UNIC

TOWARDS USER-CENTRED
FUNDING MODELS
FOR LONG TERM CARE

Models of Good Practice Report on Personal Budgets

June 2021

Key information

Grant agreement no. VS/2020/0265
Deliverable ID 2.1
Release version 1.0

Deliverable type: Report
Principle author: Konstantina Leventi (EASPD)
Internal reviewer: Asel Kadyrbaeva (EASPD)
Graphic design: Omor Ahmed (EASPD)

Acknowledgement

EASPD wants to thank all the partners of the UNIC project
for their contributions to this report

This document has received financial support from the European Union Programme for Employment and Social Innovation "EaSI" (2014-2020). The information contained in this publication does not necessarily reflect the official position of the European Commission.
For further information please consult: http://ec.europa.eu/social/easi

EASPD

Follow our work on

EASPD Brussels
@EASPD_Brussels
EASPD
EASPD

Table of Contents

List of Abbreviations

APSS CR	Association of Social Services Providers Czech Republic
ÁT	Áiseanna Tacaíochta
CRPD	Convention on the Rights of Persons with Disabilities
CZK	Czech Republic Koruna (Currency Unit)
DOP	Diensten ondersteuningsplan
DPO	Disabled persons' organizations
EPSN	European Social Policy Network
EU	European Union
GIO	Global individual support
HSE	Health Service Executive
IF	Individualised funding
JDC	Joint Distribution Committee
LSS	The term used reffering the Support and Service to Persons with Certain Functional Disabilities legislation in Sweden
LTCS	Long-term care and support
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NGO	Non-Governmental Organisation
PA	Personal Assistance
PAB	Persoonlijke-assistentiebudget - Personal Budgets Scheme for minors used in Flander, Belgium
PAB	Personal Assistance Budget
PB	Personal budgeting
PVB	Persoonsvolgend budget- Personal Budgets Scheme for adults used in Flander, Belgium
SAP-BCN	Servei D'assistència Personaldebarcelona
UK	United Kingdom
UN	United Nations
VAPH	Vlaams Agentschap voor Personen met een Handicap
WAIS	Western Australia's Individualised Services
WHO	World Health Organization
ZTP/P	ZTP (průkaz těžkého postižení)- Czech term or phrase for severe health disability card

Executive Summary

The publication of this paper is within the framework of the UNIC project, “Towards user-centred funding models for long-term care.”

The aim of this document is to build solid understanding of user-centred funding models for long-term care and support (LTCS), with a particular focus on personal budgets. It provides an overview of promising practices on the implementation of personal budgets (or similar user-centred funding models) in Europe and across the world. However, it is important to note, that this report also acknowledges some of the weaknesses of these practices and suggests on improvements that could be made.

The report starts with defining the key concepts used in this paper and introduces the methodology followed to identify the existing promising examples of user-centred funding models for LTCS. It then continues with describing the different models of promising practices in user-centred funding together with a description of the current legal framework in each of the countries where these models exist. The last part of the report draws conclusions, highlighting elements in user-centred funding systems which require improvements and relevant actions to approach these challenges.

1. Introduction

Social services are the vehicles for millions of people to enjoy their social rights, to enjoy their inherent human dignity, to live independently, and to provide the necessary support to enable them to participate actively in the society.

The UN Convention on the Rights of Persons with Disabilities (UN CRPD) calls for a paradigm shift in the way in which care and support services are provided, a shift towards home and community-based services, enabling the full inclusion of all people in the society. The European Pillar of Social Rights states that everyone has the right to affordable long-term care and support services of good quality and in particular home care and community-based services. This principle not only confirms the right to LTCS but also clarifies how these services should be developed and provided. It emphasises the provision of care and support within home and community-based services, as opposed to segregated institutional settings.

It is important to note, that currently formal LTCS is primarely delivered within large residential facilities, often isolated from the community, and it struggles to offer services which respond to the needs and wishes of each of the beneficiaries of these services. Thus, failling to respect the right of persons with disabilities and older persons to choose their place of residence and where and with whom they wish to live. There is evidence, that European Member States struggle to ensure that LTCS meets the individual needs and wishes of people with support needs. And, this is further comfirned though the European Social Policy Network‘s (EPSN) report in 2018 stating that *home care and community-based care represent the biggest challenge in terms of effective access, since in many countries they are underdeveloped*[1]; and the EU’s Fundamental Rights Agency arguing that *realising the right to independent living in practice remains (...) a significant challenge*[2].

The European Union through the European Semester and the country-specific reports, has highlighted the need for several Member States to improve access to LTCS. Policy reforms in LTCS are required to implement the principles of the European Pillar of Social Rights and the UN Convention on the Rights of persons with disabilities. One of the most important elements is to strengthen the effectiveness and efficiency of its funding model, thus ensuring the transition towards quality person-centred, inclusive and community-based services. Funding models might be assumed to be neutral instruments, but on

1 European Social Policy Network (2018). Synthesis and National Thematic reports on the Challenges of Long-term care. Available here: www.ec.europa.eu/social/main.jsp?catId=738&langId=en&pubId=8128&furtherPubs=yes
2 Fundamental Rights Agency (2017). From institutions to community living-Part I: commitments and structures. Available here: www.fra.europa.eu/en/publication/2017/institutions-community-living-part-i-commitments-and-structures

the contrary, they should be viewed as instruments, which not only affect the way services are developed and provided, but also the quality of care and support [3].

User-centred funding models are considered a radical tranformation of the traditional funding models. Traditionally, public authorities directly fund service providers, through reserved markets or public procurement and this model has the tendency to dominate and limit the choice and control of individuals with care and support needs. On the contrary, user-centred funding models, allow room for flexibility when designing and providing services, tailored towards the needs of each beneficiary and providing the needed support to individual when planning and using their chosen services. A funding model as such stipulates a shift in power, where power is placed in the hands of each individual, giving users more choice and control over the care and support they receive, allowing them to meet their individualised needs, wishes and preferences and to live their lives as they want. User-centred funding models are seen as a way to empower persons with long-term care and support needs to have more freedom, citizenship and access to their human rights, in line with the UN CRPD and the European Pillar of Social Rights[4].

The report particularly focuses on personal budgets as it is a prominent example of user-centred funding models in Europe. Therefore the **objective** of this report is to provide an overview of promising examples of user-centred funding models (particularly personal budget systems) in Europe and around the world. This report also aims at highlighting different elements in the identified examples which have been developed to support the design, development or implementation of personal budgets.

This report features 12 promising practices from Australia, Belgium, Czechia, Finland, Ireland, Israel, Italy, New Zealand, Salzburg (Austria), Spain, and the UK (Scotland). Each of these practices highlight different aspects of user-centred funding that are essential for building an effective model:

The case from Scotland provides a valuable example for building the capacity of services user, their families, formal carers and other stakeholders for self-direction in support;

- The case of Health Budgets from Trieste, Italy is an important reminder of the importance of community support;
- From Sweden, non-profit organisation JAG provides a clear example of a model that supports persons with disabilities with their personal assistance services;
- In Ireland, the Peer Support Network developed by Áiseanna Tacaíochta (ÁT) shows how leaders by experience are instumental in the take-up of personal budgets;

[3] EASPD (2019). Alternatives to public procurement in social care. Available here: www.easpd.eu/sites/default/files/sites/default/files/Publications2020/alternatives_to_public_procurement_in_social_care_final_2.pdf
[4] EASPD (2019). How to fund quality care and support services: 7 key elements. Available here: www.easpd.eu/sites/default/files/sites/default/files/bucharest_2019_conference_report__2.pdf

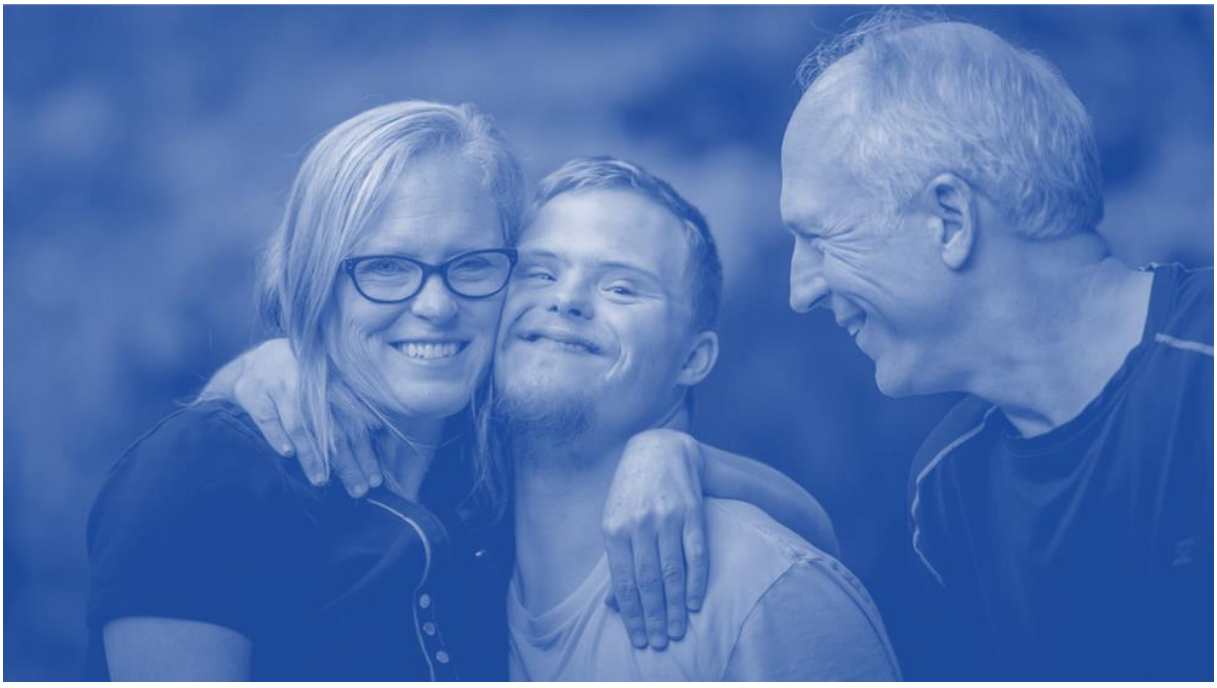
- The Shared Management approach introduced in Australia shed light on the way how responsibilites over handling personal budgets can be distributed in an efficient way;
- Host organistions, practiced in New Zealand, also provide an overview of a practice that facilitates the process of managing the payments, recruitment processes, employment contracts, etc.
- The system in Flanders, among other things, shows the importance of providing services from younger age, to ease the transition from different types of support.
- A number of pilot projects from Austria, Finland, Israel and Spain serve as an important reminder that any change starts from small steps and pilot projects are an important instrument in testing and planning social innovation.

About the project

This report is part of UNIC, an EU-funded project that aims to develop, test and validate a set of innovative tools to help key stakeholders to implement a user-centred funding model for LTCS.

UNIC tools, together with a set of policy recommendations & capacity building activities, will result in a comprehensive preparatory reform mechanism to support public authorities in the deployment of a user-centred funding model – based on the concept of personal budgets – for long-term care and support.

One of the main objectives of the project is to map existing user-centred LTCS funding models (in particular personal budgets) across the EU and identify drivers/barriers for their development.



1.1 Definition of user-centred funding models

User centred funding models

User-centred funding models have been increasingly gaining traction and interest by public authorities throughout Europe and across the world. Although these models have common goals, such as facilitating choice and control of persons with care and support needs and improving effectiveness and efficiency of traditional funding models, their implementation across countries varies. Therefore, there is not one unified international term, rather than a variety of ways to refer and describe a user-centred funding model.

One of the widely used terms is **Personal Budget**. We mainly use this term in this report, too. Personal Budgets is an amount of funding which is allocated to an individual by a state body so that the individual can make their own arrangements to meet specified support needs. This innovative model,which is used for example in the UK, in Flanders (Belgium), is growing in popularity as it allows persons with care and support needs to have more control over how they wish to receive their support[5].

In New Zealand, for example, we came across the term **Individualised funding**, which refers to a funding model which gives persons with care and support needs a way to manage directly their disability supports. This funding model gives more choice and control to the individual to decide about who provides this support, how and when. The use options range from engaging support workers and planning how to use their supports, to employing their own care providers and managing all aspects of service delivery[6].

In the UK, we also came across the term **Direct Payments.** In the Direct Payment scheme, people receive funds directly from the authorities into their bank accounts. Another form is Care Allowances, a scheme used in Czechia.

Another term which we find important to highlight is **Self-directed support**. The term is used in the UK and refers to an approach which puts the person in the centre of planning and can encompass different elements, one of these elements being the user-centred funding model. For instance, persons with long-term care and support needs can choose what kind of support they wish to receive and how they wish to use it. It is a new way of organising services dedicated to people with care and support needs. It can improve the quality of their lives through better respect for their right to active Citizenship and

[5] EASPD (2019). How to fund quality care and support services: 7 key elements. Available here: https://www.easpd.eu/en/content/new-easpd-report-how-fund-quality-care-andsupport-services-7-key-elements

[6] **Ministry of Health, Individualised Funding. New Zealand. Available here: www.health.govt.nz/your-health/services-and-support/disability-services/types-disability-support/individualised-funding-funded-ministry-health**

an independent life. Through Self-Directed Support, persons with care and support needs can be fully included in society[7].

Alongside these variations in terminology, user-centred funding models differ also in terms of structure and aims. Throughout our mapping exercise we came across funding models addressing different population groups, such as minors and/or adults, allocating their funds to different services, allowing the use of these funds with specific preconditions, allowing (or not allowing) the purchase of services from family members, etc. Variations were also reported in who manages the fund (the beneficiary or an intermediary), how these schemes are regulated, and how a support network is organised around the beneficiary. And more importantly, whether or not these funds were adequate to meet the needs, wishes and preferences of their holders.

1.2 Methodology

For the development of this report a three phases methodology was followed, which is described below:

1. Collection of practices

A survey was developed and used for the collection of data, which was circulated among UNIC's project partners and their networks. A call for promising practices was launched and the information collected were based on individual contributions, desktop research and consultations with relevant stakeholders. Therefore, the answers and the results of each consultation and the individual contributions vary in terms of comparability when presenting the different models.

