UNIC

TOWARDS USER-CENTRED
FUNDING MODELS
FOR LONG TERM CARE
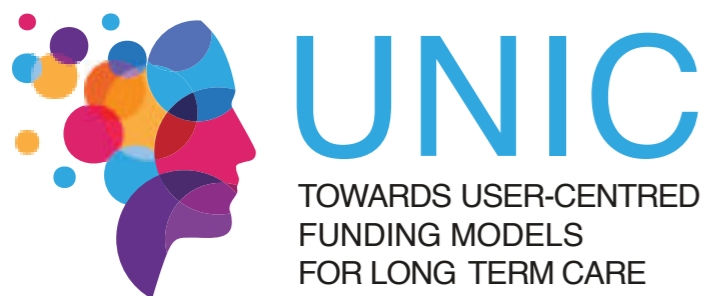
UNIC TOOLBOX

2023

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UNIC Toolbox

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Executive Summary

The publication of this document takes place within the framework of the UNIC project, "Towards user-centred funding models for Long-Term Care". The purpose of this document is to give an overview of the highly innovative - but practical - toolbox developed as part of the UNIC project. It includes three highly tools to help different stakeholders, especially public authorities, to develop, reform or implement user-centred funding models for Long Term Care and Support (LTCS). The toolbox supports three different areas that have been identified as most in need of guidance: Quality Monitoring, Service Delivery and Compliance Assurance. To support in these 3 areas, 3 tools have been developed: a quality monitoring tool, a service delivery tool and a compliance assurance tool. In addition to the elaboration and brief explanation of each specific tool in the toolbox, this document also makes explicit what the purpose of each tool is, who can use and fill in each tool, how the tool should be used in practice and how this tool was methodologically developed. This version is a draft of the tools that will be used in the test phase in Flanders.

Introduction

Countries are encouraged to design reform strategies that help individuals, families and societies to be 'prepared' for the changing nature of social risks in advanced economies by investing in human capacities from early childhood to old age, rather than pursuing policies that merely 'repair' social misfortunes after an economic or personal crisis. That is why public authorities - and other relevant stakeholders - across Europe are looking for new ways of organising the provision of social care and support, including Long-Term Care and Support, to respond to changing needs and challenges (Duffy, 2020; UNIC action and work plan, 2019).

Based on these trends in society and under the further impulse of the implementation of the European Pillar of Social Rights (EPSR) and the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD), systems for funding Long Term Care and Support (LTCS) are shifting from service-centred models towards more user-centred models. Perhaps one of the most important elements in reforming Long-Term Care and Support policy is to strengthen the effectiveness and efficiency of the financing model. The way such user-centred models will be financed will play an essential part in any new system. Personal Budgets are a tool to give people who need LTCS control over who provides support and how that support is organised (Duffy, 2020; UNIC action and work plan, 2019).

As such, the UNIC project has aimed to develop, test, and validate a set of innovative tools (toolbox) to help key stakeholders implement Personal Budgets funding models (more information about the UNIC project: https://www.unicproject.eu/). This toolbox, together with a set of policy recommendations and capacity building activities, results 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 (UNIC action and work plan, 2019). The present document is an "offline" copy of the tools, designed as reference, while the primary method of interacting with the tools is intended to be the online platform developed for UNIC, where the content of this toolbox is hosted as interactive tools: https://toolbox.unicproject.eu/

The toolbox that has been developed, is one of the outputs of the UNIC project. The toolbox developed as part of the UNIC project includes three tools to help different stakeholders, to develop, reform, or implement user-centred financing models for Long Term Care and Support. The toolbox supports three different areas that have been identified as most in need of guidance: Quality Monitoring, Service Delivery, and Compliance Assurance. To support in these three areas, three tools have been developed for practical use by 3 relevant stakeholders: a Quality Monitoring Tool for persons with Long-Term Care and Support needs, a Service Delivery Tool for Long-Term Care and Support providers and a Compliance Assurance Tool for public authorities responsible for the organisation and funding of Long-Term Care and Support. They are briefly described below, and constitute the main parts of the present document.

The Quality Monitoring Tool (QMT) is a tool that is to be completed by persons with Long-Term Care and Support needs either by filling it on their own or with the support of a peer-to-peer interviewer. The purpose of the Quality Monitoring Tool is to allow people with Long Term Care and Support needs to identify the weaknesses and strengths of the personal budgets system they use, allowing the public authority to co-produce improvements of the personal budgets system. The Quality Monitoring Tool must therefore become a real quality monitor, a test of the current system using the Quality Of Life of the Personal Budget Holders as a benchmark and assessed by the Personal Budget Holders themselves.

The Service Delivery Tool (SDT) is a tool that focuses on providers of Long-Term Care and Support and helps them to evaluate to what extent they provide or can provide person-centred, inclusive care and support in the context of a Personal Budgets system in the future, in line with the UN Convention on the Rights of Persons with Disabilities. Moreover, it helps them to identify areas for improvement for their organisation and to formulate action points with the aid of targeted advice on various relevant themes in the tool, including sharing good practises. The SDT is therefore a self-evaluation tool to support service providers to assess their services and to improve where possible.

The Compliance Assurance Tool (CAT) is directed towards public authorities that focus on the development and follow-up of policies for people who need Long Term Care and Support. The aim of this tool is to support public authorities to evaluate their policies on personal budgets for content and completeness (in line with the UN Convention on the Rights of Persons with Disabilities), to formulate action plans to promote and enforce a Personal Budgets System and points for improvement.

This toolbox is being produced together with a European roadmap for user-centred funding for Long-Term Care and Support. This document and the various tools, therefore, form a whole and cannot be seen separately from one another.

The present report compiles the offline versions of the tools presented on the UNIC online platform, including the Quality Monitoring Tool (page 13), the Service Delivery Tool (page 27), and the Compliance Assurance Tool (page 35).

Toolbox

UNIC is a project to establish a set of best practices for the use of personal budgets in long term care. The UNIC toolbox is a set of three tools intended to improve long-term care and support within the framework of personal budgets. All three tools use the UN Convention on the Rights of Persons with Disability (UN CRPD) as a framework for the goals of long-term care and support. Ideally, people receiving care should be able to exercise all of the rights found in the UN CRPD.

The Quality Monitoring Tool is designed to evaluate the quality of life of recipients of personal budgets, and help to improve their quality of life, in line with the UN CRPD. The Service Delivery Tool is designed to help service providers to evaluate the services they deliver, and work towards the delivery of more rights-based and person-centred services. The Compliance Assurance Tool is designed to help public authorities to improve their policies around long-term care.

Quality Monitoring Tool

The Quality Monitoring tool is a tool which aims at identifying the strengths and weaknesses of a personal budgets system. It is developed as a self-assessment tool that personal budget holders can use to assess the impact that the personal budgets system has on the quality of their lives.

- This aims to identify whether personal budgets can help people to have better access to support systems that can help them achieve their goals.
- It also works as a tool that can raise awareness to help people identify what else they may be able to achieve with their personal budget. And this can further support them in their advocacy actions towards the public authorities responsible for this.

This tool is one of the tools developed during the UNIC project. Together with the Service Delivery tool and the Compliance Assurance tool, this tool is part of a toolbox which can be used by public authorities to help in the design, development, implementation and monitoring of their personal budgets system(s).

Who can use this tool?

This tool can be used by any individual that receives a personal budget from their public authority. This can include: Persons with Long Term Care and Support needs, such as persons with disabilities, older persons, people with mental health problems or psychosocial disabilities and others. In order to make a proper evaluation, it is important that the individual has been receiving a personal budget for at least 6 months, before evaluating the personal budgets system of their country/ region.

How to use the tool?

If it is not possible to fill in the tool individually then the tool will be preferably introduced to personal budgets holders by peer-to-peer interviewers. Here it is important that the peer-to-peer interviewer is adequately trained on how to administer this tool. A training manual will be developed to support them, and relevant information will be included here as well. Information about how much time does it require for the tool to be filled out, on how often it should be filled out it will be included in a later stage, after the Piloting phase as well.

Methodology for the development of the Quality Monitoring Tool

The Quality Monitoring Tool is an instrument which evaluates the personal budgets system and the services offered in the framework of personal budgets from the perspective of the persons with Long Term Care and Support needs. The development of this tool follows the 8 domains of the Quality-of-Life concept, developed by Schalock and Verdugo[1] and the principles of the UN Convention on the Rights of Persons with Disabilities[2]. The steps followed during the development of this tool are:

RESEARCH	Literature review, consultations with experts on quality assurance and monitoring systems
DEVELOPMENT	Continous communication with project partners, experts and other relevant stakeholders
FEEDBACK PROCESS	By Donal McAnaney, PhD, EQUASS expert; By UNIC's Advisory Board Members
PILOT PHASE	During the period of 9 months, the tool will be tested in multiples occasions in the Flemish Agency for Persons with Disability (VAPH)
TRANSFERABILITY WORKSHOPS	Transferability workshops will take place in Austria, Czech Republic, Finland, Spain
FINALISATION	The feedback received during the Pilot and Transferability phase, will be used to develop the final version of the tool. This version will be supported by an ICT environment.

The first step towards the development of the Quality Monitoring tool was a review of relevant scientific papers which supported the development of

[1] Schalock, R. L., Brown, I., Brown, R., Cummins, R. A., Felce, D., Matikka, L., Keith, K. D. & Parmenter, T. (2002).

[2] UN Convention on the rights of persons with disabilities. May be accessed here: www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html

core quality of life indicators that can be used for assessing the personal budget system and the services that offer support in the framework of Personal Budgets. During this research we decided to design the tool by focusing on the Quality of Life concept and by being guided by the articles and principles of the UN Convention on the Rights of Persons with Disabilities.

Quality of Life Concept

The Quality of life concept can be used as a framework on how services shall be provided, as a basic principle for evidence-based policies and practises, and as a compass to develop strategies that improve quality.

Quality of Life, as a concept, is interconnected with the social model of disability, which views disability as a condition that results from the interaction between an individual and environmental factors. It focuses on the interactions between a person and the environment, and the relation between personal competence and environmental demands, as well as the opportunities which result from these interactions.[3]

The Quality of Life concept as developed by Schalock, Verdugo, Gomez
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[3] Schalock, R. L., Verdugo, M.A., Gomez, L.E., & Reinders, H. (2016).

& Reinders[4] has multiple dimensions and it is composed by eight different domains, separated in three different factors that constitute personal well-being and are shown on the table below:

Table 1.Quality of Life Factors-Domains-Examples

FACTORS	DOMAINS	RELEVANT EXAMPLES
INDEPENDENCE	Personal Development	education, personal competence, performance
	Self-Determination	autonomy, personal control, goals and personal values, and choices
SOCIAL PARTICIPATION	Interpersonal relations	interactions, relationships and supports
	Social Inclusion	community integration and participation, community roles, social support
	Rights	human (respect, dignity, equality) and legal (citizenship, access)
WELL-BEING	Emotional-well being	contentment, self-concept, lack of stress
	Physical well-being	health, activities of daily living, leisure
	Material well-being	financial status, employment, housing

UN Convention on the Rights of Persons with Disabilities

The UN Convention on the Rights of Persons with Disabilities (UN CRPD) is an international framework setting out the rights of persons with disabilit-
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[4] Ibid

ies, however it does not introduce new rights. It paves the way to a non-discrimination attitude towards people with disabilities and their recognition as equal members of the society. It promotes their independence, inclusion, and active participation in the society, while recognizing the need to receive adequate support to fulfil their needs, wishes and preferences. The UN CRPD is legally binding to the countries that have ratified it, it sets out the legal obligations of Member States to protect and promote the rights of persons with disabilities and it calls for reshaping the way services are provided, in a way that is compliant with the CRPD and Human Rights principles.[5]

Implementing the UN CRPD principles as set out in the articles is challenging. Concepts, such as self-determination, need to be translated to evidence-based practises and specific indicators need to be developed to assess the process of implementing the Convention.[6] The Quality of life concept provides an opportunity towards this aim, as it is a valid framework that can be used to assess services and systems by focusing on the outcomes that these have on the life of individuals and by bringing the individuals in the heart of the assessment process.[7]

Therefore, by taking into consideration the evidence-based applications of the Quality of Life concept and its alignment with the UN CRPD, the Quality Monitoring Tool has been developed as a tool that will reflect the objectives of assessing a personal budgets system and the services offered in the framework of this system. Relevant indicators and their alignment with the UN CRPD, as they were Introduced by Verdugo and Lombardi[8] were used as a guidance in the development of this tool.

