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Feasibility of economic evaluation of personal budgets in Finland and preliminary evaluation plan

Diak

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FEASIBILITY OF ECONOMIC EVALUATION OF PERSONAL BUDGETS IN FINLAND AND PRELIMINARY EVALUATION PLAN

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ABSTRACT

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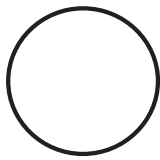
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Diak Puheenvuoro 26

[Diak Speaks 26]



One aim of social and health care services is to strengthen choice and control, involvement as well as empowerment of people with care or support needs. A personal budget (PB) is one way to achieve this. It is a sum of money a person can use for support and services corresponding to their needs, subject to agreed conditions. The personal budget approach is expected to increase the effectiveness of support and services, and reduce their costs or slow down the increase in costs – i.e. it is expected to be a cost-effective way of delivering care and support. Experience from personal budgets is mostly good, both internationally and in Finland, but little research evidence is available on the cost-effectiveness of personal budgets.

One of the tasks of the national project “The key to citizenship: participation, self-determination, freedom of choice and support through personal budgeting” (Avain kansalaisuuteen: henkilökohtaisen budjetointimallin avulla osallisuutta, itsemääräämisoikeutta ja valinnanvapautta, 2016–2019) was to determine the prerequisites for an evaluation of the cost-effectiveness of personal budgets – in other words, the prerequisites for economic evaluation. The project concluded that obtaining data from the organisations providing social and health care services about the costs and outcomes required in economic evaluation is currently extremely challenging.

The publication presents two preliminary economic evaluation plans that are based on different study designs and different data, to provide information on the cost-effectiveness of personal budgets. The publication also provides information on what is required to implement these studies. The economic evaluation, based on an experimental setting, requires the collection of an extensive body of data in cooperation with the organisations providing social and health care services.

The non-experimental study, based on register data, can only be realised once the collection of data in data systems and registers has been initiated, strengthened and standardised, and the requirements of economic evaluation have been considered in the development of the knowledge base.

Increased information on costs and outcomes and cost-effectiveness will support the development of personal budgets and social and health care services to achieve more choice and control, and as good a life as possible with the resources used.

This publication is intended for decision makers, practitioners and developers in social and health care to raise awareness of cost-effectiveness and economic evaluation, as well as what is needed to study the cost-effectiveness of personal budgets.

Keywords: Personalisation, personal budget, cost-effectiveness, economic evaluation, health and social economics, health and social services reform

Themes: Welfare and health

TIIVISTELMÄ

**Aija Kettunen &
Tuula Pehkonen-Elmi**

**HENKILÖKOHTAISEN BUDJETOINNIN
TALOUDELLISEN ARVIOINNIN TOTEUTETTAVUUS JA
ALUSTAVA ARVIOINTISUUNNITELMA**

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Tukea ja palvelua tarvitsevien henkilöiden oman roolin, itsemääräämisoikeuden ja osallisuuden vahvistaminen on tärkeää sosiaali- ja terveydenhuollossa. Yksi vahvistamisen tapa on henkilökohtainen budjetti (HB). Se on rahasumma, jonka ihminen voi käyttää omaehtoisesti tarpeitaan vastaavaan tukeen ja palveluihin sovittujen reunaehtojen mukaan. HB-toimintatavan odotetaan lisaavan tuen ja palvelujen vaikuttavuutta ja vähentävän kustannuksia tai hidastavan kustannusten kasvua – olevan kustannus-vaikuttava toimintatapa. Sekä kansainväliset että suomalaiset kokemukset henkilökohtaisesta budjetoinnista ovat pääosin hyviä, mutta tutkimustietoa henkilökohtaisen budjetoinnin kustannus-vaikuttavuudesta on vähän.

Valtakunnallisessa hankkeessa Avain kansalaisuuteen: henkilökohtaisen budjetointimallin avulla osallisuutta, itsemääräämisoikeutta ja valinnanvapautta (2016-2019) yhtenä tehtävänä oli selvittää henkilökohtaisen budjetoinnin kustannus-vaikuttavuuden arvioinnin edellytyksiä, toisin sanoen taloudellisen arvioinnin edellytyksiä. Hankkeessa todettiin, että taloudellisessa arvioinnissa tarvittavien kustannus- ja vaikutustietojen saanti sosiaali- ja terveydenhuollon järjestäjäorganisaatioista on tällä hetkellä erittäin haasteellista.

Julkaisussa esitellään kaksi mahdollista erilaiseen tutkimusasetelmaan ja aineistoon perustuvaa henkilökohtaisesta budjetoinnista kustannus-vaikuttavuustietoa tuottavaa taloudellista arviointitutkimusta ja sitä, mitä niiden toteuttamiseen tarvitaan. Kokeelliseen asetelmaan perustuva taloudellinen arviointitutkimus edellyttää laajaa tietojen keräystä yhteistyössä henkilökohtaista budjetointia toteuttavien sosiaali- ja terveydenhuollon järjestäjäorganisaatioiden kanssa. Ei-kokeellinen rekisteriaineistoon perustuva tutkimus on mahdollinen vasta sen jälkeen, kun tietojen kerääminen järjestelmiin ja rekistereihin on aloitettu, tietojen kerääminen on vahvistunut sekä yhtenäistynyt ja tietopohjan

kehittämisessä on otettu huomioon taloudellisen arvioinnin tarpeet.

Tiedon lisääminen vaikutuksista, kustannuksista sekä kustannus-vaikuttavuudesta tukee henkilökohtaisen budjetoinnin sekä sosiaali- ja terveydenhuollon kehittämistä siten, että kustannuksilla saataisiin mahdollisimman paljon itsemääräämisoikeutta ja hyvää elämää.

Julkaistu on tarkoitettu lisäämään päätöksentekijöiden, käytännön toimijoiden ja kehittäjien tietoa kustannus-vaikuttavuudesta, taloudellisen arvioinnin edellytyksistä sosiaali- ja terveydenhuollossa sekä siitä, mitä henkilökohtaisen budjetoinnin kustannus-vaikuttavuuden tutkimisessa tarvitaan.

Asiasanat: Henkilökohtaistaminen, henkilökohtainen budjetointi, kustannus-vaikuttavuus, taloudellinen arviointi, terveys- ja sosiaalitalous, sote-uudistus

Teemat: Hyvinvointi ja terveys

TABLE OF CONTENTS

PREFACE	9
1. BACKGROUND	11
2. PERSONAL BUDGET AS AN ELEMENT OF PERSONALISATION GIVING CHOICE AND CONTROL	15
Personal budgets in Finland under current legislation	16
What do we know of the costs and outcomes of personal budgets?	16
Research questions on the economic evaluation of the costs and outcomes of the personal budgets	21
3. PRINCIPLES AND COMPONENTS OF ECONOMIC EVALUATION	23
Personal budgets in the production of welfare framework	23
Questions guiding economic evaluation and types of analyses	26
Costs in economic evaluations	27
Outcomes and effectiveness in economic evaluations	27
Study designs for economic evaluation	30
4. PRECONDITIONS FOR ECONOMIC EVALUATION OF PERSONAL BUDGETS IN FINLAND	33
Personal budget scheme to be evaluated	33
Costs and data for calculating costs	34
Outcomes and collecting data on outcomes	35
Other issues related to the costs or outcomes of personal budgets	36
Potential evaluation designs	36
5. PRELIMINARY STUDY PROTOCOL FOR ECONOMIC EVALUATION OF PERSONAL BUDGETS IN FINLAND	39
Economic evaluation based on experimental design	40
Non-experimental economic evaluation based on register data	50
6. CONCLUSIONS: FEASIBILITY OF ECONOMIC EVALUATION OF PERSONAL BUDGETS IN FINLAND	55
REFERENCES	57
APPENDICES	63

PREFACE

The goal of a personal budget is to strengthen choice and control, involvement as well as empowerment of people with care or support needs. We often hear people say that personal budgets are also a cost-effective way of delivering care and support. It is believed that services purchased with a personal budget better meet people's needs, and are more effective and cost less than services delivered by other means. This publication examines this claim and asks whether it is justified, and presents a preliminary evaluation plan to investigate the subject. The goal is to promote awareness and understanding among decision-makers, practitioners and developers of cost-effectiveness in general in social and health care and the cost-effectiveness of personal budgets in particular, as well as awareness of the economic evaluation used to generate information on cost-effectiveness.

A certain type of personal budget was included in Prime Minister Juha Sipilä's government bill on the act on freedom of choice as a part of the Finnish regional government, health and social services reform. It was used as the basis for the evaluation plan in its early stages. When Sipilä's government fell, and the preparation of his government's regional government, health and social services reform ended in March 2019, there was no longer a clear-cut personal budgeting model to be implemented in Finland as a whole. This evaluation plan is therefore preliminary, as the evaluation object i.e. personal budgeting still requires further definition and agreement.

The preliminary evaluation plan was prepared as a part of the project "The key to citizenship: participation, self-determination, freedom of choice and support through personal budgeting" (Avain kansalaisuuteen: henkilökohtaisen budjetointimallin avulla osallisuutta, itsemääräämisoikeutta ja valinnanvapautta, 2016–2019). The project included pilot schemes on personal budgets not compliant with the proposed act on freedom of choice and investigated the prerequisites for an economic evaluation. In the project, managed by Metropolia University of Applied Sciences, six social and health care organisations, the cities of Hämeenlinna, Tampere and Vantaa, the social and health care co-operation district of Pori, South Karelia social and health care district and Kainuu social and health care joint authority experimented with personal budgets for groups requiring different

types of support or service, using courses of action that suited their organisations. Determining the prerequisites for economic evaluations and the preparation of a follow-up and evaluation plan were some of the tasks of the Diaconia University of Applied Sciences (Diak). At Diak, the person responsible for the work was Tuula Pehkonen-Elmi. Aija Kettunen was involved in the project's final stages. Support and comments from the Centre for Health and Social Economics of the National Institute for Health and Welfare were very important in the preparation of the follow-up and evaluation plan. For this, we wish to thank Taru Haula, Satu Kapiainen, Ismo Linnosmaa and Lauri Sääksvuori. We also wish to thank Professor Martin Knapp at the London School of Economics for his valuable comments.

The information and experience from “The Key to citizenship” project were crucial for this work. We therefore wish to thank all involved in the project. The project was made possible by ESF funding granted by the Ministry of Social Affairs and Health, for which we are grateful.

The views, interpretations and decisions expressed in this publication are those of the authors and not necessarily those of the commentators or the Ministry of Social Affairs and Health.