The survey can be found under Annex I. For the collection of information we conducted 8 interviews, 3 to identify if the proposed models fit under the criteria of this research and 5 to collect more information.

Additionally, it is important to highlight, that an in depth analysis of the applications of these models was not feasible to take place within the timeframe of this project. To evaluate the application of a user-centred funding model, there is a need to:

- Assess the amount of budget allocated to each individual and if this budget covers their individual wishes and needs
- Assess the eligibility criteria involved in each model and if it supports also for example people with higher support needs

[7] **Disability Leaders of Tomorrow. Skills for Self-Directed Support. Available here: www.dlot.eu**

- Identify the availability of services in the community to support people with care and support needs through this funding model, as well as the availability of staff
- Analyse each model, in each context, taking into consideration the overall social care and support system.

Therefore, it is vital to highlight that each of the models analysed and the different components identified in each model aim to showcase the different approaches and applications initiated in each country. And, when these components are implemented adequately, they can further support and improve the use of user-centred funding models.

2. Guiding criteria for the selection of practices.

Guiding criteria

A practice on user-centred funding models (with a focus on personal budgets) in long-term care and support was only be considered for inclusion if the practice was consistent with the principles that underpin the UN CRPD and the UN Principles for Older Persons. More specifically such practices needed to be based in the community, offer individualised support, and promote full inclusion in society. It must also incorporate the principles of participation, inclusion, non-discrimination, equality, choice, control over life, and the right to receive support adequate to individual needs.

Below is the list of essential and desirable criteria that practices in this report had to meet to be included.

Essential criteria: The practice should

1. Treats the person as a citizen with rights, freedoms and responsibilities.
2. Apply to LTCS (for at least some groups).
3. Exist as an on-going real-world practice in at least one location.
4. Assume a user-centred funding model for care and support.
5. Promote inclusion and equality.

Desirable criteria: The practice should:

6. Create clear and transparent entitlements;
7. Support people to make decisions, choices and to exercise control;
8. Encourage contribution and connection in community life;
9. Stimulate creative, flexible, person-centred support and the best use of shared resources;

10. Protect the rights and status of workers;
11. Create wider understanding of the need to protect and enhance human rights;
12. Be transferable to other contexts and locations.

The practices featured in this report address different aspects of user-centred funding models that are essential for their successful implementation. In particular, the practices were selected to reflect the wide variety of existing cases and important components such as:

- Capacity to support self-direction
- Community support
- Personal assistance
- Peer to peer support
- Coordination of support
- Shared management
- Direct payment system
- Individualised funding
- Assistance organisations
- Pilot projects

It should be noted that comparing practices across countries was neither feasible in the framework of the current study nor was it its objective.

2. Promising practices on user-centred funding models in long-term care and support

2.1 Building the capacity of self-directed support – Scotland, UK

Since 2013, in Scotland, people with care and support needs have four options to receive support, which gives them more choice and control over how they receive their support services. Self-directed support can be used in funding employment, short term individual breaks, carer's break, etc.

In Control Scotland aims at building the capacity of self-directed support by working together with organisations, health and social care services, people with disabilities and their families. They run a wide range of programmes, such as training persons with disabilities and their families on how to advocate and influence policies locally in their communities; workshops to bring together relevant stakeholders to build alliances, exchange experiences and facilitate access to self-directed support.

State of play on user-centred funding models in Scotland[8]:

Scotland introduced the Social Care (Self-Directed Support) Act in 2013 which provided people with care and support needs four options for receiving support. Self-directed support may be used in many ways, for support in daily living activities, to hire a job coach to support the individual in finding employment, or, for example, to fund a short-term break where the individual is supported, and the carer takes a break.

In the initial stage, during the assessment process the individual is an equal partner and can be as involved as s/he wants when assessing their needs and in their support planning. This process is supported by their local council, where a social worker discusses the options that the individual has and how they can best use and direct their support to reach their desired outcomes.

Individuals who have already been assessed as needing a community care service can:

a. Purchase their own support and use a direct payment to pay a person or third party;
b. Direct their own support and the local council will arrange it;
c. Allow the local council to direct and arrange their support or
d. A combination of the previous options.

[8] Social Care (Self-directed Support) Scotland, Act 2013. Available here: www.legislation.gov.uk/asp/2013/1/contents

The local council needs to explain each one of the options for self-directed support and provide information on how to manage support. In any case, the local council gives the opportunity to every individual to choose one of the four options. However, if the individual is not eligible to choose, they have to inform her/him why they consider that to be the case and they need to enable the individual in making a choice. They also assist in identifying who is able to support this individual and, if the individual agrees, to involve the supporter in assisting the individual in making decisions and managing their support.

In Control Scotland[9]

In Control Scotland is a not-for-profit organisation and a registered charity. They aim to develop a sustainable system of self-directed support by working together with organisations, health and social care partnerships and with people across Scotland. They provide training, development, and consultancy to improve the experience of self-directed support for everyone and they are part of a wider community, sharing the same goals and values in Scotland, the United Kingdom and internationally.

The organisation delivers different programmes, such as training, consultancy, and coaching services. They are also involved in programmes funded through grants by the government of Scotland and other funding sources, to build the capacity of support and share information with other organisations. Two of the programmes run by In Control Scotland aimed at building capacity of self-directed support for persons with disabilities, their families but also social and health care and support services and their workforce are:

- **Partners in policy making -** an international leadership programme for persons with disabilities and parents of children with disabilities. Through this programme, participants gain knowledge, skills and confidence to campaign and advocate for better treatment and social justice for persons with disabilities in the society. Participants are trained as the next generation of leaders, they build up their knowledge, practice developing presentations and producing information, and learn how to influence policies locally in their communities but also at a national level. The graduates of this programme build support networks, also at international level, and continue working together and exchanging ideas and knowledge after the end of the programme.
- **Working Together for Change** – a programme designed for family carers, persons with disabilities, social workers and social care and health services to learn, share and plan together.

[9] More information may be found here: https://www.in-controlscotland.org/

The aim of this programme is to bring people from different levels together, build new alliances with the common goal of learning, exchanging experiences and facilitating access to self-directed support in ways that work for the beneficiaries. This programme is funded by the government of Scotland and explores how disabled people have been supported; how the health and social care system works; how to put self-directed support into practice; how to use person centred planning and support planning and how to work together to make change happen locally and nationally.

Through webinars and other forms of support, In Control Scotland aims to provide information and assistance to further facilitate the uptake of self-directed support by persons with care and support needs and enable people to have control over their own lives.

2.2 A community of support – Italy

In Italy, Trieste Community Mental Healthcare has transitioned to community-based mental health services. Persons with mental health problems are empowered, they are part of the community, they are actively involved in all aspects of life and their human rights are respected.

Trieste's model emphasises on community-based care services, focusing on the person and not the disorder, moving away from the traditional medical-based approach. One of the elements of Trieste's reform is also the introduction of a personal budgets model, called Health Budget, which currently counts around 160 services users.

State of play on user-centred funding models in Italy:

In Italy, Law 180 is an essential piece of legislation introduced in 1978 that ultimately reformed psychiatric assistance and started the national process to eliminate mental hospitalisation by the end of the 1990s. This legislation provided the starting point to shift the focus of care from hospital to the community. Law 180 was first of its kind in the world which radically changed care and assistance methods and provided the cause to continue the reformation process of psychiatric care in Trieste. [10]

In 1971 Franco Basagila, director of the Provincial Psychiatric hospital of Trieste, oversaw Trieste's mental and asylum care reformation process. The goal of the reformation process was to go beyond the closure of asylum care and transform and replace it with a network of territorial services with multiple functions of care, accommodation, protection, and assistance.[11] Furthermore, the process was to change the place of treatment to change the methods of care. Following Trieste's footsteps, many areas across Italy closed their psychiatric hospitals by 2000. The drive behind the reform was the shift of the focus from the disorder to the person: their needs and rights, while also addressing the issues of capacity and resources. One of the main elements of this reform was the introduction of a personal budgets model, called Health Budget.

Trieste, Community Mental Healthcare:

Trieste Community Mental Healthcare's culture is to recognise the right to be 'mentally different' instead of 'mentally ill'.[12] It focused on people's right to citizenship and to participate in the social life

[10] Triestesalutementale.it (2021) FROM THE ASYLUM to territorial services for mental health. Available here: http://www.triestesalutementale.it/english/doc/BrochureTriesteENG.pdf
[11] Ibid
[12] Livingwellsystems.uk (2021) Community Mental Healthcare TRIESTE, ITALY.] Available here: https://www.livingwellsystems.uk/trieste

of their community. The Trieste community mental health model does not consist of mental hospitals, it now has 40 different structures with different roles and tasks such as home care for patients. Trieste's Community mental healthcare became a new vision for mental health services that took shape in the city. These services are fully embedded in the community, highly accessible by patients, families and local doctors. The service is delivered primarily through:

- **Four community mental health centres** (each one serves a population of fifty to sixty thousand citizens) open 24/7 and have four to eight beds.
- **One general hospital psychiatric unit** with six beds that is mainly used for emergencies at night with people usually staying less than 24 hours
- **A rehabilitation and residential service** run by its own staff and they liaise with NGOs in managing approximately 45 beds in group homes and supported housing facilities
- In 2015, **a recovery house** was established. It offers a safe space for mental health service users, their families and professionals to come together and explore different paths to recovery.[13]

Two hundred twenty professionals (psychiatrists, psychologists, nurses, social workers, rehabilitation engineers) staff in social cooperative and finally trainees and volunteers provide the mental health service within the Trieste Healthcare model. Furthermore, the Department of Mental Health collaborates with a network of 15 social cooperatives that offers a wide range of employment, training and support services.[14] One of the Trieste healthcare model's defining traits is that territorial services adopt an operating style that differs from the clinical hospital model. They go to the patients, no longer using filters and strictly standardised skills but enhancing social network relations, with a strong emphasis on the quality and abilities of people rather than symptoms.

There have been numerous positive results of the Trieste Community Mental Healthcare model, from the decrease of mental health inpatients and emergencies presentations and 40% reduction of suicide over 15 years.[15] Trieste has decreased the number of involuntary treatments, and the city has the lowest rate of involuntary treatments across Italy. There has been a decrease in incidents involving people with mental health issues and law enforcement officers on a community level. There has been an increase of people with mental health issues getting into employment (about 250 people every year are in grant-funded professional training and about 10% find jobs in the social or private sectors).

The legacy of Trieste model is still felt not just in Italy but also in all the world as the WHO has recognised Trieste's experience as a point of reference for innovative approaches to psychiatric care

[13] Ibid
[14] Ibid 2
[15] Ibid 3

since 1987. In the 1970s, Trieste's mental health plans were deemed 'futuristic' but that futuristic vision that has spread across the globe and enabled a much-needed change in mental health care and empowered persons with mental health. Under this model, service users and beneficiaries can now use services without losing any rights such as community membership, employment and the full respect of their human rights.

Finally, this model uses personal budgets with around 160 service users which takes up 18% of the yearly budget of the Department of Mental Health.[16] There has been continuous growth in community development and community culture within the medical staff and the general public since the 1980s. Trieste model shows the tangible results and possibilities if we emphasise community-based care, focusing on the person, not on the disorder and empowering those with mental health to feel part of the community rather than following the medical approach to mental health.

2.3 A Personal Assistance model – Sweden

Sweden's policies aim to close the gap between people with and without disabilities. Sweden is one of the first countries to introduce the Personal Assistance Budget (PAB) in their national law and in 1993 they passed the Assistance benefit Act. Therefore, a person with a disability may use personal assistance and choose how the assistance is provided. They can either directly employ their own assistant or choose whether the state, a cooperative or an assistance agency will support them with personal assistance.

It is essential to highlight that Sweden's Personal Assistance Model is available to people with intellectual disabilities. This is something which is rarely found in other models as such.

State of play on user-centred funding models in Sweden:

The cornerstone of Swedish disability policy is that everyone is of equal value and has equal rights. The policy aims to close the gap between people with disabilities and people without disabilities. As a result, the Act Concerning Support and Service for Persons with Certain Functional Impairments (LSS) has been created to complement the Social Services Act, the Health and Medical Services Act and the Education Act.

[16] Ibid 4

The LSS gives people with severe disabilities the right to some necessary measures when other laws' essential support is not enough. Ten measures for special support and service are to provide such persons with adequate living conditions. The responsibility for delivering social services and health care lies with local authorities (municipalities) and regional governments (county councils).

Intended Audience of the LSS:

- Persons with an intellectual disability, autism or a condition resembling autism
- Persons with significant and permanent intellectual impairment after brain damage in adulthood due to an external force or a physical illness
- Persons who have other major and permanent physical or mental impairments which are clearly not due to normal ageing and which cause considerable difficulties in daily life and consequently an extensive need of support and service.

Ten measures for special support and service included in the LSS:

1. Counselling and other personal support
2. Personal assistance
3. Companion service
4. Personal contact
5. Relief service in the home
6. Short stay away from home
7. A short period of supervision for schoolchildren over the age of 12
8. Living in family homes or in homes with special service for children and young persons
9. Residential arrangements with special service for adults or other specially adapted residential arrangements
10. Daily activities

Under measures 8 and 9, the LSS includes residential arrangements with service designed like an ordinary home and function as much like a home as possible. Group accommodation contains a maximum of five or six connecting separate flats in typical residential areas, and the staff are generally available 24 hours a day. Group accommodations are the most common alternative to institutions for those who have an intellectual disability, as well as other forms of housing are also open to people who want to lead more independent lives, regardless of their need for help and support.

The **Individual Plan** is an integral part of the LSS and other legislations and works in collaboration with other authorities. The plan includes measures approved and planned in consultation with the individual. This plan is based on the individual's wishes and the municipality's role is to inform the individual about their right to have an individual plan and coordinate the efforts.