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[5] Ferraina Sabrina
[6] Gómez L., Asunción Monsalve A., Morán L., Alcedo A., Lombardi M., Schalock R. (2020)
[7] Ibid
[8] Gómez L., Asunción Monsalve A., Morán L., Alcedo A., Lombardi M., Schalock R. (2020)

Presentation of the Quality Monitoring Tool

This chapter provides information regarding the Quality Monitoring tool. It starts with a brief overview of the tool, and a ready to use template can be found under Annex I. The chapter continues by analysing the different sections of the tool, and the items included.

Overview of the Quality Monitoring Tool

The Quality Monitoring tool is a self-assessment tool that a personal budget holder can fill out, preferably with the support of an experienced peer-to-peer interviewer. It includes 65 items, in the format of statements written in first person and using simple language. The responses are based on a Likert type of scale, offering a variety of options, either with numbers, face expressions or words. A ready to use template of the tool can be found under Annex I and instructions on how to use this tool are provided under this chapter.

The Quality Monitoring tool is separated into 3 different sections:

- Section 1 is intended to allow respondents to specify the activites that they can use their personal budget for.
- Section 2 is intended to allow respondents to rate the extent to which the personal budgets has an impact on the quality of their life.
- Section 3 of the tool contains items relating to the personal budget provider and assessing the personal budget process.

Section 1. How do I use my personal budget?

In this first section, responders will indicate the activities that they use their

personal budget for. For example they may use their personal budget to access support with daily living activities, education, employment and others. Here we need people to let us know for which activities do they use their personal budget for.

Here you will find a list with different every day activities that you may use your personal budget for.

- Click Yes on the activities that you use your personal budget for.
- Click Yes, but not now on the activities that you use your personal budget for, but not during this time.
- Click No on the activities that you do not use your budget for.

You may have a person that supports you, like an assistant with these activities and this person is paid with your personal budget or you may have a service that you use to recieve support with these activities.

Next to each activity you will see a star. You may click the star if this activity is very important for you. You can click the star even if you do not use your personal budget for this activity but it is still important for you.

Table 2. Example of Section 1. How do I use my personal budget?

HOW DO I USE MY PERSONAL BUDGET?				
1	**I use my personal budget to receive support with daily living skills:** For example, I have someone to help me everyday with my personal hygiene such as showering, bathing, dressing, grooming, toileting, mobility to get in and out of bed, attend appointments, cooking	YES	YES, BUT NOT NOW	NO
2	**I use my personal budget to have access to lifelong learning or education opportunities:** For example I have someone to support me at school. Or with my personal budget I can have access to a training or other educational opportunity that I want.	YES	YES, BUT NOT NOW	NO
3	**I use my personal budget to work and employment:** For example I use services with my personal budget to find work or to start my own business. I can have someone to support me at my workplace.	YES	YES, BUT NOT NOW	NO

There are three more elements included in the 1st section:

- Are there any other things that you use your personal budget for?
- This question supports in identifying on whether there are other things/ activities that personal budget holders can do with their budget which are not mentioned on the list of activities we have included.
- The government often has rules that tell you that you can use your personal budget for only specific every day activities. Is there something that you would like to use your personal budget for and you are not allowed to?

This question supports in collecting answers from the respondents, which are related to their individual needs, wishes and preferences. There may be activities for which their personal budget is not intended but they wish they could receive in the future. And, this may further support public authorities in tailoring their personal budgets system to the needs, wishes and preferences of the people with Long Term Care and Support needs.

- Did you have to wait in order to get your personal budget from the time that you applied for it?

There have been situations, where people had to wait many months, or even years to receive their personal budget, from the time they applied for it. And, this question will provide a good indication to the public authorities on the timeframe that people had to wait for and support in generating actions to improve the processes.

Section 2. Does the personal budget help me to improve the quality of my life?

Section 2 is intended to allow respondents to rate the extent to which the personal budgets have impacted on their Quality of Life. There are 24 statements that responders will need to rate, based on the experience that they

had with their personal budget in each aspect of their lives. However, it is important to keep in mind that there are many factors that can influence the quality of life of a person and this part of the tool aims to clarify how the personal budget has facilitated access to activities and support systems that they could not access previously without their personal budget.

The statements are separated under different sub-sections, following the domains/ dimensions of the Quality-of-life concept, introduced by Schalock and Verdugo. Each dimension includes 3 statements and examples of what each statements refers to. The statements always start with the same format „My personal budget supports me to:" continued by each statement. Below you may find the list with the domains and dimensions, as well as one example from each:

DOMAIN	DIMENSION	EXAMPLE
INDEPENDENCE	Personal Development	My personal budget supports me to improve my skills or learn new skills to become more independent.
	Self-Determination	My personal budget supports me to have a choice in how I live, where I live and with whom I live.
SOCIAL PARTICIPATION	Interpersonal relations	My personal budget supports me to improve my relationships with those close to me.
	Social Inclusion	My personal budget supports me to move around my community more easily.
	Rights	My personal budget supports me to know my rights and advocate for my rights.
WELL-BEING	Emotional-well being	My personal budget supports me to participate in activities that make me feel good.
	Physical well-being	My personal budget supports me to access the care I require to meet my health and hygiene needs.
	Material well-being	My personal budget supports me to have enough money to buy the things I want and I need.

The rating scale used in this section is as follows: 1=No, 2=Yes, but it is not enough, 3=Yes. If one of the statements is very important to them, despite the rating they have provided, then they can state that by clicking on the star, indicating it.

Section 3. How is my experience with the personal budget process?

Section 3 of the tool contains items relating to the personal budget provider and assessing the personal budget process. There are 17 items that describe the experience of getting and using a personal budget. These statements are following the principles below:

CHOICE AND DISCRETION	Respect and dignity
ACCESS	Rights
CONTROL	Decision-making
SUPPORT	Advocacy
FLEXIBILITY	Training
ACTIVE INVOLVEMENT	Assistive Technology
INFORMATION	Privacy
RULES	Assessment
BUDGET	Amount

The rating scale used in this section is as follows: No, Yes but not always, Yes. If one of the statements is very important to them, despite the rating they have provided, then they can state that by clicking on the star, indicating it.

Lastly, there are two final questions:

- How satisfied are you with your personal budget?

This question provides the opportunity to the responders to provide an overall satisfaction rating on the personal budget they are receiving. They can do that by using a scale 1-3, where 1=Not at all satisfied, 2=Somewhat satisfied, 3= Very satisfied.

- Is there anything else that you would like to share with the personal budgets provider?

This open-ended question provides the space to the responders to provide information that may not have been asked in the questionnaire.

Service Delivery Tool

This is the Service Delivery Tool. The goals of this tool are:

1. Evaluate to what extent a service organisation offers, or will be able to offer, person-oriented, inclusive and home-based care and support in the context of a personal budget system, in line with UNCRPD
2. Identify points of improvement for the organisation
3. Formulate action points using targeted advice on various relevant themes in the tool, including sharing good practices

It provides a series of questions that will help the organisation to identify their strengths and weaknesses. It also provides advice on how to create more person-centred services.

Who can use this tool?

This tool should be used by the managers of service delivery organisations to identify their strengths and weaknesses in personal budgets and person-centred services. The tool provides both advice and an opportunity to reflect on the way an organisation delivers services, and ways that these services can be improved.

Possible Filtering Questions:

- Do you provide residential services?
- Do you provide day services?
- Do you use personal budgets?
- Do you provide personal assistance?

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How to use the tool?

This should be completed in several steps (a) Mapping phase, (b) Discussion phase and (c) Planning phase.

In the mapping phase, a series of questions will be answered to provide graphical/numerical feedback that describes the current functioning of their organisation. This phase is primarily intended for self-assessment by the organisation's staff at different levels. Ideally, the tool will be filled in by different types of staff members. Not only management, but also the opinion of logistic and caregiving staff is important. to make this process of including different voices more efficient, an internal focus group could be held to decide on how and with whom to fill in the tool. One can also choose to fill in this tool individually. The data need not be consistent between different types of staff and differences in judgement and interpretation between staff completing the questionnaire are not a problem, but rather provide important opportunities for debate and research.

The aim of the discussion phase is to provide a framework for discussion and to identify problems and possible solutions for the entire functioning of the organisation. With the planning phase, we give organisations a framework to formulate action points to improve their current functioning, based on the recommendations of the UN Convention and their own insights.

Methodology for the development of the Service Delivery Tool

The tool is ultimately based on the UN CRPD and Challenges-responsive Guidelines: European roadmap for user-centred funding for Long-Term Care and Support. It aims to help service providers ensure that their services are helping users to exercise their rights under the UN CRPD. In addition, the tool was designed with reference to other documents on the rights of people with disabilities and the ways that services and communities can support these rights. It also relied on looking at other tools prepared for the disability sector. Finally, the tool relied on the expertise and advice of other partners in the UNIC project, and other experts working on the project.

The steps followed during the development of this tool are:

- First, research was conducted. Mostly, this focused on the literature around person-centred services, and how to ensure that people receiving long term care and support receive the services they need, and are respected as full citizens and autonomous people. This tool references this literature, to help service providers to work towards a person-centred service.

- After an initial draft of the tool was developed, the tool entered a phase of continuous development. It was reviewed and commented on by VAPH, a researcher from Ghent University, EASPD, and other partners in the consortium. Their comments and feedback were incorporated into the tool, refining and expanding it. After this process, the tool was presented to UNIC's Advisory Board for comments and feedback. There feedback was then also incorporated into the tool.

- The tool will go through a pilot phase, in which it will be tested multiple times by the staff at VAPH. The results of this testing will be further incorporated into the tool. In addition to the intensive testing in the pilot phase, the tool will be used in transferability workshops by partners in Austria, Czech Republic, Finland, and Spain. Feedback from these workhops will also inform the final form of the tool.

- Finally, after the pilot and workshops, the final version of the tool will be developed. This version will be supported in an ICT environment, and made available widely to organisations outside of the project.

Presentation of the Service Delivery Tool

This tool is designed to help service providers to move towards offering person-centred services. A person-centred service is a service where the needs, desires, goals, and individual traits of the service user are paramount, and at the centre of designing and delivering their services and support. With these questions, service providers should be able to identify where they are currently delivering person-centred services, and where they can improve. This tool can be used as a conversation starter for impact evaluation, quality trajectory of service providers, and policy plans, as it covers several areas in which service providers can implement person-centred policies and practices. These include practices around decision-making, personal budgets, independent living, and help service users to forge connections with the wider community. Personal budgets can help service providers to achieve these goals. Personal budgets give service users more control over their own services, and service users are more likely to prefer person-centred services. Therefore, personal budgets and person-centred services can act to reinforce each other. Providing personal budgets gives service users more say, and they act to gain more person-centred services. At the same time, a service provider that provides more person centred services is likely to be attractive to service users with personal budgets, who will then demand that service become more person-centred.

