budgets only refers to an old report from 2007. In their large-scale study, Benoot et al. (2017) referred to more recent data from 2012, which showed that 11 493 personal budgets were paid out by social assistance providers. There were striking regional differences in the number of allocated budgets, ranging from seven budgets (Bremen) to 4 800 budgets (Rheinland-Pfalz) in 2012. This indicates that the degree of implementation of the personal budgets is highly diversified geographically. However, no figures were available for the second major type of providers (long-term care providers), making it impossible to provide recent figures for the total number of people with disabilities (Benoot et al., 2017). Despite these incomplete and old data, it seems clear that Germany, which has around 7.8 million persons with severe disabilities, has a markedly low number of persons with a personal budget (Statistische Bundesamt, 2022).

A 2007 quantitative survey of 847 personal budget holders found that the vast majority (89 %) experienced positive changes since receiving the budget. Respondents cited increased opportunities to lead an independent life and increased control over the care and support they need (Metzler et al., 2007).

Ireland

Policy

As early as 2011, the Irish government announced its intention to increase the 'choice and voice' of service users in general. The idea was to move away from a classic direct service model, where services were offered directly to the person with a disability, towards a model based on personal budgets that would encourage choice, control and flexibility of users, in line with the UN CRPD¹⁰ (Government for National Recovery, 2011). Despite the enthusiasm for the idea, the Department of Health stated in its Value for Money and Policy Review of Disability Services (2012) that it was not advisable at that time to move to an integrated personal budget system for people with disabilities until more research had been done to determine whether the necessary availability of alternative support services could be guaranteed, in order to avoid a vacuum in service quality. As a result, the Department recommended that pilot projects be initiated before the full introduction of the system for persons with disabilities (Department of Health, 2012).

Four pilot projects with personal budgets for people with disabilities were subsequently initiated in different locations:

¹⁰ The Irish Government signed the UN CRPD in 2007 and ratified it in March 2018 (Irish Human Rights and Equality Commission, 2022).



1. Direct Payment project: enabled people with physical disabilities to purchase their own services in Dublin. It was organised by the *Áiseanna Tacaíochta* (AT) Network, the largest interest organisation aimed at facilitating personal budgets for people with disabilities in Ireland;
2. Bridging the Gap project: targeted young adults with disabilities, where an intermediary worked with the individuals to develop a person-centred plan (PCP) to determine access and arrangements for services on an individual basis. It was organised by a Health Service Executive (HSE) service in Donegal;
3. PossibilitiesPlus project: targeted persons with physical and intellectual disabilities, freeing-up funds normally provided for traditional service providers to be allocated to persons with disabilities as a personal budget. A service organisation in County Kildare supported this project;
4. ConnectAbility project: focused on young adults (18-25) with intellectual and developmental disabilities, living in County Kerry. Using a self-management model, a community connector supported these young adults to plan and manage their training, work, education and recreational activities. With the help of the community connector, the individuals could choose how to spend their budget (Fleming, 2016).

A number of individual personal budget projects have since been set up. Many locally embedded initiatives and pilot projects are running in different regions in Ireland (EASPD, 2021)¹¹. Recently, the Minister of State with responsibility for disability announced that the pilot project programme would be extended until 2023, with a thorough evaluation of the pilot projects expected in 2024 (Department of Health, 2022). Due to the recent government decision to continue with the pilot projects, rapid nationwide policy-based implementation of the system is not expected. Currently, there is no statutory entitlement to individualised services/supports or a statutory framework for personal budgets under Irish law (Moloney, 2019).

Recent figures

The most recent statistics on the number of people with disabilities show that, in 2016, 643 131 people (13.5 % of the population) had a disability (National Disability Authority, 2018). Again, it is important to emphasise that having a disability does not always mean that the person needs additional (financial) resources (such as a personal budget).

As eligibility for a personal budget is limited to the participants of the individual pilot projects, and given the lack of any legal right to personal budgets, persons with disabilities are not, in principle, entitled to one. Consequently, no statements can be made about its (non-)take-up. However, it is clear that those who receive a personal budget represent only a very limited proportion of the total group of persons with disabilities. For instance, a national survey on the prevalence of personal budgets shows that approximately 290 individuals received a personal budget in 2017. This is likely an underestimate, as a number of organisations did not respond to the request (National Disability Authority, 2017). Although these figures are not very recent and are incomplete, they nevertheless suggest that

¹¹ An exact number and overview of the currently running pilot projects is not available.



people with disabilities who receive a personal budget make up only a very small proportion of the total group of people with disabilities.



CONTEXTUAL FACTORS

INTRODUCTION

This section takes a closer look at the contextual factors that can influence how people with disabilities experience the acquisition and use of personal budgets. These factors are characteristics that can be linked to how the personal budget schemes are organised and the rules that apply, i.e. who gets a personal budget, what conditions must be met, and what possibilities are there for spending the personal budget. These factors can be linked to the policy on personal budgets and the consequences of certain policy decisions. The next section will look more closely at factors linked to the personal characteristics of the target group.

Several context factors will be addressed in this section:

- **Governmental organisation:** What is the impact of the general regulatory framework of the personal budget? Does the degree of decentralisation have an impact on the well-being of people with disabilities?
- **Target group:** Who is eligible for a personal budget?
- **Accessibility and accountability:** How is access to a personal budget organised and to what extent are people with disabilities controlled (administratively)? What conditions must they fulfil to obtain or retain a personal budget?
- **Information and communication:** How and by whom are the application, possibilities and limitations of a personal budget communicated? Where can people with disabilities go for information?
- **Adequacy and use of the budget:** Is the amount of the personal budget sufficient, and what can a person with a disability buy with the budget?
- **Available care and support:** How large is the supply of care and support? Are there sufficient choice options for those affected?

In each case, the research note examines the different countries' approaches and the impact on the people with disabilities who receive a personal budget. This will be complemented with key insights from broader evaluation studies.

GOVERNMENTAL ORGANISATION

The policy underpinning how personal budgets are organised has an important impact on different aspects of the budget and can determine how the person with a disability experiences and evaluates it. In the Netherlands, the decentralisation of the system of personal budgets has led to four partly existing and partly new legal frameworks (see Practices in four EU Member States). These four legal frameworks operate according to distinct objectives and principles (in terms of legislation). In the case of the personal budget system at municipal level, this complicates the cooperation between municipalities and health insurers, as well as creating issues for health insurers having contact with a large



number of municipalities. This fragmentation has led to additional complexity for people with disabilities who often do not know where they can turn for support (Van den Eeckhout et al., 2021; Kromhout et al., 2018). In addition, a large number of people with disabilities consider the administrative obligations to be burdensome, while a proportion experience the discussions with providers as controlling and suspicious (Van den Eeckhout et al., 2021). Many people with disabilities who are, in principle, entitled to a personal budget do not pursue that entitlement (Molenaar, 2022). In some other municipalities, the additional administrative requirements remain relatively limited, highlighting substantial discretionary differences within the various municipalities (Molenaar, 2022).

Like the Netherlands, the personal budget scheme in Germany is part of a very fragmented system. There is a strict division between different types of budgets (including the personal budget) and methods of support, with each type having to comply with different rules. In addition, much of the regulation of personal budgets is in the hands of the regions, creating discretionary differences in service provision. Depending on where a person lives, different rules must be met, or it may be easier/harder to obtain a personal budget (Benoot et al., 2017). Franken (2022) mentions that service organisations may even issue their own rules that are not based on laws or regulations (see Living situation). The lack of integration and communication between the different services creates the impression of a patchwork quilt, complicating navigation by people with disabilities, and leaving the provision of appropriate help and support to the goodwill of the various services (Franken, 2022; Benoot et al., 2017).

In Flanders, the system of personal budgets is much more centralised than in the Netherlands and Germany. Nevertheless, the system is rather complex, due to the different types of budgets and possible combinations with other benefits (VAPH 2019; Ceule, 2022). A double survey of persons with disabilities and representatives found that a (candidate) user of personal budgets needs a lot of knowledge and information and communication skills to be able to understand the basis of the system (Van Puyenbroeck et al., 2019). A good practice that tries to meet this need is the development of an initiative such as the Integrated Broad Reception (*Geïntegreerd Breed Onthaal*) in which the public Centres for Social Welfare, the Centre for General Welfare Work and the social work services of the health insurance funds join forces to function as a single central contact point. The initiative primarily aims to realise accessible social aid and services and to combat under-protection (Department of Welfare, Public Health and Family, 2022; Ceule, 2022). In addition to the complexity of the system of personal budgets, there is a parallel system of other forms of support within various governmental domains and levels. Although this multiplicity is good on the one hand (it contributes to freedom of choice), it can be overwhelming for many people with disabilities. Consequently, there is much ambiguity about the distinction between different types of support, cumulative conditions, registration methods, and the ceilings on certain amounts (Op de Beeck et al., 2018b).

In Ireland, the roll-out of personal budgets is limited to a number of pilot projects and there is no consistent government policy. This creates much uncertainty for those involved. If a sustainable policy on personal budgets with legal certainty is to be achieved for persons with disabilities, there is a need for a more comprehensive policy in which the government takes responsibility and develops partnerships with various service providers (National Disability Authority, 2017; Fleming, 2016; Anand et al., 2012).