Personal assistance is also included in this model and is regulated by the LSS. In Sweden, the personal assistance service has attracted the most attention to the disability reform. For many people, this service is a symbol of real reform because the purpose of the disability reform is the same as that of personal assistance – independence, self-determination, full participation and equality in living conditions. The municipality is financially responsible for those who need help for less than 20 hours a week; if an individual's basic needs are more than 20 hours a week, they may be entitled to assistance benefit (the Assistance Benefit Act 1993:389). Sweden, is one of the first countries to introduce the Personal Assistance Budget (PAB) in their national law and in 1993 they passed the Assistance Benefit Act. Therefore, a person with a disability may use personal assistance and choose how the assistance is provided. They can either directly employ their own assistant or choose whether the state, a cooperative or an assistance agency will support them with the personal assistance.

JAG[17]

In 1994, one year after the adoption of the Assistance Benefit Act, a non-profit organisation JAG started supporting persons with disabilities and advocating for personal assistance and anti-discrimination. JAG means "I" and has also established a user co-operative which provides user-controlled personal assistance to JAG's members. The members of JAG are people with intellectual disabilities, with limited autonomy, extensive physical disabilities and/or speech impairments.

JAG's members first apply for personal assistance funds to the Swedish Social Insurance Office and once their application is accepted, a contract is signed between JAG and their members. They support persons with disabilities (their members) by acting as the employer of their personal assistant. This contract supports the beneficiaries with the administrative tasks involved when using a personal assistant. For example, JAG receives money from each of their members to cover the wages of the personal assistant and JAG's administrative costs but it is also responsible to offer and pay for the training of the assistants.

JAG's members are responsible to choose their assistants, as well as decide how and when they require assistance. Moreover, JAG is also responsible for drawing a contract with the personal assistants themselves. JAG's members using Personal Assistance report to the association the number of hours of assistance that they received and JAG is responsible to pay the wages of the assistants. JAG is also

[17] More information may be found here: https://jag.se/

Tengström, Anna. Presentation of JAG. Independent Living Institute. Available here: www.independentliving.org/docs5/jag.html

European Network on Independent Living (2011). The „JAG model" avalable here: www.enil.eu/wp-content/uploads/2012/02/Pa-manual_ENG.pdf#:~:text=The%20"JAG-model"%20A%20description%20of%20how%20you%20can,it%20is%20nice%20to%20make%20my%20own%20decisions."

responsible for reporting back to the Swedish Social Insurance Office the total number of hours of assistance used each month by each member.

Each member appoints a deputy supervisor to support them. The deputy supervisor can be a family member or a friend and has to be chosen by the member, know the member very well and have an established relationship of trust. The deputy supervisor is responsible to recruit, supervise and schedule the personal assistant based on the will and preferences of the individuals. These supervisors are supported by JAG, which provides them with information regarding labour laws, contracts, and consults them for any problem that may arise.

2.4 Peer to peer support – Ireland

Ireland is in the early stages of developing a user-centred funding model, with many initiatives and pilot projects currently running. In 2016, a taskforce was set up to provide recommendations on how to develop and implement a personalised budgets model for health funded personal social services and support for persons with disabilities.

Áiseanna Tacaíochta (ÁT) has developed a Peer Support Network, bringing together leaders of experience (users of the user-centred funding model), their families and future users of such funding model to support one another, offer advice and mentoring. Moreover, AT has established a Circle of Support, made by people from their local communities, to assist them with the managerial and administrative aspects of their funds.

The members of AT, however, need to create a Company Limited by Guarantee, in order to use the direct payments. This is very challenging and has been deemed not the most appropriate way to organise and manage a user-centred funding model.

State of play on user-centred funding models in Ireland:

Ireland is in the early stages of developing a user-centred funding model, with the Government showing its commitment by setting up a taskforce on Personalised budgets in September 2016. The goal of this taskforce was to make recommendations on an approach and a suggested implementation strategy for the Government's consideration on the introduction of a system of personalised budgets in Ireland for health funded personal social services and support for persons with disabilities[18]. In addition, in 2019, they implemented a pilot project with strict eligibility criteria. During the 1st phase of the project they piloted direct payments, a co-funded model of payment, with 200 programmes. In the second phase, a brokerage model for 40-50 people was initiated but due to COVID-19 it has not been yet rolled out.

Áiseanna Tacaíochta[19]

[18] Department of Health (2018) Towards Personalised Budgets for People with a Disability in Ireland. Report of the Task Force on Personalised Budgets. Available here: www.gov.ie/pdf/?file=https://assets.gov.ie/9931/17cdb50249ef4927b2e7186f3714f8ab.pdf

[19] More information may be found here: www.theatnetwork.com

European Network on Independent Living and European Disability Forum (2019) Towards Independent Living: Collection Of Examples From Europe. Available here: www.enil.eu/wp-content/uploads/2019/03/GoodPractice_web.pdf

DR. Keogh S., Quinn G. (2018) Independent Living: an evaluation of the Áiseanna Tacaíochta model of direct payments. Available here: www.nuigalway.ie/media/centrefordisabilitylawandpolicy/files/Independent-Living_An-Evaluation-of-the-Áiseanna-Tacaíochta-model-of-Direct-Payments.pdf

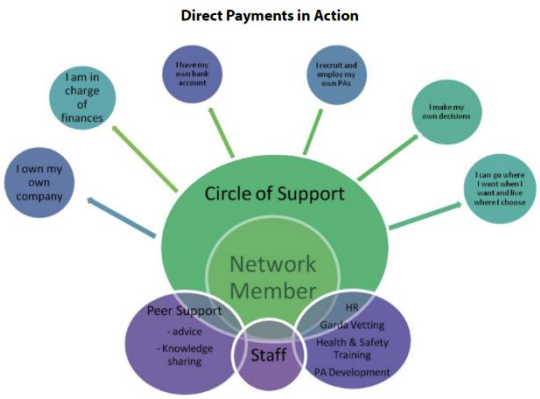
One of the first organisations facilitating access to Direct payments for person with disabilities is Áiseanna Tacaíochta (ÁT), established in 2010, AT is a leading organisation in the Independent Living Movement in Ireland. Áiseanna Tacaíochta, which translates to English as "Supported Facilities", provides two main services:

1. ÁT as an intermediary.

   The organisation facilitates the access of their members (they refer to them as Leaders) to Direct Payments by negotiating on their behalf a personalised budget with the Health Service Executive (HSE). The personal budget is transferred from the HSE to ÁT and the latter supports the Leader to establish a company. The company, is usually a Company Limited by Guarantee, through which the funds are then channelled directly to the Leaders. The Leader uses their budget to choose and manage their own services, and they also act as employers as they recruit and hire, for example, a Personal Assistant. ÁT also reports to the HSE on the use of these budgets and on their Leader's compliance with other requirements, such as personal assistance contracts. Leaders are the ones deciding on how to use their funds and for which services. They are also required to provide monthly and quarterly reports to the ÁT, which are then forwarded to the HSE. Both the Leaders and ÁT are individually audited and this ensures the financial accountability and transparency in the use of public funds.

2. ÁT supporting their Leaders to support themselves.

   Each Leader at ÁT runs their own company and acts as an employer. This may provide plenty of opportunities but at the same time running a company can be challenging. ÁT supports their Leaders by establishing their personal *Circle of Support*, and through their *Peer Support Network*. The *Circle of Support*, made by people from their local communities, assists them with running their companies, as every member of the Circle brings their own expertise to the group, such as accounting or Human Resources management. The *Peer Support Network* is a group consisting of persons with disabilities and their families, which are brought together to offer support, advice and mentoring to one another and to the new Leaders.



The staff plays an important role in supporting the Leaders. They may provide information on setting up and running a company; organising training for Leaders, Circles of Support and/or providing access to the Peer Support Network.

2.4 Coordination of support- United Kingdom

In the United Kingdom, there are three ways in which people can use and manage their personal budget, and three different ways used in local councils to calculate the personal budget of each individual:

- **The Ready reckoner approach, calculating the hours of support needed and through the hourly rate, the overall amount of the personal budget.**
- **The Resource Allocation System, using statistical information for the care costs.**
- **And, the Initial Indicative figure, the basic amount which is assessed based on the actual costs. The amount provided to the individual based on this assessment may be more or less of the initial estimated figure.**

Local Area Coordination is a scheme where coordinators are based in the community and support capacity building both at community and individual level. For example, they work closely with people and communities, identifying their needs, the challenges they face, collaborating with them to identify the most appropriate solutions and services they need. And they work with the local councils, the decision-makers and support in the transformation of the systems in place. Following a bottom-up approach, the Local Area Coordination can support the further implementation of personal budgets, promoting choice and control of the beneficiaries.

State of play on user-centred funding models in United Kingdom[20]:

In 2014 in the UK, the Care Act was introduced which supported in regulating a system that allows individuals with support needs to choose their services and control their individual budgets. In order to access this funding model, persons with care and support needs first need to contact their local authority and schedule a needs assessment. This assessment identifies the needs of each individual and assesses if they meet the eligibility criteria for care and support.

[20] Care Act (2014). Available here: www.legislation.gov.uk/ukpga/2014/23

AgeUk (2020) Personal budgets and direct payments in social care. Available here: https://www.ageuk.org.uk/globalassets/age-uk/documents/factsheets/fs24_personal_budgets_and_direct_payments_in_social_care_fcs.pdf

Moreover, the Care Act supports a personal budgets scheme which is described as the overall cost of the care and support services the local authority arranges or provides to meet the needs of individuals. This budget has three parts, as defined in the Act, the overall cost to the local authority to meet the needs of the personal budget's holder, the amount that will be paid by the individual (after first completing a financial assessment) and the amount that the local authority must pay to meet the needs of the individual.

The Care Act has also foreseen different ways to calculate the personal budget of each individual:

1. Ready reckoner approach - in this process the social worker identifies together with the individual the hours of care and support needed and calculates through the hourly rate the overall amount of the personal budget.
2. Resource Allocation System – this process uses statistical information for the care costs and, based on this, calculates the personal budget which, unfortunately, may not always meet the needs of an individual.
3. Initial indicative figure – in this process, a basic amount is calculated based on the actual costs. The amount provided to the individual based on this assessment may be more or less of the same as the initial estimated figure.

Additionally, there are three ways in which personal budgets can be managed:

1. The individuals receive direct payments and manage the budget themselves.
2. A service provider or a broker manages the budget, following the wishes and needs of the individual, as agreed in the care plan.
3. The local authority manages the personal budget following the wishes and needs of the individual, as agreed in the care plan.

The Act has also set out rules of transparency, timeliness and sufficiency. This obliges the local authority to make their calculation processes clear and to provide an up-front indicative budget to the individual at the start of the care planning process. The final personal budget needs to be sufficient to meet the actual needs and wishes of each individual with care and support needs.

Local Area Coordinator[21]

Local Area Coordination is an interesting scheme that can be found in the UK. It started in 1988 in Western Australia and today it is implemented across Australia, New Zealand, Scotland, Northern Ireland, England, and Wales. It was first initiated to support persons with disabilities and their families,

[21]More information may be found here: www.lacnetwork.org

but it has progressively included persons with mental health needs and older people. For the successful implementation of this programme there is the need for small-scale initiatives but also reforms in the social care systems to support in shifting the balance of power towards individuals and their families. Therefore, a systematic reform on the care and support systems together with a bottom-up approach initiated by the Local Area Coordination approach will support the further implementation of individualised funding, promoting choice and control[22].

Local Area Coordinators are based in communities of around 10.000 people and support capacity building both at community and individual level. They help people and families to identify their strengths, to " develop their own vision for a good life", to find solutions for their problems and to actively participate in their local community. From a community perspective, the Coordinators help to strengthen the connections within each community by providing linkages between citizens, communities and services. The Local Area Coordinators are employed by the local councils and they support anyone who is introduced to them, often people excluded from the community facing health and wellbeing challenges. One of the main aims of the Coordinators is to identify natural supporting connections, between neighbours, family members, reducing the need for external services input.

One of the key contributions of Local Area Coordinators is their influence in transforming the local systems of support. They have a dual role: on the one hand, they work closely with citizens and communities, identifying their needs and the challenges they face, and collaborating with them to identify the most appropriate solutions and services. On the other hand, they work with the local councils and support in the transformation of the systems in place. Following this co-production approach, they aim to influence decisions to achieve a fundamental change towards support and care systems providing person-centred, accessible and high-quality services.

[22] Broad R. (2015) People, places, possibilities. Available here: https://www.centreforwelfarereform.org/uploads/attachment/463/people-places-possibilities.pdf

2.5 A Shared Management approach - Australia

In Australia, the National Disability Insurance Scheme (NDIS) provides three support budget options, depending on the types of activities covered. The activities that can be covered include consumables, such as every day use items, daily activities, assistance for participation in social & leisure activities, employment, transportation, home modifications, assistive technology tools, etc. The personal budgets holders can choose how their budget is managed: the funds may go directly to services providers, to an intermediary or the persons themselves.

Shared management is an approach initiated by Western Australia's Individualised Services in 1990. It promotes a trusted partnership between people, their families and service providers to manage their individualised disability funding. This approach gives an opportunity to the budget holders to control their care and support services without having to manage all the other aspects of their funding. The principles underpinned in this approach are Independent Living, Self Determination, Flexibility, Choice, Mutual Agreement and Trust.

State of play on user-centred funding models in Australia[23]:

The National Disability Insurance Scheme (NDIS) provides support to persons with intellectual, physical, sensory, cognitive and psychosocial disabilities to get the support they need to improve their skills and their independence over time. In order for people to access the NDIS, they need to apply and once they receive their acceptance letter, they can schedule an appointment with the NDIS to create their support plan. The funding received by the NDIS is based on what is reasonable and necessary for each individual to achieve their goals. There are three support budgets that may be funded by NDIS:

- The Core Supports Budget is the most flexible and includes consumables, such as everyday use items, daily activities, such as self-care activities, assistance with social and community participation, such as support in social and recreational activities and transportation.
- The Capacity Building Budget is allocated under eight support sub-categories, each matches the goals of the plan and includes: choice and control; daily activity; employment; health and wellbeing; home living; lifelong learning; relationships and social and community participation.
- The Capital Support Budget can be used for assistive technology and/ or home modifications.