The goal of this tool is not to shame service providers for failing to meet every goal. Rather, it is to help providers to see areas where they can improve. It is not expected that service providers will be able to change everything overnight. Instead, the goal is to start a process of contentious improvement, moving services towards a more person-centred model. For instance, a service provider could return to this tool every quarter, to see what improvements they have made, and where improvement is still

needed and possible. There may be sections of the tool that you cannot implement, because of laws and regulations in your country. When this is the case, note this, and think about what laws or regulations would have to change, and how they would have to change, to allow you to create a more rights-based service. But also keep in mind what changes are within your power, and what you can do to create a more person-centred service, regardless of the regulations in your state or region. In many places, the tool will ask about obstacles you might face in implementing person-centred care and support, and whether your organisation can address these obstacles. It could be a useful exercise for your organisation to make a list of obstacles, and a plan to address them. Even if a service provider is not currently planning to make the move towards personal budgets or person-centered services, this tool can be useful. As state above, as personal budgets become more common, service users are likely to demand more person-centred services. This tool can help an organisation to future-proof for that eventuality, or consider what a move to more person-centred services would look like, and how it might benefit the organisation. Much of the advice found in this tool is based on the UN Convention on the Rights of Persons with Disabilities (UN CRPD), which is the standard in respecting the rights of people with disabilities.

Table 1.Overview of the Service Delivery tool

SECTIONS	SUB-SECTIONS
CITIZENSHIP	Self-Advocacy
	Risky Decisions
	Capacity to make decisions
	Everyday decisions
	Romantic and sexual decisions
	Communicating opinions
	Political involvement
COMMUNITY LIFE AND INDEPENDENT LIVING	Freedom of choice to use personal budgets
	Decisions around technology and the internet
	Everyday Living Skills
	Employment
	Privacy
	Embedding Services
	Access to the Wider Community
	Family Involvement
	Interests and hobbies
	Setting Goals
LEGAL AND ADMINISTRATIVE FRAMEWORK	Regulations
	UN CRPD
	Contracts
RISK MANAGEMENT AND SUPPORT SERVICES	Partnerships
	Personal Budget Information
	Support for Personal Budgets
	Voice in Supports
	Addressing Needs
	Quality of Life and Satisfaction with Services
	Safeguarding Service Users
	Vulnerable Service Users
	Health and Safety
	Assistive Technology
WORKFORCE	Knowledge of Personal Budgets
	Who Supports Service Users
FUNDING	Funding Changes

(For these questions, the follow scale is used: 1: strongly disagree, 2: disagree, 3: neither agree/disagree, 4: agree, 5: strongly agree, don't know; / does not apply)

Conclusion

The overall goal of this tool is to help you deliver a better, more rights-based service. This tool cannot, of course, cover every situation that a service organisation might encounter. For some situations, there is no currently established best practice. This is true of supporting people to make their own decisions. There are many hard cases that simply do not have easy answers, although it's hoped this tool will help organisations establish some basic procedures. As well, this tool does not fully address the tension between support individual choices, and the limitations of a collective setting. Again, there is no established best practice here. Person-centred services require that the individual's needs come first, as the service is centred on the individual. But this can be challenge in a traditional collective service environment. With no best practice to rely on, organisations must used the principles of the UN CRPD and person-centred services, and try to find the best way to help each service user make their own path through life, while providing services to a large group.

The hope is that these questions, and the advice provided, will help you to identify both what you are doing well, and what you can improve. The tool might also suggest ways that these improvements can be carried out. While you might not be able to make all of the changes suggested in this tool, it should help you to see where you can make changes. It might also help to advocate for better laws and policies in your state or region, so that the people you support can become equal, active citizens. After filling out the tool, either individually or in groups, your organisation should have a discussion, comparing where results identified the strengths and weaknesses of your organisation. Areas of disagreement can be as useful as areas of

agreement. Where different parts of the organisation disagree, there is clearly a disconnect, and finding out why there are disagreements could help identify new areas for improvement. Once areas for improvement have been identified, an action plan can be developed, to work on weaknesses and ensure strengths remain.

Organisations and individuals should feel comfortable filling out the tool honestly. No data linking the tool to any organisation that has filled it out will or should be published, so that results cannot be tied to any organisation or person. The tool should also not be linked with care inspections or other methods of meeting government regulations. The purpose of this tool is internal reflection and improvement, so it should be a separate process.

The Service Delivery Tool can be found under Annex II.

Compliance Assurance Tool

Who can use this tool?

This is a self-assessment tool that has been designed to help improve Long Term Care and Support (LTCS) policy, and in particular to help ensure LTCS is consistent with the UN CRPD and provides a good system of Personal Budgets.

In principle the tool could be used by anyone who is familiar with the LTCS in a particular area. However it has been primarily designed to support a team that is working together to review and make improvements to the LTCS system.

Methodology for the development of the Compliance Assurance Tool

This tool is based on the European Roadmap for User-centred Funding for Long Term Care and Support. It is designed to help public authorities evaluate how well they are living up to their human rights obligations under the UN Convention on the Rights of Persons with Disabilities (UNCRPD) and how far they have come in shifting their funding models for Long Term Care and Support (LTCS) towards a user-centred approach.

As the UNIC proposal sets out the purpose of this tool is:

"to help public authorities in the promotion, engagement and enforcement of Personal Budget systems, including the development of home care and community-based services (looking into the transformation of current services and the creation of new services)."

It has also been designed to be sensitive to the high degree of variability between public authorities and the different stages of development across the EU. Its function is to provide feedback that will assist good planning by drawing attention to areas of relative strength and weakness and areas of policy that require more attention.

This tool was developed using the following steps:

- Initial research, including literature review
- Development by continuous communication with project partners
- Validation by UNIC's Advisory Board Members
- Piloting over a period of 9 months in multiples occasions by the Flemish Agency for Persons with Disability (VAPH)
- Transferability testing workshops in Austria, Czech Republic, Finland, Spain.
- Finalisation: The feedback received during the Pilot and Transferability phase, will be used to develop the final version of the tool. This version will be supported by an ICT environment.

The evaluative framework is based on the human rights principles and best practice identified in UNIC Challenges-responsive Guidelines: European roadmap for user-centred funding for Long-Term Care and Support (2021). The definition of key terms is based both on those guidelines and upon Common European Guidelines produced by European Expert Group on the Transition from Institutional to Community-based Care (2012).

How to use the tool?

The Compliance Assurance Tool (CAT) will be an online system to help any public authority responsible for Long Term Care and Support (LTCS) to improve their systems and move towards an effective system of Personal Budgets.

Figure 1. FOUR STEP PROCESS OF CHANGE
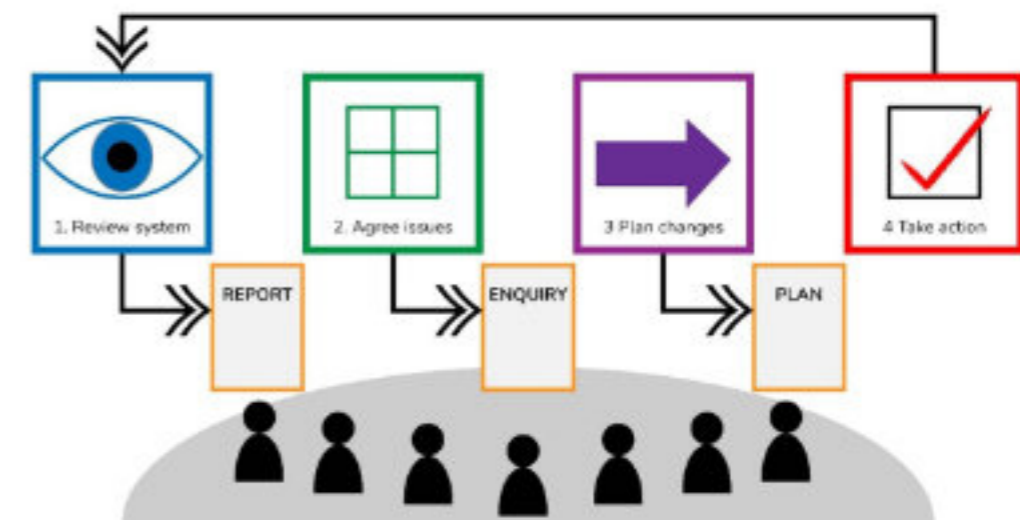
It is recommended that the public authority brings together a leadership team in order to use the tool and take the necessary steps to bring about meaningful change. The tool is designed to be useful in the first of a four-step process (see Figure 1).

The four-step process is:

1. Review the system - gather a wide range of perspectives on the current LTCS system.
2. Agree the issues - build consensus around the most important strengths to build on and the problems that need to be addressed.
3. Plan the changes - identify strategies to achieve the necessary changes
4. Take action - carry out the plan of action, and then review progress.

Applying the tool in practice

There a number of important things to remember when applying the tool in practice:

1. Coordination - There needs to be clear coordination if the tool is to be used by a large number of people. Ideally the tool will be completed by a group of people and this will require clear communication, deadlines and review in order to ensure sufficient data is gathered.

2. Target audience - The tool assumes that people have a reasonable level of knowledge about the whole LTCS system. This could include people who use LTCS, families and other professionals. Ideally the tool will be completed by a wide range of people, in particular public officials working within different parts of the system.

3. Setting the right level - The tool has been designed so that it can operate at different levels and for different groups. The questions in Section 1 are filtering questions. They establish which groups use LTCS will be considered and how well developed the overall LTCS system is. This means, when being used by a team, that the coordinator should answer the questions in Section 1 for everyone, and so define in advance the scope and depth of the report for all other users.

4. Self-assessment - The tool is a self-assessment tool and it does not aim to provide an objective measure of progress or to create results which will be comparable between different public authorities. Instead the average scores and ranges of results are presented to aid discussion and the identification of issues.

5. Human rights standards - The tool has been designed to compare existing systems to human rights standards. Low scores are not a sign of failure by current standards. The tool's purpose is to raise standards and to encourage innovation and new development.

Scope and depth of progress

The international evidence suggests that making progress in applying human rights standards to LTCS is complex work that takes time. Public authorities vary in at least two important dimensions:

1. Scope - Different public authorities may only provide LTCS to some of the possible groups who need it.

2. Stage of Development - Public authorities may be at different stages on the journey to the full application of human rights standards.

In the tool the following groups are identified as potential users of LTCS:

- People with physical disabilities
- People with sensory disabilities
- People with intellectual disabilities
- Older people who need support
- People with mental health problems or psychosocial disabilities
- People with long-term health conditions
- Children with disabilities and their families
- People with substance dependence
- Families with people with support needs
- Homeless individuals

Once the scope has been defined the evaluation of the system will be limited to the defined groups and the tool will turn off questions that are not relevant.

The tool has also been developed to offer increasing levels of detail depending on the development stage the public authority has reached:

1. Foundational level - If a public authority has made limited progress on Personal Budgets then questions focus on matters of fundamental principle.

2. Framework level - If a public authority is at an early stage in developing a Personal Budgets system then questions focus on the essential features of such a system.

3. Innovation level - If a public authority is seeking improve their Personal Budget systems then questions focus on the challenge of improving uptake, efficiency and usability of the system.

Presentation of the Compliance Assurance Tool

The tool is organised in 9 sets of questions each based around both key principles of human rights and the essential components of any sustainable system:

1. Introductory - What is the scope and depth of the LTCS system?
2. Services - What services are available for LTCS?
3. Freedom - Does LTCS protect people's freedom?
4. Inclusion - Are people supported to be full members of the community?
5. Rights - Does the system create meaningful rights?
6. Workforce - Does the system strengthen the workforce?
7. Finance - Is the system properly funded?
8. Policy - Is the system created in partnership with the people who use it?
9. System change - How can change best be produced in the system?