Pieksämäki, 15 May 2019

Aija Kettunen and Tuula Pehkonen-Elmi

As the publishing of this English version of the report was delayed, we had an opportunity to ask for comments on the evaluation plan from Dr John Woolham and Simon Duffy. They have supported “The key to citizenship” project by lecturing on their experiences and research related to personal budgets (Self-Directed Support in UK) in the seminars organized by the project. Their comments are of great value and will be considered in developing the evaluation. Therefore – with their permission – we have attached their comments to this report.

1 BACKGROUND

A personal budget (PB) aims to strengthen choice and control, involvement as well as empowerment of people with care or support needs. This is expected to make support and services more effective and reduce their costs or slow down the increase in costs. If these expectations are true, a personal budget is a cost-effective way of delivering support and services. The expectation of the cost-effectiveness of the personal budget approach is often raised, but no Finnish research data regarding it is available. This publication determines what the cost-effectiveness of a personal budget means, why it should be studied and what is required to conduct such a study. The prerequisites are made more concrete by presenting a preliminary evaluation plan for two potential support and service user groups of personal budgets. This publication is intended for decision-makers, practitioners and developers in social and health care.

Step-wise approach to develop complex interventions

When a new way of delivering services, such as the personal budget, is being developed, it should be consistently studied whether it will offer “more value for money” than the conventional course of action, i.e. whether it is cost-effective and with what prerequisites. In the case of the development and evaluation of complex systems such as personal budgets, a step-wise approach is recommended (Craig et al. 2008, Moore et al. 2015a and Moore et al. 2015 b):

- (1) During the development phase, the evidence base should be identified and the new way of delivering services should be modelled based on previous research data and experience. This is how the PB has been modelled in Finland.
- (2) During the pilot phase the feasibility of the model should be studied and developed further using small scale pilots. Several fairly small-scale PB pilot projects have been implemented in Finland, and the feasibility of PB has been looked into and developed.
- (3) To carry out a robust evaluation study, the feasibility of the evaluation methods, including measuring outcomes and costs, should also be studied and developed alongside the feasibility of the intervention. Evaluations of the

PB pilot projects carried out in Finland have been made, but no evaluation study that provides more robust evidence has been carried out, nor have the opportunities to carry out one been systematically studied. Very little evidence on the feasibility and cost-effectiveness of PB is therefore available (Economic Policy Council Report 2018, p. 104). The Key to citizenship project was used to clarify the opportunities to carry out a more robust evaluation study (Rousu 2019).

- (4) Once the new intervention has been drawn up and the prerequisites for an evaluation study are known, a more extensive pilot programme and a robust evaluation study are required. In the case of personal budgets, the study should generate evidence on their implementation and impact. The study should also include an economic evaluation to produce evidence on cost-effectiveness. The more extensive pilot programme and related evaluation study should guide more specific planning of implementation within the framework provided by current legislation, or the preparation of any new legislation. Furthermore, the evaluation study should provide information on which issues should be systematically monitored in future by, for example, entering data in client data systems. For example, the implementation of personal budgets in social care and health care were preceded by economic evaluation studies in England (Forder et al. 2012, Glendinning et al. 2008).
- (5) When reliable information on the feasibility, prerequisites and cost-effectiveness of PB is available, it is time to introduce the “improved” personal budget. Systematic collection of data on costs and outcomes must also be started alongside the introduction of personal budgets. The register data collected can be used to evaluate and study how PB works in changing real world environment.

The preparation of the Finnish act on freedom of choice, which was part of the regional government, health and social services reform ended in the spring of 2019 when Prime Minister Juha Sipilä’s government fell. The plan was to carry out pilot projects on the freedom of choice in compliance with related legislation before the actual implementation of the act. Some EUR 15 million had been earmarked for the implementation of the personal budget pilot projects. No resources had been reserved for an economic evaluation study, nor was any such study included in the evaluation plan of the pilot projects. The pilot projects were not implemented, because the proposed act was not passed by parliament.

What are the benefits of an economic evaluation?

An economic evaluation is a structured way to provide information on the outcomes and costs of various alternative courses of action and to compare them to determine which is best. It will help decision-makers to get the best out of available resources. Evidence from economic evaluation supports decision-making especially in social policy fields, where there is reason to suspect that the free markets without the state's influence will not lead to the optimal result. Health care is one such field (Arrow 1963, Barr 2014) where economic evaluations have been used to inform decision-making for decades (Drummond et al. 2015). The use of economic evaluations has also started in the field of social welfare (Knapp 1984, Sefton et al. 2002).

An evaluation study, including an economic evaluation, requires an understanding of the phenomenon being evaluated, which in this case is the social and health care system. The social and health care system is structured with the help of the production of welfare framework (Davies & Knapp 1981, Knapp 1984). The framework simplifies reality and makes visible key elements of the system and their interconnectedness.

Content of the publication

The second chapter describes the key principles of PB and includes a brief presentation of previous research. The chapter concludes with the research questions of the planned evaluation study. To determine the prerequisites for an economic evaluation of personal budgets, one must understand what an economic evaluation is all about and what is needed to carry out such an evaluation. The third chapter provides more information on economic evaluation, and structures the components and key questions of economic evaluation within the production of welfare framework. The fourth chapter studies the availability of the data needed for an economic evaluation of PB and the feasibility of the evaluation designs in the Finnish social and health care system, based on information and experience from the previous PB pilot projects and the Key to citizenship project (Rousu 2019). Finally, the fifth chapter presents two preliminary PB economic evaluation plans, based on different study designs and data, and discusses their feasibility.

2. PERSONAL BUDGET AS AN ELEMENT OF PERSONALISATION GIVING CHOICE AND CONTROL

Different systems and processes to implement personal budgets have been used in many countries for a long time. The implementation and focus areas vary, but the following general characteristics can be identified (see e.g. Rousu & Pekonen 2019, Karsio 2019, Perälä & Hiilamo 2019, Whellamms 2016):

PB is based on an assessment of needs, and it is an amount of money that a person can use for support and services corresponding to their needs, subject to a personalised care and support plan and agreed conditions. It is based on legislation that determines the person's right to support or services. The amount of money must enable the person to meet the needs agreed in the personalised care and support plan.

Personal budgets require a holistic human-oriented approach. Hence:

- The role and active participation of the person needing support are emphasised both when the plan is being prepared and when decisions on support and services are made
- The person can use the budget in ways which they find to support the goals specified in the plan and at the times they feel they need support or services
- The person will be provided with sufficient information on the determination and use of the budget, and they will be supported as necessary during all stages of the process.

Achievement of the principles of a personal budget also requires commitment from the organisation. The organisation must enable and support the systems and processes and provide the tools needed to implement the personal budget in practice.

Personal budgets in Finland under current legislation

Personal budgets were included in the proposed act on freedom of choice in social and health care services of Juha Sipilä government as one of the ways of promoting clients' freedom of choice. The preparation of the act ended when the regional government, health and social services reform failed in March 2019, but current social welfare legislation does not prevent the use of PBs to respond to support and service needs. Existing legislation emphasises people's needs, preferences and choice and control, encouraging the use of individual solutions that are supported as necessary. (Rousu & Pekonen 2019.)

A special characteristic of PB is that the support or service to be acquired can be something other than the traditional social and health care services that can be acquired with a service voucher, for example. One of the prerequisites is, however, that the service must respond to a need, or the service aims defined in the legislation, which entitles the person to receive the support or service specified in the personal plan. The opportunity to actually implement personal budgets in Finland is still poor, however. PB can be implemented through vouchers or invoicing procedures. Health and social services vouchers have also been used, but in such cases the service must be selected from among the services provided by approved providers. Cash can be deposited in the bank account of a private individual only if the intended use is clear and the person reports the use in a manner approved by the tax authorities. There are as yet no process framework, data systems or tools for the determination of budgets, and the data systems of the social and health care service organisers do not support access to the required data. Furthermore, the development of easy-to-use payment methods and systems to enable monitoring of PB has just started. (Rousu & Pekonen 2019, Rousu 2019.) In other words, PB is possible, but there are no clearly determined systems and processes that could be implemented in a standardised manner in Finland. This is one reason this evaluation plan is preliminary.

What do we know of the costs and outcomes of personal budgets?

International studies, of which only a few have been methodologically strong, highlight some of the outcomes of personal budgets. These results should be applied to Finnish society and the Finnish social and health care system with extreme care, however, as the social and health care systems and the implementation of personal budgets vary. Several methods to manage personal budgets are used in England, one of which is a direct monetary payment that allows a person to purchase

the services. The public sector or a third party manages the budget in the other cases. In the Netherlands, the budget is based on a centralised and standardised assessment of needs. (Whellams 2016, Hallituksen esitys eduskunnalle laiksi asiakkaan valinnanvapaudesta sosiaali- ja terveydenhuollossa ja eräiksi siihen liittyviksi laeiksi 8.3.2019.)

Most robust research has been carried out in England and the USA. The use of PB has been shown to increase satisfaction and the sense of control and feeling of empowerment, especially among the young and people with disabilities. For older people, PB has also been found to increase stress and it might become a burden. Some of the PB users require support from social or health care professionals or a third party to use the PB and benefit from it, and such support influences the costs of the PB. (Karsio 2019.) Furthermore, it has been noted that the opportunity to choose – even though people highly value it – does not always improve the service's desired outcomes. (E.g. Woolham et al. 2017, FitzGerald Murphy & Kelly 2018.) For example, a 2018 report by the Economic Policy Council for the Finnish government states that evidence on whether PBs improve the outcomes of the support and services received by people is insufficient. Effectiveness and the mechanisms that promote it in the case of PB and other ways of delivering services that promote freedom of choice require further study. (Economic Policy Council Report 2018 2019.)

International studies on costs and outcomes of PB

The evidence-base on the costs and cost-effectiveness of PB is weak. (Karsio 2019.) John Woolham and Chris Benton (2013) observed that the costs of PB users in England were higher than those using conventional ways, even though the users feel that they benefit from the PB. In the Netherlands PB was found to increase the use of services and encourage people to purchase more expensive services, both of which increased the costs of the PB (Juntunen 2010, Van den Berg & Hassink 2008). Costs may also be higher because the use of private services increases the indirect costs and reduces the economies of scale for public service providers (Foged & Houlberg 2015, according to Karsio). According to an evaluation study conducted in England, the use of a personal health budgets did not influence the costs or increase people's health-related quality of life. It did increase their social care-related quality of life, however, and was cost-effective when the outcomes were measured based on people's social care-related quality of life. Budgets were cost-effective for people who needed continuing health care and people with mental

health problems. (Forder et al. 2012.) According to a previous personal social care budgets evaluation study (Glendinning et al. 2008), the PB did not influence costs but improved quality of life, particularly in the case of young disabled people and people with mental health problems.