NDIS participants are offered three options on how to manage their NDIS plan and funding. They can choose one or a combination of three options for different parts of their plan. Therefore, participants may choose between NDIA-, Plan- or Self-Management.

[23] National Disability Insurance Scheme: www.ndis.gov.au

- **NDIA-management** - funding is provided directly to the service providers on behalf of the person. Once the providers have offered their services, they need to submit a payment request to the NDIS to receive the funds.
- **Plan-management** - a Plan Manager is responsible to get the payment requests from the NDIS and to pay for the support and services used on behalf of the individual. The Plan Manager is also paid by the funding, as people receive an addition to their funding to cover the cost of the Plan Manager.
- **Self-Management** - individuals or their representatives organise and manage their services on their own and the funding goes directly to them.

Western Australia's Individualised Services[24]

Western Australia's Individualised Services (WAIS) is a member-based organisation working in partnership with people, families, service providers and the government to promote and advance individualised self-directed support and services. The organisation provides support, informs and offers mentoring and coaching on Individualised Services and Self-Directed Support to persons with disabilities, their families and service providers. WAIS is committed to developing Shared Management, an approach initiated in Western Australia in 1990 that seeks to create a partnership among people, their families and service providers to manage individualised disability funding. This approach can be established under any of the NDIS's approaches, namely Management by the National Disability Insurance Agency (NDIA), Plan-Management or Self-Management. It has been evaluated as a tremendously positive experience by all involved parties.

The Shared Management approach provides the opportunity to individuals to control their care and support services without having to manage all the other aspects linked to their funding. In Shared Management arrangements, the person (or their representative) and the service provider share the responsibility for completing key tasks and meeting all of the legal obligations associated with delivering funded support services to the individual. Each party's responsibilities are recorded in a signed written agreement between the individual or their representative and the provider. The principles underpinned in this approach are Independent Living, Self Determination, Flexibility, Choice, Mutual Agreement and Trust.

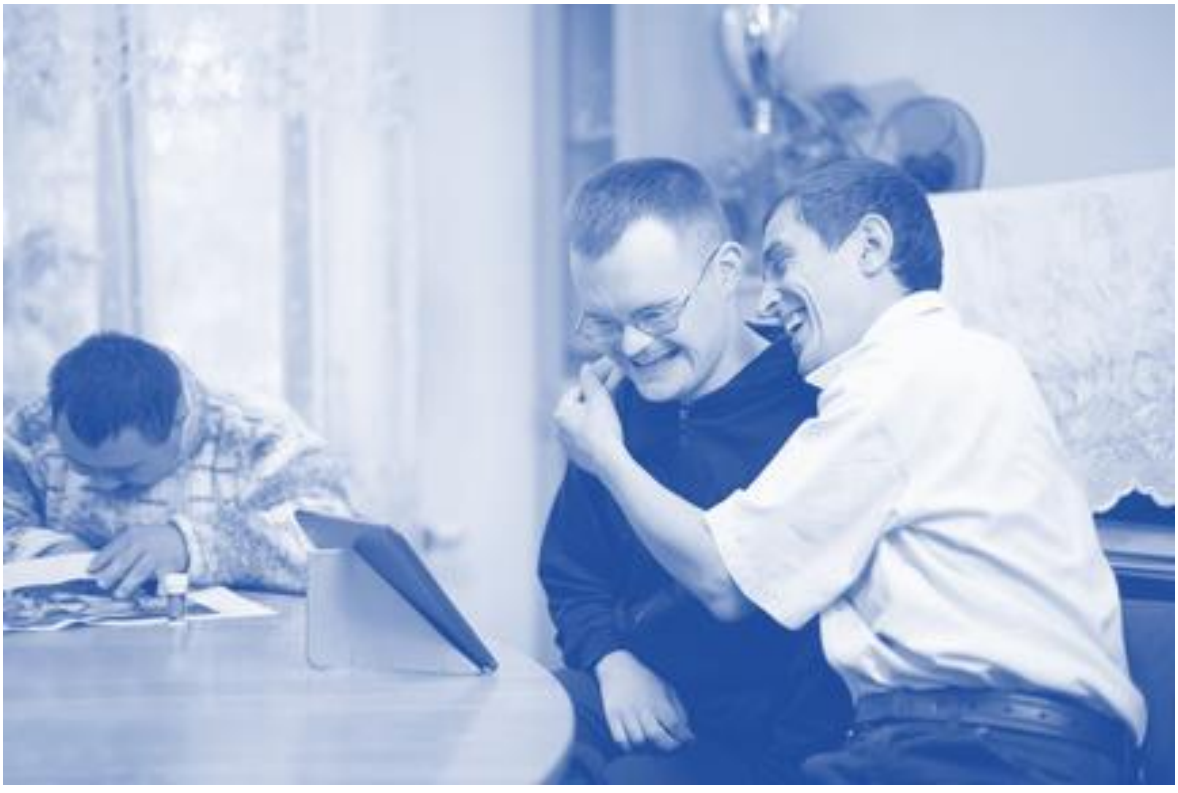
[24] More information may be found here: www.waindividualisedservices.org.au

WAIS (2012) Shared Management A guide for Support Organisations exploring Shared Management. Available here: www.centreforwelfarereform.org/uploads/attachment/356/shared-management.pdf

WAIS, Shared Management course for service providers. Available here: www.waindividualisedservices.org.au/online-courses/shared-management/

Currently, the funding model allows most of the funding to be provided directly to a Support Organisation and the organisation has the responsibility to plan, organise, implement and monitor the provided support on behalf of the person. Shared Management gives an opportunity to the organisations to partner with the person and to give more choice and control to them in leading their care and support services. However, it is important to clarify that directing the support and managing the support are not the same thing. It does not indicate that people are less in control when somebody else is managing their support. The support provided to manage the funding needs to be flexible to cover the needs, wishes and preferences of each individual. All the necessary safeguards need to be in place to ensure that individuals direct their own support. Therefore, the Shared Management approach allows individuals to have more control over their support and less responsibilities in managing the required tasks.

While this model provides many opportunities, there are also some challenges that must be noted. The approach comes with implications related to legislation and regulations, such as taxation, insurance, health, safety and others. If the individual acts as an employer, there are certain obligations that the employer must face, e.g., paument of taxes, compliance with labour regulations, health and safety requirements, administration of workers‘ insurance, etc.



2.6 A Direct payment system – Czechia

In Czechia, the Care allowance is provided monthly as a direct payment and is allocated to each individual who, due to care and support needs, depends on another person's assistance for participating in daily living activities. It can be used for services provided both from a licenced provider but also from an informal carer. This monthly care allowance is based on the level of care and support needs of each person and it falls under four categories. Additionally, there is the allowance for mobility which covers transportation costs and the grant for special aid, supporting those with severe physical, visual or hearing disabilities to pay for aids that help in self-reliance, working activities, education and social interactions.

Since the introduction of the care allowance, the role of the receiver of care and support has been strengthen and this has also facilitated access and affordability of care services.

State of play on user-centred funding models in Czechia[25]:

The care allowance has been regulated in Czechia since 2007, when the Act No. 108/2006 on Social Services came into force. This allowance is provided monthly and supports people who due to care and support needs depend on another person's assistance for participating in daily living activities. These activities include mobility, orientation, communication, self-feeding, putting on clothes and footwear, washing oneself, toileting, looking after one's health, personal activities and household tasks. Moreover, it supports individuals by providing social services and other forms of social assistance needed to handle basic life needs defined by the Act and it can be used either for formal or informal type of support. It can be used for example, by a family member or a registered social services provider or even a care assistant without license (but in this case a contract needs to be drafted). The size of the care allowance allocated to each individual corresponds to the degree of *dependence on care*, as defined by the Ministry of Labour and Social Affairs, which is based upon an assessment of the ability to manage the above mentioned 10 basic living needs.

There are 4 levels of dependence, divided into 4 different grades. The assessment process is done by a medical doctor of the Medical Assessment Service, followed by a final assessment, a home visit by a

[25] European Commission, Czechia - Persons with disabilities. Available here: www.ec.europa.eu/social/main.jsp?catId=1106&intPageId=4476&langId=en

Ministry of Labour and Social Affairs, Social assistance benefits for people with disabilities. Available here: www.mpsv.cz/web/en/disability#sabfpwd

social worker who evaluates the *dependency on care* in the real social environment of the person. The different grades and the care allowance allocated in each individual are described in the following table.

Grades	Dependency on care	Care Allowance Children & Adolescents* >1 year old <18 years old	Adults >18 years old
Grade I	slight dependence	CZK 3 300	CZK 880
Grade II	medium-heavy dependence	CZK 6 600	CZK 4 400
Grade III	heavy dependence	CZK 9 900 for people in residential care CZK 13 900 for people not in residential care	CZK 8 800 in residential care CZK 12 800 not in residential care
Grade IV	total dependence	CZK13 200 in residential care CZK 19 200 not in residential care	CZK 13 200 in residential care CZK 19 200 not in residential care

*The allowance is increased by CZK 2 000 for recipients who are dependent children below 18 years of age if the income of the family is under 2.0 family's living minimum.

Based on data provided by the Association of Social Services Providers Czech Republic (APSS CR) for 2017, the care allowance is mainly used for support by a family member (72,13%), followed by 19,68 % in residential care, 3.84 % in day care centers and 4.35 % in home care services. It is important to clarify that this allowance cannot be used for health care support, but only for social services, such as preparing meals, cleaning, shopping and others.

Furthermore, in Czechia there are two other types of allowances for persons with care and support needs.

- T**he allowance for mobility**, which is allocated to individuals who are older than 1 year old, they hold a certificate of person with disability ZTP[26] or ZTP/P[27] and they need to cover their transportation costs. The monthly amount of the allowance is CZK 550.

[26] A person with severe impairment of mobility or orientation, including people with autism spectrum disorder.
[27] A person with particularly severe functional impairment or complete impairment of mobility or orientation with the need for a guide, including persons with autism spectrum disorder.

- T**he grant for special aid**, which helps those with severe physical, visual, or hearing disabilities to pay for aids that help in self-reliance, working activities, education and social interactions. The amount of the grant for special aid is settled under 3 regimes: aids with price under and over CZK 10 000, and a vehicle. The grant in the case of an aid with price over CZK 10 000 is not income-tested, client´s participation is 10 % of the price of the aid, at least CZK 1 000. Some exceptions for low-income people are allowed, but minimal participation is always CZK 1 000. Maximum amount of the grant is CZK 350 000, or CZK 400 000 in the case when the aid is used to install a staircase lift. Maximum grant in the case when the aid is used on a vehicle is CZK 200 000. The amount is set with respect to the income of the entitled person (and related persons). This grant can be spent, for example, on different aids that may facilitate the everyday life of individual such as a vehicle, a guide dog, a braille printing machine, a signal for a doorbell, certain modifications in a vehicle or an apartment and others.

Care allowance

The direct payments via the social allowance have strengthened the role of care receiver as a client/customer. The usage is very broad, as the payments from the Care allowance could be used as a financial reward for family members or any other person (care assistant) that is willing to provide care and support. The Care allowance can be also used to "buy" community-based services, residential care or respite care. It is also possible to change the usage of care allowance without any limits or combine it (in between home care providers, daily care providers, respite care providers, family members or care assistants. Once the care allowance recipient is in a nursing home, he/she is obligated to pay the payment for provided social care at the same level of his/her care allowance income. The care allowance recipient declares only the way(s) of care.

There is no specific service or care provider which offers services only through the Care allowance system. The Care allowance is supposed to empower accessibility and affordability of care. The model of friend-based informal caregivers improves community-based care providing and makes a promising practice in homecare (when no specialised care, such as palliative or psychiatric, is needed). In residential care, it is used to cover part of the costs related with care provision in these facilities. In fact, social services are not included in the health insurance system in Czechia (yet 5 % of the total incomes are covered by health insurance system for health nursing activities. The system of social services and the system of health insurance are strictly divided so that the Care allowance substitutes the missing social (care) insurance. Social insurance exists but does not include/cover payments for social services.

The new system of Care allowance was introduced in 2007 linked with a crucial reform of social services. As part of this reform, a list of 33 social services was introduced, some of the services being redefined or modified. After 2007 several studies, prognoses and researches were done (2013, 2018, 2020). These reports have also shown that a significant share of care allowance is used for resources that are not in legal compliance of the usage (food, gas, transport, rental costs, medicament payments, etc.)

The care allowance resource is just one of the funding pillars of the whole system of social services in Czechia. Some data count the total yearly number of services recipients at 500.000 persons and the needs of care services at 36%[28]. 24% of the funding structure in Czechia is based on the care allowance system, bringing it to the second place on the pillar of funding.

Every social service provider in Czechia has the duty to provide the basic social advice to the current and potential users, including advice on how to access or increase the Care allowance. This kind of consultancy and assistance are also provided by all the social workers at the municipality level and/or at the Labour offices across the country.

2.7 Host organisations - New Zealand

Individualised funding (IF) is a payment arrangement under which persons with disabilities are allocated hours (translated into an annual budget) and choose who will support them, how and when. It is not a direct payment model, as the funds go to the Host organisation, which then supports individuals in managing and arranging their support services.

Manawanui is a host organisation which supports the budget holder through different types of supports ranging from management of the budget, administrative aspects, such as payroll services, supporting the individuals in purchasing a range of ICT products and learning how to use them, in accessing a training grant to train their supporters, etc.

State of play on user-centred funding models in New Zealand[29]:

Individualised funding (IF) is a payment arrangement that allows persons with disabilities in New Zealand to decide who will support them, how and when. Individuals have different options ranging

28 https://www.mpsv.cz/documents/20142/225517/Anal%C3%BDza+financov%C3%A1n%C3%AD+soci%C3%A1ln%C3%ADch+slu%C5%BEeb_2019.pdf/3c8c3bf8-c747-09b0-9308-3838a646c465

[29] **Ministry of Health, Individualised funding. Available here: www.health.govt.nz/your-health/services-and-support/disability-services/types-disability-support/individualised-funding-funded-ministry-health#hosts and here: www.health.govt.nz/our-work/disability-services/disability-projects/new-model-supporting-disabled-people**

from engaging their support worker and planning how to use the support, to employing care providers and managing all aspects of service delivery. Beneficiaries may use IF for home and community support services but also for respite services, either facility-based respite, carer support or in-home support. However, IF is not a direct payment model. Funds do not go directly to the individuals, but to Host organisations that deliver services. These Host organisations support people in managing their support arrangements and the amount of support received is flexible, depending on the needs and wishes of the individuals. IF allocates support hours, which are then translated into an annual budget. Each individual can choose how to spend it, together with their Host organisation.