A large-scale evaluation study in three countries (Germany, the Netherlands, UK) confirmed that administrative organisation has a crucial impact on different facets of the personal budget (Benoot et al., 2017). For example, a higher degree of decentralisation and dispersion across different laws and/or agencies results in a higher likelihood of referrals and increased administrative burden for persons with disabilities. This can play a role not only in the allocation phase but also in monitoring and informing those concerned. Despite attempts by the authorities to develop general frameworks, there is considerable discretion in deciding on budgets or the possibilities of using them. This can lead to different approaches between different local actors, reducing access and lowering budgets due to the limited financial context (Benoot et al., 2017). Some studies have advocated a systematic integration of the system of personal budgets for these reasons (Martinez and Pritchard, 2019; Anand et al., 2012). If the intended outcomes of different services operating close together are the same or similar, more integration (across services, or cooperation between services) is advantageous for the person with a disability. However, many services are reluctant to change and the siloed approach is maintained (Martinez and Pritchard, 2019; Anand et al., 2012).

Success factors

These cases clearly show that the administrative structures in which personal budgets are embedded can have a major impact, ranging from obtaining information on access to the budget to the possibilities for its use and the amount of the budget. Strong decentralisation with a lot of decision-making freedom for local actors often leads to different interpretations, increases complexity, uncertainty, and generates unequal access and thus inequality for persons with disabilities. If overall governmental structure requires the organisation and implementation of personal budgets to be strongly decentralised, the processes should be standardised as much as possible to ensure equal treatment of people with the same care needs. The integration of services with similar tasks, such as the Integrated Broad Reception initiative in Flanders, can contribute to this. A less far-reaching form may be to intensify the cooperation between services or stimulate communication between organisations that often work alone. Pursuing greater uniformity does not mean standardising processes to such an extent that people with disabilities with different care needs must all follow an identical path. Rather, personalised approach should always be pursued.

TARGET GROUP

In the Netherlands, the four legal domains (see Practices in four EU Member States) have different target groups and subgroups¹². These target groups reflect the objectives and nature of the law concerned. In theory, similar processes have been set up within the four domains to provide access to the

¹² People who need long-term intensive care (PGB-WLZ), people who need material help and support in and around the house (PGB-WMO), people who need personal nursing and/or care (PGB-ZVW), and minors in need of a personal budget (*Jeugdwet-PGB*).



personal budget for the right target groups. In principle, the four laws cover the people who would benefit from a personal budget and no group is excluded (Molenaar, 2022). In practice, however, people who are not entitled to a personal budget may also succeed in obtaining one. There are examples where applicants clearly know what to say in an access discussion, sometimes helped by acquaintances or, in more extreme cases, by the potential care providers (Van den Eeckhout et al., 2021). In certain municipalities, the personal budget is used as a stopgap measure for people with a disability for whom suitable care and support cannot be offered. It serves as a lump sum whereby the municipal responsibility for the provision of care is shifted onto the person with the disability themselves, assigning them a personal budget where other forms of support would be more appropriate. This creates an improper target group (Molenaar, 2022). To counteract this improper use of the personal budget, a new instrument allows allocation officers to acquire more certainty about the access rights of people with disabilities. This Skills Scan (*PGB Vaardigheidsscan*) consists of a set of 15 skills that can be tested online. It provides uniform tools for assessing the skill of the person with a disability and thus increases uniformity in decision making (Britt et al., 2020; PGB-OKE, 2022).

In Flanders, an evaluation of the personal budget confirmed that too few persons with disabilities receive a personal budget, resulting in long waiting lists (Op de Beeck et al., 2018) (see Practices in four EU Member States). This is seen as a huge drawback by welfare organisations and service providers. Reasons for the too-limited target group include age limits, very long waiting lists (see below) and a lack of coordination between scaling systems that jeopardises continuity of care (continued receipt of support as long as the situation and needs remain unchanged). The selection of the 'right' additional target group is considered one of the biggest challenges. People with disabilities who are exclusively supported by informal carers and are not known to the social work services are at particular risk of insufficient coverage (Op de Beeck et al., 2018b). People with early-onset dementia, for example, may not yet qualify for the personal budget, whereas people with neuro-degenerative diseases (e.g. ALS, which often follows a similar course) are eligible to apply (Ceule, 2022). The researchers suggest that those on very long waiting lists for intensive support should be given the personal budget for light support need in the meantime (Op de Beeck et al., 2018b).

In Germany, the personal budget is intended as an option for all persons with disabilities who need it. In practice, however, a large group is excluded and the non-take-up rate is relatively high (Franken, 2022). The first reason for the gap is that many people who would be eligible for the personal budget simply do not know about it, due to the lack of an information policy (see Information and communication). A second reason is that some public servants, service providers and providers of collective living facilities may advise against the personal budget because they fear a higher workload and complexity, or fear that people with a personal budget will leave collective facilities because of the increased freedom of choice. Despite the potential benefit for the person with a disability, this barrier is created to deter them (Franken, 2022).

Ireland has no general policy on personal budgets (see Practices in four EU Member States), thus no clear target group is defined. However, the pilot projects for which information is available suggest some focus on a broader group of people with physical and intellectual disabilities, while others deliberately focus on young adults (with disabilities) (Fleming, 2016).



Success factors

These experiences show that the definition of the right target group for the personal budget is far from evident, for various reasons. While in some cases people with disabilities who are entitled to a personal budget do not receive it (long waiting times, lack of coordination, etc.) there are also situations where people receive a personal budget to which they are not entitled (improper use of the system). Both practices are very harmful to the persons with disabilities who receive (or who should receive) a personal budget. Part of the solution could be to make the process of defining the target group and the final access to the budget (see below) as objective as possible. The use of instruments/tools that increase this objectivity, such as the skill scan in the Netherlands, should be encouraged.

ACCESS AND ACCOUNTABILITY

Access and control

In the Netherlands, the organisations that determine whether a person needs care/support (indication) initially had difficulties in achieving coherence in the terminology and criteria for the determination of the care/support need and the related allocation of personal budgets. This led to differences in interpretation and increasing legal uncertainty for people with disabilities. In 2004, the Netherlands' transitioned to a central organisation responsible for the indication, with the main objective of promoting objectivity and uniformity of the procedure. The 2015 decentralisation across four different legal frameworks, in which the municipalities were given a lot of autonomy (see Practices in four EU Member States) saw a further fragmenting in the determination of the care/support need of persons with disabilities. This is not conducive to uniformity, and the place of application can influence the decision (Van den Eeckhout et al., 2021). There is a risk that people with disabilities who find themselves in the 'grey zone' between two regulatory frameworks will follow an ambiguous path. It is often more difficult for them to identify the correct access point and they run the risk of unhelpful, circular information (Benoot et al., 2017). In the case of personal budgets issued on the basis of municipal laws, an additional obstacle is evident for those entitled to a personal budget. As the personal budget was often associated with fraud, the regulatory framework in many municipalities was gradually tightened through additional rules (Molenaar, 2022). Due to the high level of distrust, persons with disabilities must follow a demanding administrative procedure every second year in order to have the indication determined. This administrative burden restricts the feeling of freedom of choice of many people who receive a personal budget in many municipalities (Van den Eeckhout et al., 2021)

In Flanders, the allocation of personal budgets for persons with a light support need is different to those with heavy needs. It is often very easy to obtain a personal budget, especially for people with light support needs. The allocation is granted automatically and the budget can be spent freely, meaning that administrative obligations are often very limited (see Types and (associated) freedom of use).



The non-take-up rate is very low for this target group (Op de Beeck et al., 2018b). In addition to meeting a number of basic conditions, persons requiring frequent or intensive support must go through a number of steps in the application process. For many, this involves quite a large administrative burden of proof, based on an interview with Ceule (Ceule, 2022). After mapping out the demand, a support plan must be completed and submitted. A multidisciplinary team will then issue a report describing the person's disability and support needs. The Care Needs Instrument (*Zorgzwaarte Instrument*) is specifically designed for this purpose and maximises the objectivity of the decision on the amount of support. The instrument consists of a number of questions asked by a trained member of a multidisciplinary team (MDT). The answers are then converted into scores (VAPH, 2022e; De Boever, 2019). In addition, persons with disabilities can rely on an extensive network of organisations representing the rights of persons with disabilities to help them with the application procedure (VAPH, 2019).

In Germany, obtaining the personal budget requires a plan defining the needs of the applicant and the measures to be taken to meet those needs. In theory, this is not complex, but in practice it can be difficult for certain subgroups. Much depends on the goodwill of the contact person within the government service handling these applications (Franken, 2022). A wide variety of organisations can be used to obtain a personal budget. The most important bodies are social services and care funds (see Practices in four EU Member States), but a carer can also receive support in the form of a personal budget from the labour integration service, accident insurance and pension insurance. This fragmented field complicates access for certain people, particularly those with complex care needs, who have to apply to different institutions (see Level and complexity of care needs) (Benoot et al., 2017). In order to facilitate this process, a user association (BAG) organises budget conferences to bring policy officers directly together with the person with a disability (Franken, 2022).

In Ireland, the conditions for obtaining and maintaining a personal budget are particularly complex (Ryan, 2022). Consequently, going through the entire procedure is often only worth it for people with high needs, with the burden of proof being overly burdensome for people with a lower support need (Ryan, 2022). A survey of interest organisations found that administrative challenges were the most frequently cited obstacles to a positive experience with the personal budget (National Disability Authority, 2017). As a result, many people are put off, resulting in a high non-take up rate (Ryan, 2022).