Figure 2. ORGANISATION OF THE QUESTIONS
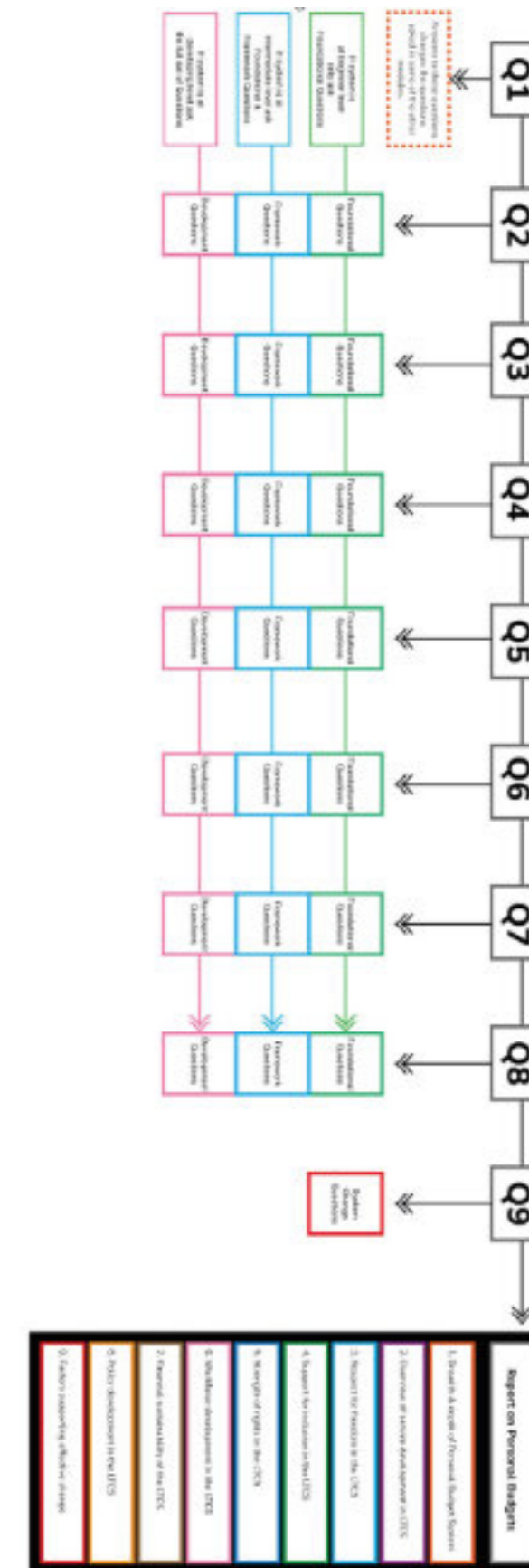
Next Steps

As explained above the survey tool is just the first part of a four step process:

1. Review the system - gather a wide range of perspectives on the current LTCS system.
2. Agree the issues - build consensus around the most important strengths to build on and the problems that need to be addressed.
3. Plan the changes - identify strategies to achieve the necessary changes
4. Take action - carry out the plan of action, and then review progress.

The following guidance may be useful in making best use of the survey.

Agree the issues

It is not essential that everyone shares the same judgement. Respondents might have doubts about whether the report is accurate or they might disagree about the meaning or importance of specific questions. Good opening questions for a discussion might include:

- How accurate does this report feel to you?
- What was your overall impression from the report?
- Did anything surprise you about the report?
- Did anything seem inaccurate or strange about the results?

These questions can get people talking, thinking and exploring their different perspectives. In facilitating this discussion it is important to encourage people to see that they can disagree.

The next stage of the process requires the team to consider their view of the current LTCS in the light of the report. The principles of Appreciative Inquiry are useful to apply here (see Table below). This encourages teams to evaluate the current reality from the perspective of its strengths, values and opportunities for positive change.

Figure 3. SOAR Model of Appreciative Enquiry

STRENGTHS: WHAT CAN WE BUILD ON?	ASPIRATIONS: WHAT DO WE CARE DEEPLY ABOUT?
• What are we most proud of as an organization? • What makes us unique? • What is our proudest achievement in the last year or two? • How do we use our strengths to get results? • How do we do or provide something that is world-class for our customers, our industry and other potential stakeholders?	• When we explore our values and aspirations, 'what are we deeply passionate about'? • Reflecting on our strengths and Opportunities conversations, who are we, who should we become, and where should we go in the future? • What is our most compelling aspiration? • What strategic initiatives (projects, programs and processes) would support our aspirations?
OPPORTUNITIES: WHAT ARE OUR STAKEHOLDERS ASKING FOR?	RESULTS: HOW DO WE KNOW WE ARE SUCCEEDING?
• How do we make sense of opportunities provided by the external forces and trends? • What are the top three opportunities on which we should focus our efforts? • How can we best meet the needs of our stakeholders? • Who are possible new customers? • How can we distinctively differentiate ourselves from existing or potential competitors? • What are possible new markets, products, services or processes? • How can we reframe challenges to be seen as exciting opportunities? • What new skills do we need to move forward?	• Considering or Strengths, Aspirations and Opportunities, what meaningful measures would indicate that we are on track to achieving our goals? • What are the 3 to 5 indicators that would create a scorecard that addresses a triple bottom line of profit, people, and planet? • What resources are needed to implement vital projects? • What are the best rewards to support those who achieve our goals?

The purpose of the discussion at this stage is to help the team listen to each other's perspectives and identify areas of strong agreement from which to build. This requires teams to think through what seem like the most important problems to solve and priorities for action or change. At this stage the focus of discussion may be on finding common themes, grouping issues together or eliminating issues that do not seem a priority for action.

At this stage a systemic analysis may also be useful. The team should identify what factors are supporting progress, what factors are hindering progress and what loops or feedback behaviour is supporting or hindering change.

Plan the change

Priorities for planning will vary significantly depending on the stage of development the public authority has reached. The actions below may all be relevant at some point, but some will be more relevant at different stages of the journey. These lists are not meant to be exhaustive – there may well be other important ideas that emerge from discussion.

Stage 1. Priorities

For public authorities who are at a very early stage of development and where commitment and support for Personal Budgets is only just emerging then these actions may be useful:

- Find opportunities for pilots, experiments or other innovations
- Support advocates of Personal Budgets
- Make Personal Budgets available where possible
- Allow changes or clarifications to rules to open up possible space for testing
- Find people eager to use Personal Budgets and enable them to make changes quickly

- Identify areas of crisis where Personal Budgets could help solve problem
- Celebrate examples of good practice that are similar to Personal Budgets
- Support the development of leadership communities to develop innovations
- Join transnational communities sharing good practice on Personal Budgets

Stage 2. Priorities

When there is a commitment to establish Personal Budgets in practice then these are likely to be some of the priority actions:

- Create a legal framework to make Personal Budgets possible
- Give people a right to convert a right to service into a Personal Budget
- Give people flexibility in the use of their Personal Budget
- Create systems of advocacy and protection for Personal Budget users
- Create systems to protect rights of employers and employees using Personal Assistance
- Provide a clear and attractive narrative about why changes are necessary
- Targeting areas where changes can be achieved most easily
- Support for leadership communities to lead the process of public and professional education
- Create the necessary legal or administrative changes to make the process real
- Create an investment strategy that moves resources from the old to the new system

Stage 3. Planning

Once a framework is in place the challenge is to create the necessary practical and systemic innovations to make Personal Budgets more effective and to widen their application across more groups. These are some possible priorities:

- Increase uptake and scope of Personal Budgets across LTCS
- Make Personal Budgets the default system
- Make it easier for people to control and use their budget
- Shift the service system towards more personalised supports
- Create incentives for people to innovate
- Make Personal Budgets a requirement for LTCS, not just an option
- Create plans for existing services to move to Personal Budgets
- Help people who do not want to Self-Manage Personal Budgets to use alternatives
- Eliminate unnecessary complexity and confusion from national and local systems
- Design specific implementation strategies for people in the old system
- Define when and how the new system of Personal Budgets will apply to everyone
- Close institutional services which have not chosen to change or adapt
- Integrate additional relevant funding streams into the Personal Budgets system
- Harmonise existing professional roles with the new models of support

Glossary

Community-based services

Community-based services refer 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, education, employment, culture and leisure, which should be accessible to everyone regardless of the nature of the 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

Deinstitutionalisation

Deinstitutionalisation (DI) is a complex and multipurpose process which implies a fundamental reshaping of how society can provide the necessary tools to individuals to participate on an equal basis. As a process, it is often wrongfully associated to the simple closure of institutional settings, however, deinstitutionalisation embodies the transition away from isolating and segregating institutional care towards community-based care and services and the development of a range of support and other services in the community which enable participation and inclusion, such as prevention, early childhood intervention (ECI), family support, health, education, employment and housing. Indeed, access to person-centred and individualised support is a pre-requirement to the enjoyment of human rights. When developing community-based options caution should be taken not to re-create smaller versions of the large institutions.

Inclusion

'Inclusion' is the principle underlying Art. 19 UNCRPD (Living independently and being included in the community), which refers to a person's right to live and participate in the community, with choices equal to others.

Independent Living

The principle underlying Art. 19 UNCRPD (Living independently and being included in the community), which refers to a person's right to choose their place of residence and where and with whom they live on an equal basis with others. To guarantee this states have to provide access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community and other community services and facilities, such as accessible transport.

Long-Term Care and Support

There is no single definition of care at EU level, with terms such as social care, long-term care, healthcare & social services having different meanings in each country. This is often due to historical, cultural, economic and social differences across the European Union, as well as the evolving variety of care needs that people may have.

Within the consortium of UNIC we believe that the definitions of LTC focus widely 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" 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.

Therefore, Long-Term Care and Support (LTCS) is defined as support people need to enable Independent Living and to be safe, well and fully involved in the life of their community, whatever their support and care needs. Home and community-based services are the types of services needed to implement this definition.

Peer Support

Mutual help provided by people and families who also need assistance, use services or share common experiences. [UNIC Guide]

Personal budgets

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.

Supported decision-making

Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) acknowledges the right of persons with disabilities to enjoy legal capacity on an equal basis with others in all aspects of life. It also affirms their right to have equal access to own or inherit property and to control their own financial affairs. All of which is subject to safeguards which are proportional and tailored to the personal circumstances and applied during the shortest possible period. In line with this principle, Supported Decision Making (SDM) represents an alternative to guardianship or other types of substituted decision making. This shift in paradigm is funda-

mental to advancing towards the real inclusion of persons with disabilities into the society.

SDM consists of several measures designed at setting the sufficient conditions for a person with disabilities to make informed decisions on all aspects of her or his own life. The range of decisions is very broad and goes from very routine decisions such as how to dress and what to eat, through to decisions that can greatly affect the life of a person, such as where to live, who to vote for, or whether or not to accept a particular medical treatment.

Supported Decision Making is key to promoting self-determination, control, and autonomy and it fosters individual independence. As a new paradigm, it can be considered as a revolutionary change in the support principles applied to persons with disabilities, and sets a firm base to advance towards de-institutionalisation and the development of community based services.

User-centred funding models

User-centred funding models are considered a radical transformation 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 individuals 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.

Annex I - Quality Monitoring Tool template

Section 1. How do I use my personal budget?

Here you will find a list with different every day activities that you may use your personal budget for.

- Click Yes on the activities that you use your personal budget for.
- Click Yes, but not now on the activities that you use your personal budget for, but not during this time.
- Click No on the activities that you do not use your budget for.

You may have a person that supports you, like an assistant with these activities and this person is paid with your personal budget or you may have a service that you use to recieve support with these activities.

Next to each activity you will see a star. You may click the star if this activity is very important for you. You can click the star even if you do not use your personal budget for this activity but it is still important for you.