Research on costs and outcomes of PB in Finland

There are even fewer studies on the costs, outcomes and cost-effectiveness of PBs when implemented in the Finnish social and health care system, although several pilot projects and experiments have been conducted. Typically, the experiments have concerned the development of the process framework rather than collecting robust evidence on the outcomes and costs. (See also Karsio 2019, Economic Policy Council Report 2018 2019.)

The city of Helsinki conducted a PB experiment in its elderly services in the project Lauttasaaren asiakaskeininen palveluverkko in 2010–2013 (Soini et al. 2013). The PB target group consisted of families receiving support for informal care where the family member being cared for was over the age of 65 (some 50 families). Vouchers and existing health and social services vouchers were used to implement the PBs. User experiences were positive: the attitude of the companies involved towards the experiment was positive, and the families getting support for informal care were satisfied (Soini et al. 2013, pp. 48–49). The quality of life of those receiving support for informal care was also studied during the project period, but not in an attempt to determine the outcome of the personal budget on the quality of life (Soini et al. 2013, p. 53; Linnosmaa 2013). No information on the impact of PB on costs was found in the report either.

The city of Tampere also conducted an experiment involving informal carers in 2014 (Sola et al. 2015). This experiment was carried out with vouchers. A total of seventeen dyads were selected for the experiment. They were given the opportunity to use the allocation of resources intended for statutory caregivers' respite more freely to purchase services they needed. The status of the families and caregivers was surveyed at the beginning and end of the experiment period. In most cases, the health or physical wellbeing of the caregivers had not changed, but many of them felt that their mental wellbeing had improved, and they were able to cope better with their workload. The opportunity to make decisions made them feel that their caregiving was appreciated. On the other hand, some of them felt that using and managing the PB was initially distressing. (Sola et al. 2015, pp. 27–37.)

The Finnish Association on Intellectual and Development Disabilities and the Service Foundation for People with an Intellectual Disability experimented with personal budgets in 2010–2013 (Ahlstén 2014). The outcomes of PBs were mainly studied through theses with a small number of clientclients. In her thesis, Elina Ristimäki (2013) concluded that the choice and control, independence and quality of life of the clientclients somewhat improved or remained unchanged.

At the time of the writing of this publication, **the service voucher experiment is in progress as part of a Government key project called Palvelut asiakaslähtöisiksi** (Services responsive to client needs, 2016–2018); the experiment will continue during 2019 (Valtioneuvosto. Sosiaali- ja terveystieteiden ministeriö. Palvelut asiakaslähtöisiksi). One of the three themes related to the freedom of choice is personal budgets. An experiment on personal budgets in six regions is being conducted, applying the Act on Social and Health Care Service Vouchers (laki sosiaali- ja terveydenhuollon palvelusetelistä, 569/2009) and the Act on Client Charges in Healthcare and Social Welfare (734/1992). Some EUR 18.5 million has been granted for the PB experiments, and there was a total of 115 PB clients at the beginning of December 2018. Most of the clients are people who require services for the elderly or services for the disabled, but there are also clients who require other services (Valtioneuvosto, Maakunta- ja sote-uudistus 2018). The experiment will be evaluated, and the goal of the evaluation is to gauge the changes in clients' functional capacity and costs. (Henkilökohtaisen budjetin kokeilujen arviointi. Palvelusetelikokeilu 2019, p. 3). Information on the changes in functional capacity and quality of life has been collected by means of surveys, interviews, separate follow-ups and an RAI (Residential Assessment Instrument) follow-up. The evaluation included a clientsurvey to which 40 clients replied. (Henkilökohtaisen budjetin kokeilujen arviointi. Palvelusetelikokeilu 2019, p. 13, p. 14). The funding provider did not require the parties receiving the experimental funding to commit to any comparison or the provision of any related evaluation data. The experiments will not therefore provide robust evidence on the costs or outcomes of the personal budgets when compared to other ways of delivering the services. Without such a comparison, it is difficult to interpret which changes are due to PBs, and which are due to other factors. The necessity of comparison is also stated in the evaluation report (Henkilökohtaisen budjetin kokeilujen arviointi. Palvelusetelikokeilu 2019, p. 22). According to the report, *“the impact of the personal budget on the client's functional capacity or quality of life*

cannot be reliably verified on the basis of the evaluation observations” and “it is likely that the personal budgets have not influenced the client-specific costs when compared to a situation where the services are provided as public services” (Henkilökohtaisen budjetin kokeilujen arviointi. Palvelusetelikokeilu 2019, p. 16–17; see also p. 15). The evaluation came to the conclusion that *“the effects on costs should be monitored and evaluated during the further funding”*. Regarding evaluation development needs, the report mentioned the statistical monitoring and separate evaluations, and especially the need *“to measure the effects of other ways of delivering services with the same indicators to enable comparability”*. (Henkilökohtaisen budjetin kokeilujen arviointi. Palvelusetelikokeilu 2019, p. 17, p. 22)

The Key to citizenship project studied the availability of data on the costs and outcomes that is required for an economic evaluation of PBs. As five out of six piloting municipalities were involved in the project without any additional funding, no actions that would require a large amount of additional work to provide the necessary data could be expected of them. Hence, the The Key to citizenship project clearly indicated the prevailing situation in the municipalities in terms of the documentation and provision of the data on outcomes and the inability of the current data systems to provide client-specific cost data. The project determined that without a conscious effort in the development of standardised recording of data on the outcomes and client data systems, financial administration as well as human resources (HR) systems, a study of cost-effectiveness based on register data is not possible. If the evaluation of the costs and outcomes is to be carried out as a separate study, a clear study design and resources to carry out the study for the researchers and the municipalities responsible for organising the services will be required. Cooperation with the municipalities will be absolutely necessary to create a personal budget study and control groups, as well as to collect the required data on costs and outcomes. (Pehkonen-Elmi & Kettunen 2019.)

The government’s plan was to continue the personal budget experiments in **“freedom of choice pilot projects”** once the act on freedom of choice was approved (Sosiaali- ja terveystieteiden ministeriö 2018). In the spring of 2018, a total of EUR 15 million had been earmarked for four areas responsible for organising social and health care services for conducting the personal budget pilot projects (Valtioneuvosto. Maakunta- ja sote-uudistus. Valinnanvapauspilotit; Finnish Government 15 May 2018. Valinnanvapauspilottien rahoitus). As the preparation of the regional government, health and social services reform halted in the spring of 2019, the freedom of choice pilot projects were not given permission to start.

Research questions on the economic evaluation of the costs and outcomes of the personal budgets

As the evidence-base on the costs and outcomes of personal budgets compared with other ways to deliver services is weak, there is a need to conduct an economic evaluation of personal budgets.

The evaluation's general aim would be to improve the evidence-base on the outcomes and costs of personal budgets and increased freedom of choice.

The more specific research questions would be:

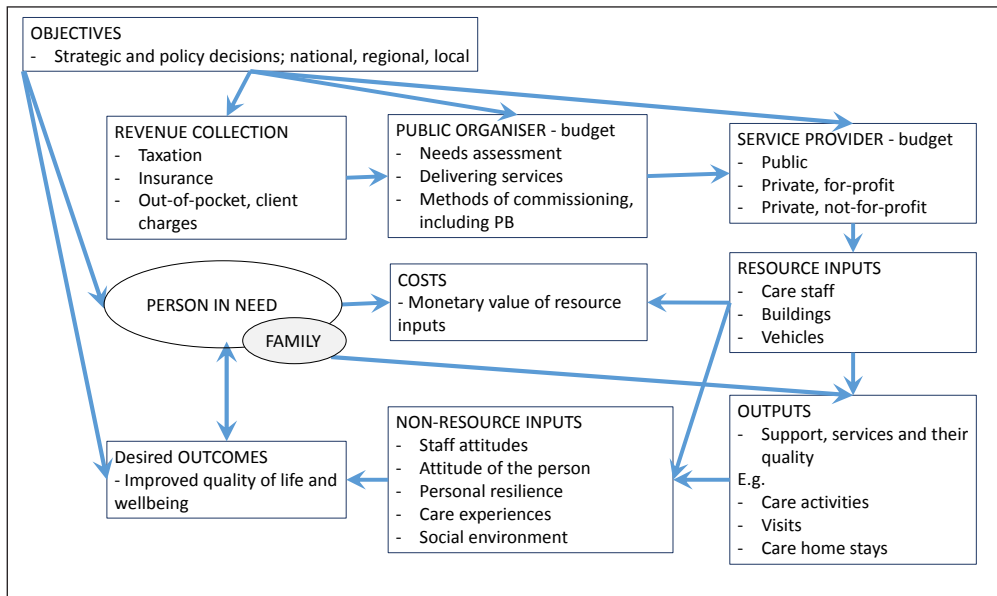
1. How do personal budgets and increased freedom of choice influence in choice and control, experiences of support and services and the wellbeing outcomes for individuals needing support?
2. What would the costs of personal budgets be?
3. Are personal budgets cost-effective?
4. Which factors promote or prevent the cost-effectiveness of personal budgets?

3. PRINCIPLES AND COMPONENTS OF ECONOMIC EVALUATION

This chapter presents the economic evaluation, focusing in particular on what is needed to conduct such a study. The preliminary evaluation plan is a description of what these necessary elements mean if the economic evaluation focuses on PB, i.e. what is required for an economic evaluation of PB. The evaluation object is summarised with the help of the production of welfare framework before presenting the preliminary study protocol for an economic evaluation. (Drummond et al. 2015, Sefton et al. 2002, Knapp & Kettunen forthcoming.)

Personal budgets in the production of welfare framework

An economic evaluation focuses on how resources should be used to achieve as much of the desired outcomes as possible – in the case of social and health care services, as much health and wellbeing as possible – for those in need of support. When one tries to determine whether personal budgets would increase desired wellbeing without increasing costs or whether wellbeing could be achieved with lower costs, one must understand the system in which decisions on services and support are made. The production of welfare framework describes this and the key connections between needs, resources, outputs and outcomes. The framework simplifies the reality to facilitate the understanding of connections and factors. The framework was developed by Bleddyn Davies and Martin Knapp (Davies & Knapp 1981, Knapp 1984), and it has been used as a conceptual framework in economic evaluations in the social welfare field especially in the United Kingdom. It focuses on questions faced by people who make strategic decisions and other decisions. Hence it assists in the formulation of economic evaluation questions, the pinpointing of components and the interpretation of results. Figure 1 is an adaptation of the production of welfare framework to the Finnish social and health care system, in which PBs are also used.