Waiting lists

There are virtually no waiting lists for people with disabilities who apply for a personal budget in the Netherlands (Molenaar, 2022). The main reason is that an immediate allocation of the personal budget has been enforced in court (Molenaar, 2022): In a ruling by the District Court of Zwolle in 2000, it was decided that previously unrecognised care may be purchased via a personal budget on penalty of a financial penalty (De Rechtspraak, 2000). This is in stark contrast to the situation in Flanders, where a 2018 survey of persons with disabilities with a light support need showed that the long waiting lists for obtaining the budget is considered a key bottleneck. Many beneficiaries see the personal budget as the solution to their needs, but they often have to wait (far too) long for it: 49 % of the respondents indicated that they were on a waiting list before they were granted the personal budget



(Op de Beeck et al., 2018b). In 2021, almost 16 000 people were waiting for a personal budget (see Practices in four EU Member States). Depending on the estimated need (determined on the basis of different priority groups), the duration of the waiting period can vary significantly. In the highest priority group (1), it can amount to three or more years. In 2021, the Flemish government decided to provide extra budget to reduce the waiting list for the high priority group to a maximum of one-and-a-half years (Willems, 2021).

In Germany, a person with a disability often encounters a waiting period before they can claim a personal budget. In theory, the waiting lists for obtaining a personal budget are limited to four weeks by law. In practice, however, in certain regions the waiting lists can extend to one year or even longer (Franken, 2022). In Ireland, there are also long waiting lists to obtain a personal budget. This is because the system is limited to a number of (local) pilot projects. In addition, people with disabilities must first have a traditional supply-driven budget before they can claim a personal budget (Ryan, 2022).

Success factors

The overview of the practices in the four case studies shows that although the access to a personal budget often seems relatively simple on paper, several obstacles arise in practice. Firstly, extensive decentralisation means that it is often not clear where to apply, and people may experience unequal treatment due to a lack of uniform procedures. Secondly, in certain cases, a certain suspicion about system abuse leads to an excess of administrative procedures to obtain or retain the budget. For people with disabilities who are only eligible for a relatively low budget, this can lead them to waive their right to the budget, increasing the non-take-up rate. Thirdly, there are very long waiting lists to obtain a personal budget.

These obstacles could be limited through automatic allocation of the personal budget if clear, objectively verifiable criteria are met. A good example is the Care Needs Instrument in Flanders. The instrument allows an allocation to be made very quickly – if the person with a disability meets the criteria, they receive a personal budget. Secondly, the use of objective and clear criteria ensures that the discretionary room for decision-making – and thus the room for unequal treatment – is reduced, even where the administrative organisation is highly decentralised.

INFORMATION AND COMMUNICATION

General information and communication policy

A 2021 survey of more than 3 000 budget holders in the Netherlands found that more than 80 % indicated that they were sufficiently informed about the possible forms in which they could receive care. Three out of four respondents indicated that they were sufficiently informed about what the personal budget entailed before they opted for it, and more than 9 out of 10 respondents (93 %) were aware of the amount of the allocated budget (Van den Eeckhout et al., 2021). Despite these generally good results in respect of the information obtained, these findings should be nuanced (Molenaar, 2022).



For personal budgets issued on the basis of municipal laws, in particular, there is a considerable difference in service provision (including the provision of information) between municipalities. Obtaining a personal budget in the Netherlands is spread across four different laws and a multitude of implementers (see Practices in four EU Member States), creating greater chance of a fragmented communication policy. Much depends on the quality of the client support worker (*cliëntondersteuner*), who is the main contact for persons with disabilities (Molenaar, 2022). Their tasks include providing information and advice on the range of care/support available, help in choosing the desired care/support provider, and help with drawing up, implementing, evaluating and adjusting the care or support plan. Given that the client support worker supports the person with a disability in important facets of the process, having a 'good' or 'poor' support worker can have a significant impact on the experience (Benoot et al., 2017).

Various surveys of persons with disabilities in Flanders in 2017 and 2018 found that a large subgroup of (potential) beneficiaries had insufficient knowledge of the system of personal budgets (Van Puyenbroeck et al., 2019; Op de Beeck et al., 2018b). Not everyone found the available support and many believed that the allocation criteria were unclear. For instance, some indicated that they did not know the allocation criteria and often did not even know why they received a personal budget. Some beneficiaries even referred to incorrect information they received, having to wait a long time for information, and feeling trapped in a circular information system. In addition, the surveys established that the people who looked for information themselves were often active, enterprising people, which may not be true of a large group of others. A higher Matthew effect¹³ appears to occur, as the complexity for those involved increases, i.e. people with a better starting position (higher education and/or a better income) are generally better informed. In addition, researchers also observed a learning effect, suggesting that people with disabilities who had already received support were generally better informed (Van Puyenbroeck et al., 2019; Op de Beeck et al., 2018b). There is a significant gap in the referral process by primary care providers such as doctors and specialists. While people with disabilities often come to them first with a question for care and support, these professionals are often not sufficiently aware of the existence and possibilities of the personal budget (Ceule, 2022). Given the special focus on more vulnerable people with a disability, initiatives such as the Integrated Broad Reception (see Governmental organisation) or the provision of free intensive counselling courses by organisations defending the rights of persons with disabilities (e.g. Independent Living (*Onafhankelijk Leven*)) should be encouraged. The fact that the Flemish government financially supports these organisations to set up such initiatives can be considered very positive (Ceule, 2022; Departement Welzijn, Volksgezondheid en Gezin, 2022).

In Germany, many people with disabilities who have or want a personal budget also experience difficulties in receiving (sufficient) information about their budget. Although the personal budget has been an option for German people with disabilities for decades, many people do not even know about it.

¹³ The Matthew Effect refers to a 'pattern in which those who begin with advantage accumulate more advantage over time and those who begin with disadvantage become more disadvantaged over time'. The result is ever-widening differences between the advantaged and disadvantaged (George and Ferraro, 2016). In this particular case, it implies that people with a higher income and/or education are often better informed, making them more likely to be (able to be) adequately assisted in obtaining a personal budget. This further improves their situation compared to the more precarious group.



For those who do have questions, the information they receive can be very unclear, with difficult to understand technical jargon. Various regions are using 'easy to read' initiatives that focus on tailored communication for people with disabilities. However, this does not happen in all regions (see Living situation).

In Ireland, personal budgets can be obtained only through small-scale individual pilot projects and there is no general government policy on informing and communicating with people with disabilities. As a result, the quality of the information provided relies heavily on the interpretation of the organisation in question, leaving the person with a disability dependent on the goodwill of organisation staff. Several organisations are now facing major staff shortages and there is often not enough guidance for the persons concerned (Ryan, 2022).

Several other evaluations confirm that persons with disabilities often lack accessible and understandable information on the conditions and spending options of a personal budget in practice. In the UK and Scotland, for example, communication about the (new) system of personal budgets is often very difficult and people with disabilities are often left partly to their own devices. This lack of information and communication is often accompanied by a high degree of uncertainty and has a negative impact on the person's experience of the budget (Benoot et al., 2017; Pike et al., 2016; Martinez and Pritchard, 2019).

Providing unambiguous and sufficient information is more challenging where the system of personal budgets differs greatly from the traditional supply-driven funding model. For policymakers, liaison officers and support organisations alike, this often means an entirely new way of working. It is important to provide sufficient training and time for these actors to be fully aware of the possibilities of the new system in order to support people with disabilities, in line with the UN CRPD (Benoot et al., 2017; National Disability Authority, 2017).

Policymakers are advised to be cautious about the digital approach to communication (Martinez and Pritchard, 2019). Although it can be very useful for many people with disabilities, it risks (partially) excluding certain subgroups, such as the elderly and people with certain types of disability, if no alternative is provided. However, the importance of a good contact person (see below) can remedy this risk (Martinez and Pritchard, 2019).

Contact person

In the Netherlands, a person receiving a personal budget can turn to a client support worker as their support and anchor (Molenaar, 2022). A client support worker knows what is on offer in terms of care and support in the person's region and can discuss where and with whom care and support can be obtained. They can also accompany people to talks about (potential) care/support options with providers if desired. In recent years, this system of client support has been greatly expanded, benefitting people with disabilities in receipt of a personal budget (Ministerie van Volksgezondheid, Welzijn en Sport, 2022b).



In Germany, the role of contact person is fulfilled by a national independent user organisation (*Bundesarbeitsgemeinschaft Persönliches Budget*), which has a very wide range of tasks from providing first line information to organising training (BAG, 2022). However, the organisation is understaffed and cannot cope with the large number of questions it receives from people with disabilities. Another important contact point promoted by the government is the Supplementary Independent Participation Counselling (*Ergänzende unabhängige Teilhabeberatung* - EUTB). However, this organisation is limited to providing information and cannot help with effective application of the personal budget (EUTB, 2022a; Franken, 2022).

The evaluation of the Irish pilot projects underlines the importance of the contact person taking enough time to listen to the wishes of the person with a disability. Most individuals previously received support in a very structured and prescribed environment and the adjustment to their new decision-making freedom requires time and guidance (Fleming, 2016). Having the same contact person contributes enormously to a feeling of security and control for people with disabilities, as they have a trusted person to turn to with their questions (Ryan, 2022). For those who have a limited entourage, in particular, the importance of such a contact person cannot be underestimated (Ryan, 2022). The creation of the 'Peer Support Network' by AT Network (see Practices in four EU Member States) is a positive development, bringing together former and future users of personal budgets for advice and mentoring (EASPD, 2021).