HOW DO I USE MY PERSONAL BUDGET?				
1	**I use my personal budget to receive support with daily living skills:** For example, I have someone to help me everyday with my personal hygiene such as showering, bathing, dressing, grooming, toileting, mobility to get in and out of bed, attend appointments, cooking	YES	YES, BUT NOT NOW	NO
2	**I use my personal budget to have access to lifelong learning or education opportunities:** For example I have someone to support me at school. Or with my personal budget I can have access to a training or other educational opportunity that I want.	YES	YES, BUT NOT NOW	NO
3	**I use my personal budget to work and employment:** For example I use services with my personal budget to find work or to start my own business. I can have someone to support me at my workplace.	YES	YES, BUT NOT NOW	NO
4	**I use my personal budget to receive support to participate in the community:** For example I use my personal budget to have support to participate on social or recreational activities, such as going to the cinema, going to the theater, going to the gym.	YES	YES, BUT NOT NOW	NO
5	**I use my personal budget to have access to therapeutic interventions:** For example I use my personal budget for services for recovery, speech therapy, occupational therapy, physical therapy, emotional support and others.	YES	YES, BUT NOT NOW	NO
6	**I use my personal budget for assistive technologies:** Assistive techology is any product or technology-based service that can enable people to participate in any aspect of life. For example I use my personal budget to buy and learn how to use a hearing aid, a screen reader, a walker, a wheelchair.	YES	YES, BUT NOT NOW	NO
7	**I use my personal budget to make changes on the place I live or my car or my work:** For example I use my personal budget to make changes on my home or my car, or my work that can help me be more independent. For example I can install a wheelchair ramp in the house, lower the kichen countertop to be able to reach it.	YES	YES, BUT NOT NOW	NO
8	**I use my personal budget to go from point A to point B more independently:** For example I use a service that can pick me up and transfer me to my house, my work.	YES	YES, BUT NOT NOW	NO
9	**I use my personal budget to be able to live as an average person lives in my community:** For example I use my personal budget to pay my rent, to buy groceries.	YES	YES, BUT NOT NOW	NO

Are there any other things that you use your personal budget for?	
The government often has rules that tell you that you can use your personal budget for only specific every day activities. Is there something that you would like to use your personal budget for and you are not allowed to?	
Did you have wait in order to get your personal budget from the time that you applied for it?	YES NO 0-1 YEAR 1-5 YEARS 5-10 YEARS MORE THAN 10 YEARS

Section 2. Does the personal budget help me to improve the quality of my life?

There are 24 statements that you will need to rate, based on the experience that you had with your personal budget in each aspect of your life. However, it is important to keep in mind that there are many factors that can influence the quality of life of a person. This part of the tool will help us to understand how your personal budget has support you to access activities and services that you could not access previously without your personal budget.

Instructions on how to answer the following questions:

1. Read each sentence
2. Then rate each sentence, depending on if your personal budget supports you to do the activities that the sentence indicates.
   - If the personal budget doesn't support you to do this you will select (include a picture with all the 1 options).
   - If the personal budget supports you to do this but it is not enough to meet your needs and wishes you will select (include a picture with all the 2 options)

- If the personal budget supports you to do this and it is enough to meet your needs and wishes you will select (include a picture with all the 3 options)

If this is very important to you, you may select the star next to each question. Even if your personal budget does not support you to do this activity, you can select the star if this is important to you.

SECTION 2. DOES THE PERSONAL BUDGET HELP ME TO IMPROVE THE QUALITY OF MY LIFE?

Item #	Domain & Dimension	Item	No / 1 / Sad face	Yes, but it is not enough / 2 / Neutral face	Yes / 3 / Happy face	This is important to me
1.1		My personal budget supports me to improve my skills or learn new skills to become more independent.				
		The skills that I can learn will help me be more independent at my work, my home, at school and in the community. For example I can learn how to use public transportation, so I can take the bus and go to my job alone or with support.				
1.2	Independence: Personal Development	My personal budget supports me to have new experiences and try new things that I could not before.				
		People do not always have the opportunity to try new things and have new experiences. My personal budget has helped me on that, since for example, I can use public transportation, I can go to the cinema or participate on another activity in the community that I want with or without support, I can cook by myself.				
1.3		My personal budget supports me to get help to achieve my personal and life goals.				
		Each person has different needs, wishes in their life and it is important to understand if the personal budget you receive helps you reach your goals.				

SECTION 2. DOES THE PERSONAL BUDGET HELP ME TO IMPROVE THE QUALITY OF MY LIFE?

Item #	Domain & Dimension	Item	No 1 Sad face	Yes, but it is not enough 2 Neutral face	Yes 3 Happy face	This is important to me
2.1		**My personal budget supports me to have a choice in how I live, where I live and with whom I live.** One of the main goals of the personal budget is to help people live independently in the community. So it is important to know if your personal budget helps you to live independently wherever you wish to live and with the people that you want to live with.				
2.2	Independence: Self-Determination	**My personal budget supports me to make decisions for myself while receiving the support I need.** For example, I have the opportunity to express my opinion, make choices on where I want to work, what job to do. I can decide where I go, with whom, the activities I do.				
2.3		**My personal budget supports me to be treated as an individual with wishes, needs and aspirations.** The people that support me ask my opinion, listen to my needs and my wishes and respect them. I am not forced to do things with others because this is how the service is organised. For example, I am not forced to eat at 2pm everyday because this is the time when lunch is provided on the service I am.				

SECTION 2. DOES THE PERSONAL BUDGET HELP ME TO IMPROVE THE QUALITY OF MY LIFE?

Item #	Domain & Dimension	Item	No 1 Sad face	Yes, but it is not enough 2 Neutral face	Yes 3 Happy face	This is important to me
3.1	Social Participation: Interpersonal Skills	**My personal budget supports me to improve my relationships with those close to me.** The people close to me can be my family, friends, colleagues, neighbors. And my personal budget help me to create opportunities to improve my relationships. For example, I can see my friends and family when I want, they can visit me at any time.				
3.2		**My personal budget supports me to be better able to pursue and engage in close or romantic relationships.** For example I can engage with other people whom I like in a private and personal way, whenever and how I wish.				
3.3		**My personal budget supports me to meet people where and when I want to.** For example I can meet my friends, family and other people close to meet outside of the place I live and at any time.				

SECTION 2. DOES THE PERSONAL BUDGET HELP ME TO IMPROVE THE QUALITY OF MY LIFE?

Item #	Domain & Dimension	Item	No 1 Sad face	Yes, but it is not enough 2 Neutral face	Yes 3 Happy face	This is important to me
4.1	Social Participation: Social Inclusion	**My personal budget supports me to volunteer in activities in the community, outside of my house.** For example I can volunteer in activities outside of the place I live. And that also means that I can have a person if I need to, to support me participate in these activities.				
4.2		**My personal budget supports me to move around my community more easily.** If I want, I can go to any part of the community. I can use public transportation like others do. I can get into buildings and other facilities.				
4.3		**My personal budget supports me to participate more in activities in the community, outside of my house.** For example I can participate in activities outside of the place I live. That means that I am not participating in activities only inside the place I live and with only the people I live with. And that also means that I can have a person if I need to, to support me participate in these activities.				

SECTION 2. DOES THE PERSONAL BUDGET HELP ME TO IMPROVE THE QUALITY OF MY LIFE?

Item #	Domain & Dimension	Item	No 1 Sad face	Yes, but it is not enough 2 Neutral face	Yes 3 Happy face	This is important to me
5.1	Social Participation: Rights	**My personal budget supports me to know my rights and advocate for my rights.** For example my personal budget has created opportunities for me to participate in places/ services in my community, where I can learn about my rights. I can participate in meetings and events to advocate for my rights.				
5.2		**My personal budget supports me to participate in a peer-to-peer network.** My personal budget provides me with the opportunity to go to places and services, where I can meet my peers for example, and ask them for advice and support.				
5.3		**My personal budget supports me to exercise my right to vote and make my views known.** My personal budget provides me with support if needed to vote in elections. I can also participate in meetings in my community and be part of decisions that may affect me.				

SECTION 2. DOES THE PERSONAL BUDGET HELP ME TO IMPROVE THE QUALITY OF MY LIFE?

Item #	Domain & Dimension	Item	No	Yes, but it is not enough	Yes	This is important to me
			1	2	3	
			Sad face	Neutral face	Happy face	
6.1		**My personal budget supports me to participate in activities that make me feel good.** That means that with my personal budget, I can have access to activities that I like and that make me feel good.				
6.2	Wellbeing:Emotional Wellbeing	**My personal budget supports me to feel better about myself and more confident about what I can achieve.** For example I can use my personal budget to receive support to succeed in the activities I do.				
6.3		**My personal budget supports me to feel good with the help I get.** With my personal budget I can choose the services I need and I want and that makes me feel good.				

SECTION 2. DOES THE PERSONAL BUDGET HELP ME TO IMPROVE THE QUALITY OF MY LIFE?

Item #	Domain & Dimension	Item	No	Yes, but it is not enough	Yes	This is important to me
			1	2	3	
			Sad face	Neutral face	Happy face	
7.1	Wellbeing:Physical Wellbeing	**My personal budget supports me to access the care I require to meet my health and hygiene needs.** With my personal budget I can also access care which can support me with my hygiene needs and my health needs, such as a support person that can help me toileting, showering, making sure that I am taking any medications I need, following up with doctor's appointments etc.				
7.2		**My personal budget supports me to exercise if I want.** For example, I can have a support person that helps me to exercise. I can have access to a gym that can accommodate my needs.				
7.3		**My personal budget supports me to maintain a diet and the lifestyle I want.** I can eat or drink the things I want and whenever I want. I do not have to follow a specific lunch and dinner schedule for example.				

SECTION 2. DOES THE PERSONAL BUDGET HELP ME TO IMPROVE THE QUALITY OF MY LIFE?

Item #	Domain & Dimension	Item	No 1 Sad face	Yes, but it is not enough 2 Neutral face	Yes 3 Happy face	This is important to me
8.1		**My personal budget supports me to have enough money to buy the things I want and I need.**				
8.2	Wellbeing:Material Wellbeing	**My personal budget supports me to find or keep a job more easily.** For example, with my personal budget I can have a support person that can help me do my job. I can have access to services that help people find and keeping a job.				
8.3		**My personal budget supports me to live in a place that I feel safe and comfortable.** For example I can use my personal budget to make changes to the place I live so it can be more comfortable for me. I can adapt it to my needs, such as put a stairlift or lower the countertop.				

Section 3. How is my experience with the personal budget process?

Below you will find a list with 17 different sentences. Please read the sentences carefully and answer:

1. If you believe that a sentence is true, you may select Yes.
2. If you believe that a sentence is true but not always, you may select Yes, but not always.
3. If you believe that a sentence is not true, you may select No.

If this is very important to you, you may select the star next to each question.

SECTION 3. HOW IS MY EXPERIENCE WITH THE PERSONAL BUDGET PROCESS?

		Items	No / Sad face	Yes, but it is not enough / Neutral face	Yes / Happy face	This is important to me
1	Information	It was easy to find information about the personal budget system.				
2	Rules	It is easy to understand the rules of the personal budget.				
3	Access	If I have questions, I can easily get in contact with an employee from the personal budget provider.				
4	Assessment	I was involved in the assessment process when I applied for a personal budget.				
5	Active Involvement	I am involved in drafting my support plan.				
6	Decision-making	I am asked my opinion before a decision is made about my personal budget.				
7	Respect and Dignity	When I make a decision, it is respected by the personal budget provider.				
8	Training	I was given all the training I needed to use my personal budget properly.				
9	Choice and Discretion	I can choose how to use my personal budget.				
10	Flexibility	When I receive my personal budget, I have the right to choose the support services that I want.				
11	Support	If I cannot manage my personal budget alone, I have the right to choose the support services I want to help me manage it.				

SECTION 3. HOW IS MY EXPERIENCE WITH THE PERSONAL BUDGET PROCESS?

