



UNIC

TOWARDS USER-CENTRED
FUNDING MODELS
FOR LONG TERM CARE

UNIC

Personal budgets: a human rights-based way to fund and organise support

13th September 2023
Courtyard by Marriot Brussels
Avenue des Olympiades 6, 1140 Brussels



EUROPEAN
AGEING
NETWORK
former EDE | EAUSA
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CITIZEN NETWORK
FOR A WORLD WHERE EVERYONE MATTERS



Association of Social Services Providers
Czech Republic

VAPH

VLAAMS AGENTSCHAP VOOR
PERSONEN MET EEN HANDICAP



SERVICE FOUNDATION
FOR PEOPLE WITH
AN INTELLECTUAL DISABILITY

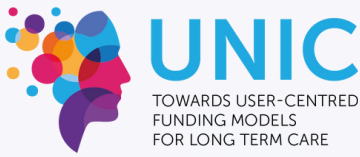
lebenshilfe
Salzburg

support
CIRONA

Inclusió social i suport en la presa de decisions
Social inclusion and supported decision making



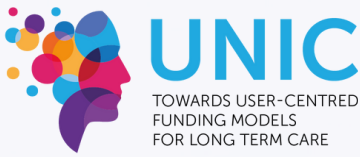
The project has received financial support from the European Union Programme for Employment and Social Innovation "EaSI" (2014-2020)



On September 13, 2023, the UNIC project on user-centred funding models for long-term care hosted its final European conference in Brussels. This conference, the final event of the EU-funded UNIC project on personal budgets, aimed to capitalise on the current momentum to transform support. Personal budgets are a key tool to ensure persons with disabilities have choice and control over their support. Together, EASPD and the UNIC partners call on national and European decision-makers to further support the development and scaling up of these innovative and effective approaches.

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 is organised, enabling people with support needs to have choice and control over their lives and enabling the full inclusion and participation of all people in society. Furthermore, the European Pillar of Social Rights (EPSR) and the European Care Strategy call for affordable long-term care and support services of good quality, and in particular home and community-based services.

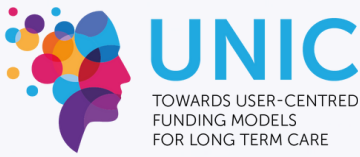
It is thus essential to develop and scale up funding tools to support this transition towards quality person-centred, inclusive, and community-based services.



This is what the UNIC project, with the support of co-funding from the European Union, has aimed to accomplish: supporting public authorities to develop, implement, and evaluate an innovative and effective funding model. This new approach must empower persons with long-term care and support needs and lead to more autonomy in decision-making, more choice and control over their own lives, and active participation in the development of services. With this model, public authorities distribute an amount of money directly to individuals with care and support needs, as well as advisory measures, enabling them to actively organise their own care and support services. Several countries and regions across Europe are exploring this model, but more support, in the form of funding and peer learning is needed to go beyond the piloting phases.

The present document contains a brief overview of the content discussed during the event.

[The PPTs shared by the speakers are available here.](#)



Welcome messages

Welcoming the participants, Jim Crowe, EASPD President, stated “We believe in the human rights and autonomy of persons with disabilities, and that they deserve to have voice, choice, and control over their life and the services which support them. That’s what the Personal Budgets are all about.”

In her introduction, MEP Sirpa Pietikäinen emphasised the potential and importance of personal budgets for long-term care and confirmed that the European Parliament will prioritise further support for such innovative approaches.

[The video of the input from MEP Pietikäinen is available here:](#)

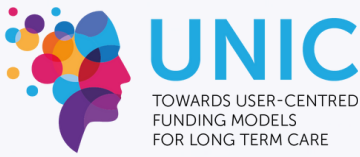
Keynote Speaker

In his intervention as keynote speaker, Simon Duffy, from Citizen Network UK, emphasised 4 broad categories of rights enshrined in the UNCRPD:

Support: knowledge of what an individual is entitled to.

Freedom: an essential part of the human condition.

Participation: how an individual lives life within the community.

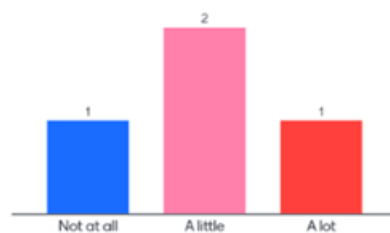


Simon Duffy also stressed that a systematic change is needed to create real change. Changing the approach around how individuals with disabilities spend money is key to overcome the modern paradigm of controlling what people spend their money on and foster a transition towards enabling them to make their own choices. He remarked that innovation is led by persons with disabilities and listening to their stories offers a great learning opportunity.