In 2010, New Zealand approved a new model of support for persons with disabilities, which offers more choice and control to the individuals. This model was developed through consultations with persons with disabilities, their families/carers and the wider disability community. It is made up of four elements:

- Choice in Community Living - an alternative to residential services that aims to provide opportunities to persons with disabilities and their families to choose where they live, who they live with and how they are supported.
- Local Area Coordinator - a coordinator working with individuals, their families, and their communities to make a difference in the everyday lives of individuals.
- Enhanced Individualised Funding – funding that gives people more choice, control and flexibility in the way they user their funds and it allows them to spend their funding on a wider range of supports.
    - It is a new assessment form that allows individuals to assess their needs at any time, place and pace that suits them and with the support from whoever they want.

Moreover, New Zealand has passed the Pay Equity Act 2017, also called the Care and Support Workers Settlement Act 2017, which obliges the holders of IF to pay their eligible care and support workers the new minimum pay and to ensure that these workers are able to attain qualifications.

Manawanui[30]

Manawanui is a leading provider of Self-Directed Funding in New Zealand. It provides support as a Host organisation to individuals who receive IF or other funds. This can range from simply choosing who the client wants to support them to letting the host organisation manage the payments, through managing the recruitment, employment and payment of staff themselves. Together with a Manawanui Coach, each client develops their service plan based on their needs, wishes and preferences. Therefore, the

[30]More information may be found here: www.manawanui.org.nz

support plan is individualised to meet the needs of each individual and flexible to meet their wishes and preferences.

Manawanui offers a range of support services including:

- Management services, such as coaching support on how to use your budget, network meetings in the community, a Client Web Portal where individuals can set their budget, manage their expenditure, submit expense claims, and manage their support staff.
- Payroll management services, such as processing time sheets, provision of payslips and other administrative requirements.
- Administrative services to assist users in purchasing support from a family member, including assistance in ensuring that all the necessary requirements and conditions are met.
- Management of E-mploy, a platform which gives access to a pool of people who want to work as support staff. Both clients of Manawanui and people who are looking for employment as support staff can register and use this service. This allows individuals to find support staff closer to their location, choose staff based on interests, skills, qualifications and hobbies but also find staff that will support with different activities, either at home, in the community or even while travelling.
- Employer Protection Package, which offers insurance and access to expert support for all aspects of employment relations, covering liability insurance, employment disputes and a membership to the Employer and Manufactures Association which provides access to employment relations advice, seminars and online resources.
- Computing Solutions, which gives the opportunity to the clients to purchase a range of products, such as iPads, iPhones, laptops, accessible technology, monitors, keyboards, and others, using their funding. Additionally, they provide training on how to best use the technology and provide technical support.
- Health and Safety, provides information and a Health and Safety Kit that provides support in ensuring that the house of the individual is a safe working environment.
- Training for Support Staff. Manawanui supports in accessing the New Zealand Certificate in Health & Wellbeing which offers different levels of training, from an introductory course for staff with limited experience to a more advanced course for experienced support workers. The organisation can also support the individual in accessing a Training Grant, which covers part of the cost and the rest of the cost is covered by IF.

Manawanui offers webinars, and other opportunities to individuals to ask questions, share their ideas and give their feedback.

2.8 Personal Budgets System - Flanders (Belgium)

In Flanders (Belgium), persons with care and support needs may receive a limited amount of direct services, but when these services are insufficient to meet their needs, they can apply for a Personal Assistance Budget (for minors) or a Personal Budget Scheme (for adults). Since 2017, all adults with disabilities have been entitled to a Personal Budgets Scheme (PVB). Those interested in this scheme can apply through the Flemish Agency for Persons with Disabilities, VAPH. The PVB can be used either as a cash allocation or through vouchers, or a combination of both. The vouchers can only be used to purchase services from certified suppliers, whereas the budget in cash can also be used with a non-certified supplier.

Global individual support (GIO) is a scheme that supports children with a presumed disability in their transition to and from childcare and up to the primary school. GIO initiates a well-established network of support for the families while also preparing the ground for a more intensive future support, such as the Personal Assistance Budget for minors (PAB). the Service support plan organisations (DOP), assisting individuals to identify their needs and wishes then helps them in developing a service support plan; small-scale initiatives; and Assistance Organisations (Bijstandsorganisaties), aiming to support Persons with disabilities who receive personal budgets on how to navigate through the personal budgets system.

State of play on user-centred funding models in Flanders (Belgium):

VAPH is a government agency in Flanders, the Dutch-speaking part of Belgium, responsible for organizing and providing a personal budgets model for persons with disabilities. In Flanders, persons with care and support needs may receive a limited amount of direct services, but when these services are insufficient to meet their needs, they can apply for a Personal Assistance Budget (for minors) or a Personal Budget Scheme (for adults).

The Personal Assistance Budget (PAB) can be used only by minors for individualised one-on-one care and support, counselling, and collective day care services in a Multifunctional Centre. The PAB is currently in a transition process towards a personal budget system, which will broaden the scope of the current PAB.

Additionally, since 2017, all adults with disabilities are entitled to a Personal Budgets Scheme (PVB) and those interested in this scheme can apply through the VAPH. During the application process, VAPH clarifies the demand together with the applicants (persons with disabilities) and makes the final

decision regarding the identification of needs of each applicant. In addition, VAPH finances organisations which support individuals to draw a support plan. Once the application process is finalised, the applicant enters a waiting list for the allocation of the budget. In emergency situations, when the individual has very urgent support needs, the allocation of the budget is prioritised, in this case people do not have a waiting time and get their budget immediately. This is called an automatic allocation group. In addition, minors who are already entitled to a PAB and minors who make use of support of a multifunctional centre, enter automatically under PVB when they turn 21 years old. The PVB can be used either as cash allocation or through vouchers or a combination of both. Vouchers are only used for services from certified suppliers, whereas cash allocation may be used to purchase services from a non-certified supplier or from a certified supplier. Budget holders need to submit a proof of these cash expenses. Budgets in cash with a non-certified supplier can usually only be spent for individual support functions. But it is also possible to get individual support from a certified supplier with a voucher. Collective day care or residential support can only be used with a voucher with a certified supplier (with exception of parental initiatives of green care initiatives who are not certified suppliers but can give collective support functions).

VAPH is currently in a pivotal moment, assessing the use of personal budgets, developing projects to evaluate and monitor their progress to identify the challenges of the personal budget scheme and how to address them. The toolbox developed by the UNIC project will be piloted for one year in Flanders within VAPH.

Personal Budget System Initiatives

- Global Individual Support[31]

Global individual support (GIO) provides support to children with a presumed disability in the school system, up to the first year of primary school. It is in total 30 hours of assistance on an annual basis, and it aims to provide support to children in their transition to and from childcare and up to the primary school.

GIO is a mixture of stimulation, coaching, training and assistance activities. The assistant/care giver accompanies the child in the classroom or in the daycare, offering practical support and planning a sustainable inclusion process for the child, so that inclusion can also be maintained after the transition period. Additionally, the assistant coordinates the different actors involved, including school workers,

[31] More information may be found here: https://www.vaph.be/globale-individuele-ondersteuning-voor-minderjarigen-gio

parents, service providers and others. GIO further establishes a sustainable inclusive trajectory at a very young age, while empowering both the parents and the schools involved.

GIO is a directly accessible from of support, promoting inclusion while establishing a strong basis of support under the principles of early childhood intervention. And, more importantly, it initiates a well-established network of support for families while also preparing the ground for a more intensive future support through the Personal Assistance Budget for minors (PAB).

- Service support plan (DOP)[32]

The DOP organisations assist persons with care and support needs to identify their needs and wishes and develop with them a service support plan. The people supported by these organisations are people with a presumed disability, aged up to 65 years old, who have not received a personal budget by VAPH (exceptions may apply). They can either develop a plan without then applying for the personal budgets system of VAPH or develop a support plan to submit to the VAPH and join the personal budgets system.

The services of the DOP's last up to 1 year and may be extended to 18 months. Users of this service participate in regular meetings and identify their care and support needs, their wishes, and preferences, as well as the support that can be provided to them by service providers and their immediate environment (family members, neighbours, etc.). The users draft their support plan with the support of the DOP organisations and then meet regularly to re-evaluate the plans.

- Small Scale Initiatives

Small scale initiatives have also been developed within the Personal Budgets System in Flanders. Examples of such initiatives are Parents' and Green Care Initiatives. The first ones are formulated by the parents and/or other family members of persons who wish to organise care and support for persons with disabilities. These initiatives can be registered with the VAPH and offer collective care and support. And the latter are initiatives of a company, association or private individual in which activities of agricultural or horticultural production are part of the daytime activities for persons with disabilities.

The number of small-scale initiatives has been gradually increasing. Parents' initiatives have increased from 13 official agreements in 2017 to 28 in 2019 and from 9 registered initiatives in 2019 to 17 in 2021. Official agreements refer to the people that are using a small-scale initiative financed by their personal budgets. The Green Care initiatives increased from 18 official agreements in 2017 to 63 in 2019 and from 25 registered initiatives in 2017 to 84 in 2021.

[32] More information may be found here: www.dienstonderhulpingsplan.be / www.dop-vbb.be

This increase in both aspects of small-scale initiatives has initiated a project within VAPH with the objectives to identify how to stimulate innovative inclusion-oriented initiatives that offer high-quality care and support. The project investigated whether it is desirable to increase possibilities for collective support within the cash expenditure; to facilitate infrastructure support for small-scale initiatives on an equal basis as that provided to licensed care providers; to formulate recommendations on adjusting their organisational and legal framework; to explore the need for support and coaching for new small-scale initiators; and the possibilities to meet this need by recognising and subsidising a facilitating organisation.

- Bijstandsorganisatie[33]

The Bijstandsorganisaties, or in English the Assistance Organisations, operate in the region of Flanders in Belgium with the aim to support persons with disabilities in navigating through the personal budgets system. Once persons with a disability receive their personal budget, they may use it on their own or they may become members of a Bijstandsorganisatie and receive additional support in managing the budget.

Bijstandsorganisaties organise webinars and one-on-one coaching services, operate call centers to answer questions and develop tools to support their members on the use of the budgets. Members pay a membership fee to join one of the organisations and have access to the different services/ information. When more intensive support is needed, they can use their personal budgets to pay for that. Once personal budget holders join a bijstandsorganisatie, they receive support in identifying their needs and wishes and translating them into support plans. This support is person-centred can be offered in the residence of each individual. Each individual is supported in making their own decisions under the principles of choice and control over their lives. Moreover, managing a personal budget involves the administrative aspects, such as drawing contracts, recruiting assistants, searching for services. Personal budget holders who do not wish to manage these matters may request the bijstandsorganisatie to handle these administrative elements for them.

Bijstandsorganisaties, on the one hand, support personal budget holders to access their budget more easily, to optimise the use of budgets and to provide necessary information for making well-informed decisions. On the other hand, based on their experience and on their close contact with the holders of personal budgets, bijstandsorganisaties also directly advocate for changes in the model.

[33] More information may be found here: https://www.onafhankelijkleven.be/
https://www.absoluutvzw.be/
http://www.zoomvzw.be
www.alin-vzw.be
http://www.myassist.be/

2.9 Pilot Projects on user-centred funding models

In Salzburg, Austria a Personal Assistance Pilot Project was launched in 2017. The support provided by the assistants is flexible and defined by the needs and wishes of the beneficiaries. There are also two ways of organising Personal Assistance: i) service users employ their assistants themselves and are responsible of all employer related aspects; ii) a service provider acts as the employer and cooperates closely with the service users to ensure choice and control.

In Spain, in 2006 the Personal Autonomy and Dependency Care law came into force establishing a framework for services and benefits for persons who, due to illness, disability or age, could not lead an independent life without support. This law initiated the Personal Assistance Pilot Project, allowing individuals to direct their own support and ensuring that their right to independent living is respected. Beneficiaries can hire their personal assistants through an accredited care company or hire directly a personal assistant who is registered as a self-employed worker in the Social Security System.

Since 2015, Israel has been introducing a personal budgets model for persons with disabilities through pilots. A pre-pilot phase lasted for three years and they are currently in transition to a pilot phase which may last for 3-5 years.

In Finland, the citizenship project (Personal Budgeting) was carried out from 2016 to 2019. It tested the personal budget with a coordinated approach from public authorities and universities. It was funded by the European Social Fund. The project supported the development of freedom of choice within the Healthcare and Social Welfare Reform.

2.9.1. Personal Assistance pilot project - Salzburg, Austria

State of play on user-centred funding models in Austria:

In Austria, services and support systems for persons with disabilities are mostly a regional responsibility and there are many differences between regions in terms of legal frameworks, services and eligibility criteria. Meanwhile, employment-related services are a national responsibility. Personal Assistance and Personal Budgets were included as priorities in the National Action Plan but, unfortunately, since 2012 there have been no actual outcomes. The majority of services are provided by service providers which are contracted by the government and are paid directly for the services provided. However, there is also a care allowance provided to beneficiaries in cash, which is also available to other groups, such as older people, and a personal budgets model that can be used for personal assistance at work/ education (national responsibility), and for all other domains of life (regional responsibility).

The Personal Assistance scheme for work and education is provided mainly to persons with physical disabilities. In the region of Salzburg, the scheme currently supports 20 users. This scheme is, however, not available for persons with intellectual disabilities.

The Personal Assistance scheme for all other domains of life is, on the other hand, open to persons with various disabilities and high support needs.

Personal Assistance Bundesland Salzburg

Since 2017, Personal Assistance in Salzburg has been in a pilot phase. It first started with 17 users in a region of 560.000 inhabitants (yearly budget € 878.000). In the spring of 2020, the number of users increased to 28 (yearly budget € 1,8 million), and in 2021 to 35 (yearly budget € 2,4 million). Further increases are planned for the following years.