		Items	No / Sad face	Yes, but it is not enough / Neutral face	Yes / Happy face	This is important to me
12	Control	If I want, I can change the person or the service that helps me use my personal budget.				
13	Advocacy	I can appeal for a decision made regarding my personal budget.				
14	Budget amount	I am satisfied with the amount of the personal budget I receive.				
15	Rights	I feel that my rights are respected by the personal budget provider.				
16	Assistive Technology	I can use my budget to buy equipment to support me with the activities I want to do.				
17	Privacy	My personal details are protected by the personal budget provider.				

How satisfied are you with your personal budget? (You may rate this question from 1-3, where 1 is the least satisfied and 3 the most satisfied.)	1	2	3
Is there anything else that you would like to share with the personal budgets provider?			

Annex II - Service Delivery Tool template

(For these questions, the follow scale is used: 1: strongly disagree, 2: disagree, 3: neither agree/disagree, 4: agree, 5: strongly agree, I don't know, It does not apply)

1. Citizenship

Being a full citizen has many facets. This section focused on hearing and respecting the voice of service users, helping service users to advocate for themselves and issues important to them, and respecting the rights of service users to make decisions. In a person-centred service, service users are supported to make their own decisions. This includes decisions that may seem to carry risks. Service providers may be hesitant to support service users to make decisions seen as risky, either due to government regulations, concerns about liability, or the culture in the organisation. While answering the questions, think about how you could provide service users with the greatest freedom to make their own decisions.

Self-Advocacy

- Our organisation provides service users with the skills to advocate for themselves.
- Our organisation encourages service users to advocate for themselves.
- Our organisation provides service users with the tools to support each other in advocacy
- When service users do advocate for themselves, our organisation supports them in achieving changes they are advocating for.
- Our organisation has an advocacy committee.

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- Our organisation has a human rights committee
- These committees have an impact on our service provision

Advice: In order to deliver a person-centred service, a service provider should make sure that their organisation is listening to and incorporating the voice of service users. Encouraging service users to find their voice, and express their needs, helps them to advocate for their own rights. One place where your organisation should help service users practice self-advocacy is within your organisation. Your organisation should encourage service users to speak up for themselves, and change services and processes based on what service users ask for. This is also helpful when service users have personal budgets, as service users are going to choose services that are responsive to their needs.

Decisions Seen as Risky

- Service users have the freedom to make decisions others may view as unwise or risky
- Families and the wider support network of service users are involved in deciding what kinds of risks service users can take
- Our organisation supports people to make decisions that could be seen as risky or unwise
- Our organisation helps people to understand risks and consequences of their actions
- When a service user wants to make a decision seen as risky, our organisation works with them and their support network to develop a plan to mitigate risks

Advice: The freedom to make our own decisions is one of the most fundamental freedoms a person can have. This right must not be denied to people with disabilities, even under the idea of protecting and caring for them. Article 12 of the UN CRPD makes it clear how important this right is

for people with disabilities. This includes the freedom to make decisions other people might disagree with, or consider risky or unwise. For instance, drinking alcohol, or eating unhealthy food, are generally not seen as "wise" or "healthy" decisions. But society sees these as individual choices, and most of us engage in them at some point. However, many service users might be protected from making these decisions. All of us have to make individual decisions, and make mistakes, to grow and develop as a person. Protecting service users from every mistake doesn't allow them this growth and learning. There are a number of reasons that it might be difficult for an organisation to support a person to make a risky decision, of course. Regulations and liability are both concerns in these cases.

However, it's important to do the best an organisation can to support people with disabilities in all their decisions. This includes helping service users understand the risks of their actions, and talking with them about ways to address and mitigate these risks. If a service user wants to make a complex decision, the service should support them in making a plan. Issues around risk and support come up for every service organisation, and no one has fully solved this issue. What's important is to respect the autonomy and capacity of service users at all times. Work with the service users around what is important and meaningful to them, to see if there are other ways to achieve their goals. Service users with personal budgets are also more likely to choose service providers who will support their decisions, even if those decisions seem risky or unwise. Of course, providing support can also mean intervening to protect someone from very destructive behaviour, and helping service users to understand the risks of destructive behaviour. In this area, supporting service users to make all decisions, there is little best practice to fall back on, because it is a fairly new idea. Every organisation will have to grapple with different situations, and work towards procedures that work for their service users.

Capacity to make decisions

- Our organisation provides information and advice to service users making decisions
- Our organisation works to ensure service users who need support understand all of their options when they are making a decision
- Our organisation supports people to make all decisions that are within their capacity
- Our organisation has clear policies and processes around determining what decisions a service user has capacity to make
- Our organisation supports people to make decisions that are difficult for them
- Our organisation understands that some people experience changing capacity, and may be able to make some decisions at some times but not others. We have a process for addressing this.
- Our organisation involves a service user's family and support network to help them make their own decisions

Advice: It is true that some service users may not have the capacity to make all decisions without support. It's also important to remember that capacity is not a simple yes or no question. Some people might not have the capacity to make complex financial decisions, but still be perfectly capable of making minor day-to-day decisions. And some people have disabilities where capacity might change over time. In cases like this, for instance, if a decision is not time sensitive, it can be put off until a service users is in a better frame of mind to address the decision. Service users should be supported to make whatever decisions they can make. Determinations of capacity should also leave towards the presumption that a person has the capacity to make a decision.

Everyday Decisions

- Service users have the freedom to make everyday decisions
- Our organisation encourages service users to make small decisions for themselves, such as what the wear and what to eat
- Our organisation encourages service users to make big decisions for themselves, such as how to arrange their finances and where to live
- What decisions can a person make? Service users can choose:
  - What to eat
  - When to eat
  - When to go to bed/get up
  - Their daily activities
  - Where they go
  - Who they interact with
  - Other daily decisions
- Service users can choose when to have visitors
  - Visitors can come without making an appointment
- If you provide housing, people can choose who they live with

Advice: All service users should be capable of making small, everyday decisions. These can be important to developing a sense of autonomy and independence, and as a way to practice decision making for service users who might not be used to making their own choices. Service users who have personal budgets, and can more easily choose their service provider, will likely prefer service providers who foster this autonomy. They will also prefer organisations that allow service users to make their own choices.

Relational and Sexual Decisions

- Our organisation supports service users to make sexual and relational choices

- Service users have autonomy to make sexual and relational choices
- Service users who want support are supported to make relational and sexual choices
- Our organisation provides support around topic such as contraception, pregnancy, STIs, and other issues that arise in sexual relationships
- Our organisation helps service users to understand consent and other factors of a healthy sexual or other intimate relationships.

Advice: One of the most important choices that people make is in their intimate relationships. Who people choose as a relational and sexual partner is both very personal and very important. In the past, people with disabilities were often forbidden from making these choices, with laws preventing people with certain disabilities from marrying or even consenting to a sexual relationship. A service organisation should be able to support service users in these decisions, ensuring that service users have all the information they need to make these choices, and have the freedom to do so. Article 23 of the UN CRPD establishes the right of people with disabilities to make choices around intimate relationships and starting families. Certainly, for many service users with personal budgets, an organisation that is supportive of sexual and relational relationships will be more appealing.

Communicating Opinions

- Our organisation helps people to communicate their ideas and opinions
- Our organisation creates spaces where service users feel safe and supported in sharing their opinions, including their opinions on the services we provide
- There is a process in our organisation to help service users feel safe in sharing their opinions
- If a service user expressed a negative opinion about staff or the ser-

vices they receive, this would not result in retaliation against the service user

Advice: The right to express your opinion is one of the most basic rights a person can have. In the UN CRPD, it is covered under Article 21, which states that people should be allowed to express their opinion, and to express themselves in whatever way is best for them, whether that is speaking, sign language, or using technology. A service provider should encourage service users to express their opinions on a wide range of topics. This should include their opinions of the service provider. If a service user is willing to criticise their service provider, it can be a sign that the feel safe and supported, and don't fear retaliation for expressing a negative opinion. This willingness to criticise can also be useful for the service provider, as it can help to identify areas where services could be improved.

Political Involvement

- Our organisation supports service users to participate in politics.
- Our organisation supports or would support service users:
  - To vote
  - To join political parties
  - To advocate for political causes
  - To join and form political advocacy groups
  - To stand for office

Advice: The right to participate in politics is important to many people. It is also found in the UN CRPD, in Article 29. People with disabilities should have the right to vote, to join political parties, to run for office, and to engage in political advocacy, in the same way as the rest of the population. Service providers should support service users to engage with politics in the ways that they choose. Engaging in political activity has several bene-

fits. It can help service users to learn to advocate, both for themselves and causes they care about. It can be a way to engage with the wider community. And it can help improve the rights of people with disabilities.

2. Community life and every day living skills

This section of the tool focuses on the wider community. A person-centred service should be able to help its service users to become part of the community, rather than remaining segregated in specialised services. Even residential services can open up to the wider community. Becoming part of the community is an important part of living independently. It is also an important part of daily life for most people. Most individuals rely on and enjoy being part of a community, and people with disabilities are no different. Supporting people to become part of the community, and to build connections outside of services, is one of the most important things that a service provider can do. As you answer these questions, think about steps your organisation already takes to help service users become part of the wider community and what more you could do to achieve this goal.

Freedom of Choice to Use Personal Budgets

- Service users are free to use their personal budget within our organisation in on any services or supports they want
- Our organisation is able to give service users freedom to spend their personal budget
  - Our organisation provides service users freedom to spend their personal budget
- Our organisation does support service users to use their personal budget on services outside of our organisation

Advice: One of the reasons for using personal budgets is to help service users gain more autonomy and independence in their lives. This goal will fail if they are not supported to use their personal budget with as much freedom as possible. This might mean, in some cases, supporting your service users to take part of the budget outside of your organisation. While doing so may feel counterintuitive, as it means your organisation loses that money, it will lead to more satisfied servicer users overall, which may help your organisation gain service users. It could also benefit your organisation to create partnerships with other service providers. If you aren't a good fit for a service user, you could refer them to a partner organisation, and they could do the same for you. In this way, service users will receive better services, and each organisation will be able to reach more people who can benefit from their services.

Decisions around technology and the internet

- Our organisation supports service users to use technology and the internet in the way that they choose
- Service users have a lot of freedom to use technology and the internet
- Services users are supported to make choices about how they use technology and the internet

Advice: These days, using the internet and device such as computers, smartphones and tablets is an important part of most people's lives. Most service users will want the same freedom to access devices and the internet that other people enjoy, and your organisation should support service users to use technology and the internet in the way that they choose. Access to communications technology and the internet is also considered a right in the UN CRPD, in Article 21. It is true that there are risks to be navigated in the internet, but service users should be supported to make decisions about how they want to engage with the risks of technology and

the online world. Service users who are choosing a service provider are likely to look for this kind of freedom and support to access the internet and other mainstream technology.

Everyday Living Skills

- Our organisation does a good job teaching service users the everyday skills of life
- We teach service users skills such as
    - Cooking
    - Cleaning
    - Taking care of a home
    - Budgeting
    - Shopping
    - Gardening
- Our organisation encourages service users to learn everyday living tasks, such as household chores

Advice: Developing skills for everyday living, such as cooking, cleaning, and looking after one's own home can help a person to be more in control of their life, as they rely less on other people. For service users who want to gain these skills, this can be an important part of promoting autonomy and a sense of control over one's own life. Like controlling one's own services with a personal budget, developing the skills to exercise better control one's own life is an important part of person-centred services.