Further information on these reflections can be found in the **UNIC Models Of Good Practice Report On Personal Budgets and European Roadmap For User Centred Funding For Long-term Care And Support**. [Both these documents are available on the UNIC website here.](#)

Panel 1:

How supportive would you say are the public authorities of your country regarding the development of personal budget systems?





- Fionn set up his own company with his father.
- Fionn participates more in his community.
- Fionn got more involved in politics.

They spotlighted the challenges in using personal budgets in Ireland, such as the lack of guidelines in using such tools and the lack of training and certification for the persons that individuals can hire as part of their support system.

Fionn is involved in several activities and feels happy about his life and the opportunity to pursue his passions. To reduce food waste, every week alongside his dad, he collects left-over food from supermarkets and distribute it to the neighbours. He has also found a new interest in politics as he campaigns with others to raise awareness on the “Down Syndrome Act”, a recent piece of legislation enacted in 2022.

However, as the two pointed out, the Irish legal framework does not offer guidelines on what an individual can do with the personal budgets, which generates confusion and significant bureaucratic burden. The two overcome these challenges through the help of volunteers, the use of supplementing budget and by building their own network with service users and service providers.



Maggie Woods, from *Áiseanna Tacaíochta* (Ireland), explained how personal budgets move away from the “one-size fits all” approach, giving individuals full control over their life, enabling them to be completely independent wherever they go.

Talking about older persons, Maggie highlighted how personal budgets give them greater control over the services they receive, including hiring personal caregivers or purchasing assistive devices.

Personalised budgets mark a shift towards more person-centred and flexible approach to resource allocation. Despite some increased burden, such as being more responsible over health and safety, as well as contracts (e.g., for rent), it is overall a positive shift.

The model of direct payment breaks the historical culture of having people receiving such support depending on service providers and promotes a shift towards a personalised and empowering model, which entails tailor fundings to answer an individual’s requirements.



Maggie listed the areas in which personalised budgets can be used:

- **Social services (e.g., hiring personal caregivers or purchasing assistive devices).**
- **Healthcare (e.g., choosing their healthcare providers or therapies).**
- **Education (e.g., allowing individuals to use budget for specialised educational services).**
- **Employment support (e.g., helping people with disabilities find and maintain employment by providing resources for vocational training, job coaching and workplace accommodation).**
- **Housing (e.g., choosing housing solutions that best meet their requirements).**

The last point poses substantial challenges in Ireland where renting premises needs a lot of work to adapt them to the individuals' needs.

Viviane Sorrée from Onafhankelijk Leven (Belgium) explained to the audience how personal assistance budgets enabled her to make life choices on her own, such as:

- **Hiring her own assistants.**



- Taking on household responsibilities.
- Becoming more mobile in all aspects of her life.
- Living on her own.

She has always chosen to use her budget entirely as cash budget since it gives her complete control over its use: which assistant she wants to hire, when and for how long she wants their support or which activities she requires assistance with. She explained that the 2017 “Personal Budget Decree” represents a lever for self-determination, autonomy and individuals’ meaningful life. Through this, people with disabilities can, in theory, organise their own care and support. However, as the panelists who spoke before, she stressed the difficulties in making this framework works. Practical challenges, such as few accessible houses on the housing market, prevent persons with disabilities from choosing autonomously where to live and forces them to turn to service providers that have accessible housing solutions.

Her hope is that the public authorities promote, develop, and support active policies that foster decision-making and community-based services that enable a more inclusive life, employment with full and fair wages, and inclusive education.



To reach a full implementation of the UNCRPD, she called for public authorities to develop and implement a master plan that leads to inclusion in all policy areas. She also asked for stakeholders to be involved in this implementation. As they provide crucial insights, they could be empowered using support-decision-making approaches, peer counselling, and supporting groups. The government should also make sure that families are supported by the introduction of a full-fledged personal budget for minors with disabilities. Overall, such plan should be seen as an investment in a more inclusive and sustainable society.

John Dalrymple, from Radical Visions, focused on the main dynamics in developing person-led approaches in Scotland. He explained that trials on assigning financial budgets have only been conducted on a small scale and the next step is to transfer personal budgets to the mainstream and make them available on a wider scale. He also pointed out a conflicting dual role played by social workers, who are facilitators and gatekeepers of the local authority's interest at the same time.

This panel served as an ideal way to introduce the importance of the topics being discussed during the event, and what the impact of these programmes can be.