Peer counselling and independent assistance can have a positive influence on the implementation of care/support and follow-up with regard to the spending of budgets (Benoot et al., 2017). Indeed, experiences and support of (former) peers and independent experts from assistance organisations can help people with disabilities to feel objectively supported. It is therefore an important task of the government to facilitate and integrate such forms of support (Benoot et al., 2017).

Success factors

Despite the decades-long tradition of personal budgets in some of the countries surveyed, it appears that (future) recipients are often insufficiently informed – or even completely unaware – of the various facets of personal budget policy. This leads to a great deal of uncertainty and confusion for many of those involved. In countries where policies are highly decentralised, this problem may be even more pronounced. Experiences from different countries show that the role of a central contact point (or even a single contact person) can be crucial to overcome these problems. Having one independent point of contact for all kinds of questions contributes enormously to the sense of trust and security. This is even more true for people who are less communicative and/or cannot rely on external help from their entourage. New initiatives such as the Integrated Broad Reception in Flanders – in which different services join forces to function as a central point of contact – or the further development of existing services such as the client supporter in the Netherlands, are very positive. An additional advantage is evident in cases where the central contact point works with experts who have once been in the same situation, which increases empathy. A good practice example is the Peer Support Network in Ireland, which brings together experienced and new users of the personal budget.



ADEQUACY AND USE OF THE BUDGET

Adequacy

The determination of personal budgets in the Netherlands is not sufficiently customised (Molenaar, 2022). The use of modules means that persons with disabilities are divided into certain categories, while a more tailored approach would be better for the individuals concerned. In other words, there is not enough detail and differentiation in determining the budgets (Molenaar, 2022). The municipal interpretation of the calculation of budget levels leads to considerable diversity in the amounts people receive in practice, i.e. the personal budget can differ significantly depending on the municipality where the person lives (Benoot et al., 2017). Many municipalities have lowered the rates of the budgets in recent years (for budgetary reasons), yet costs of living are increasing. This has reduced the purchasing power of people with disabilities, with many reporting the personal budget to be insufficient (Molenaar, 2022).

Regional autonomy in Germany means that there are considerable regional differences in budget levels. Depending on where a person with a disability lives, they may receive a different amount for the same needs. Personal budgets are calculated on the estimated costs for services in kind; however, the amount may not exceed the cost of the previous services in kind, but can be lower (Grieser, 2018). This shows that the German government (partly) considers the personal budget system as a cost-saving measure. As the personal budget may not exceed the value of comparable care in kind, its use will ensure that the total costs resulting from the implementation of personal budgets will not increase compared to the previous system of in kind care/services.

In Flanders, a distinction can be drawn between persons with disabilities who have an intensive support need and those who have a light support need, with the two groups receiving a different type of personal budget (see Practices in four EU Member States). Surveys suggest that many of those with an intensive support need consider the personal budget to be sufficient, in contrast to those with a light support need. Of the latter group, 40 % of almost 2 400 respondents considered the budget adequate or very adequate, with a roughly equal proportion considering it inadequate (Op de Beeck et al., 2018a; Op de Beeck et al., 2018b). These differences in the assessment of adequacy by both groups may stem from the large budgetary differences between the two personal budget types (see Practices in four EU Member States). For those receiving a perceived inadequate personal budget, their freedom of choice is negatively impacted because the budget does not meet their actual need for disability-specific support, they are restricted in living independently and have to make certain choices and/or postpone certain support (Leyseele, 2019).

No information was available on the adequacy of the personal budget in Ireland.

A large-scale evaluation in several countries found that the basic idea of the personal budget – more autonomy and freedom of choice for the budget holder – is only feasible if the budget is sufficient (Benoot et al., 2017; Anand et al., 2012). Indeed, in a context of austerity, where policymakers are trying to keep the total cost of the personal budget as low as possible, it often means that the person



with a disability has little/no choice if they are granted a budget, or even worse, are not granted a personal budget due to excessively strict eligibility conditions. There is a danger that the personal budget is seen too much as ‘an instrument tailored to the local financial situation and not enough as an instrument tailored to the user’ (Benoot et al., 2017; Anand et al., 2012).

Types and (associated) freedom of use

In the Netherlands, the way a person with a disability can spend the personal budget depends on the law under which the budget falls (see Practices in four EU Member States):

- For personal budgets, based on the two laws for which the municipalities are responsible for the implementation of the personal budget (PGB-WMO; *Jeugdwet-PGB*) and PBG-WLZ, the social insurance bank pays the care providers directly, implying that the person with a disability does not receive their personal budget directly;
- In the case of a personal budget under PGB-ZVW, the person with a disability must declare the costs of the care purchased. The health insurance company then pays the amount into their bank account, after which the care providers are paid (Per Saldo, 2022c).

This implies that the person with a disability must use the personal budget for care purposes and cannot part of it for other purposes. However, the degree of freedom to choose certain forms of support may still vary depending on the law to which the personal budget is linked (see Practices in four EU Member States):

- In the two laws for which the municipalities are responsible for the implementation of the personal budget (PGB-WMO; *Jeugdwet-PGB*), there is no mention of how it should be spent. As a result, each municipality has its own rules and the differences in spending freedom for the user between different municipalities can be considerable;
- The PGB-ZVW determines the types of care that are reimbursed by the healthcare insurer. The amount of spending freedom in the personal budget also depends on the healthcare insurer;
- The PBG-WLZ regulates the freedom of spending. The indication states the amount of the personal budget and the user may determine how that budget is spent. However, an important condition is that the care purchased must be on the WLZ reimbursement list, which determines what the personal budget may (not) be used for. Another restriction is that the user may purchase a maximum of 40 hours of care per week from the same care provider (Per Saldo, 2022d).

Despite the limitations, a 2021 survey of persons with disabilities with a personal budget in the Netherlands found that they appreciated the freedom granted by the personal budget. The vast majority indicated that it enables them to organise their lives in a way that suits them, whereby they can adapt the care to their lives rather than their lives to the care. More specifically, 61 % of respondents indicated that the combination of hours and tariffs allocated in their personal budget offers sufficient



room to purchase good quality care (n = 1 841). Those who experienced insufficient freedom in their personal budget cited insufficient tariffs (14 %) and the number of hours allocated (19 %). Budget holders are less dependent on regular supply compared to the traditional system of care in kind (Van den Eeckhout et al., 2021). Despite the relatively high level of satisfaction with the current options with the personal budget, organisations are in favour of the free spending possibility of a certain part of the budget, as a way of increasing flexibility for persons with a disability and maximising the freedom of choice intended with the personal budget system (Molenaar, 2022).

Similarly, personal budgets in Germany are not freely disposable. The person with a disability has to consult a contact point (see Practices in four Member States) to clarify the supports for which they would like a personal budget and the services for which they are actually eligible. If the person does not agree with the determination of the personal budget, they can appeal to the service provider who issued the decision (Bundesministerium für Arbeit und Soziales, 2020). A 2016 EUTB survey found that even without this possibility, about 90 % of the recipients of a personal budget felt that their independence had improved as a result of the budget. They cited the considerably greater range of spending options compared to the traditional supply-driven support. An example is given of a family that was able to find care in the form of a personal assistance for their daughter in a regular kindergarten. This would not have been possible without the personal budget (EUTB, 2022b).

In Flanders, the possible uses of the personal budget depend on the type of budget. While the personal budget for persons with a light support need is only paid as a cash budget, persons with a more intensive support need can use the personal budget with a cash system, with a voucher system, or with a combination (see Practices in four EU Member States). These different types of use also have an impact on what they spend the budget on and the associated freedom of choice. Budget holders who use their personal budget in cash mainly realise their care and support through employment contracts, volunteers, service cheques and agreements with natural or legal persons. The cash option is often used by users who (want to) organise support in the home environment, as this is only possible via cash. By contrast, vouchers are often used to pay for institutions (VAPH, 2022d). This suggests that, in practice, there is greater freedom of choice in the cash option, as it offers many spending options, while the voucher system can be linked more to the traditional supply-driven system (with support in institutions).

In Flanders, persons with disabilities who need more intensive support can freely spend a limited part of their personal budget. A large-scale survey of more than 1 000 people with a disability with a more intensive support need who are entitled to such a freely disposable portion of the personal budget investigated the possibilities, bottlenecks and areas for improvement in respect of the freely disposable portion from a user perspective (Op de Beeck et al., 2018a). Two-thirds of respondents had requested the option to spend part of the budget freely, citing greater freedom to decide, flexibility, creativity and the possibility of using other services. The budget holders who requested the freely disposable portion used it for a wide variety of care and support forms, such as reimbursement of volunteers, practical help, day support, cleaning and chore service, regular services. Leisure and transport were also frequently mentioned. Other forms of expenditure that recurred frequently related to (the co-payment of) support devices, medication, certain forms of therapy, etc. These are



items that are not or only partially reimbursed by ordinary health insurance. The survey also found that almost everyone who has requested the discretionary portion felt positive or very positive about their choice (93 %). The researchers concluded that a freely disposable portion of the personal budget can be seen as positive for users, as it encourages them to exercise more control, freedom of choice and creativity. It also provides an administrative simplification for most budget holders. Despite the many advantages for the person with a disability, it is striking that the survey shows that only half of the respondents indicated that the freely disposable portion should increase, while the other half left this open, or noted that the current free to use proportion was high enough; no reason was given (Op de Beeck et al., 2018a). A similar survey of the subgroup of people with a disability with a light support need who can freely spend their entire (much lower) budget (2 390 respondents) revealed the same findings. Indeed, the ability to spend the budget freely allowed budget holders to make more personalised choices that took into account their own wishes, preferences and needs, and made a difference to their lives and to their support needs (Op de Beeck et al., 2018b; Ceule 2022). In addition, free spending allows for a limited regulatory and administrative burden of proof, which is beneficial for those involved (Ceule, 2022).