- The starting point is that the **person who needs support and assistance** and their families know their situation and needs.
- In the service system, the recognised needs are defined by reference to national, regional and local **objectives** that also determine desired outcomes. The needs and goals to be supported are concretised in laws and regulations, as well as in local and regional decisions and guidelines. These influence services, resources and the conditions of service providers.
- **Funding** is required. It is collected as taxes and in part as insurance contributions, and a share of it is paid by people themselves. The funding is required to acquire **resources** that are needed to provide support and services. In the case of social and health care services, an important resource is the people; the paid staff. The families are also a resource, as the time they spend also has a monetary value. Furthermore, costs arise from buildings, tools and supplies.
- The **organiser of the services** ensures that the person receives the support they need and that the **funding** is used to cover the **costs** incurred by the service provider. In many cases, some of the prerequisites are a needs assessment, an individual plan made based on the assessment and a decision on the right to receive the support or services. The organiser's budget is a factor that enables support and services, but also one that restricts them. The support from family members and other unpaid carers also creates costs, because their time is limited and has – as economists call it – an opportunity cost.
- **The services – care and support – are provided** by public providers, private enterprises or not-for-profit often third sector providers, enabled by the funding they receive. Family and other unpaid carers also provide care and support. The organiser can guide the person to services provided or purchased by the public sector, offer them a health and social services voucher that they can use to select a service provider from a group of approved service providers or plan a personal budget that the person can use to

purchase the support or services they need and that are linked to the aims documented in their individual plan from a party they deem suitable.

- The support, care, services and their quality are **outputs** that seek to achieve the desired positive outcomes and other **outcomes** in the lives of the people who need the support. Outcome can be a better quality of life and wellbeing that could reduce people's need for support. A desired outcome could also be the slowing down of the deterioration of the quality of life, for example. When an economic evaluation uses the concept of effectiveness, it refers to an outcome that is known to have been caused by the activity being evaluated, i.e. where the causality is known.
- There are also **non-resource inputs** which act as mediators between intervention (services) and outcomes, and which strengthen or weaken outcomes. Unlike regular resources, non-resource inputs cannot be bought from markets, which is why they do not have any 'price'. The attitudes of care staff is an example of a non-resource input: care given by a friendly carer improves the quality of life more than care given by an unfriendly carer. The atmosphere of the entire organisation, such as a care home, is also a non-resource input. Other important non-resource inputs are the attitude of the person in need of support themselves, their willingness to cooperate, their motivation and their resilience. These are personal characteristics, but they can also be linked to previous experience. Attempts to change the attitude of the person in need of support can be made.
- When using PBs, the goal is to increase the effectiveness of support and services with a resource-based approach and by supporting the person's choice and control and, therefore, the person's own non-resource inputs.

FIGURE 1. The Production of Welfare framework (modified from Knapp & Kettunen forthcoming)

PB may be seen as a link between the organiser and the services provided to the person who needs the support and services. PB is expected to make support and services better meet their needs and thus to strengthen wellbeing outcomes. The message of the production of welfare framework is that the ability of a system to respond to people's need for support and services depends on the resources available – the quantity, type and use of the resources – as well as on the support and services provided, whose effects on wellbeing are mediated by non-resource inputs. Needs to be supported and related goals – who is entitled to receive publicly funded support and services, and in which situation – are laid down in laws and decrees that are often further specified and interpreted regionally, locally or even by organisations. Decisions on the needs to be supported and the support and services granted to specific people are linked to resources and funding, and the channels along which funds flow to the production of support and services. The assumption is, however, that decision-makers at different levels would like

the resources to get the best outcomes for the people in need of support and, in a broader sense, for the wider community.

In the PBs, the effects of support and services are boosted by a resource-based approach that strengthens individuality, choice and control and involvement to also engages the person's own non-resource inputs. When the role of the person in need of support is strengthened in the definition and selection of the support and service, the assumption is that the service will better meet that person's needs.

Questions guiding economic evaluation and types of analyses

Economic evaluation is guided by two questions: firstly, whether the activity being evaluated is effective in the sense that it produces the desired outcomes. In social and health care, the outcomes are related to people's health and wellbeing. If the activity is effective, the second question concerns costs: what are the incurred costs; and whether the outcomes are worth the cost of the resources needed. In other words, whether you get value for money (Knapp & Kettunen forthcoming). The goal is to find the course of action, where the relationship between the desired outcomes and the costs needed to achieve them is the best. Hence, an economic evaluation requires the comparison of at least two courses of actions or interventions. One of the options may be – and in many cases is – the 'conventional'. There are therefore four principal components to an economic evaluation:

1. Two or more courses of actions or interventions to be compared, and an evaluation design that enables the comparison.
2. The desired wellbeing outcomes of the compared courses of actions or interventions for the person who need support or services during the period being considered.
3. The costs arising from the courses of actions or interventions being compared during the period.
4. A method that helps choose the best option when one of the alternatives is more effective, but its costs are higher. In such a case, the question is how much the additional outcomes are valued and how much one is willing to pay for them. (Drummond et al. 2015; Knapp & Kettunen forthcoming.)

Economic evaluations can be conducted using three main types of analysis: a cost-effectiveness analysis, a cost-utility analysis and a cost-benefit analysis. Cost-effectiveness is also used as a general concept to describe the economic evaluation and its results. The conceptualisation and measurement of costs follow the same

principles in all types of analysis. The outcomes are also understood in the same way at the general level, but the types of analysis differ from each other in how the outcomes are specified and measured. The definition of outcomes and choosing the outcome measures also influence the usability of the different types of economic evaluation at different levels of decision making.

Costs in economic evaluations

In an economic evaluation, the term “costs” refers to the monetary value of all the resources for the organisation, provision and use of services, and the goal is to determine the overall costs. Costs can arise directly from work, materials and supplies needed for the provision of the service, and also from administration and properties, for example. Furthermore, the users of the support or services and their family members incur costs for travelling and time they would have otherwise used differently, such as for recreational activities, voluntary work or gainful employment (opportunity costs). Absenteeism also causes costs for employers (productivity costs). Other service sectors may also incur costs: social support and services may affect the use of health care services, for example.

In practice, costs are calculated by combining data on the amount of usage of the support or services, and the unit costs of each resource. For example, the number of working hours is multiplied by the costs of one working hour. In Finland, the National Institute for Health and Welfare publishes a report on the average nationwide social and health care service unit costs at specific intervals (Kapiainen, Väisänen & Haula 2014). Use of the national unit costs allows for a comparison of evaluations. If the unit costs are to describe the costs of the organisation or location studied, they must be evaluated on a case-by-case basis.

The starting point for an economic evaluation is the consideration of all costs incurred by all parties involved. However, the **perspective** of one of the parties involved, such as a public service organisatiser, is often selected. As the perspective determines which costs and savings are considered, the choice of perspective must be clearly described. The selected perspective can also influence the selection of outcomes and outcome measures.

Outcomes and effectiveness in economic evaluations

The intention of an economic evaluation is to identify courses of action that generate the best outcomes from the resources deployed. Hence, an economic evaluation cannot be conducted without information on the desired outcomes. In the social welfare field, aims are often loosely defined, and operationalising

them is challenging. This means that the definition of outcomes and choosing the outcome measures is also challenging. In addition, there is discussion concerning who and at which level should decide the goals: those who fund or decide of the support and services (public sector decision-makers and professionals) or the people who need services. This is also related to the definition of outcomes and the selection of outcome measures. (E.g. Brouwer et al. 2008; Drummond et al. 2015, 31–37; Coast, Smith & Lorgelly 2008; Greco, Lorgelly & Yamabhai 2016; Layard 2016; Mitchell et al. 2016.)

In the context of economic evaluation, the term **effectiveness** refers to the desired change, the benefit that the evaluated activity causes. According to Finnish health economists Harri Sintonen and Markku Pekurinen (2006, p. 53), *“The effectiveness of an activity simply refers to the net change in the ultimate aim of the activity that can be attributed to the activity...”* To evaluate effectiveness, the activity to be evaluated must be determined and described so clearly that it can be repeated in a (sufficiently) consistent manner. One must know what kind of activity (intervention) is being evaluated, i.e. what is effective.

At least two measurements must be taken to detect the change (before and after the intervention), but a comparison is usually required to verify that the change was caused by the activity. If any change is detected, a before-and-after examination cannot reveal whether the change was caused by the activity being evaluated or by another factor.

The outcomes evaluated in the field of social and health care should primarily be related to people’s wellbeing, which can refer to physical health, mental health or social wellbeing, depending on the aims of the service. A person basically evaluates their own status. Also the consequences of the wellbeing outcomes, such as employment, a reduction in school absences, fewer days in hospital or the ability to continue living in one’s own home, have been used to describe the outcomes.

In an economic evaluation, the measures must either be quantitative or it must be possible to convert them into quantitative scale, because the ratio between outcomes and costs must be calculated. A reliable measure requires testing, which is why measures that have been previously used, tested and standardised are recommended for evaluation studies. Furthermore, comparison with previous studies is possible when using measures that have been previously used. However, there are very few standardised measures that describe the final outcomes linked to the aims of services in the social welfare field. There are more such measures in the field of health care. However, when using a standardised measure, one must ensure that it measures what one wishes to explore. (E.g. Drummond et al. 2015;

Sefteon et al. 2002; Knapp & Kettunen forthcoming.)

It was previously mentioned that the outcome measures differentiate the economic evaluation types. In a **cost-effectiveness analysis**, the outcomes are measured using ‘natural’, simple and specific measures. In health care, these can be increased life expectancy, blood pressure or blood glucose levels, for example. Identifying ‘natural’ indicators is more challenging in the case of social welfare. In any case, the outcome measures must describe the changes related to the needs of or the aims of the service for the specific group in need, which means that the evaluation results of different services or need groups cannot be compared.

The aim of the support or service may be improved quality of life across several aspects of a person’s life. In such a case, several cost-effectiveness analyses for all the important outcomes can be conducted. This is also called a cost-consequence analysis. Another option is to combine the different aspects of a person’s life into a single measure. As the significance of the different areas varies, a study of how the population values the different areas can be conducted before the measures of different domains are combined. For example, the valuations of the components of the ASCOT measure (described in more detail in Chapter 5, Economic evaluation based on experimental design) in the Finnish population were studied (in the EXELC project; the preference weighting has not been published yet). ASCOT is also an example of a generic outcome measure that can be used across different adult groups and services that aims to support the independent lives of adults (adult social care). (E.g. Drummond et al. 2015; Sefteon et al. 2002; Knapp & Kettunen forthcoming.)