Personal Assistance (PA) in Salzburg fosters self-determination, independent living, and equal participation in society of persons with disabilities through support by personal assistants in different domains of life. The support is flexible and defined by the needs and wishes of the users. Persons with disability can choose between two ways of organising Personal Assistance[34]:

Employer Model: service users employ assistants themselves and are responsible for all aspects of the employer role and the organisation of support. They receive monthly payments directly to their dedicated bank accounts.

Service Provider Model: a service provider acts as the employer and cooperates closely with the service users regarding the choice and recruitment of assistants. They organize assistance when needed, based on wishes of users, ensuring choice, control and self-determination. Currently, service users can choose between 2 service providers.

Additionally, service users must document the dedicated use of the money for PA. If their support needs change, service users can apply for the adaptation of the budget.

In both models, assistants are employed and paid according to the collective agreement for social services. They do not need any specific professional training but readiness to participate in initial and/ or continuous training specific to their role, show empathy and communication skills. They assist with basic needs (e.g., getting up, personal hygiene), housekeeping (e.g., laundry, cleaning, shopping), mobility, leisure activities, communication, appointments and other things the user wants/needs to do outside home. They do not provide support in employment nor in education, as these types of support go under the Personal Assistance scheme for work and education.

This model supports persons with physical or cognitive impairments or mental health issues in need of support in different domains of life (18 – 65 years). The main target group are people with severe physical impairments. However, currently the model does not support persons living in residential

[34] Main source: Guidelines of the Salzburg State for Personal Assistance and its funding, September 1st, 2019

services, persons receiving “24-hour support”, persons exclusively in need of medical care, or persons only needing support for housekeeping. The personal budgets are granted independent of income or other financial assets and service users do not have to contribute to the costs.

The granted amount of monthly personal budget and support hours are based on self-assessment and information collected during a meeting with the service user. There is no ceiling for the monthly amount of support hours/budget. The authorities coordinate the Personal Assistance in the Salzburg region and if the person is eligible, s/he receives a self-assessment form for support needs/wishes. The applicant is entitled to peer counselling by Knackpunkt (an independent living DPO), and support for filling in the self-assessment form if s/he wishes. After receiving the self-assessment, the authorities invite the applicant to a personal meeting to discuss the amount of support/ personal budget that will be funded. The applicant may bring a confidant to this meeting and the application procedure is easy and well supported (by the peer counselling support).

During the pilot project phase (2017- 2019), Lebenshilfe coordinated Personal Assistance for 2 users with high support needs and in 2020, this changed considerably, and Lebenshilfe currently organises PA for 18 users. The organisation started small and developed the new type of service in close cooperation with service users and the Peer Counselling DPO. Initial and continuous training for assistants were jointly developed and organised by both service providers and the DPO in cooperation with users. There have been few formal structures in the pilot phase (small number of users) apart from meetings of each support team (1 – 2 times a year) and one team also used group supervision. There has been close contact (mostly by phone) with the users to ensure their satisfaction with services.

In 2018, the pilot project was evaluated positively by service users, service providers and assistants, which led to the decision by the authorities to continue and increase funding for PA. Service users reported a considerable increase in quality of life, self-determination and independence. Their families and close social contacts also experienced positive effects, mostly in terms of a happier life, relief and a reduction of burden. Service users perceived the allocated monthly hours of support as appropriate. In terms of practical handling, service users receiving assistance through the service provider model expressed high satisfaction with both providers (Lebenshilfe Salzburg & Caritas Salzburg), e.g., self-determination of users characterises the process of choosing and recruiting personal assistants. Also, the users employing the assistants themselves (the employer model) were very satisfied. But most users preferred to delegate the employer role to a service provider (service provider model). Peer counselling by the Independent Living organisation Knackpunkt was considered a valuable feature, especially in the context of the self-assessment of service users’ support needs at the beginning.

Assistants were mostly satisfied with their work. Their feedback revealed different views on whether specific training was necessary. The wish for more initial training and continuous education was often tied to the needs and challenges of specific target groups, e.g., persons with mental health issues. Results also indicated that it was not always easy to find and recruit adequate assistants, e.g. more difficult in rural areas, for persons with a lower number of support hours; it was especially difficult in case of specific requirements for assistants (e.g., knowledge of sign language), and sometimes delayed the beginning of PA as assistants had to attend specific trainings first.

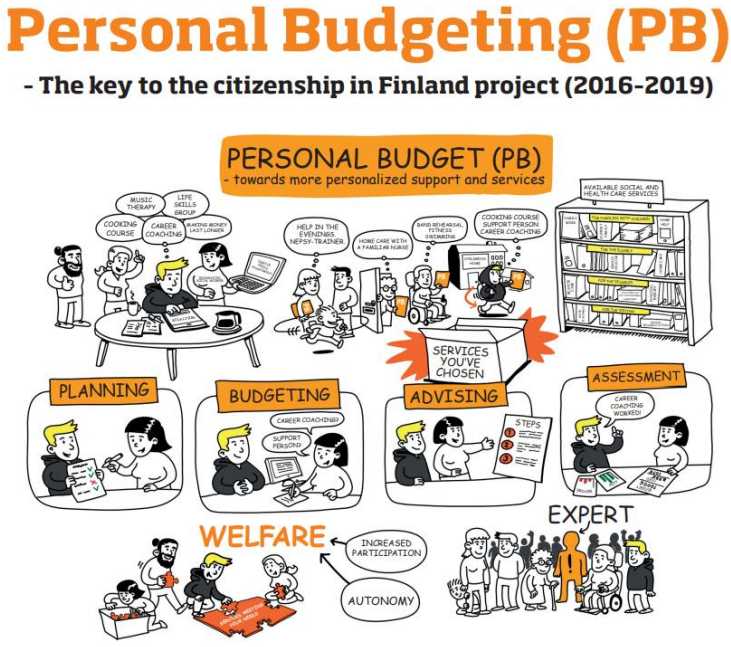
2.9.2 Personal Budgeting pilot project – Finland

State of play on user-centred funding models in Finland:

Finland first introduced a personal budgeting model through a pilot project in 2010, called *I know what I want*. In 2014, through the Social Welfare Act, they implemented a transformation and reform of the social care sector, where the health and social care services of citizens fall under the 300 Municipalities of Finland. Additionally, between 2017-2019, they continued piloting a personal budgeting and self-directed support model, which supported the government in preparing the *Freedom of choice Act*. Currently, the government implements aims to pilot a common personal budgeting model in nine different regions.

Key to the citizenship project (Personal Budgeting)[35]

The key to the citizenship project (Personal Budgeting) in Finland supported the development of freedom of choice within the Healthcare and Social Welfare Reform. The project was carried out from 2016 to 2019, was financed by the project partners and the European Social Fund through the Finnish Ministry of Social Affairs and Health. The project developed and tested the Personal Budgeting approach in six organisations. Three universities of applied sciences were responsible for supporting and monitoring the project and nationwide partners were also involved in the development of the project.



[35] More information may be found here: http://www.henkilokohtainenbudjetointi.fi/in-english/

The main goals of the project were to produce a variety of new information on the bases of personal budgeting (PB) experiments, to describe the PB approach, to increase awareness of personal budgeting, and to strengthen PB expertise among social workers and organisations. Moreover, the project supported the development of freedom of choice within the Healthcare and Social Welfare Reform. It produced follow-up data to support the legislation on freedom of choice, a report on the possibilities and prerequisites of Personal Budgeting, and a plan for a follow-up study on the national implementation or further trials of the PB model. Freedom of choice means that services users would have the right to choose for themselves where to get health and social services and these services would be provided by both public and private organisations and NGOs, such as associations and foundations. Client fees would be the same across all service providers. Wider freedom of choice would increase clients' role in decision-making. Another goal of the reform is to improve the availability, quality and cost effectiveness of the services.

As a result of the project the clients' skills to make choices concerning their life and opportunities for employment and education will improve. The cooperation in supporting clients will be goal-directed and systematic. The authority-centred working culture will become more client-directed and the co-operation and co-development with the labour market will strengthen. When a person participates in PB, it means the focus is on empowering and strengthening their self-confidence. The participation of the service user within their peer and local communities and close ones increases. The services are understandable, tailor made, manageable and available for them, thus reducing the risk of exclusion and services being cost effective.

2.9.3 Developing a personal budgets funding model – Israel

State of play of user-centred funding models in Israel:

In 2015, the Joint Distribution Committee (JDC), the Government of Israel and the Ruderman Family Foundation, organised workshops with leaders and policy makers from Israel and the United States with the aim to introduce a personal budgets model for persons with disabilities. Since then, they have launched a pre-pilot phase and currently preparing for the pilot phase before mainstreaming this model in Israel.

Personal Budgets pilot project[36]

36 Zero Project (2015) PIONEERING A PERSONAL BUDGET MODEL AS PART OF NATIONAL SOCIAL SERVICES. Available here: www.zeroproject.org/practice/pra191416isr-factsheet/

In 2018, there were 50 people with disabilities using the personal budgets model and 200 professionals had been trained on how to deliver and support them in the framework of a user-centred funding model. In 2019, the number of participants grew to 75 and the pre-pilot phase was finalised.

In January 2021, after the assessment of the pre-pilot, JDC launched the pilot phase, which will last for 3 years. During the pilot process, they will implement a personal budgets funding model addressing 130 people in different locations within Israel. The model provides a care coordinator for each beneficiary who engages with them in a discussion to identify their needs, wishes and preferences. After this initial assessment, the individual is offered a flexible and individualised spectrum of services, in the framework of a personal budgets funding model. The personal budget is not provided to the individual as a direct payment, but it is provided to an organisation that is responsible to allocate the budget towards the services chosen by the individual. The care and support plan of each individual is regularly assessed, approximately every 3 months.

The JDC is working closely with the Government of Israel, planning a step-by-step expansion and together with the findings from the pre-pilot phase they will aim to identify solutions to the challenges they have identified. The identified challenges which they will need to overcome are the need for the development of managing mechanisms, related to the administrative perspectives, the quality of services provided and the adequate skilled professionals; the development of an assessment tool, which will support in assessing the needs of each beneficiary; and how the identified needs, wishes and preferences of each beneficiary can be translated to a personal budget.

Moreover, during the pilot phase, there will be a basic personal budget aimed to support with the leisure activities of the beneficiaries, around €400 to €600, which will be complemented based on the needs and wishes of each individual. They will also aim to pilot different approaches in the use of the personal budgets funding model, where the local authorities will be responsible for:

- purchasing the services for the individuals and managing all the related administrative matters or
- providing a Smart Cart to the beneficiaries so that they can use it to pay for the services themselves.

2.9.4 Personal Assistance pilot project – Spain

State of play on user-centred funding models in Spain:

In 2006, the Personal Autonomy and Dependency Care Law (39/2006) came into force in Spain, establishing a new and universal framework of services and economic benefits aimed at supporting persons who, due to illness, disability or age could not lead an independent life without support.

The main economic benefits included in the Spanish Dependency Law are diversified between the economic benefit of personal assistance, received by the person to self-direct their own support for a certain number of hours; economic benefits linked to specific services, usually day-care centres or residential facilities, and economic benefits received by a family member as a non-professional caregiver at home. The Personal Assistance was initially conceptualised and regulated to offer support to highly dependent persons (level III) and since 2012 this benefit has been extended to ensure that less dependent persons (level I and level II) could access it (RD 1051/2013)[37]. The beneficiaries have the option to hire personal assistance through an accredited care company or to directly hire a personal assistant registered as a self-employed worker in the Spanish Social Security System.

Personal Assistance pilot project:

The Personal Assistance Service, as recognised in the aforementioned *Dependency Law,* has facilitated the creation of a new profession throughout Spain: the Personal Assistant. This professional offers support to persons with disabilities so they can carry out their own life project. The personal assistance service allows persons with disabilities to direct their own support, hence enabling them to fulfill their right to independent living, recognised in the Article 19 of the United Nations Convention on the Rights of Persons with Disabilities is respected, as well as the standards defined in the General Comment Number 5 are met[38].

Over the years, studies have revealed new data from the Personal Assistance Professional in different Spanish Autonomic Regions. A study made in Valencian Community[39] highlights the setbacks of this universal actor in this region. The main findings of the study point at the lack of accessible information on this on behalf of the Public Administration who does not properly inform potential beneficiaries of its existence, and insufficient or appropriate funding, amongst others.

A similar study analysing the Dependency System in Spain[40] highlights the importance of promoting the personal assistance in its current form. It has obtained interesting results in the province of Guipuzkoa. To contextualise the latter affirmation, it is important to understand that, as of 28th

[37] https://www.boe.es/eli/es/rd/2013/12/27/1051
[38] CRPD/C/GC/5
[39] Carbonell Aparici, Gonzalo José. (2019). La experiencia de la asistencia personal en la Comunidad Valenciana. Zerbitzuan. 47-64. https://doi.org/10.5569/1134-7147.68.04
[40] Eguía-Careaga, SIIS. (2020). Algunas pistas para la mejora del sistema de atención a la dependencia en España. Zerbitzuan. 77-90. https://doi.org/10.5569/1134-7147.72.06

February 2021[41], the Basque Country, which includes Guipuzkoa, comprises the 78% (6.265) of the total of Personal Assistances in Spain (8.025), followed by Castilla y León (17%; 1.371); Galicia (1%; 110); Community of Madrid (1%; 87) and Catalonia (1%; 76). The remaining 3% is shared between Andalucía (13), Principado de Asturias (6), Castilla La Mancha (23), Comunitat Valenciana (38), Murcia (4) and Comunidad Foral de Navarra (22). The only Autonomic Regions that do not have persons who enjoy the Personal Assistant service are Aragón, Illes Balears, Canarias, Cantabria, Extremadura, La Rioja and Ceuta y Melilla.