The possibility of being able to spend part of the personal budget freely was found to be positive in itself (Ryan, 2022). In Ireland, however, where a large-scale implementation of personal budgets is not yet on the agenda, the freely disposable portion should be contained initially: both political willingness and broader acceptability will be greater if persons with disabilities must demonstrate that they are using the budget for care purposes (Ryan, 2022). However, from the perspective of the person with a disability, the freely disposable portion is a good thing and should be considered at policy level (Ryan, 2022). Evaluation of the Irish pilot projects has found that one of the most basic but often challenging skills is to learn to deal with money (money management) in order to purchase the (new) care/services themselves. Therefore, good guidance from contact persons or their own entourage is often crucial (Fleming, 2016).

The positive impact of the free disposability of (part of) the personal budget on people with disabilities was confirmed in one study, which referred to the main purpose of personal budgets as maximising the freedom of choice of the persons concerned (Martinez and Pritchard, 2019).

Success factors

The case studies show considerable variety in the assessment of the adequacy of the personal budget. Nevertheless, it is clear that a relatively large group of people who receive a personal budget believe the amount to be insufficient. This has an important impact on the general evaluation of the personal budget as it makes them feel that they cannot (sufficiently) cover their care and support costs. Some are forced to look for cheaper alternatives to their preferred choices due to a (too) limited budget, curtailing the central objective of the personal budget. It is extremely important that policymakers should not view personal budgets as a cost-saving measure, as is the case in some regions of the studied cases.



The fact that (part of) the budget is freely disposable maximises the feeling of freedom of choice and is positive from the user perspective. It also contributes to administrative simplicity. When implementing a system of personal budgets, it may be pragmatic to limit this freedom (initially) in order to increase acceptability to the rest of the population and/or policymakers.

AVAILABLE CARE AND SUPPORT

Size of the offer

There is a large shortage in the labour market of service providers in the Netherlands, complicating identification of an appropriate support for many persons with disabilities receiving a personal budget (Molenaar, 2022). This was confirmed by a 2021 survey, where 9 % of people with disabilities noted the shortage in the labour market as one of the main limiting factors for finding an appropriate offer (Van den Eeckhout et al., 2021).

The supply of available care and support in Germany is also too low (Franken, 2022). An important reason for the general low supply is that care providers are not obliged to respond to the request of a person with a disability. Thus, conservative organisations sometimes refuse to respond to the request of a person with a disability on a personal budget (see below) (Franken, 2022). In addition to the reluctance of some service providers, an expert survey in 2018 found that the variety of service providers was generally rather limited, with no personal assistance providers at all in some rural areas (Grieser, 2018). An evaluation study in four countries (Belgium, Germany, the Netherlands, UK) found that the supply of care and support can often differ substantially from region to region within the same country (Benoot et al., 2017). The supply often seems to be too limited, particularly in rural areas. This should be taken into account when introducing personal budget systems (Benoot et al., 2017).

Ireland also has a problem with choice, due to large staff shortages among service providers (Ryan, 2022). Although Ireland has a highly trained workforce, increasing the pool of service providers without compromising on quality should be a priority. The availability, recruitment, training and employment conditions of personal assistants will be crucial (Anand et al., 2012; Fleming, 2016).

Flanders is also dealing with personnel problems in different types of service providers, with a negative impact on the support offer. This is even more pressing in more rural areas, where personal assistants are a bottleneck profession (Ceule, 2022). Consequently, a broadening of the supply should be encouraged. More specialised alternative/out-of-the box forms of support, such as possibilities to buy help for very short periods during daily peak moments, are still insufficiently available (Op de Beeck et al., 2018b). The evaluation of a small-scale pilot project (*Experiment Persoonsgebonden Budget*) dating back to 2001 in Flanders shows that the personal budget can indeed lead to a more diverse spending pattern compared to the traditional supply-driven policy. In addition to the use of the traditional offer, the personal budget ensured that extra regular care and personal assistance could be purchased to fill the gaps in the daily care plan of the people involved (Breda et al., 2011).



A sufficiently wide range of choices for care and support is a crucial factor for a positive evaluation of the personal budget (Ryan, 2022; Molenaar, 2022). If the person with a disability feels that they have an extensive range of options on which to spend their budget, the great advantage of freedom of choice comes into its own. If that range of choice is (too) limited, they may be better off with the classical supply-driven assistance, which provides certainty that they will get the right support (Ryan, 2022). Personal budgets can only work if there is a sufficiently well-functioning, sustainable and high-quality market of service providers (Martinez and Pritchard, 2019). If this condition is met, the system of personal budgets can ensure that the quality of services improves and the efficiency of service provision increases. This is because the freedom of choice of the person with a disability stimulates market forces whereby new providers can fill gaps in the system and providers who deliver poor quality services leave the market (Martinez and Pritchard, 2019).

Resistance among care/services providers

In addition to the potential problem of an overly limited supply, there is a danger that the demand-driven personal budget model will create resistance among care/services providers. Whereas in the classic supply-driven model they were often certain of their recipients in advance, with personal budgets the person with a disability has more freedom of choice, creating uncertainty for many providers (Benoot et al., 2017; National Disability Authority, 2017). This does not have to be a disadvantage for people with disabilities, as the providers may improve the quality of the service. On the other hand, it can also result in certain providers 'ring-fencing' their services for persons with a personal budget.

In Germany, many traditional care/services providers show such path-dependent behaviour and view possible changes with suspicion. The increased mobility of their care/services receivers is one of their greatest concerns. They are afraid of change and prefer to stick with what they know. Various providers also fear an increased workload and complexity. Some conservative organisations often advise people with disabilities against choosing a personal budget, telling them they are safer within the classic supply-driven financing system. Sometimes, people with disabilities are refused if they opt for a personal budget. On the other hand, personal budgets lead to new opportunities by creating new service providers that particularly focus on people with disabilities receiving a personal budget. The first evaluations of such new service providers are extremely positive. In addition to high quality, one of the most frequently mentioned advantages is the importance they attach to the idea of being able to live independently and act accordingly (Franken, 2022).

Success factors

Having a sufficiently large choice of care and support services is crucial for people with disabilities on a personal budget. In practice, however, the possibilities are often insufficient. Various reasons are given, ranging from an insufficient supply in less populated areas to resistance on the part of certain providers, who see people with a personal budget as a threat to the established system.

A limited offer restricts the possibilities for persons with disabilities and low supply may prevent them from using their full potential for freedom. As a result, some experts argue that people may be safer



within the certainty of the supply-driven financing model. An essential condition for positive use of the personal budget is a well-functioning market of care/services provision with sufficient choice options. In addition, market forces can have a positive effect on the overall quality by driving out poor healthcare providers and allowing new, high-quality and often innovative healthcare providers to emerge¹⁴. Although not all of these new initiatives have emerged as a result of the introduction of the personal budget, the extra possibilities created by the budget have ensured that such initiatives have a greater chance of success. Increased flexibility means that it is possible for many people with disabilities to receive appropriate support in innovative smaller-scale initiatives. These embody the trend towards the socialisation of care and greater inclusiveness in society. This integration is reflected in the location of most initiatives. An inventory of these new residential care initiatives shows that most are in line with the concept of personal budgets and the UN CRPD, emphasising demand-driven care and self-determination. For example, the living situation of people with disabilities is often intended to fit in with living in an ordinary house in an ordinary neighbourhood (Schepers et al., 2020).

¹⁴ See Chapter 2 of Schepers et al. (2020) for a description of innovative (residential) care practices in Flanders.



USER-RELATED FACTORS

INTRODUCTION

This section examines the impact of certain personal factors on users' experiences of personal budgets. User-related factors are characteristics that can be directly linked to the person with a disability themselves, and that may affect the individual's experience with the personal budget compared to another subgroup.

It will look at the following user-related factors:

- **Type of disability:** Does the nature of the disability play a role in the individual's experience of the personal budget? Is there a difference for people with physical versus mental disabilities, or does this have no influence?
- **Level and complexity of support needs:** Does the complexity of the support request and the level of support need affect experiences of the personal budget?
- **Communication skills:** Do people with disabilities who are more articulate/language-savvy evaluate the personal budgets better or does this have no influence?
- **Living situation:** Is the individual's residence (collective institution, living alone, etc.) decisive in their experience with the personal budget? Does the location (specific regions, rural vs. urban) where the person lives have an impact?

These questions will be addressed in relation to the situation in the four case study countries, as well as through important insights from broader evaluation studies. The answers will serve as an important input for determining the success factors for a personal budget.

TYPE OF DISABILITY

In the Netherlands, most people experiencing physical disabilities are able to express their preferences clearly (Molenaar, 2022). This may be less true of people with intellectual disabilities. For this group, there is often too little support, with the first steps in finding information and knowing where to go proving especially difficult. A good practice in Flanders is the initial coaching for this group by service providers (Molenaar, 2022).

Research in Flanders has established that people with an intellectual disability often have more difficulty understanding the personal budget, and are more likely to indicate that support is desired (Ceule, 2022; Op de Beeck et al., 2018b). Offering support and clearer explanations by social workers, their immediate entourage and others is therefore crucial for this target group.