A **cost-utility analysis** is used particularly in health economy evaluations. In such cases, the outcomes are measured as utilities – quality-adjusted life years (QALY). A special benefit of quality-adjusted life years is that the same outcome measure can be used as a generic measure in health care across different disease groups or treatments. For generating QALYs, the most common measure used to evaluate health-related quality of life is the EQ-5D, and in Finland the 15D measure developed by Harri Sintonen (2001). The quality of life is then multiplied by the length of life. Very few similar utility measures have been developed for economic evaluation in the social welfare field. There is the English ASCOT measure (Netten et al. 2012). ICECAP (Proud et al. 2019; Goranitis et al. 2017; Coast et al. 2015) is also a generic measure across different groups, but it is not used to describe “life years”; instead, it is used to describe years during which a person has enough functioning and ability to achieve things that are important to them (“years of full capability” or “years of sufficient capability”). ICECAP-A is

described in more detail in Chapter 5, Economic evaluation based on experimental design.

A **cost-benefit analysis** allows for a comparison that is even more extensive than a cost-utility analysis. Unlike other economic evaluation types, a cost-benefit analysis evaluates both costs and outcomes in monetary terms. One should emphasise that the word “benefit” does not refer to savings; rather, it refers to wellbeing outcomes expressed as a monetary value. If outcomes converted into money (benefits) exceed costs, the course of action is recommended from the perspective of economic evaluation. If a cost-benefit analysis could be conducted in social and health care, the social and health care sector could be compared with activities in other sectors of society. Techniques valuing outcomes in monetary terms have been developed, but converting wellbeing outcomes into monetary units is especially challenging and controversial. (See Drummond et al. 2015, pp. 181–217, for example.)

As broader comparisons are desired but monetising wellbeing outcomes is controversial, subjective wellbeing as the objective and as a general outcome measure of all policies has been raised in recent decades. All policies in society should promote people’s subjective wellbeing. A discussion of measures describing subjective wellbeing is underway, and these measures are being developed. (See, for example, Mukuria et al. 2016, Dolan et al. 2017, Wright & Peasgood 2017.)

Study designs for economic evaluation

An economic evaluation uses a comparison to determine whether the changes are caused by the activity being examined. **Experimental designs** are considered the most rigorous. In this study design, two groups as similar to each other as possible are formed. One of the groups, the study group, uses the intervention being evaluated, and the other, the control group, uses another, usually the conventional one. When the groups are randomly assigned (RCT; randomised controlled trial), they can be expected to be similar in all other respects except the intervention. In such a case, one can be (almost) certain that any differences detected between the groups after the activity is complete were caused by the activity being evaluated. “In real life” and in the field of social and health care in particular, a study design based on randomisation is considered challenging for many reasons. Ethical factors and the fact that people cannot be randomly left outside the scope of support or services are often emphasised. **Quasi-experimental designs**, where groups are ‘naturally’ formed, are easier to implement. Such groups are formed, for example, when a new initiative is gradually introduced or introduced at different

times in different areas. (E.g. Drummond et al. 2015; Sefteon et al. 2002; Knapp & Kettunen forthcoming.)

An **economic evaluation based on register data** uses data generated during everyday life that is saved in registers. For an economic evaluation to be possible, standardised register data on the users of the services, their needs, achievement of desired outcomes, costs, as well as factors related to achieving outcomes and incurring costs must be available. The analyses are conducted using statistical methods. **Modelling** refers to using previous research results and a variety of available data. The reliability of the results depends on the reliability of the data used. (E.g. Drummond et al. 2015; Sefteon et al. 2002; Knapp & Kettunen forthcoming.)

4. PRECONDITIONS FOR ECONOMIC EVALUATION OF PERSONAL BUDGETS IN FINLAND

The preconditions for an economic evaluation of PBs are studied based on experience obtained from previous experiments. We discuss whether personal budgeting is defined in a manner that allows its evaluation, whether the required data on costs and outcomes is available and what the prerequisites are for the study designs (Figure 2).

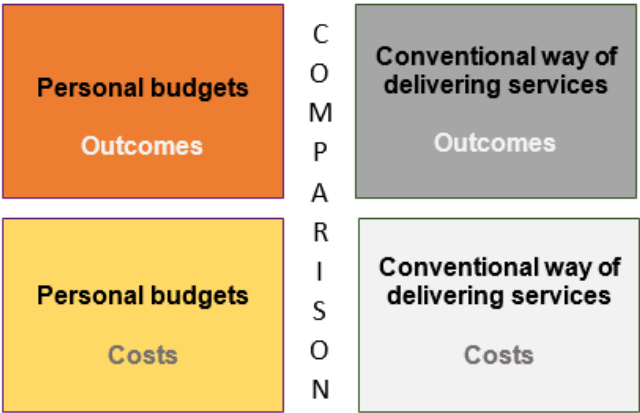


FIGURE 2. Elements of the economic evaluation of personal budgets

Personal budget scheme to be evaluated

The evaluation requires that the activity being evaluated has been determined and described clearly. The personal budgets have been developed by several projects, experiments and pilot projects. The general principles of PB guided the experiments, but there is currently no concrete, generally agreed personal budget process framework. Before conducting the economic evaluation, the process framework of personal budgets must be described in a manner that will allow its implementation in the same way in all the organisations participating in the economic evaluation. Issues that need to be determined in more detail and on which agreements must be made include the client process, the determination of

the level of funding to be made available for a PB, the enabling of support for the PB holder, limitations on the use of the PB, means of payment and monitoring of the use of the PB, as well as managing the changes in PB and abandoning the PB.

The comparator is the conventional way of delivering services where the professional has a stronger role. A professional can offer social and health care services that the organiser has purchased from public or private providers. There is also an option to give a health and social services voucher for buying services from approved health and social care service providers.

Costs and data for calculating costs

When the costs of support or services delivered by a personal budget are compared to the costs of other ways of delivering, the costs arising from the organisation and the costs arising from the actual services must be taken into account. The costs to the organiser of the service and the client and their families should be studied separately, as the PB can cause – and is even expected to cause – changes in the allocation of costs. (Pehkonen-Elmi & Kettunen 2019.)

Data on the services and support used, the number of working hours the professionals used, the facilities and equipment used, as well as administration costs and other related overhead costs is required. Furthermore, data on the time used by those who used the support or service and their family members and any other costs they incurred, such as travel expenses, and time used by any PB support people other than professionals or family members is also required. (Pehkonen-Elmi & Kettunen 2019.)

At present, this information is very challenging and laborious to obtain. The financial administration and human resources (HR) systems used by Finnish municipalities have been designed to monitor the budget for individual units, cost pools or tasks, for example. As the systems do not support the collection of client or client group specific data, and the data can be spread across several systems that do not “talk to each other”, the required data on support and services and their costs must be manually collected. Some of the information has to be obtained directly from the users of the support or service. Comparison of the costs arising from the work of professionals offering PB and others using conventional ways of delivering services requires working time monitoring, which is considered arduous. (Pehkonen-Elmi & Kettunen 2019.)

Municipalities are not accustomed to considering costs incurred by parties other than the organiser itself. In PB, however, some duties might move over to the PB user and their families, which means that some of the costs will be incurred

by them as well. To evaluate the costs arising from the work done by the PB support people other than professionals or family members (if any), information on the duties and working hours of the support people is required. This piece of information must also be collected from the PB users and their families. (Pehkonen-Elmi & Kettunen 2019.)

Outcomes and collecting data on outcomes

When the outcomes of the support and services delivered with PBs and the methods to be compared are determined, the starting point will be peoples' needs and the support and services required to meet the needs in the lives of the people being supported. Aims are determined by legislation, according to which people are entitled to the support or service. However, how clearly aims are determined in the legislation varies. An aim can be supporting an informal carer to cope or, in the case of daytime activities for the disabled, promoting independent coping and increasing social interaction, for example.

The desired outcome must be assessed at the start, and follow-ups must be arranged as the person receives support or uses the service. In the case of an economic evaluation, data on outcomes is usually collected directly from the users of the support or service. If information on the desired outcomes was collected by social work professionals as part of their work, the information would be available not only for research purposes but also for professionals, clients and for knowledge-based management.

However, very little data on the users of the support and services is currently collected and recorded in the social sector's client data systems in a format that would allow use of the data to monitor the desired outcomes in people's wellbeing and lives. Hence, information on outcomes cannot be obtained from client data systems, nor is any information to be used in the comparison of the services or the ways of delivering them.

In general, understanding of outcomes and the evaluation of effectiveness varies a great deal especially in the social welfare field. For outcome data to be used in an economic evaluation, it must be related to the ultimate personal wellbeing aims of the support or service. There are currently very few such outcome measures in the social welfare field. The intended use of a measure can be research, work with the clients or self-assessment of the individuals, or the measure may be applicable for a variety of purposes. Measures developed for research purposes are often long and disconnected from the perspective of everyday work. On the other hand, the measurement characteristics of measures developed for work with clients or self-

assessment purposes have not always been studied, which means the reliability of the results is unknown.

A special aim in the case of PBs is the strengthening of choice and control, and this should therefore also be monitored and evaluated as well as being studied in relation to the costs. If the costs of the PB and the service's desired wellbeing outcomes are the same as with a conventional way of delivering services but the choice and control increases, for example, the PB is cost-effective from the choice and control point of view. Many of the PB users who responded to a client feedback survey conducted by the Key to citizenship project felt that their choice and control had increased: 21 respondents out of 25 stated that they were able to influence their services a great deal or to some extent (Kylliäinen et al. 2019).

Other issues related to the costs or outcomes of personal budgets

When conducting an economic evaluation of PBs, information on factors that are known or expected to influence the costs or outcomes of the PB should also be collected. Such issues include the implementation of personal budgets as a specific mechanism, for example. When the study is being started and carried out, it should be ensured that all the participating organisations implement the PB in an agreed manner, and that the agreed manner is sufficiently standardised. Standardisation of the implementation of PBs influences the PB process, the competence and orientation of the professionals offering PBs, the selection of the PB users, the enabling of support for users, other than from professionals or family, as they need it and integration between sectors and services. The amount of money to be available with the PB and its determination method are linked to the costs incurred from services, and the local or regional supply of support or services is linked to availability and the cost level.