It is especially significant that the Personal Assistant Service only represents a 0,56% of the Spanish Dependency Scheme, underrepresented in comparison with the economic benefits for a non-professional caregiver (31,74%), teleassistance (17,90%), domiciliary care (17,84%), residential services (10,88%), economic benefits linked to a specific service (10,66%), day and night centres (6,15%) and other preventive measures (4,27%).

Amongst the specific causes of the Personal Assistance scheme underrepresentation we can identify the lack of information about this figure, including professionals working in Public Social Services, hence creating unawareness on potential users; the lack of proper financing of this figure; incompatibilities of this benefit with other types of services or benefits; a marginal perception of the role of the personal assistant or the lack of a qualification framework for personal assistants, often relying on socio-sanitary training programmes focusing on care instead of a global Human Rights approach.

Despite this uneven distribution among the different Spanish regions, in the regions where the Personal Assistant role has been widespread and successfully implemented, this model of self-directed support has shown an improvement in the quality of life of persons with disabilities as well as proven as a valid service model that has contributed to avoid institutionalisation.

In this diverse context, several initiatives such as the Personal Assistance Model of the municipality of Barcelona (SAP-BCN)[42] and the study focusing on the skills of the personal assistant as a professional figure[43] have contributed to generate debate about the need to review the current accreditation system for the provision of the Personal Assistance Service in Catalonia, develop an agile and effective

[41] https://www.imserso.es/InterPresent2/groups/imserso/documents/binario/im_061364.pdf

[42] Department of Independent Living Services, Social Rights Area, Municipal Institute for People with Disabilities, Barcelona City Council (2019). Personal Assistance Model SAP-BCN. Available at: https://ajuntament.barcelona.cat/dretssocials/sites/default/files/arxius-documents/model-servei-assistencia-personal-barcelona.pdf

[43] ECOM (2021). Estudio sobre la Formación de Asistente Personal. Available at: https://www.ecom.cat/sites/default/files/images/estudio_ap_cast_interactivo_def.pdf

inspection system in Catalonia and to develop specific formation to address the gap in current curricula.

It is particularly noteworthy that the Department of Labour, Social Affairs and Families of the Catalan Government has started processing the Decree that will regulate Personal Assistance in Catalonia. Its approval and release date is still an uncertainty.

3 Drivers and Barriers for the development of a user-centred funding model

From the mapping exercise we conducted, we identified that there are different user-centred funding models already established across Europe and across the world. **Such funding models have gained traction around the world**, with many countries, such as Israel, Austria, Spain and Finland developing pilot projects to test the efficacy of such models. At the same time, from the already well-established models, we have identified many differences not only in the way they were developed but also in the way they are offered to persons with care and support needs. We have also noted some of the challenges or limitations which may be included in a funding model as such.

There is a need to highlight **that user-centred funding models are and should be viewed as a way to empower persons with care and support needs to make decisions, have more choice and control over their own lives and thus, enjoy their right to legal capacity**[44].

The development of a user-centred funding model is a **radical transformation of the traditional funding streams**, it has clear benefits for persons with care and support needs. It supports them in accessing their right to legal capacity, it empowers them to make decisions and lead their lives while being fully supported to have their needs met. The model was initiated in the late 1960s in the US and 1990's in the UK and Sweden, but it has not yet been mainstreamed across Europe and across the world. It requires a transformation process, with many challenges which may not be as clear as the benefits of developing a model as such. In Israel, for example, they started with a pre-pilot phase for 3 years. Now they have introduced a pilot phase, which may be in place for 3-5 years, before mainstreaming their user-centred funding model. That demonstrates the **careful planning** that a transformation requires. It also indicates that **bureau hurdles** and **inflexibility** can also be important factors in systems run by public administrations.

Furthermore, this radical transformation of funding can be geared through also the active involvement of the persons themselves, the actual future holders of personal budgets. This is often called **co-production** and it is described as an inclusive working practice between experts by experience (users), organisations providing support, public authorities, and, if relevant, families and other stakeholders. The goal of this approach is the creation, design and delivery of a service, policy or activity that will meet the needs, wishes and preferences of individuals with care and support needs in line with the UN CRPD. This approach empowers all relevant stakeholders and allows persons with care and support

[44] Article 12. UN Convention on the Rights of Persons with Disabilities. Available here: www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-12-equal-recognition-before-the-law.html

needs to be in control of their lives, while taking ownership and expressing choice through active and meaningful partnerships.

Examples that support an approach as such are the **Local Area Coordinator model**, described in the UK, and their influence in transforming the local systems of support but also the model of In Control Scotland, working to **build the capacity of self-directed support** for persons with disabilities, their families but also social and health care and support services and their workforce.

The role of the Local Area Coordinators brings them in a position where they can influence the decision-making process by connecting the people of the community with the local councils, following a bottom-up approach. They may bring the perspectives of the community up front the decision-makers to influence decisions and achieve a fundamental change towards support and care systems providing person-centred, accessible to all and high-quality services. In addition, In Control Scotland through their initiatives, such as the Partners in policy making programme and the Working Together for Change supports participants to gain the knowledge, skills and confidence to campaign and advocate for better treatment and social justice for persons with disabilities in the society. People from different levels are brought together, new alliances are built with the common goal to learn, exchange experiences and facilitate access to self-directed support in ways that work for the beneficiaries.

Furthermore, it is important to highlight the important role of **peer-to-peer support** as well as other support established at a community level. We are not yet certain if we have identified the most appropriate model of user-centred funding in Ireland as different pilot projects have been emerging. We decided, however, to decribe the initiatives of Áiseanna Tacaíochta, despite possible limitations that a model as such may have. ÁT has developed a Peer Support Network, which brings together leaders of experience (users of the user-centred funding model), their families and future users of such funding model to support one another, offer advice and mentoring. Moreover, ÁT has established a *Circle of Support*, consisting of people from local communities, to assist them with the managerial and administrative matters linked to the funds. In this model, we need to focus on the dynamics that have been developed in the community and how they have demonstrated that **community support** and **neighbourhood connections** are feasible. It is important to highlight that the models should be complementary to other support persons get through their peers and their communities. It is the responsibility of public authorities to provide adequate services and to meet the needs and wishes of their citizens.

Additionally, to the sense of community, as mentioned previously, in Italy, Trieste's Community mental healthcare demonstrates practically how and why we need to focus on the development of services

based in the community. Trieste's model has become a new vision for mental health services that took shape in the city where services became **fully embedded in the community** and **accessible by all**.

Long-term care faces many challenges, such as accessibility and affordability, sustainability, employment and workforce development, and quality of the services provided. Looking closer at the different examples of user-centred funding models and the practices developed we further identified the following:

In the majority of the user-centred funding models presented in this report, disability is a precondition for access. Personal budgets are not offered to any person with care and support needs, irrespective of age and disability.

- ➔ Services and policies need to be flexible; they need to **acknowledge and adapt to the provision of services for all persons in need of care and support, based on their individual needs and preferences.** For instance, services shall not be put in silos and designated only for specific groups. Services shall focus to respond on the needs of every individual, regardless of age and/or disability. This comes also in accordance with one of the aims of the UNIC project to transfer the personal budget model into not only different countries but also different services, such as childcare, homelessness services and mental health services.

Throughout our consultations, we identified that existing user-centred funding models are often **not easy to use and understand,** not only by persons with care and support needs, but also the social workers responsible for supporting their clients in accessing these models.

- ➔ For this reason, in some countries, they **provide intermediaries to facilitate access and use of personal budgets,** both for the budget holders and the services. In New Zealand, for example, individuals may receive an individualised funding only through "Host organisations" which support them in identifying how to make the best use of their funds. In Flanders (Belgium), an individual may use their funds without going through an organisation, but organisations have been developed to support anyone needing additional support when using their funds. And, as we saw in Scotland, individuals have four different options to choose from when it comes to deciding how they will receive and how they will manage their funds. In other countries, peer-to-peer support initiatives, user-led organisations and user cooperatives strengthen the use of funding models.

Additionally, **as persons with care and support needs are not a homogenous group, they have diverse needs, preferences and require different forms of support.** Easy-to-read materials and accessible

buildings and transportation are some of the examples that need to be put in place to allow more autonomy and better access to services and information by persons with care and support needs.

- ➔ Moreover, **"Support" is a broad term** that encompasses both informal and formal support arrangements, of varying types and intensity. Examples may include a trusted support person to assist individuals in making decisions, peer support, advocacy, assistance with communication, or measures relating to universal design and accessibility. For example, requiring private and public actors to provide information in an understandable format or to provide professional sign language interpretation. All the options should be non-discriminatory, and should be provided to a person, where and when desired[45].

As mentioned previously, getting a budget means more **administrative and managerial responsibilities from the holders of the budgets**. This may be detrimental for many persons with care and support needs on whether they will use the model.

- ➔ Through the **Shared Management Approach** in Australia, a person and a service provider may share responsibility for completing key tasks and meeting all of the legal obligations associated with delivering funded support and services to the individual. Therefore, an individual has the opportunity to decide on the use of the budget without having the burden of the administrative tasks involved. This approach is equally beneficial for the service providers themselves, as they play an equally important part in the service delivery even with the use of a user-centred funding model. However, this is an approach that has not yet been mainstreamed, but has been evaluated as a tremendously positive experience from all involved parties. This approach can also be found in Flanders (Belgium).

There is a tendency from public authorities to focus on the cost-efficacy of a funding model, rather than its benefits. Here it is also important to highlight, that **transparency** of the budget that is allocated to the individual. Knowing all the relevant information **up-front** is an important aspect of the user-centred funding models. This provides to the individual clear and transparent information, the ability to request a budget that will meet their needs and wishes and provides them with the opportunity to plan their support and care services. Additionally, it is not always possible to identify the needs of an individual in advance. It is vital for individuals to receive a budget that will meet their needs and wishes.

- ➔ Therefore, **the budget needs to be flexible and to respond to the actual needs of individuals and not the apparent needs** identified in the initial application process.

[45] Article 12 on the UN Convention on the Rights of Persons with Disabilities -protects equality before the law for all persons regardless of age.

User-centred funding models, **shift the power**, **from the service provider to the individuals themselves, thus bringing new roles and different responsibilities**. On the one hand, we identified that, in some cases, personal budget holders need to act as employers to start receiving and using a funding model as such. On the other hand, this has an **impact on social services** as well. This shift requires a change in the mindset, in the way services are provided and the way staff is trained. It also means that the service needs to find new ways to attract the personal budgets holders to their services.

- ➔ It is important that safeguards are put in place to ensure that it is the persons themselves who decide how the services are provided and what the level of involvement of the services providers is.
- ➔ A way towards this is **Supported Decision-Making**[46] which needs to be in the core of every service, as this is key in fostering self-determination, autonomy, control over one's life and further promoting independence. When applied in policy and practice, it allows individuals to retain their decision-making capacity and prioritise their will and preferences.
- ➔ Traditionally, social services are facing challenges related to staff shortages and/or inadequatey trained staff to respond to the needs and wishes of individuals. Unattractive working conditions, the lack of recognition and limited opportunities for professional development create challenges to the recruitment and retention of staff[47]. User-centred funding models can support in promoting the care and support sector as a career choice; there is evidence that professionals are more satisfied with their jobs, when they see the increased impact they have on the quality of life of the individuals they support. Additionally, models as such, have the possibility to create professional environments where the personal budget holders and their supporters work together to co-produce a service that responds to the needs and wishes of each individual.

Funding models affect the way social care and support services are developed and they shall not be seen as neutral instruments. They also have an **impact on the ability of a service provider to develop better quality services**, based in the community and in line with the principles of the UN CRPD and the European Pillar on Social Rights. Care and support services are the vehicles of millions of people to live dignified lives and to enjoy equal access to their social rights.

[46] Article 12 on the UN Convention on the Rights of Persons with Disabilities -protects equality before the law for all persons regardless of age.
47 EASPD, 2019, Staff Matters: from care workers to enablers of change. Available here: www.easpd.eu/sites/default/files/sites/default/files/easpd_helsinki_conference_report_2019.pdf

➔ Therefore, funding should not only be **sufficient for the needs and wishes of each individual** with care and support needs, but also it should allow the **necessary flexibility to the service provider** to meet those needs and wishes[48].

4 Conclusions

This report provided an overview of promising examples of user-centred funding models (particularly personal budget systems) in Europe and around the world. It also aimed at highlighting different elements in the identified examples which have been initiated to support the design, development or implementation of personal budgets. In the last chapter, we aimed to provide a brief overivew of the long-term care challenges, with the objective to introduce the readers to the subject of the next report, published under the UNIC project. Therefore, we invite you to read the Challenges-responsive guidelines, which provide an overview of the long-term care challenges and how can a user-centred funding model respond to these challenges.

[48] EASPD (2019 How to Fund Quality Care and Support Services: 7 key elements). Available here: https://www.easpd.eu/sites/default/files/sites/default/files/bucharest_2019_conference_report__2.pdf

Glossary

Community-based services

Community-based services, or community-based care, refers to the spectrum of services that enable individuals to live in the community and, in the case of children, to grow up in a family environment as opposed to an institution. It encompasses mainstream services, such as housing, healthcare, social care, education, employment, culture and leisure, which should be accessible to everyone regardless of the nature of their impairment or the required level of support. It also refers to specialised services, such as personal assistance for persons with disabilities, respite care and others. In addition, the term includes family-based and family-like care for children, including substitute family care and preventative measures for early intervention and family support[49].

Long-term care and support

There are various definitions of long-term care (LTC), including the types of care (residential, semi-residential, institutional or community-based) provided or LTC locations. Different organisations have different interpretations/definitions of LTC based on their perspective or approach, whether political, humanist, or medical. It is important to note that there is no universal agreed definition of LTC and it can mean something different to each country and organisation. However, the usual target audience for LTC definition is the elderly, and in some cases, some descriptions would specifically include disability or any underlying conditions.

Some of the providers have defined LTC based on the Social Protection Committee and the European Commission, who determined that "LTC is defined as a range of services and assistance for people who, as a result of mental and/or physical frailty and/or disability over an extended period of time, require support with daily living activities and/or are in need of some permanent nursing care. The daily living activities for which help is needed may be the self-care activities that a person must perform every day or maybe related to independent living."[50] Other scholars emphasise, in the terminology of LTC, values such as independence, autonomy, participation, personal fulfilment and human dignity.[51] The above values are seen throughout all these definitions between international organisations and local care providers with a strong focus on the human approach to LTC.