In Germany, people with disabilities must sign a plan justifying their needs and the measures necessary to meet them (see Accessibility and control). People with intellectual disabilities may need more



support in doing this, such as through more accessible information (easy-to-read initiatives) and tailored assistance. It is important that people are well supported by their entourage and/or able to count on the expertise and goodwill of the policy officer drawing up the plan (Franken, 2022).

General evaluations of personal budgets in different countries confirm that people with intellectual disabilities often face more obstacles to obtain a personal budget and, if they do, often consider the personal budget experience less positive. However, this could be remedied by support from family and caregivers, and professional assistance such as the client support worker in the Netherlands. The importance of the entourage and contacts should not be underestimated (see Information and communication; Communication skills and entourage) (Benoot et al., 2017; Anand, 2012).

Success factors

In general, there is evidently a clear differentiation by type of disability of (potential) budget holders. Informing themselves and being able to grasp all possibilities and necessary conditions for the personal budget often appears to be more difficult for people with intellectual disabilities. The case studies show, however, that much can be remedied if the person can be assisted by their relatives (family, friends, etc.) or by a professional contact person, such as the client support worker in the Netherlands (see Information and communication; Communication skills and entourage) (Benoot et al., 2017; Anand, 2012). While policymakers have little influence on informal contacts, the provision or encouragement of a well-developed contact organisation is an important issue. In addition, an easily accessible system, such as the automatic granting of a personal budget for persons in need of light support in Flanders can also support this subgroup. Other case studies (Germany, in particular) show that many people with disabilities who are in principle eligible for a personal budget are not (sufficiently) aware, nor (sufficiently) supported to obtain that budget. Exploring automatic granting of the personal budget (possibly in phases) would therefore be a significant step forward in accessibility.

LEVEL AND COMPLEXITY OF CARE/SUPPORT NEEDS

In the Netherlands, people with high support needs are generally more satisfied with their personal budget than people with relatively low support needs. An important reason for this is that the first group has to comply with far fewer obligations and often receives a higher amount without as much administrative effort (Molenaar, 2022).

In Ireland, people with higher support needs are generally more satisfied with a personal budget, as they can obtain it relatively easily (greater need is easier to prove) and receive a higher amount compared to those with low support needs. For the latter group, the (administrative) burden of proof to obtain (and maintain) a budget often does not match the benefit of the personal budget (Ryan, 2022).

Despite the potential advantages of a higher budget and reduced administrative burden in some countries for people with greater needs, there are potential disadvantages in respect of the personal budget in other countries. A complex support need often leads to a more complex process. This is



particularly evident in the application and indication phase, but also in the way in which a person with a disability must account for the use of their personal budget (Benoot et al., 2017). In Flanders, customised care is more challenging for people with complex care needs, who often have to combine different service providers and/or different types of support (personal budget, allowances for aids and adaptations, etc. (see Practices in four EU Member States), increasing the likelihood of coordination problems (Ceule, 2022). In countries where the regulatory framework of the personal budget is fragmented across different laws and agencies, this can have an even more negative impact.

In Germany, the fragmentation of the system means that a user with complex care needs who requires support from various bodies is sent from one to another. This is often because these agencies are often not sufficiently aware of the forms of support and options offered by others (Benoot et al., 2017).

Success factors

The impact of the individual's complexity and severity of care need on their experience of the personal budget is not entirely clear. On the one hand, it appears that in certain countries (Ireland, the Netherlands), those with a more intensive support need are more satisfied with the personal budget because of the higher amount and a relatively limited (administrative) burden of proof. On the other hand, complex care needs can add to the complexity and thus to the lack of clarity, especially if the person concerned has to apply to various agencies for help (Flanders, Germany). This is particularly true in highly decentralised systems with insufficient integration/cooperation between the various services. The importance of a more streamlined framework and greater uniformity cannot be overlooked (see Governmental organisation) can hardly be overestimated.

COMMUNICATION SKILLS AND ENTOURAGE

In the Netherlands, when accessing and obtaining the personal budget, there is a significant difference between people with disabilities who can express themselves well and those who cannot (Molenaar, 2022). This is because the extent to which a person with a disability identifies their care needs and is able to draw up a concrete plan to meet those needs is crucial to whether or not they obtain a personal budget (Benoot et al., 2017). A good entourage is essential for less communication-savvy people. Similarly, the role of the support worker can be of central importance, as these service providers can assist with advice and assistance where necessary (see Contact person) (Benoot et al., 2017; Molenaar, 2022).

A similar problem arises in Germany, where the plan determining the allocation of the personal budget must be signed by the person with a disability, thus it is vital that it is fully understood. Policy staff indicate that if the person with a disability is sufficiently well-able to formulate their needs and questions, they can obtain a personal budget more quickly, implying that the system is less accessible for people with certain types of disabilities (Benoot et al., 2017). Plans are often drafted in very technical formal jargon, which makes them much more difficult to understand (see Accessibility and control).



In response, user organisations (e.g. BAG) have created easy-to-read initiatives that focus on simple use of language tailored to the individual (Franken, 2022).

The communication skills of the person with a disability not only have an important impact when applying for the personal budget, but also when spending the budget. A double survey of persons with disabilities (in 2017 and 2018) in Flanders established that the majority needed help with administration and decision-making (Van Puyenbroeck et al., 2019). Only 27 % of the persons with disabilities stated that they could perform administrative tasks completely independently; 32 % needed a little help; 25 % asked for a lot of help; and 8 % gave the task completely to someone else. There is a risk that many people with a personal budget could be given too much autonomy too quickly and will not know how to handle it if they cannot count on sufficient (in)formal support. Accordingly, user organisations have been instructed by the government to profile themselves as information points (Van Puyenbroeck et al., 2019). Since 1 May 2021, people with disabilities who have a personal budget can apply for free membership and free assistance with an assistance organisation of their choice for the first year. This form of free assistance aims to ensure timely, correct and targeted use of the personal budget and can be particularly useful for persons with disabilities with high support needs but a limited entourage (VAPH, 2021). The person's linguistic abilities are an important factor that can influence the process throughout all phases, from registration to accountability (Benoot et al., 2017). In general, people with disabilities who have better communication skills can more easily express their care and support needs, improving their experience with the personal budget. However, this can be significantly mediated by the presence of a strong, committed network. This may be an informal network (family members, friends, etc.) or official bodies, such as the client support service in the Netherlands (Benoot et al., 2017).

An evaluation of the Ireland's pilot projects found that empowering a person with a disability can have a significant impact on their perception of the personal budget (Ryan, 2022). However, much depends on their direct entourage: if the person can count on family, friends, etc., or on representatives from formal networks for help and support, their limited language skills do not have to be an obstacle to making full use of the personal budget (Ryan, 2022). The research supports the importance of having a 'circle of trust' that the person with a disability can rely on. Indeed, having a good entourage (either informal or formal) has significant benefits for people with disabilities, providing support in making decisions while encouraging them to take control. However, the entourage can also have a negative impact – one major risk is that the person with a disability may not be sufficiently involved because they are 'treated like a child' and as if they cannot make decisions for themselves. Nevertheless, the importance of an entourage, especially for less language-savvy persons with disabilities, is hard to overlook (Fleming, 2016). The situation is different for people with disabilities who are mostly alone. Here, if they have poor communication skills, the personal budget can be a disadvantage because the freedom of choice that comes with the personal budget also places more responsibility on the individual (Ryan, 2022). Evaluations in the UK and Scotland showed that people with disabilities with limited communicative skills who are not adequately supported by an (in)formal network can experience the personal budget negatively, as it comes with too much responsibility and can have a suffocating effect (Pike et al., 2016).



Success factors

Communication skills are indispensable to smoother handling of the personal budget, both in the initial phase when expressing the care/support need and drawing up a plan, and in the eventual use of the budget. As the personal budget is demand-driven and the person themselves has far more decision-making power, the lack of such skills can be problematic. A good entourage can provide the necessary support, or, where no informal support exists, the formal contact person should encompass this support. It is crucial that such formal networks are developed if they are to fill the gaps in informal networks and ensure access to all subgroups of people with disabilities. If no such support exists, the freedom of the personal budget – which is generally seen as its biggest advantage – may instead be experienced as overwhelming. Contact organisations should place special focus on this vulnerable subgroup and make them a priority.

LIVING SITUATION

Location

In the Netherlands, two important laws for obtaining the personal budgets fall within municipal competence. Given the significant differences in accessibility between municipalities (see Accessibility and accountability), it is possible for two people with the same care/support needs to go through a completely different procedure. These differences can be considerable, as some municipalities have good, open policy, while others have a discouraging policy (Molenaar, 2022). This has been referred to as a 'postcode lottery' in which access to a personal budget – and indeed the options within that budget – differ according to local government interpretation of the policy (Benoot et al., 2017).

Similarly in Germany, the regions have substantial autonomy in the organisation of personal budgets. This leads to large differences, depending on where the person with a disability lives. These differences are evident in all facets of the personal budget, such as the allocation, size of the offer, and support by policy organisations and independent user organisations, etc. (Franken, 2022; Grieser, 2018; Benoot et al., 2017).

In Flanders, it is generally easier to find the necessary care and support in an urban context, where the supply is usually greater and adapted transport can be easily arranged (Ceule, 2022).