Employment

- Our organisation is able to support service users to seek both mainstream and supported employment
    - Service users can chose which type of employment they want to

pursue, mainstream or supported
- Our organisation does a good job helping people who wish to access employment and employment training
- Our organisation helps service users to access mainstream vocational training, if they wish to.
- Our organisation supports service users to do volunteer work
- Our organisation is succeeds in helping people access employment and vocational training, judging by people placed and remaining in employment

Advice: Employment is an important human right. According to Article 27 of the UN CRPD, people with disabilities should have equal access to mainstream employment. In many places, this is not the case. In some places, people with disabilities cannot seek work in mainstream employment. Service providers should do everything possible, within their legal framework, to help people who want a job to seek mainstream employment. This can include accessing education and job training, or supporting someone to find and apply for jobs. In places where this is impossible, service providers might support service users to advocate for access to mainstream employment. There are also other options, beyond mainstream employment, that service users may want to pursue, include supported employment, social economy, and volunteer work. Service users should be supported to understand all their options.

Privacy

- Our organisation has an official privacy policy, that is followed by all staff
- Our organisation protects and respects the privacy of our service users
- Our organisation consults with service users about their privacy and what they want to keep private or share

- Our organisation collects information on the satisfaction of service users with privacy standards at your organisation
  - Service users are satisfied with the level of privacy our organisation provides
- Our organisation talks to service users about privacy, and their needs and desires around privacy
  - Our organisation allows different policies for different individuals, based on their desires

Advice: Privacy is an important human right for everyone. Article 22 of the UN CRPD states that people with disabilities have the same right to privacy as everyone else. It is important that an organisation works with service users, to help them develop a policy around privacy that suits each individual. Different people may feel comfortable sharing different pieces of information with different people, and so individualised policies around privacy are best. In the context of personal budgets, service users are unlikely to stay with an organisation that doesn't respect their wishes around privacy.

Embedding Services

- Our organisation is able to support service users to seek both mainstream and supported employment
- Service users can chose which type of employment they want to pursue, mainstream or supported
- Our organisation does a good job helping people who wish to access employment and employment training
- Our organisation helps service users to access mainstream vocational training, if they wish to.
- Our organisation supports service users to do volunteer work
- Our organisation is succeeds in helping people access employment

and vocational training, judging by people placed and remaining in employment

Advice: It is important for service providers to help service users to be part of the wider, mainstream community. One way to accomplish this is to ensure that service provision is embedded in the community. Service provision should not be segregated from mainstream society, or invisible to the wider community. The more that the service is part of the community, the easier it will be for service users to find a place in the community. Being part of the community is a right in the UN CRPD, found in Article 19 (the right to live independently and be part of the community). This right includes the right to receive services in one's own home, and the right to have all services in the community, disability and mainstream, be accessible and disability friendly. Realising this right is much easier if disability services are already an integrated part of community.

Access to the Wider Community

- Our organisation does a good job helping service users access the wider community
- Our organisation talks to service users about what they want from the community, and helps them achieve these goals
- Our organisation helps service users to:
  - Use public transport
  - Shop
  - Go to cafés/restaurants
  - Engage in hobbies in the community
  - Join groups in the community
- Our organisation supports people to access mainstream community services

- Our organisation supports people to develop connections in the wider community

- Our organisation could do more to help service users access the wider community

- Our organisation works with the wider community to make it more welcoming and accessible to your service users

Advice: As previously discussed, one of the duties of a service provider should be to help its service users to integrate into the wider community. One way of doing this is ensuring that the service provider itself is part of the community. In addition, each service user should be able to find their own place in the community as an individual. Service users should feel that they are welcomed in the community, and feel comfortable moving through the community. This is part of living an ordinary life, which is an important goal for many people with disabilities. Most of us take normal activities, like shopping or meeting a friend for coffee, for granted. For many people with disabilities, these activities might be full of obstacles, and difficult. Service providers should do everything in their power to support their service users to carry out these kinds of ordinary, everyday activities.

Family and support network involvement

- Our organisation involves the family of service users in their services

- In addition to family, our organisation involves other support networks that a service users has in their service

- Service users can choose how their family and support network is involved

- Our organisation has a policy for handling conflicts between a service user and their family or other support networks

Advice: Service users may wish to involve the people around the in their services. This can often be family, but it can also be friends or other people important to the service user. Allowing service users to involve their other supporters, if they want, in their service provision, can give them more control over their service.

Interests and hobbies

- Our organisation does a good job helping service users to discover their interests and talents

- Our organisation helps service users to engage in sport, if they are interested
    - As a fan and spectator
    - As a participant in mainstream or specialised sports

- Our organisation helps users to engage in art, if they are interested
    - By helping service users obtain art supplies
    - By helping service users attend art classes, both in the service and in the community
    - By helping service users join art groups and clubs

- Our organisation helps service users find ways to contribute to society

- Our organisation helps service users connect with others who have their hobbies and interests, including in the wider community

Advice: Most people have hobbies or interests that they use to fill their leisure time. These can include sports, arts, crafts, games, and other hobbies. People with disabilities can find that they are not encouraged to discover these interests and develop them. However, having a hobby can help someone connect with other members of the community. Sometimes, a persons' hobbies or talents can contribute to the community. And finally, there is a right to sports and other leisure activities in the UN CRPD, in Art-

icle 30. This article notes, for instance, that people have the right to parti-
cipate in sport, both as a spectator and a participant. They also have the
right to develop their creative talents, and access leisure activities such as
cinema, theatre, and tourism. A service provider should help service users
discover what hobbies and activities are fulfilling to them, and to engage in
these activities, not just within the wall of the service organisation, but
within the wider community as well.

Setting Goals

- Our organisation has processes we use to help service users set long
  term goals, including goals around living independently and building
  a career
- Our organisation does a good job helping service users set long term
  goals for their lives, and working towards these goals
  - Our organisation produces good outcomes, as far as helping ser-
    vices users work towards and achieve their goals
  - Service users are generally satisfied with the support we provide
    to help the set and work towards goals

Advice: Generally, people have long term goals for the life and career.
People in disability services may not be encouraged to set such goals, as
they may be seen as dependent and being cared for. However, service users
still have aspirations, and should be encouraged to form long terms plans
to achieve these goals. They should also be supported, as much as possible,
to work towards these goals. Not every goal will be achievable, but that is
also true for the goals held by the general population. This does not mean
that it's not worth setting a goal and working towards it. In this work, the
service user can learn to advocate for themselves, develop plans, and ima-
gine a life outside of the world of service provision. For instance, should
a service user say they would like to be prime minister, the organisation
could support them by helping them to join a political party and attend

meetings, as a starting point. All of these will help the service user to move
towards a more independent life in the community.

3. Legal and administrative framework

This section relates to the regulations around your organisation. All organ-
isations that deliver services work within a framework of laws and regula-
tions. Ideally, these regulations support organisations to deliver person-
centred services that help service users to live autonomous lives that realise
their rights. In practice, laws and regulations can sometimes make deliver-
ing person-centred services more difficult. In this section, think about how
your organisation relates to the laws and regulations in your state and re-
gion, and the best way you can deliver person-centred services in your con-
text.

Regulations

- Our organisation feels supported by our state/region to use personal
  budgets
- The regulations/protocols that our organisation complies with allow
  us to provide person-centred services
  - Regulations allow and support our service users to access main-
    stream employment
  - Regulations make the public sphere accessible to people with
    disabilities
  - Regulations make housing accessible to people with disabilities
- The regulations in our state would need to change to help us to imple-
  ment or imporve personal budgets
- Regulations in our state/region give service users access to personal
  budgets
- Regulations in our state/region give service users control over their
  services and supports

Advice: It is true that service organisations cannot unilaterally determine what services they provide and how they provide them. Most organisations operate under strict regulations, and these regulations may not always be designed with human rights or person-centred services at the forefront. It's also true that many public authorities have not yet introduced legislation that would support or allow organisations to move to a personal budgets model. The questions here are designed to help your organisation think about the regulations you comply with, and what changes would help you to better implement person-centred services and personal budgets.

UN CRPD

- The management of our organisation is knowledgeable about the UN CRPD
- Our organisation incorporates the UN CRPD into our overall vison
- Our organisation incorporates the principles of the UN CRPD into our processes
- Our organisation has taken clear steps to incorporate the principles of the UN CRPD into our work
- There is a clear plan to continue to work to make sure our organisation respects the rights laid out in the UN CRPD

Advice: As much as possible, within their regulatory framework, service organisations should work to fulfil the rights in the UN CRPD for their service users. Person-centred services can be an important element of implementing the UN CRPD. Since the ultimate goal of any work on the UN CRPD is to improve the human right of people with disabilities, it's important to keep in mind any work on the UN CRPD that is taking place in your state or region. It's also important to work on incorporating the principles of the UN CRPD into the work of your own organisation.

Contracts

- Our organisation contracts with:
  - the state or region
  - service users
  - someone else
- Our organisation sees benefits to contracting with service users
- Our organisation would be in favour of changes to allow us to contract with service users

Advice: Under many personal budgets systems, service organisations contract with service users, rather than the state. This gives service users more power over the services they receive. As discussed elsewhere in this tool, it also can mean significant changes for service organisations. Reflecting on these changes can help prepare a service organisation for a new contracting model that give more power to service users.

4. Providing support services

The questions in this section relate to how you run your service. Ideally, a person-centred service is run with meeting the needs and wants of service users as the primary goal. It is true that a service provider might have to consider the views of a number of people, including public authorities, families, and the people that it serves. A service provider might also find that regulations that it has to comply with interfere with delivering a service that its service users want. But the goal of any service should be meeting the needs and desires of its users. While answering these questions, in addition to thinking about changes you can make, think about ways that regulations, legislation, funding, and other factors can interfere with providing the best service for your users, and think about what would need to change for you to provide the best service.

Partnerships

- Our organisation works with other service providers for disability in our area
- Our organisation supports service users to make use of mainstream, specialised health services
- Our organisation works with mainstream services, (focused on the general public) in our area
- Cooperation among service providers in our area could be improved
- Our organisation supports service users to receive services from multiple service providers

Advice: Under a personal budget system, service organisations often need to be more flexible. Service users may want to obtain services from a number of different organisations. Therefore, it is important that organisations learn to work together to offer services between organisation that are still joined-up and support the individual to move between organisations. Even if you are not currently implementing personal budgets, working with other organisations can help your organisation to deliver a more flexible service, and prepare your organisation for the implementation of personal budgets.

Personal Budget Information

- Our organisation informs service users about their personal budget finances and the possibilities of their personal budget
- Our organisation explains to service users what a personal budget is, in a way that is clearly understood and useful to service users

Advice: Personal budgets are an important way to help service users take more control over their services. With a personal budget, money is given to

the service user, rather than the organisation, and the service user can choose to purchase the supports that are most useful to them. Service providers should support service users to spend their personal budget in a way that best supports the service user, rather than the organisation. Organisations should encourage service users to have as much knowledge and take as much control of their budgets as the service user would like to have.

Support for Personal Budgets

- Our organisation supports service users to use their personal budget
- Our organisation feels that service users are satisfied with the support they receive from our organisation to use their personal budget
- Service users sometimes request support with their personal budget that our organisation has not been able to provide

Advice: Service users may need and want support to use their personal budget. Your organisation should be prepared to offer this support. This is another case where supports should be responsive to the needs and desires of service users. Service users may need different kinds of support, and it's important that they are satisfied with the support they receive.

Voice in Supports

- Our organisation does a good job incorporating the voice of the service user and their support network into their care and support plan
- It is easy for a service user to change their support plan

Advice: As discussed previously, services should be tailored to the needs of each individual service user. For this reason, each service user should have a care and support plan with your organisation, setting out what their supports and goals are. The service users should direct as much as possible the creation of their service plan, as it should reflect their needs and desires for

their lives. As a person's life changes, the support plan should also change, to reflect their current needs and desires. Service users with a personal budget are likely to choose a service organisation that is responsive, and gives them a voice in their services.