[49] European Expert Group on the Transition from Institutional to Community-based Care (2012). Common European Guidelines on the Transition from Institutional to Community-based Care, p.27

[50] Social Protection Committee and the European Commission. 2014. Adequate Social Protection for Long-term Care needs in an ageing society. Luxembourg. Publications Office of EU. Available at < https://op.europa.eu/en/publication-detail/-/publication/71532344-ddf1-4d34-a7aa-f65c701a22a2

[51] Nies H., Leichsenring K., Mak S. (2013) The Emerging Identity of Long-Term Care Systems in Europe. In: Leichsenring K., Billings J., Nies H. (eds) Long-Term Care in Europe. Palgrave Macmillan, London. https://doi.org/10.1057/9781137032348_2

Within the consortium of UNIC we believe that the definitions of LTC focus on a medical approach of disability, where an individual is viewed as a passive recipient of services and not as an individual with equal rights, strengths, abilities, and aspirations. With the aim of focusing on a human rights-based approach, where individuals with care and support needs are empowered to make choices, be autonomous and participate on an equal basis in the society, we will include the word "support" after "Long-term care". Therefore, we will be using the term "Long-term care and support" (LTCS) and when referring to the recipients of such services we will refer to them mainly as persons with care and support needs. The term "support"[52] refers to the provision of services with the aim to empower and enable an individual to lead a life with dignity and participate equally in the community, thus focusing on LTCS from a human rights-based perspective.

52 EASPD's glossary available here: Glossary | EASPD

About UNIC

UNIC aims to support the transition to user-centred funding models in Long-Term Care, by developing innovative instruments to support the take-up and scale-up of personal budgets. The project duration is 36 months / October 2020 – October 2023, funded by European Union Programme for Employment and Social Innovation "EaSI" (2014-2020).

Partners

Belgium	EASPD	European Assosication of Service Providers for Persons with Disabilities
Luxembourg	EUROPEAN AGEING NETWORK	European Ageing Network
UK	THE CENTRE FOR WELFARE REFORM	Centre for Welfare Reform
Ireland	dfi	Disability Federation of Ireland
Belgium	VAPH VLAAMS AGENTSCHAP VOOR PERSONEN MET EEN HANDICAP	Flemish Agency for Persons with a Disability
Czech Republic		Association of Social Services Providers Czech Republic
Spain	support GIRONA	SUPPORT Girona Foundation
Finland	SERVICE FOUNDATION FOR PEOPLE WITH AN INTELLECTUAL DISABILITY	Service Foundation for Persons with an Intellectual Disability
Austria	lebenshilfe Salzburg	Lebenshilfe Salzburg

Annex I - Survey for the collection of promising practices

Dear participant,

Thank you for taking the time to fill in this questionnaire. (Approximate time to fill: 10 minutes)

In the framework of the UNIC project "Towards user-centred funding models for long-term care" (Grant Agreement: VS/2020/0265), we are looking for examples of promising practices on user-centred funding models, such as personal budgets, addressing primarily persons with disabilities and older persons but also children, persons with mental health problems and other target groups from Europe and across the world.

The aim of this questionnaire is to understand existing Long-Term Care (LTC) funding models in Europe and across the world. In particular, we aim to understand the development of personal budgets models - or other funding models that promote user-centred care and support. This report will gather the successful elements of existing user-centred funding models and will then combine them to develop a theoretical model for Personal Budgets in LTC.

Personal Budgets is defined as an amount of money which is allocated to an individual by a state body so that the individual can make their own arrangements to meet their specified support needs.

An example of promising practice on user-centred funding models, such as Personal Budgets, can only be considered for inclusion in the report if the practice is consistent with the principles that underpin the United Nations Convention on the Right of Persons with Disabilities (UNCRPD) and the UN Principles for Older Persons. More specifically we expect such practice to be based in the community, offer individualised support and promote full inclusion in society. It must also incorporate the principles of participation, inclusion, non-discrimination, equality, choice, control over life, and the right to receive support adequate to individual needs.

We have set our criteria down in a numbered list as follows:

Essential criteria

1. Treats the person as a citizen with rights, freedoms and responsibilities
2. Applies to Long-Term Care (for at least some groups)
3. Exists as an on-going real-world practice in at least one location
4. Assumes user-centred funding for care and support
5. Promotes inclusion and equality

Desirable criteria

6. Creates clear and transparent entitlements

7. Supports people to make decisions, choices and to exercise control

8. Stimulates creative, flexible, person-centred support&the best use of shared resources

9. Encourages contribution and connection in community life

10. Protects the rights and status of the staff

11. Creates wider understanding of the need to protect and enhance human rights

12. It's transferable to other contexts and locations

The models submitted will be assessed by a panel of experts and selected models will be published in the form of a report made available to the UNIC project for further dissemination.

Thank you in advance for sharing your knowledge and experience. We appreciate your time and your contribution. For any further information you may reach out to konstantina.leventi@easpd.eu

-UNIC project team

Questions:

Name and surname

E-mail address

Organisation

Name of the example of promising practice on personal budgets or other similar user-centred funding models.

Specify the country of origin of this model.

Please provide us with the link of the website of this model and if possible, contact information - in case we need to complement the information received.

Why do you propose this model?

In which of the criteria do you believe that this model fits under?

1. Treats the person as a citizen with rights, freedoms and responsibilities

2. Applies to Long-Term Care (for at least some groups)

3. Exists as an on-going real-world practice in at least one location
4. Assumes user-centred funding for care and support
5. Promotes inclusion and equality
6. Creates clear and transparent entitlements
7. Supports people to make decisions, choices and to exercise control
8. Stimulates creative, flexible, person-centred support&the best use of shared resources
9. Encourages contribution and connection in community life
10. Protects the rights and status of the staff
11. Creates wider understanding of the need to protect and enhance human rights
12. It's transferable to other contexts and locations

Is there anything else about this model that you would like to share with us?

I agree to be kept informed about UNIC project. Yes No

Data protection agreement: By clicking "I agree" you consent to EASPD to use the data you provide on this form for technical purposes limited to the UNIC project. We will process this information in accordance with our privacy policy. I agree

References and Further reading

- AgeUk (2020) Personal budgets and direct payments in social care. Available here: https://www.ageuk.org.uk/globalassets/age-uk/documents/factsheets/fs24_personal_budgets_and_direct_payments_in_social_care_fcs.pdf
- Broad R. (2015) People, places, possibilities. Available here: https://www.centreforwelfarereform.org/uploads/attachment/463/people-places-possibilities.pdf
- CRPD/C/GC/5
- Carbonell Aparici, Gonzalo José. (2019). La experiencia de la asistencia personal en la Comunidad Valenciana. Zerbitzuan. 47-64. https://doi.org/10.5569/1134-7147.68.04
- Department of Independent Living Services, Social Rights Area, Municipal Institute for People with Disabilities, Barcelona City Council (2019). Personal Assistance Model SAP-BCN. Available here:https://ajuntament.barcelona.cat/dretssocials/sites/default/files/arxius-documents/model-servei-assistencia-personal-barcelona.pdf
- Care Act (2014), UK. Available here: www.legislation.gov.uk/ukpga/2014/23
- Disability Leaders of Tomorrow. Skills for Self-Directed Support. Available here: www.dlot.eu
- Department of Health (2018) Towards Personalised Budgets for People with a Disability in Ireland. Report of the Task Force on Personalised Budgets. Available here: www.gov.ie/pdf/?file=https://assets.gov.ie/9931/17cdb50249ef4927b2e7186f3714f8ab.pdf
- Duffy S., Dalrymple J.,Crosby N. (2018) Self-Directed Support for Service Providers. Available here:www.easpd.eu/sites/default/files/sites/default/files/Publications2018/5.7.3_study_on_self_directed_support_funding_systems_-_report.pdf
- EASPD (2019 How to Fund Quality Care and Support Services: 7 key elements). Available here: https://www.easpd.eu/sites/default/files/sites/default/files/bucharest_2019_conference_report__2.pdf
- EASPD (2019). How to fund quality care and support services: 7 key elements. Available here: https://www.easpd.eu/en/content/new-easpd-report-how-fund-quality-care-andsupport-services-7-key-elements
- ECOM (2021). Estudio sobre la Formación de Asistente Personal. Available at: https://www.ecom.cat/sites/default/files/images/estudio_ap_cast_interactivo_def.pdf
- Eguía-Careaga, SIIS. (2020). Algunas pistas para la mejora del sistema de atención a la dependencia en España. Zerbitzuan. 77-90. https://doi.org/10.5569/1134-7147.72.06
- https://www.imserso.es/InterPresent2/groups/imserso/documents/binario/im_061364.pdf

- Eurofound (2020), Long-term care workforce: Employment and working conditions, Publications Office of the European Union, Luxembourg
- European Commission, Czech Republic - Persons with disabilities. Available here: www.ec.europa.eu/social/main.jsp?catId=1106&intPageId=4476&langId=en
- European Network on Independent Living (2011) The „JAG model“ avalable here: www.enil.eu/wp-content/uploads/2012/02/Pa-manual_ENG.pdf#:~:text=The%20“JAG-model”%20A%20description%20of%20how%20you%20can,it%20is%20nice%20to%20make%20my%20own%20decisions.”
- European Network on Independent Living (2011). The „JAG model“ avalable here: www.enil.eu/wp-content/uploads/2012/02/Pa-manual_ENG.pdf#:~:text=The%20“JAG-model”%20A%20description%20of%20how%20you%20can,it%20is%20nice%20to%20make%20my%20own%20decisions.”
- European Expert Group on the Transition from Institutional to Community-based Care (2012). Common European Guidelines on the Transition from Institutional to Community-based Care. Available here: www.deinstitutionalisationdotcom.files.wordpress.com/2017/07/guidelines-final-english.pdf
- European Network on Independent Living and European Disability Forum (2019) TOWARDS INDEPENDENT LIVING: COLLECTION OF EXAMPLES FROM EUROPE. Available here: www.enil.eu/wp-content/uploads/2019/03/GoodPractice_web.pdf
- European Social Policy Network (2018). Synthesis and National Thematic reports on the Challenges of Long-term care. Available here: www.ec.europa.eu/social/main.jsp?catId=738&langId=en&pubId=8128&furtherPubs=yes
- Fundamental Rights Agency (2017). From institutions to community living-Part I: commitments and structures. Available here: www.fra.europa.eu/en/publication/2017/institutions-community-living-part-i-commitments-and-structures
- Keogh S., Quinn G. (2018) Independent Living: an evaluation of the Áiseanna Tacaíochta model of direct payments. Available here: www.nuigalway.ie/media/centrefordisabilitylawandpolicy/files/Independent-Living_An-Evaluation-of-the-Áiseanna-Tacaíochta-model-of-Direct-Payments.pdf
- Livingwellsystems.uk (2021) Community Mental Healthcare TRIESTE, ITALY. Available here: https://www.livingwellsystems.uk/trieste
- Ministry of Health, Individualised funding. Available here: www.health.govt.nz/your-health/services-and-support/disability-services/types-disability-support/individualised-funding-funded-ministry-health#hosts and here: www.health.govt.nz/our-work/disability-services/disability-projects/new-model-supporting-disabled-people

- Ministry of Health, Individualised Funding. New Zealand. Available here: www.health.govt.nz/your-health/services-and-support/disability-services/types-disability-support/individualised-funding-funded-ministry-health
- Ministry of Labour and Social Affairs, Social assistance benefits for people with disabilities. Available here: www.mpsv.cz/web/en/disability#sabfpwd
- Rodrigues, R. (2020), 'Caring relationships and their role in users' choices: A study of users of direct payments in England', Ageing & Society, Vol. 40, No. 7, pp. 1469–1489.
- Social Care (Self-directed Support) Scotland, Act 2013. Available here: www.legislation.gov.uk/asp/2013/1/contents
- Social Protection Committee and the European Commission. 2014. Adequate Social Protection for Long-term Care needs in an ageing society. Luxembourg. Publications Office of EU. Available at < https://op.europa.eu/en/publication-detail/-/publication/71532344-ddf1-4d34-a7aa-f65c701a22a2
- Triestesalutementale.it (2021) FROM THE ASYLUM to territorial services for mental health. Available here: http://www.triestesalutementale.it/english/doc/BrochureTriesteENG.pdf
- Tengström, Anna. Presentation of JAG. Independent Living Institute. Available here: www.independentliving.org/docs5/jag.html
- National Disability Insurance Scheme, Australia: www.ndis.gov.au
- United Nations. Article 12-UN Convention on the Rights of Persons with Disabilities. Available here: www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-12-equal-recognition-before-the-law.html
- Zero Project (2021) Mental Health Department & WHOCC – Italy/Trieste. Available at: https://zeroproject.org/practice/mental-health-department-whocc-italytrieste
- Zero Project (2015) PIONEERING A PERSONAL BUDGET MODEL AS PART OF NATIONAL SOCIAL SERVICES. Available here: www.zeroproject.org/practice/pra191416isr-factsheet/
- WAIS (2012) Shared Management A guide for Support Organisations exploring Shared Management. Available here: www.centreforwelfarereform.org/uploads/attachment/356/shared-management.pdf
- WAIS, Shared Management course for service providers. Available here: www.waindividualisedservices.org.au/online-courses/shared-management/

EASPD is the European Association of Service providers for Persons with Disabilities. We are a European not-for-profit organisation representing over 17,000 social services and disability organisations across Europe. The main objective of EASPD is to promote equal opportunities for people with disabilities through effective and high-quality service systems.

Handelstraat 72 Rue du Commerce, B-1040 Brussels+32 2 233 77 20
info@easpd.eu | www.easpd.eu

Credits and Rights

Photo credit

mycarespace.com.au, Danny Nee, Atikah Akhtar, carehome.co.uk, Zachary Kyra-Derksen

This document has received financial support from the European Union Programme for Employment and Social Innovation "EaSI" (2014-2020). The information contained in this publication does not necessarily reflect the official position of the European Commission.