Potential evaluation designs

A preliminary study protocol using an experimental study design and a study design that is mostly based on register data will be presented. Both of these could be implemented in principle. In the evaluation using an experimental design, a study group can choose the PB, and a control group will receive support and service in the conventional way. Randomisation will be used in assigning the study and control groups, and the design will utilise the gradual introduction of the PB. The data regarding the participants needed for the study will be collected using applicable methods during the study. This design is possible because PBs are

not commonly used in social and health care in Finland, and current legislation allows their use, but does not require that PBs be offered to everybody. However, the implementation of the design requires that a sufficiently large number of social and health care organisers commit to the study, that the PB study and control groups can be recruited and that the necessary information can be collected.

A study based on register data will be possible when a sufficient amount of data required in the economic evaluation has been collected in registers. Such data is not currently available. Hence, the preliminary plan for economic evaluation based on register data is more a description of what data should, at the very least, be recorded in registers and made available so that such a study could be conducted. If such data was available from the registers, the economic evaluation based on register data would not require any action on the part of the social and health care organisers or service providers at the study implementation stage.

5. PRELIMINARY STUDY PROTOCOL FOR ECONOMIC EVALUATION OF PERSONAL BUDGETS IN FINLAND

A preliminary plan for an economic evaluation of PBs using an experimental design and the design based on register data are described below.

Experience from previous experiments with PBs has influenced the target groups for this preliminary research plan. The studies are designed for the following target groups:

People with disabilities who require support

- The aim of the services for people with disabilities is to promote their ability to live and act as members of society equal to people without disabilities, as well as to prevent and eliminate disadvantages and obstacles caused by their disabilities (Act on Disability Services and Assistance, 380/1987).
- People with disabilities were PB users in some of the previous experiments, and the experience was positive in many cases.

Informal carers who care for an older person

- An informal carer is the family member or another person close to the person being cared for, i.e. the person who organises and gives care to the elderly person at home, receives support for informal care that is granted by the social and health care authority and has signed an agreement on such support with the municipality.
- According to the Act on Support for Informal Care (937/2005), *“the purpose of the act is to promote the realisation of informal care by guaranteeing sufficient social and health care services, as well as continuity of care and support for the caring tasks”*. According to the act, the social and health care organiser must also arrange social and health care services that support the carer’s wellbeing and caring tasks as necessary.
- Informal carers were PB users in some of the previous experiments, and the experience was positive in many cases.

Economic evaluation based on experimental design

Study setting and locations

The availability of support and services varies depending on the location. This influences people's opportunity to use a PB. Organisations in Finland responsible for organising social and health care in large or medium-sized urban areas that are willing to commit to introducing PBs meeting minimum criteria (to be separately agreed) either immediately or within approximately two years will be invited to join the study. Organisations in charge of organising social and health care in small locations will also be invited to join the study. The organisations will be offered training and support on the introduction and use of PBs. The municipalities will commit themselves to providing information for the study and supporting the collection of data.

The following will be selected from among those interested in joining the study:

- Two organisations responsible for organising social and health care in large urban areas (a central city with more than 100,000 residents; on 1 January 2019, there were nine municipalities with more than 100,000 residents in Finland: Suomen Kuntaliitto ry, 3.4. 2019)
- Two organisations responsible for organising social and health care in medium-sized urban areas (a central town with 30,000–70,000 residents; on 1 January 2019, there were 23 such municipalities in Finland: Suomen Kuntaliitto ry, 3.4. 2019)
- Four organisations responsible for organising social and health care in small locations (a central town with 5,000–10,000 residents; on 1 January 2019, there were 75 such municipalities in Finland: Suomen Kuntaliitto ry, 3.4. 2019)

Based on previous experiments, recruiting PB users is not easy. Different methods of assigning people to the study and control groups will therefore be envisaged the locations of different sizes: the study designs for the social and health care organisers operating in large and medium-sized urban areas will be based on randomisation. At least six months should be reserved for the recruitment phase. Factors influencing the required recruitment time include the desired sample size, which will be specified in detail using power analyses. The small locations will be invited to participate in a complementary multi-method study.

Randomisation

Randomisation will be done using three means (specified below). In all cases, all clients who contact a professional, are entitled to receive the service, are included in one of the two target groups and who meet the inclusion criteria will be assigned to either the study group or the control group. Those in the study group can choose the PB if they want and those in the control group will not be given this choice. Next, the professional will provide the people assigned to both the study group and the control group with oral and written information on the study and ask them whether they are willing to participate. All those willing to participate in the study will be asked for permission to submit their contact information to the researchers. The researchers will contact them and ask their permission to use information obtained from registers and their consent to participate in the study.

As a result of this approach, the study group will be divided into two groups: those who chose PB and those who were given the option, but did not choose PB. A similar approach was used in an economic evaluation of a personal health budget in England (Forder et al. i.a., p. 6). Both groups – together and separately – will be compared with the group that was not given the opportunity to choose PB (the control group). If consent for participation in the study was requested before randomisation, people whose attitude to the PB option is basically positive will be selected for the study.

The results may be influenced by the fact that the people in the control group are also aware of the study and may thus change their behaviour. Another challenge will be that all the people who contact a professional – including existing clients – will be accepted for the study. This means that the situation of the participants will differ in terms of needs and the use of services. There will be existing clients in both the test group and the control group, however.

Randomisation has been criticised in social and health care for ethical reasons. Randomisation can be considered an ethically acceptable study design when studying PBs, because the opportunity to choose a PB is not common, the right to get a PB is not based on legislation and all the people who need services will be delivered services at least in the conventional way. It will be explained to all the people selected for the control group that they will also have an opportunity to choose a PB in approximately twelve to eighteen months, i.e. after the research period.

Another source of criticism of randomisation of the choice of a PB is the fear that the PB is not a safe and risk-free option for all and it could have negative

effects on some of the people who need services. In previous PB experiments, professionals have chosen the people to whom they offer the opportunity to choose a PB. To avoid this risk, criteria on when the PB option is not to be offered (exclusion criteria) will be determined in cooperation with social and health care professionals before the study starts. Furthermore, one should keep in mind the fact that randomisation and the opportunity to choose a PB do not eliminate the obligation of the professional to support and assist the client in selecting support and services that meet their needs, even though the idea in the PB approach is to trust the client more than previously.

1. Design based on randomisation of service users in social and health care organisations in large urban areas

In one of the large urban areas, all those who contact the professional, are entitled to the service, are included in the target group and meet the inclusion criteria will be divided by lot (randomised) into two groups: the study group, the members of which can select a PB if they want, or the control group, the members of which will not be given such a choice and with whom the professional will continue working in the conventional way.

After randomisation, the professional will ask

- the people in the test group, whether they wish to become PB holders; and
- everyone, whether they are willing to participate in the study.

2. Design based on randomisation of professionals in social and health care organisations in large urban areas

Since the way professionals work can affect the implementation of PBs, the second design will be based on the randomisation of professionals: they will be randomly divided into those who will offer PBs and those who will continue with the conventional approach.

- The professionals who have been randomly selected to create the study group will ask all those people contacting them and who are entitled to the service whether they wish to select a PB.
- Both professional groups will ask all those people contacting them and who are entitled to the service whether they are willing to participate in the study.

3. Design based on randomisation of locations in social and health care organisations in medium-sized urban areas

Locations with as similar conditions as possible (in terms of economic structure, demographics, distances, etc.) will be selected. After the drawing of lots, one of the towns (town A) will create the study groups and commit to offering all people who contact a professional, are entitled to receive the service, are included in the target groups and meet the inclusion criteria, the opportunity to choose a PB. The second town (town B) will create the control groups. The professionals will ask all those who contact a professional, are entitled to receive the service, are included in the target groups and meet the inclusion criteria whether they are willing to participate in the study.

4. Multi-method study in social and health care organisations in small locations

No study groups or control groups will be created in the small locations. The organisations will be supported in the introduction of PBs, and the challenges and opportunities of PBs will be studied using mostly qualitative methods.

Study perspective

The perspective will particularly determine the costs that will be considered in the evaluation. The perspective will also influence the selection of outcomes to be studied: whether the outcomes will describe what the service organiser aims to achieve with the service, or whether the outcomes will also describe the desired outcomes from the perspective of the people and their families. The proposed perspectives are

- the perspective of the public social and health care organiser; and
- the perspective of the person who requires support and services and their family.

These perspectives will be considered separately and combined.

The consideration of both perspectives is logical, as a PB strengthens the service user's role and transfers some of the responsibility, work and costs from the organiser to the service user. A broader societal perspective that would include, for example, lost production was considered too challenging in this case in relation to the added value of the assumed use of the results.

Time period of the study

The study should last long enough for the outcomes for people to be generated by support and services and by the ways of delivering them, as well for the costs to be incurred.

On the other hand, long-term studies are challenging for both the participants and the researchers. Compromises on the duration of the study must therefore be made. As the planned follow-up period is at least twelve months, and the recruitment of participants will take approximately six months, it will take approximately eighteen months from the selection of the first participants to the final collection of outcome data. Hence, the total duration of the study when the preparation phase is included will be at least three years: six months for planning the PB process framework and organising cooperation with social and health care organisers; eighteen months for the actual intervention phase; and twelve months for finalising data collection and analysis. Because the length of time over which the cost and outcomes are being evaluated is not longer than twelve months, discounting is not needed to adjust for time preferences.

Sample size

Power analyses are used to determine the minimum number of participants needed to conduct the study (See Matthews & Farewell 2015, for example). Preliminary calculations were conducted according to Tuomas Selander's guidelines (2014). The probability (p-value) used was 0.05 and the power-value 0.80. The calculations were conducted for the primary outcome measures ASCOT SCT4 and ASCOT-Carer SCT4. Figures needed to conduct calculations were estimated using studies from England and the Diaconia University of Applied Sciences (esim. Forder ym. 2012; Rand, Malley & Forder 2018; Saukkonen ym. 2018; Steffansson 2017).

The preliminary calculations suggested that there should be at least 65 fully completed ASCOT forms for all groups. Because it is known that all participants do not answer every question on the ASCOT questionnaire it would be good to have at least 100 participants in each group. The EXCELC project will provide new information on ASCOT values in the Finnish population, and power calculations should be updated after the EXCELC project's results have been published (EXCELC i.a.).

Selection criteria

For the group of people with disabilities will be selected people who

- require support or services as laid down in the Act on Disability Services and Assistance (380/1987),
- are able to express their opinion alone or when assisted and
- are considered to be capable of providing the required information and their consent for the study and the use of their data.

For the group of family members who organise and give care at home will be selected people who

- have signed an agreement on informal care in the manner laid down in the Act on Support for Informal Care (937/2005) with the social and health care authority and
- are, by virtue of the said act, entitled to receive social and health care services that support their wellbeing and work as a caregiver.