In Ireland, the fact that the pilot projects are generally limited to certain urban regions means that the place where a person lives plays a huge role in their chances of obtaining a personal budget (Ryan, 2022). In very rural areas, it is almost impossible for people with disabilities to obtain a personal budget. There is an urgent need for policy actions to introduce the personal budget nationwide (Ryan, 2022).



An evaluation study in the Netherlands showed that the place of residence of the person with a disability can have a significant impact on access to care and support, with a local offer more widely available in urban areas. This suggests that freedom of choice is seriously restricted in rural areas (Benoot et al., 2017).

Housing type

In the Netherlands, the personal budget has enabled people with disabilities to make the step from collective housing (institutions) to independent living. Thus, it not only increases freedom of choice in care and support, but can also be an important factor in increasing independence in living situations. This is seen by many people with disabilities as an important step forward. Many people who are involved in large-scale collective initiatives often report rather negative experiences with the personal budget because they cannot make full use of their freedom of choice and instead continue to live within certain restrictions. For people living in small-scale local residents' initiatives, however, the experiences with the personal budget are much more positive because they can choose tailored solutions (Molenaar, 2022).

In Germany, the personal budget can be an important incentive for people with disabilities to move from collective housing to their own home. The increased flexibility provided by the budget enables them to find solutions for care and support that could previously only be provided by a collective institution. This often leads to very creative solutions. One interesting example is the use of a baby monitor for a person who mainly needs support at night (Franken, 2022). Previously, the person could only be helped by a night nurse in an institution, but they now have a neighbour on hand to offer support when they call through the baby monitor. The personal budget can be used to pay the neighbour for this support, which would not have been possible with the traditional supply-driven financing model (Franken, 2022).

A large 2018 survey in Flanders found that a large proportion of recent movers cited obtaining a personal budget as having an impact on their choice of move: for 58 % of those moving from a collective dwelling to an individual dwelling; and for 43 % of those moving from an individual to a collective dwelling. It is not possible to ascertain whether the personal budget led to more persons with disabilities moving to individual housing as a result of the budget (Schepers et al., 2020). New personal budget beneficiaries are quicker to choose an individual form of living (Ceule, 2022). Persons with disabilities who have been living in a collective facility for a long time are less likely to make the step to individual living once they receive the personal budget (Ceule, 2022).

In Ireland, obtaining a personal budget in one of the pilot projects is only possible for people who live in an individual home and not for those who live collectively with a care provider with residential support, even though many would choose individual housing on receipt of a personal budget. This leads to a great deal of frustration among those who want to move (Ryan, 2022).

Success factors



A number of cases (Germany and the Netherlands) show that where the person with a disability lives can have a significant impact on the exact modality of their personal budget. Decentralisation leads to big differences in the allocation and amount of the budget. In addition, the spending possibilities and quality of service of contact organisations and care/support providers can differ considerably by region. This implies that people with disabilities with the same care/support need may have a completely different experience depending on where they live. The use of clear and objective criteria when setting out the policy can (partly) meet this need (see Governmental organisation).

On a positive note, the Dutch, Flemish and German cases show that having a personal budget has facilitated the step to more independent living for many people with disabilities. In this way, the budget contributes to the central objective of having more control over their own lives.



CASE OVERVIEW OF CONTEXT AND USER-RELATED FACTORS

Table 1: Case overview of *context* factors

Factors	Netherlands	Flanders (Belgium)	Germany	Ireland
Governmental organisation	Strong decentralisation leads to increased complexity due to insufficient integration/partnerships	More centralised structure but also complex due to the existence of parallel systems of other support measures	Strong decentralisation leads to increased complexity due to insufficient integration/partnerships	No consistent government policy leads to much uncertainty
Target group	Inappropriate use of the personal budget leads to stricter approach, which is detrimental for the right target group	Too few people receive a personal budget due to very long waiting lists and lack of coordination between scaling systems	Too few people receive a personal budget due to lack of communication and reluctance among service providers	Personal budget schemes are limited to pilot projects, thus a lot of people are unable to receive a personal budget
Accessibility	Complex administrative procedures (consequence of inappropriate use). Introduction of instrument to make the access procedure more objective	Relatively easy access for persons with light support need. People in need of more intensive support must meet a lot of (administrative) requirements	High level of fragmentation leads to very different experiences, depending on the organisation/region, and uneven access.	Very complex access procedure leads to high levels of non-take up
Information and communication	A relatively high number of people are adequately informed (based on surveys) but high regional differences exist due to quality differences between service providers	Perceived lack of information among certain subgroups. The provision of free intensive counselling courses is positive	Perceived lack of information among certain subgroups, with many potential beneficiaries unaware of its existence. Easy to read-initiatives aim to mitigate this lack of clear communication	No general communication policy means that the person is dependent on the goodwill of the pilot project organisers



Factors	Netherlands	Flanders (Belgium)	Germany	Ireland
Adequacy of the budget	Regional differences (due to high decentralisation) lead to low budgets in municipalities with a strict(er) budgetary policy	Relatively high proportion of people with light support needs consider the budget inadequate (based on surveys). This has a negative impact on their freedom of choice. People with more intensive support needs are more satisfied with the level of the personal budget (based on surveys)	Regional differences (due to high decentralisation) lead to low budgets in municipalities with a strict budgetary policy	/
Use of the budget	Despite the fact that the budget is not entirely freely disposable, the vast majority of budget holders are satisfied with the possibilities the budget offers	Budget holders can use (part of) the personal budget freely. Different surveys show that the large majority are very happy with this option, which maximises freedom of choice	Despite the fact that the budget is not entirely freely disposable, the vast majority of budget holders are satisfied with the possibilities the budget offers	Due to policymakers' reluctance to implement the personal budget, it is advised to keep the freely disposable part limited. Certainty that the budget will be used for care purposes is expected to enhance its acceptability
Available care and support	Freedom of choice is limited due to staff shortages in care and support providers	Staff shortages mainly in rural areas. Personal assistants are a bottleneck profession in certain rural areas	Freedom of choice is limited due to staff shortages in care and support providers. Certain providers are reluctant to provide their services to personal budget holders	Freedom of choice is limited due to staff shortages in care and support providers. There is a particular lack of personal assistants



Table 2: Case overview of *user-related* factors

Factors	Netherlands	Flanders (Belgium)	Germany	Ireland
Type of disability	Often more difficult to get access and too little support for people with intellectual disabilities	More difficulties in all phases (information, communication, use, etc.) for people with intellectual disabilities	People with intellectual disabilities often struggle with the important care needs plan. Easy to read-initiatives try to tackle this imbalance	/
Care/support needs	People with high support needs are often more satisfied with the personal budget because they may have to comply with fewer administrative requirements to receive a higher budget	Customised care/support is more challenging for people with complex needs. Combining services increases the likelihood of coordination problems	High fragmentation of personal budget schemes increases the risk of confusion for people with complex care/support needs	People with high support needs are often more satisfied with the personal budget because they may have to comply with fewer administrative requirements to receive a higher budget
Communication skills	The care/support needs plan is often a challenge for people with limited communication skills. The client support worker can be vital, especially where users cannot rely on family or friends	Individual communication abilities are an important factor in all phases (from registration to accountability). People with disabilities who have better communication skills can more easily express their care and support needs, which often improves their experience with the personal budget	The care/support needs plan is often a challenge for people with limited communication skills. Easy to read-initiatives and support from their entourage or service providers is crucial	If the person can count on people within their immediate entourage (family, friends, etc.) for help and support, limited language skills do not have to be an obstacle to make full use of the personal budget
Location	High level of decentralisation creates large differences in accessibility between regions. Two people with the same need but living in two different places may have to go through completely different procedures	It is easier to find the necessary care and support in an urban context, where the supply is usually greater and adapted transport can be more easily arranged	Regional differences manifest themselves in all facets of the personal budget. This high local autonomy leads to unequal treatment of individuals with the same need	Pilot projects are limited to a number of urbanised regions, making it almost impossible for people with disabilities to obtain a personal budget in rural areas. Nationwide implementation of the personal budget scheme is necessary



CONCLUSION

This research note investigated the extent to which the financing system of personal budgets for people with disabilities meets the central objective, i.e. increasing their freedom of choice to make their own decisions about their care and support. In contrast to a supply-driven model, where the person with a disability is often a passive actor, the aim of this demand-driven personal budget model is to enable the person to participate more actively in society. This is in line with Article 19 of the UN CRPD, which prioritises the rights for people with disabilities to live independently and to be fully included in the community. The success of the personal budget was examined from the perspective of the user, i.e. the person with a disability. The focus was mainly on practices in four EU Member States where personal budgets for people with disabilities have been implemented for some time (the Netherlands, Belgium (Flanders), Germany) or large-scale pilot projects have been set up (Ireland). Literature research (including several evaluation surveys of persons with disabilities) was combined with interviews with representatives of organisations defending the interests of persons with disabilities.

It is clear that the personal budget has considerable potential to increase the freedom of choice of people with disabilities. Compared to the traditional supply-driven model, the personal budget allows people to choose the care and support they buy, as well as when and how that care is provided. However, the degree of (perceived) autonomy and freedom depends on the exact modalities of the system. While in Flanders, the personal budget for people with a light support need, and part of the budget for people with an intensive support need, can be spent completely freely, in the other cases its use is limited to care purposes (although this term is often broadly interpreted). There is also an important difference in the way the personal budget is paid out. In the Netherlands and Germany, the personal budget is not actually handed to the person with a disability, or the service on which it will be spent has to be clearly shown beforehand. In Flanders, by contrast, the feeling of freedom is expected to be greater, as people with disabilities can decide themselves how the money will be spent. This is particularly true where the person with a disability receives their personal budget in cash (compared to the system with vouchers).