Dries Bleys, from VAPH, explained that UNIC Project's toolbox helps service users, public authorities, and service providers implement user-centred funding models and support service users in long term care move to these models. [The toolbox is available here.](#)

Dries Bleys then presented a comprehensive video on people's experiences with the pilot that was conducted for this toolbox in Flanders, Belgium. In their testimonies, the participants explain the supportive mechanism it represents as it helps them determine their goals, needs, and preferences; visualise what is possible; increase autonomy and quality of life. Dries Bleys then presented some key messages from the national conference held in Flanders to promote the UNIC budget and discuss the outcomes of the various activities, including the piloting of the toolbox. Both videos are available here:

1. [Video 1](#)

2. [Video 2](#)

Panel 2

In her introduction, moderator Petra Rantamäki from KVPS Finland, explained the efforts undertaken as part of the project to adapt and transfer the model piloted in Flanders to other regions. Reflections on these efforts and recommendations for public authorities are included in the UNIC Transferability.

Study available [here](#)

Brian Higgins, from the “Disability and Mental Health Service” in Ireland, illustrated how the personalised budgets, a funding allocated to individuals to let them make their own arrangement instead of relying on the state, is a governmental priority, which is corroborated by the pilot programme he presented.

During the 2-year programme, approximately 180 adults (school dropouts over 18 and individuals younger than 65) were selected and tested through 3 different models:

1. Person managed fund.
2. Co-managed fund with a service provider.
3. Broker managed fund.

Recipients could only spend the direct payment on specific personal supports funded by the HSE (Health Service Executive) agreed in their Personal Support Plan. They could not use the payment for informal care, pay therapeutic services provided by the HSE or other national agencies within the community.



They were also asked to keep records of what they had spent their budget on and whether it aligned with the Plan agreed beforehand. The programme poses some challenges. Among the others, Brian listed:

- Clearly defining the meaning of personal budget on what can it be used for.
- Capacity building with participants on how to effectively run a business.
- Limited number of resources.

Alongside these, participants stressed:

- In some cases, the quantum of service that could be purchased with a portion of the budget was less than the service provision provided back then.
- The uncertainty around the continuation of the project.
- The concern upon services that may have not been provided under the new service programme.

On the CHO side (Regional structure for health service in Ireland), Brian noted that:

- A liaison staff is needed, in alignment to a CHO.
- Support and trainings should be ensured to participants across multiple areas (e.g., how to manage staff, establish a company).



- The overall responsibility is challenging when the service is provided off-framework.
- There is a need to assess the impact on the budget when a contingency plan is in place (e.g., COVID-19).

Jiří Bína, from Region Vysočina (Czech Republic), exposed the case of personal budgets programme in Czech Republic. Such social benefit is paid to persons with disabilities and is intended to provide them with the necessary assistance.

Assistance can be provided via different channels:

- A contract or agreement with a professional social service provider.
 - Paying services of a close relative as personal assistant.
 - Paying service of an external individual who agrees to this.
 - Developing a small network of unregistered and unofficial caretakers. This, however, violates the current legal framework.
1. Such relationships are not in line with the standards of social services.
 2. Authorities are unable to protect people who are given not professional services.



Lluís Torrens i Mèlich, Secretary of the Department of Social Rights of the Catalan Government, illustrated the current Spanish “Dependency law”, which established two systems:

1. A sum is paid by the administrations according to their financial capacity.
2. Another amount is provided by entities accredited by the administrations who meet minimum quality standards.

Overall, personal budgets are helpful because they give receivers freedom of choice and ensure them an equal access to different services. Such framework requires a transformation of services offered, whose quality needs to represent a priority, especially in rural areas and for people with severe support needs.

James McNulty, from the Scottish government, noted that after the UK’s UN CRPD ratification in 2009, the social model of disability has slowly found its way in policy and support/care.

In particular, he stressed that Scotland is leading such shift within the United Kingdom. In 2014 a “Self-Directed Support” guidance was issued to local authorities. However, the aftermath of Brexit and COVID-19 showed how the social care system is fragile and such crises demonstrated its weaknesses.



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In 2021, the guidance was relaunched and two years later a third version was issued. This guidance aims to guarantee individuals dignity and participation within their communities. The related legislation offers a framework to establish such support mechanism. To make this framework more homogeneous, involve people in their care design and strengthen community-based support, Scottish ministers will become accountable for social care delivered through the National Care Service (NCS), a single and simplified platform where 32 current local authorities will converge by 2027.

To conclude his intervention, James remarked the key ingredients to improve personal budgets, all interconnected aspects that support a culture of choice. Among others, he listed:

- **Leadership.** Persons with disabilities are experts in their own life.
- **Digital innovation.** Better data, AI tools and digital platforms have the potential to scale up personal budgets schemes.
- **Multi-disciplinarily.** Involving multiple parties, not a single decision maker.
- **Advocacy.**
- **Proof of autonomy.**

Panel 3

Introducing the session, moderator **Karin Astegger** from Lebenshilfe Salzburg, Austria, mentioned that it is crucial to capitalise on the existing momentum mentioned by keynote speaker Simon Duffy and visible throughout the different panels and sessions of the day. All the speakers in this final panel will have a key role to play to further support the development and scaling up of personal budgets across Europe.