Criteria on when the PB option is not to be offered (exclusion criteria) will be determined in cooperation with professionals and experts familiar with the target groups and services before the start of the study to avoid any situation where a PB could cause harm to a person who requires support or services.

Outcomes

All the outcomes mentioned below will be measured before the intervention begins, at midpoint and end of the follow-up period.

All the study participants will be asked about how their choice and control has been exercised, and about their experiences of the support and services by asking about the following issues:

- Experience regarding choice and control, decision-making powers and their own role
- Satisfaction with the support or services they have received
- Experience of the quality of the support or services.

Outcomes for people with disabilities who require support

The selected primary outcome measure is the Adult Social Care Toolkit (ASCOT) SCT4 (Rand, Malley & Netten 2012). This measure has been developed for

assessing social care-related quality of life in an economic evaluation. ASCOT measures eight domains of the quality of life. The lower order domains include personal cleanliness and comfort, food and drink, accommodation cleanliness and comfort, and feeling safe. Higher order domains include social participation and involvement, control over daily life, and occupation and employment. The eighth domain, dignity, is about how the way care staff treat them make them feel. ASCOT is based on Amartya Sen's capability approach, according to which people want the ability to achieve - to 'do' or 'be' - things they deem important. (The intellectual property rights of ASCOT belongs to the developers that are members of the Personal Social Services Unit at the University of Kent.)

The measure has been translated into Finnish and the preference weight for the Finnish population has been studied (in the EXCELC project, <https://www.excelc.eu/>; preference weights have not been published yet). The weightings can be used to combine the answers to the different domains into one value. At the end of the follow-up period, information will also be collected using the ASCOT INT4 interview instrument, which provides information on the impact on the quality of life caused by the activity studied.

The secondary measure selected is ICECAP-A. It is one of the ICECAP capability measures based on the work in the Investigating Choice Experiments for the Preferences of Older People programme (the ICEpop CAPability measure; ICECAP; Al-Janabi, Flynn, Coast 2012; Al-Janabi et al. 2013; a questionnaire is included as Appendix 2). The ICECAP measures have been designed to produce outcome data for economic evaluations, and they are based, even more profoundly than the ASCOT measures, on Amartya Sen's capability approach, according to which people want the ability to do things that are important in life. A disability limits this ability, and support and services can restore it. ICECAP-A consists of five questions involving five aspects of life that are important for adults: attachment: an ability to have love, friendship and support, stability: an ability to feel settled and secure, achievement: an ability to achieve and progress in life, enjoyment: an ability to experience enjoyment and pleasure and autonomy: an ability to be independent. The measure has not been translated into Finnish, which means that it will need to be translated before the study. The Finnish weight for the domain has not been studied, but the answers to the different questions can be combined into one numerical value based on the British weighting.

Outcomes for family caregivers who care for an elderly person

The selected primary outcome indicator is ASCOT-Carer (Rand, Malley & Netten

2012, Rand et al. 2015). The ASCOT-Carer measures seven aspects of the quality of life related to the burden of caring and the support received: opportunities for meaningful occupation and enjoyable activities, control over daily life, self-care, (carer specific) personal safety, social participation and involvement, time and space to be oneself, and feeling supported and encouraged as a caregiver. As mentioned above ASCOT is based on Amartya Sen's capability approach. The measure has been designed for economic evaluations. It has been translated into Finnish and the preference weights of the domains for the Finnish population has been studied (in the EXCELC project, <https://www.excelc.eu/>; preference weights have not been published yet). The weightings can be used to combine the answers to the different domains into one numerical value. At the end of the follow-up period, information will also be collected using the ASCOT-Carer INT4 interview instrument, which provides information on the impact on the quality of life caused by the activity studied during one interview session.

Secondary outcome measures for both groups

The following measures describing quality of life in general and health-related quality of life will be used as the secondary outcome measure for both groups:

- How the respondent feels about his/her quality of life using the first question of the WHOQOL-BREF measure. (WHOQOL Group 1998; TOIMIA database 13 January 2015)
- Satisfaction with health using the second question of WHOQOL-BREF. (WHOQOL Group 1998; TOIMIA database 13 January 2015)
- Health-related quality of life (EQ-5D), which includes questions about mobility, self-care, usual activities, pain/discomfort and anxiety/depression (Williams 1990; TOIMIA database 31 October 2013).

Background information

The following background information will be collected from all participants either by asking the participants themselves or from client data systems:

- Age; education; income; employment; gender; family relations
- Experience of workload
- Social support network
- Functional capacity/support need: ADL (bathing, dressing, toileting, transferring, continence, and feeding Katz et al. 1963, Laukkanen et al. 2000) and IADL (ability to use a phone, shopping, food preparation,

housekeeping, laundry, transport, responsibility for one's own medication and the ability to handle personal finances; Lawton & Brody 1969, Graf 2008)

- Previous services received (twelve months before the start of the study)
- Personal service plan and decision

In addition to above mentioned, the following information will be collected in the case of informal carers:

- Diagnosis of the person being cared for
- Functional capacity/support need of the person being cared for; ADL and IADL (Katz et al. 1963, Laukkanen et al. 2000, Lawton & Brody 1969, Graf 2008).

Resource use and costs

The following information will be acquired to evaluate costs:

- User-specific costs of the services and support, manually taken from data systems.
- Costs arising from the professionals' work, based on actual working hours; to determine the working hours, employees will be asked to monitor their working hours for a separately defined period of time.
- Overhead costs (administration, managerial work, support services, etc.); manually taken from data systems and allocated using appropriate principles.
- The time used by PB support people other than professionals or family members and other costs for the support people; an estimate of the time used and other costs will be asked from the PB support people during interviews.
- Costs arising from the time used by the service users themselves and their family members as well as other costs for them; an estimate of the time used and other costs will be asked from the service users and their family members during interviews.

Data for the supplementary multi-method study

The economic evaluation will be supplemented with a mixed-method study based mostly on qualitative data. Answers to the fourth research question in particular will be sought: Which factors promote or prevent the cost-effectiveness of personal

budgets?

By interviewing professionals, the following will be explored:

- The implementation of personal budgets,
- the method in which the size of the PB is determined,
- education and approach of the professionals to their work,
- development of public and private services to meet service needs,
- service integration, and
- how the services purchased with PB differ from the services organised in the conventional way.

By interviewing people in the study and control groups, their family members and their PB support people, other than professionals or family members, the following will be explored:

- Experience of the participants on the approach of the professionals to their work
- experience of the participants of support from the professional providing the PB and from other social and health care professionals during the process
- Experience of the participants on the information available to them when compared to the information they feel they would need to make decisions on their PB and to use their PB
- non-professional support received by the participants from their family members or voluntary support persons, and
- how the services purchased with the PB differ from the services organised in the conventional way.

By interviewing service providers, the following will be explored:

- Competition and any changes in the competitive situation, and
- development of services to meet service needs.

Statistics will be used to explore:

- Local supply, market situation and competitive situation and
- local cost level.

Analysis

A cost-effectiveness analysis will be implemented for each outcome measure and the incremental cost-effectiveness ratio will be calculated, i.e. how much additional costs will arise from one additional unit of the measure of effect. The analysis can be continued by exploring the impact of society's willingness to pay on cost-effectiveness (the cost-effectiveness acceptability curves; CEACs). I.e. the

probability that the intervention would be seen as cost-effective compared with the conventional course of action given various values for society's willingness to pay for an additional unit of effect. Sensitivity analyses will be carried out to assess the impact of uncertainties on the results.

Whenever possible, analyses on a variety of sub-groups, such as age groups, socioeconomic groups and groups based on functional capacity will be made. Such analyses can highlight questions related to fairness, for example.

Risks

The following challenges may hamper the implementation of the study:

- Will there be social and health care organisers willing to commit to the use of PBs, provide information for the study and support the collection of the information required for the study?
- Will comparable social and health care organisers be found (in such a manner that the organisers operating in large urban areas can be compared, and the organisers in medium-sized urban areas can be compared)?
- Can user-specific information required for the evaluation of costs be obtained?
- Will the professionals commit to the PB scheme and the study?
- Will the professionals implement the PB scheme in a sufficiently standardised manner?
- Can the study groups and control groups be recruited in a reasonable time (approximately six months)?
- Can comparable study groups and control groups be created?
- How much will the fact that the people in the control group are aware of the PB scheme influence the results?
- How many of the participants will drop out?
- Are the selected measures sensitive enough to describe the desired outcomes of the services?
- It is likely that the study will influence practices. Can the research results be applied to real life situations?

Non-experimental economic evaluation based on register data

The non-experimental economic evaluation based on register data can only be conducted if sufficiently reliable, extensive and standardised user specific information on the costs and outcomes is available. At present, no such data is

available.

The non-experimental designs will be realised using statistical methods; econometrics when applied to actual economic phenomena. Regression analysis will play a strong role, and the three most commonly used methods will be propensity score matching, instrument variables and differences in differences. Much background data is required for propensity score matching, and instrumentation and the differences in differences method is based on a known random state of affairs that, apparently naturally, selects the people for the study and control groups. Furthermore, the differences in differences also uses panel data. (E.g. Pekkarinen 2006.)

As the implementation of the non-experimental evaluation depends on the available data, suggestions of how the register data and its availability should be developed are given below. The goal is that the data becomes better available for analyses such as economic evaluations and for knowledge management in the future as well.

Data on outcomes for non-experimental economic evaluation

No information on the people seeking social services that would describe the outcomes - the desired changes - in any standardised manner is currently being collected in client data systems. Neither is such information collected about the the groups used as examples: people with disabilities or informal carers. Recording of such data would be possible as a fixed part of the professionals work if structural documentation were used.

- A prerequisite of reliability and for research use of the data would be that the key information on outcomes is asked and recorded in the same way by all the social and health care organisations. Furthermore, the information would have to be asked and recorded in a way that would allow for its quantification. The systems would also have to enable access to the data in a manner that allows for combining the data with the person's other data and information on her/his service use.
- A prerequisite for the practical implementation of the recording as part of the professionals' every day work would be that the questions asked and the data collected are perceived as sensible and useful from the perspective of both people who need the support and service and the professional, instead of something extra that feels disconnected. The information would have to serve people who need support in the recognition of their own situation and

the employees in the identification of the support and services that meet these needs.

The reliability of such data in research use could be challenged. Nonetheless, the data is generated together by the professional and the person seeking support on the basis of which the professional makes decisions regarding support and services.