The increased freedom is apparent in the impact of the personal budget on the possibility of moving from collective care institutions to an individual home. Certainly in cases where (part of) the personal budget can be spent freely, the possibilities are far greater and give far more control to the individuals themselves. The evaluation studies show that the majority of people with disabilities are satisfied with the possibilities offered by the personal budget. In other words, the personal budget enables people with disabilities to adapt care to their lives rather than their lives to care.

Despite the clear confirmation of its potential, the application of personal budgets in the countries examined shows that this central goal (more freedom of choice) for certain (sub)groups may not always be foremost in practice.



The first observed gap is that many persons with disabilities who are, in principle, entitled to a personal budget do not receive it, due to long waiting times, a lack of coordination between implementing services, or a lack of information (some people with disabilities do not know about personal budgets as an option). In addition, some people do not want to receive the budget because the complex procedure and administrative burden of proof are overly onerous for the small amount received. This high degree of regulation and control is obviously detrimental to the feeling of freedom of choice.

The freedom of choice of people with disabilities who receive a personal budget can be limited in other ways. These include the amount of the budget, or a lack of offer from service providers (due to staff shortages and/or resistance from conservative providers), which prevents them from purchasing all the necessary support. In Germany and Ireland, this inadequate supply can lead to the conclusion that some people who receive a personal budget would be better off with the certainty of traditional supply-driven support.

The general administrative context in which the personal budget is embedded can have a significant impact, ranging from obtaining information on accessing the budget, to the possibilities within and the amount of the budget. A high degree of decentralisation often goes hand-in-hand with different treatment of people with disabilities with the same care/support needs, reinforcing inequality.

Recommendations

Organisation of the personal budget must meet a number of crucial conditions if it is to fully enable people with disabilities to organise their own care and support. Based on the user-related success factors for personal budgets, several recommendations can be made:

- To ensure equal treatment, the different processes for information provision, determination of the care/support need, and application for a personal budget should be harmonised to the extent possible. This is most important in highly decentralised systems where the various tasks are spread across different services. Integration or strengthened cooperation between services with the same range of tasks, and the use of clear and objective criteria when formulating policy are important elements. These streamlining processes should not prevent tailored approaches – flexibility remains important, as every situation is unique;
- A central contact point (or contact person) is an important element for the person with a disability. The certainty that they can always turn to the same place with questions or for support contributes enormously to the feeling of trust and (legal) certainty. This is particularly important for people with disabilities who are less able to communicate and/or cannot count on support in their closest surroundings. Without such trust, there is a danger that people will become overwhelmed in dealing with complex or difficult-to-access procedures. Vigilance will be needed for certain subgroups;



- As the size of the budget is a crucial element in being able to fully experience the ensuing freedom of choice, policymakers must not view the system of personal budgets as a cost-saving measure. Again, an assessment based on clear and objective criteria will help here;
- The modalities used to grant the personal budget (e.g. cash vs vouchers) play an important role in the (perceived) freedom of people with disabilities. The Flemish case study shows that the use of the cash option can increase spending options. In terms of housing, this implies that personal budgets can (partly) be used to receive support in the home environment, while vouchers can often only be used for support in residential institutions. As the primary purpose of personal budgets is to give the person with disabilities more control over their own life, the increased use of the cash option is preferable from a user perspective. It can have a significant impact on the process of deinstitutionalisation by facilitating receiving support in smaller housing initiatives or in the home;
- Another essential factor for persons with a disability to be able to make full use of the possibilities of the personal budget is the availability of a sufficiently diverse supply of care and support providers. The presence of a well-functioning market of providers, with a variety of options that allow for a customised approach, is indispensable. The increased competition resulting from the personal budget can result in poor quality providers exiting the market and being replaced by more innovative initiatives. Policymakers can therefore play an important role in facilitating innovation.

This research note provides an initial basis for determining the critical factors for the successful implementation of the personal budget, further research is needed to explore these factors in greater depth. For example, the direct engagement of persons with disabilities, as promoted by the UN CRPD and by the tagline 'Nothing About Us Without Us', should be an essential strand of any future research.



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APPENDIX

METHODOLOGY EXPERT INTERVIEWS

The experts received an email invite to an interview, stating the purpose of the research. They were asked to confirm their participation or their refusal, allowing a new expert from the long list to be invited in their place.

Following confirmation of participation, a number of interview dates were proposed, with an online meeting scheduled for the agreed date. If an expert was not available on any of the proposed dates, they were sent a number of new suggestions (via email) until a solution was found. Interviews were carried out with an expert from an organisation representing the interests of people with disabilities receiving a personal budget within each of the four case study Member States (the Netherlands, Flanders, Germany and Ireland).

Before the start of the first interview round, each expert received and completed an electronic informed consent form, including information on the purpose of the study and how the interview results would be integrated in the research note.

The interviews were conducted in May and June 2022 (see below). The interviews with the contact persons in the Netherlands and Flanders were conducted in Dutch and the interviews with the contact persons in Germany and Ireland were conducted in English.

LIST OF INTERVIEWED EXPERTS

Table 3: Overview of interviewed experts

Name	Function and organisation	Country	Interview date
Aline Molenaar	Director of Per Saldo, a national interest organisation for people with disabilities	the Netherlands	2 May 2022
Dave Ceule	Director of Independent Living, a national interest organisation for people with disabilities	Flanders (Belgium)	15 June 2022
Stephanie Franken	Board member of Bundesarbeitsgemeinschaft Persönliches Budget, an organisation representing people with disabilities with a personal budget	Germany	8 June 2022
Gordon Ryan	Director of AT Network, a user-led network that represents people with disabilities	Ireland	12 May 2022

QUESTIONNAIRE



A semi-structured questionnaire was used for the interviews, i.e. the questions were prepared in advance, but it was possible to deviate from the order of questions to clarify something or to pursue an interesting line of discussion raised by the expert.

Practical questions

- 1) Is it OK if the conversation is recorded (for processing only, not shared with others)?

Introduction

- 2) Can you briefly explain what your organisation does and what your function is?

Purpose and use of the personal budget

- 3) What do you think are the **main goals** of introducing personal budgets?
- 4) Is the personal budget **used for care purposes** or is it also used for other purposes?

General evaluation of the personal budget from the user perspective

- 5) What **possibilities** does the budget offer for people with disabilities?
 - In general
 - Compared to **traditional forms of service**?
- 6) What **restrictions** are experienced by persons with disabilities?
 - In general
 - Compared to **traditional forms of service**?
- 7) Does the **personal budget contribute** sufficiently to the independent living of the recipients?
 - To what extent? (enabling people to live in the community, guaranteeing financial autonomy, etc.)
- 8) Does the personal budget (partially) **meet the demand for care and support of people with disabilities**?
- 9) Do recipients generally experience **sufficient freedom of choice and flexibility**?
- 10) Do you feel that the recipients are **generally satisfied** with the personal budget?



Contextual (success) factors

Information and communication

- 11) Are persons with disabilities adequately **informed** about obtaining and using the personal budget?
- 12) Is it important to have the same contact person/organisation for those involved?
- 13) What do you think is still indispensable in terms of **communication** with the target group?
 - Importance of a single contact person/organisation

Target group

- 14) Do you think that the right people receive a personal budget in your country/region?
 - Are there certain people who are overlooked?

Amount and use of the budget

- 15) Is the size of the budget important for the successful operation of the personal budget?
 - What are important conditions regarding the amount of the budget?
 - On what basis should the budget be differentiated?
 - Is this happening sufficiently?
- 16) **Does** the personal budget sufficiently **compensate the additional costs caused** by the disability? To what extent?
- 17) Do you consider **a freely disposable part** of a personal budget as something positive? (This means that the budget does not have to be spent on care and support, but that the person with a disability can freely decide what to do with that part of the budget)

Support offer

- 18) Does the **support offer have** a significant impact on user evaluation of the personal budget?
 - What are important conditions?

Accessibility and non-take up

- 19) Is it **easy to** obtain a personal budget in your country/region?
 - Why yes/no?
 - What needs to change?
- 20) Are there **long waiting lists**?
 - If yes: How can this be solved (organisationally) in your opinion?
- 21) Is the non-take-up of personal budgets high in your country/region?
 - What is important to reduce or avoid this non-take up organisationally?



User-related (success) factors

Linguistic/soundness

- 22) Do the person's **language skills have** a significant influence on their experience with the personal budget?
- How can this be addressed (in case of bad experiences?)

Type of disability

- 23) Does the **type of disability** of the user significantly influence their experience with the personal budget?
- How can this be (better) taken into account?

Complexity of demand for care

- 24) Does the complexity of the care request have an impact on the user experience with the personal budget?
- How can this be (better) taken into account?

Living situation

- 25) Does the **locally available supply** determine the options for the user as to how to spend their resources? The distinction between the rural and urban context is often referred to.
- In other words, does the **place where a person lives** influence their experience?
 - If yes: What can be done about it? What is needed?
- 26) Does the **type of housing in which the person of a facility resides** (collective institution, individual, with/without assistance, etc.) have an impact on their experience with the personal budget?

Final questions

- 27) Are there any **other comments/suggestions** in the context of this study?
- 28) May what you have said be incorporated into the report in a way that can be attributed to you (by having your name in the list of interviewees of the report)? Or would you prefer this to be done anonymously?

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