Susanna Ulinski, from the EU Commission, explained the European care strategy presented in September 2022. Its aim is to support member states in improving care services, working conditions in the sector and more broadly investing in care. This strategy focuses mainly on care with a lifelong perspective. In her view, personal budgets schemes mark a paradigm shift in the care sector to promote person-centred care as well as home and community-based care. She echoed some challenges such mechanism could bear:

- **Target group.** Who is eligible to receive this support?
- **Accessibility.** Is the info provided easily accessible?
- **Availability.** Are there enough choices?



The major and more concrete risk is that it becomes an easy way out to lay on the person who needs care any responsibility without addressing the external challenges that may arise.

Sam Van Bastelaere, from VAPH in the Flanders region, highlighted how people there have free choice to organise care and support thanks to the local personal budgets system, which is regarded as one of the most advanced of such systems. He still posed some interesting questions around the implementation on a large scale of this support:

- How do we ensure that people become aware of personal budgets schemes?
- How do we encourage people to change their current system of support to a personal budgets model?

He also pointed out that the Flemish government currently invest 1.8 billion euro for personal budgets, but it should increase the amount by 1.6 billion euro to meet the actual demand.

VAPH has three priority groups that are included in the waiting list to access personal budgets schemes:

1. Urgent. These people receive their budget within 18 months.
2. Moderate. They receive half of the personal budgets amount they asked for to solve the most urgent needs.



3. Mild. This latter group will not get their personal budgets straight away but are placed on the waiting list.

Teodor Mladenov, from the European Network of Independent Living and University of Dundee, underlined how personal budgets are sometimes used by policymakers to introduce austerity measures, which undermines the concept of independent living and a person with disabilities' right to choose. As for the case of Scotland, even if funding is adequate, there is a potential low uptake of personal budgets due to lack of appropriate support for persons with disabilities (e.g., access to relevant information).

Teodor affirmed that policymakers should commit to ensure policies align with the independent living movement. He also flagged the need to make sure that personal budgets are not used to institutionalise persons with disabilities. For him, institutional care is not a legitimate option in the spectrum of community-based care. Personal budgets should only be given to persons with disabilities living in institutions to help them in the transition towards community-based care. He also brought up important issues in the development of schemes for personalised funding models. He cited:

- Level of funding.
- This is a systemic issue which keeps persons with disabilities as subjects of care.



- Eligibility assessments.
- It is vital to move away from a medical/functional approach and foster a person-centred model (e.g., HR approach).
- Persons with disabilities may be forced to rely on relatives or choose institutional forms of support.
- When personal budgets schemes are used to introduce austerity measures by policymakers, persons are objectified rather than “active” agents.
- Infrastructure for personal budgets to work effectively.
- This proves to be very complex and, as it is often limited, it leads to low uptake of personal budgets schemes.
- Personal budgets are not sufficient on their own.
- Other pillars are needed to create real opportunities for independent living.
- A holistic approach is needed: accessible transport, supported decision making, adequate income support.
- Monitoring of new personalised funding system should be led by persons with disabilities.

Jiri Horecky, from the European Ageing Network and APSSCR, defined supervision as a significant barrier in public budgets schemes. There are ongoing debates around the extent of control on financial expenditure individuals receiving personal budgets should be subject to. Such frequency ranges from no control whatsoever to monthly check-ins.



He also discussed who personal budgets should be addressed to, stating that receivers should include children, adults with disabilities and those in need of care.

In relation to the supervision and control aspect, Jiri said that it is necessary to prevent users from spending such budget in non-care-related expenses and it is also vital to gain useful insights on the evolution of the schemes in the form of feedbacks.

He also pointed out that these schemes only work if carers are properly involved in the mechanism.

As last point, he focused on sustainability and increasing the user base. On a long-term view, personal budgets should be linked to inflation to cope with economic fluctuation. They should also be extended to a wider audience in need of support and care.

Concluding Remarks

Pep Sole, from Support Girona, noted how the UNIC Project constitutes a significant step forward by platforming the voice, choice, and control of persons with disabilities and older persons. It has also offered a means to prioritise their feedback to further improve the personal budgets systems. However,



a lot remains to be done to have more people and organisations formally committed to change. Pep Solé concluded by encouraging all speakers and participants to capitalise on this opportunity to continue raising awareness, networking, exchanging ideas and concepts, and advocating for increased support for personal budgets systems, and all innovative tools which help persons with disabilities organise the care services they receive.

For more information about the UNIC project and to continue supporting the development and scaling up of person-centred funding models please visit the UNIC website. [You can access the UNIC website here.](#)



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