The reliability would increase if validated measures designed for research use could be used in health and social care practice. However, such measures are often deemed difficult and disconnected. There are some validated measures suitable for use both in research and practice. The ASCOT measure suggested above as the measure for both people with disabilities and informal carers, was designed for research use but is also applicable for work in care practice. The ASCOT measure is commonly used in services provided to adults who need support in Northern Ireland, for example (O'Donnell 2018). The South Savo Social and Health Care Authority (ESSOTE) has made a decision to adopt the ASCOT-Carer indicator designed for informal carers as a tool for needs assessment and monitoring of informal carers. The usability of the measure was tested as part of a project on the development of informal care practice in ESSOTE (Saukkonen et al. 2018).

In many cases, no standardised measure that is also suitable for use in practice is available. In these cases, the approach for each need group could be the professionals and researchers together studying the measures that have been deemed good for research use and selecting the most suitable questions. The questions selected in this manner would be included in the pool of data to be collected in the same way by all.

Data on resources and costs for non-experimental economic evaluation

An economic evaluation using register data requires that information to evaluate the costs of the support and services used by each person – in this case with both PBs and the conventional scheme – is available from the registers, and that the services purchased using PBs can be separated from the services organised in the conventional way. The data must be available in a manner that allows it to be combined with the outcome data and the person's other data. The data included in the registers must be determined and guidance on the data must be provided for the data to be comparable.

As mentioned before, the current financial and administrative data systems of

almost all social and health care organisers have been designed for monitoring the budget. They do not support extracting data on costs arising from the provision or acquisition of support or services in a format – separately for each service user – that would allow for the use of the data in an economic evaluation based on register data.

A separate question related to an evaluation based on register data is the consideration of the professionals' working hours as costs and using the working hours as the basis when allocating overhead costs for example. There are no easy-to-use tools for monitoring working hours and working hours are not routinely monitored. Costs arising for support and service users from sources other than client charges would also remain outside a study based on register data.

Study perspective

In the case of a study based on an experimental design, the selected perspective could be that of the public social and health care organiser, and that of the person who requires support and services and their family, because the required information will be collected when implementing the study. In the case of a study based on register data, the perspective is determined by the data available from registers. Hence, the perspective of the public organiser of social and health care is emphasised. The perspective of the person who requires support and services and their family can only be considered in a limited manner, as no data is available unless it is separately collected.

6. CONCLUSIONS: FEASIBILITY OF ECONOMIC EVALUATION OF PERSONAL BUDGETS IN FINLAND

An economic evaluation based on an experimental design requires the collection of data in cooperation with organisations responsible for organising social and health care using the personal budget method. Committed social and health care organisers from different regions who are willing to cooperate are required to achieve this. For the evaluation and a comparison design that offers as reliable information as possible to be successful, the organisers must commit to gradually implement the agreed PB scheme, to provide information and to support the researchers in the collection of the required data. Such a study requires background information, the collection of an extensive body of data on the outcomes of the PB scheme and the conventional way of delivering services, and on the costs incurred by the different parties involved. On the basis of previous research and of experience from Finnish experiments, one can assume that many factors related to the implementation of PB and local conditions influence the costs and outcomes of PBs. Hence, and to provide support for the interpretation of the results, the economic evaluation should be complemented by a multi-method study especially focusing on the conditions which facilitate or inhibit the implementation of PBs.

A study using an experimental design requires a major input from the social and health care organisers, and much research expertise and a major input from the parties implementing the study. When the social and health care organisations who are willing to become partners in the experiment have been identified and they have made a commitment, results will be available in approximately three years.

A non-experimental study based on register data can only be realised once the collection of data in systems and registers has been initiated, strengthened and standardised. Changes to structural documentation in client data systems and financial and administrative data systems, and the possibility to combine data from different systems are required, for example. For the implementation of

an economic evaluation to be possible, reliable data on outcomes for the people using support and services, the use and costs of the support and services and other information on the users and their situation, separately for each user and user group, must be available from registers. Another prerequisite for an economic evaluation based on register data is the PB scheme having been in use for a sufficiently long time in a relatively extensive area, but not everywhere. If such data is available, the actual study phase will not cause any additional workload for the social and health care organisers. It will probably take several years for such reliable data to be available from registers in a manner that will allow the economic evaluation to be implemented. The prerequisites could be improved by means of development cooperation currently in progress on knowledge-based management in Finland (Toivo –ohjelma. Sosiaali- ja terveystieteiden ministeriö 2018).

Social and health care services will also be provided in the future, and information will be needed for knowledge-based management and decision-making. If there are preconditions for economic evaluation of personal budgets and of social and health care in general, economic evaluation can provide valuable information for management and decision-making.

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APPENDICES

Appendix 1

Comments from Dr John Woolham

3rd September 2019

The plan you sent me is essentially a protocol for a very ambitious mixed method evaluation of their impact and cost-effectiveness. I think it's very comprehensive. There are very few RCTs focusing on personal budgets – in the UK there are only two I am aware of and you have cited both) so if the evaluation gets the 'go-ahead' any data it produces will be valuable. I think the design is good and the choice of data collection instruments is appropriate. There are others of course – such as EQ5D, or the Warwick/Edinburgh Wellbeing Scale but the ones you have chosen are tried and tested. You have also carefully considered the potential risks, though the effective management of some of these (for example getting support from local professionals) could be very difficult.

You have also carefully set out the claimed benefits of personal budgets: it will be important that the study evaluates these carefully rather than seeking to validate them: when I came to Finland to speak in 2017 I drew on my own work, (which you have also cited) which found little evidence of real benefit for some groups of people. There is no credible evidence that they deliver better outcomes for older people that I'm aware of, though I think there is some good evidence that they may 'work' for younger adults if certain things are in place. If I have understood the proposal correctly, your sample sizes are very small for an RCT design and will probably not permit an analysis by age, but I think it is worth bearing in mind.

A practical problem that impacted on my work, and the IBSEN trial was that the local infrastructure needed to support such a radically new way of organising services was not very robust. Giving people a budget and asking them to choose is not helpful if, for example, there is only one local service to purchase, or, if there are several, finding that local care professionals are unwilling to advise on the most appropriate one because their organisation has a contract with them and to do so would be to offer preferential treatment to a particular care provider. Almost important is to very carefully map out the 'customer journey' (you have done this to some extent) to avoid people falling between gaps between different

organisations. Finally, further consideration of some of the potential ethical issues might be useful.

Dr John Woolham
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Appendix 2

Comments from Dr Simon Duffy

30th August 2019

It is excellent to insist on the importance of research economic efficiency at the earliest possible stage. In fact I think the most interesting question is NOT "Is self-directed support efficient?" but "Which MODELS of self-directed support are most efficient and why?"

Efficiency (or inefficiency) in self-directed support is the result of multiple design factors which often vary and it is to a high degree to build efficiency into the system (or to accidentally design it OUT of the system). Design factors include - but are **not limited** to the following:

- If decisions about setting resource levels are complex, contestable and involve many different professionals then transaction costs will increase.
- If resources can only be used on existing services or on solutions that seem more 'normal' then the room for innovation and efficiency decreases.
- If people do not feel that their budgets are secured by strong rights then people may adopt conservative behaviours that lock people into more expensive options e.g. preferring a residential school over a creative community solution
- If management systems are managed by agents who are disconnected from local communities then they are unlikely to see opportunities for engaging community.
- If resources cannot be invested in families then families will have an incentive to provide less support in order to increase the person's budget.
- If the support from families or communities is completely discounted from assessments then all needs will generate increased costs.
- If local communities do not benefit from the efficient use of personal budgets then systems for calculating budgets will tend to be put under pressure from local advocacy systems.
- If services are highly regulated in what solutions they can offer then service systems are likely to lock people into higher cost solutions.

Interestingly, while it is often assumed that self-directed support is a 'market-reform' I have not seen ANY evidence of price competition as driving efficiency into any system. This is very interesting because many countries have implemented

SDS because it seem consistent with ideological assumptions about the value of markets. But in fact there is **NO evidence** for this assumed consistency.

I have 3 suggestions for how you could develop your proposal.

1. Focus on supporting the active development of economically efficient models of self-directed support

The experience of research self-directed support in the UK suggests there are significant dangers on fixing on a model too early. In fact there may be NO FINAL model. There is a significant risk that (a) the model becomes out-of-date during the research phase or (b) the model that is being tested becomes too loosely defined (often in order to increase sample size). UK research on personal budgets - while it can appear impressive - has often been vitiated by these factors and much of it is of very questionable value.

It makes more sense to treat efficiency as a design principle for SDS - and researchers could be incredibly useful if they helped leaders to test whether emerging models are (or are likely to be) efficient. In fact some things (like the costs of assessment) are very easy to research - but there is often little attention paid to these important variables.

2. Ensure the model of social value is consistent with human rights, equal citizenship and citizenship

Of course 'the purpose' of SDS is contestable. However leaders in SDS have really emerged from the disability movement and from champions of Inclusion. SDS and other new forms of social support have been developed in order to challenge:

- institutional models used in most social care
- segregation of people away from community life
- failure to support families
- low expectations

It is at least paradoxical that the 'testing' of SDS is often carried out using old fashioned measures of well being or satisfaction rather than in terms of the values that led to the creation of SDS. [e.g. Glendinning et al. recognises that "Individual Budgets" was created to advance citizenship - and then never explores what citizenship means nor whether SDS does or does not help. In fact the word "citizenship" is never mentioned again.]

In my opinion:

The true purpose of personal budgets is to advance citizenship for all people, and included within this as connected sub-goals would be:

- ensure people are able to exercise all their human rights
- strengthen families as a foundation for personal development
- create inclusive and welcoming communities
- enable effective social work and social pedagogy

Clearly all of these goals have an economic component and (arguably) all contribute to wider social economic change.

3. Ensure the economic model is broad enough to capture the most important factors

Figure 1 in the paper strikes me as a very 'service-centric' model of the economic factors in social care. If you look at the discussions of real wealth and the community supports described in *Architecture for Personalisation* I think you will see you need a broader economic model. This is also important more generally as we move to a better understanding of the relationship between formal (funded services) and the community factors that actually are the most important factors in promoting citizenship.

Finally - I would really encourage you to explore how research work could be linked to:

The ongoing development and piloting process. I think talking to Petteri Kukkanemi and Kirsi Konola (Service Foundation for People with an Intellectual Disability), and working with Suunta (www.suunta.fi; The Centre for Personal Budgeting) would be ideal as they aim to support and connect the different pilot efforts.

The design-thinking that Markus Vähälä (Coordinator for Citizen Network in Finland) is leading and the wider SDS Global Research Group that Citizen Network is hosting.

Dr Simon John Duffy
Director of the Centre for Welfare Reform
Secretary for Citizen Network

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