Addressing Needs

- Our organisation tries to identify the individual needs of our service users
- Our organisation addresses the individual needs of each service user
- Our organisation uses these methods to help to identify the needs of service users:
- Individual interviews
- Questionnaires
- Group interviews
- Our organisation's users' council

Advice: To be person-centred, services should be tailored to each service user's needs and desires. Finding ways to identify these needs, and address them, is an important part of helping a service user to live a more autonomous and self-directed life. When people have access to personal budgets, they are likely to choose services that cater to their needs, and help them to live the life that they want.

Quality of Life and Satisfaction with Services

[Note: It is important to remember that while both measures are important, quality of life is a better measure of good service delivery than satisfaction. It is possible for service users to feel satisfied with services that still delivery a poor quality of life, because, for instance, they lack the basis for comparison]

- Our organisation tracks the satisfaction of service users with the services we provide
- Our organisation tracks the quality of life of your service users
- Our organisation gathers data on the satisfaction of our service users
    - Our organisation acts on this data
- Our organisation gathers data on the quality of life of our service users
    - Our organisation acts on this information
- Our organisation does a good job addressing issues around the satisfaction and quality of life of our service users

Advice: Service users should receive supports that they are satisfied with, and that improve their quality of life. The goal of service delivery should be to help people to lead the life they want to live, and satisfaction and quality of life are two ways to measure whether this goal is being achieved. This is also important when thinking about personal budgets. As service users have more power to choose their services, they are much more likely to choose and stay with services that satisfy them and improve their quality of life. It is important to remember that while both measures are important, quality of life is a better measure of good service delivery than satisfaction. It is possible for service users to feel satisfied with services that still delivery a poor quality of life, because, for instance, they lack the basis for comparison.

Safeguarding Service Users

- Our organisation safeguards service users, while allowing them to continue to make decisions and live independent lives
- Our organisation helps services users to understand what abuse is, and how they can report any abuse or mistreatment
- Our organisation helps service users to understand that they should be treated respectfully and with dignity by everyone

Advice: It is of course important to protect marginalised people, such as people with disabilities, from abuse and exploitation. The UN CRPD includes this obligation, in articles 15 and 16. At the same time, it is important not to use the idea of protection to prevent people with disabilities from living their lives out in the community. Organisations must therefore find ways to protect their service users from abuse, while not putting restrictions on their service users. One way to accomplish this is to ensure that service users know how to identify and report any abuse, and feel able to advocate for themselves. In the context of personalised budgets, service users are likely to want a service that both makes them feel safe, but also support them to live an independent life in the community.

Vulnerable Service Users

- Our organisation does a good job supporting service users who cannot easily communicate their needs and desires
- Our organisation does a good job supporting service users who do not have a support network outside of our organisation
- Our organisation has a plan to help those with no support network in the community e.g. no family or friends outside of the organisation
- Our organisation has a system to support service users with severe intellectual disabilities, who may have difficulty or be unable to communicate desires and needs
  - Our organisation ensures that these service users are treated with dignity

Advice: Ideally, service users are supported both within the organisation and outside of it by a network of supporters, which includes friends and family in the community. Some service users, however, have no support network, and are entirely reliant on the service provider. These service users should still receive the same level of care and support, to hopefully make

new connections in the community. Some service users may find it more difficult to communicate their needs and desires, and to advocate for themselves. These service users should be supported to find ways to communicate, and their needs and wants should still be at the centre of the service they are receiving.

Safety

- Service users have control over the safety standards that govern their lives
- Parents, family and guardians and other members of our service users support network are involved in setting the safety standards for service users
- Our organisation has a plan that supports both the physical and mental health of our service users
- Our organisation has a process to balance the safety of our service users with their autonomy
- Service users can personalise their safety and health standards

Advice: Different people prefer different levels of protection. Some service users may want to be more protected by their service provider, and their support plan should reflect this. Service users who are comfortable with less protection should be allowed to decide that they want less protection, just as people not supported by a service organisation live more or less protected lives. Of course, there are regulations that set a base level of protection for anyone supported by a service organisation. In the context of personalised budgets, service users should be able to demand the ability to take greater risk if they want to.

Assistive Technology

- Assistive Technology is used in our services

- Our organisation provides service users with access to assistive technology
- Service users are interested in access to assistive technology
- Our organisation supports service users to access technology that can help them be more independent

Advice: Assistive technology is a broad category, and can cover anything from a laptop stand to hold a laptop at a comfortable height and angle for the user, to hoists, to complex computers that help a person communicate. Any device that helps a person to function more independently. Assistive technology can be an important tool to allow people to live more independently. It is very popular among people with disabilities. Service users looking for an organisation are likely to prefer one that can offer assistive technology that will improve their lives.

5. Workforce

This section of the tool relates to the staff at your organisation. Staff should have the knowledge and training to deliver the best services possible. They should understand the rights of service users, and how to deliver a person-centred service.

Knowledge of Personal Budgets

- Our staff are knowledgeable about person-centred services This includes:
  - Care staff
  - Administrative staff
  - Management
  - Volunteers

- Our staff are knowledgeable about personal budgets
- Our staff of knowledgeable about the UN CRPD and the rights it contains
- Our staff are trained to apply the UN CRPD to their work in the organisation
- Our staff are taught to think and act with the principles of the UN CRPD in mind
- Any volunteers who work with our organisation are also aware of the UN CRPD, and have been trained to work with its principles in mind
- Our staff are trained in providing person-centred services
- Service users are involved in directing their own services and supports
- Our organisation consults service users on our services
  - Our organisation changes services based on these consultations
  - Our organisation would you be open engaging more with our service users

Advice: One of the goals of personal budgets is to give service users more control over the services they receive. This in turn gives service users more control over their lives. An inclusive service, that involves service users in decisions about the organisation, and responds to their feedback, is another way to give service users this kind of control. Whether you are currently using personal budgets or not, you can still create an inclusive and responsive environment for service users at your organisation.

Regardless of whether personal budgets are currently an option in your state or region, it is useful for your staff to know about them. It is also useful for you staff to be aware of the UN CRPD, and to be trained in applying its principles. Your service users may have heard of personal budgets, and might want to know more about them. Your organisation also may want to advocate for personal budgets. The same is true of person-centred services.

Even if you are currently unable to deliver fully person-centred services, knowing about the concepts could help to improve the services you currently deliver. It's important to ensure that your services are as person-centred as possible, and that your organisation understands what policy changes are required to improve services.

Who Supports Service Users

- Service users get to decide which staff members provide their support
- If service users do not feel comfortable with a particular staff member, they can request support from someone different
- Our organisation assists service users in selecting who supports them
- Our organisation could give service users more control over who supports them

Advice: Previous sections of this tool have discussed the importance of including people with disabilities in their own supports and services. In addition to including people with disabilities in the processes of the organisation and in their own services, service users should also be able to choose who provides their supports. This can include family, friends, and staff members in the organisation who the service user has a rapport with. It is important that everyone involved has a voice in the process. When service users have personal budgets and more control over their services, they are unlikely to stay with a service that gives them little choice in who supports them.

6. Funding

This section focuses on funding for your organisation, and how funding relates to issues around person-centred services and personal budgets.

Funding Changes

- Our organisation receives adequate funding, from personal budgets or other sources, to deliver person-centred services
- Our funding is adequate to allow us to changes services whenever needed
- All available resources are being used efficiently
- Our organisation has changed recently to become more person-centred
- Our organisation has changed recently to incorporate personal budget
    - If yes, these changes had a positive effect on our funding
- We do not currently used personal budgets, but feel that the transition to personal budgets would be more an opportunity for our organisation

Advice: The switch to personal budgets can have an effect on the funding of an organisation. If service users are now paying organisations themselves, rather than the public authorities funding organisations to provide services, then the funding model has changed, and this will affect funding levels. Popular service providers may find that they have more funding, as demand for their services increases among service users, while other may lose funding as service users leave. Other changes can also occur. Reflecting on these changes, and how to prepare for them or cope with them, will help service providers to implement personal budgets.

Annex III – Compliance Assurance Tool template

Introductory Questions

These questions help you clarify who your Long-Term Care and Support (LTCS) system serves and how far your system has developed in offering Personal Budgets.

Does your public authority aim to make personal budgets available to any of these groups?	YES	NO	POSSIBILITY
Adults with physical disabilities			
Adults with sensory disabilities			
Adults with intellectual disabilities			
Older people who need support			
Adults with mental health problems or psychosocial disabilities			
Adults with long-term health conditions			
Children with disabilities or health problems and their families			
Adults with substance dependence			
Families with support needs			
Homeless people			

Development

As discussed in the European Roadmap for User-Centred Funding for Long-Term Care and Support (see p.75) [European roadmap for user-centred funding for Long-Term Care and Support (unicproject.eu)](#) the journey can take time and different questions are relevant depending what stage of the journey you have reached.

Please select the questionnaire most relevant to your needs:

Questionnaire	This is relevant for me
1 - This is for authorities in the **initial experimentation** phase of development who have not yet made a full policy commitment to user-centred funding. This questionnaire will take about 15 minutes to complete.	
2 - This is for authorities with a **policy direction** committed to user-centred funding but who are at an early stage in developing that policy. This questionnaire will take about 30 minutes to complete.	
3 - This is for authorities who already have a user-centred funding system but who want to improve it and **increase the uptake or scope of the system**. This questionnaire will take about 45 minutes to complete.	

Services

These questions are organised to identify the nature of the LTCS services that are currently available and to help public authorities identify strategies for improving the development of Community-based services in line with the UNCRPD.

Current Service System

In your opinion how would you rate the services currently available to the people you support: (using a 0 - 10 scale)

Inclusive

Services exclude people from the community	People are active contributors to community

Local

Services are not local	Support is based in the local community

Empowering

Services have all the power	People control their own lives

Flexible

Services find it very difficult to change	Support is innovative and quick to adapt

USE OF PERSONAL BUDGETS: SHOULD PEOPLE WITH PERSONAL BUDGETS BE ABLE TO USE THEM ON THE FOLLOWING KINDS OF SUPPORT?

ITEM	YES	NO	SOMETIMES
Personal assistance [Support at home and in the community, which may include people employing their own support or paying others to employ staff.]			
Equipment and adaptations [Changes to the home, equipment or anything that make it easier to have a good life.]			
Alternative forms of support [Help from family, friends, neighbours, live-in supporters, or flatmates.]			
Professional support [Therapists, planners, community connectors, job coaches, advocates, trainers, or teachers.]			
Community life [Costs of joining community, transport, holidays, setting up a business, education.]			
Residential services [Group homes, care homes, day centres or residential respite services.]			

Freedom

Each individual should be able to live their own life in their own way. Freedom is a fundamental human right and these questions explore whether the LTCS system is designed to respect and support our right to freedom.

RESPECT FOR FREEEDOM: DO YOU AGREE WITH THE FOLLOWING STATEMENTS?

ITEM	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE OR DISAGREE	AGREE	STRONGLY AGREE	DON'T KNOW
Support is available to help people make decisions.						
People who uses LTCS can choose who helps them make decisions.						
Every effort is made to involve people in decisions about their lives.						
Important information is always available in easy-to-read formats.						

MANAGING PERSONAL BUDGETS: WHICH OF THE FOLLOWING OPTIONS EXIST TO HELP PEOPLE MANAGE THEIR PERSONAL BUDGET?

ITEM	YES	NO	NOT SURE
People can receive their budget as cash and take direct control of their budget.			
A family member can control the budget on the person's behalf.			
The budget can be managed cooperatively by person and a support organisation.			
The budget can be managed by a group set up to support one person.			
The budget can be managed on behalf of the individual by a support organisation.			
The budget can be controlled by the public authority on the person's behalf.			
People can select services without using cash			

EMPOWERMENT: DO YOU AGREE WITH THE FOLLOWING STATEMENTS ABOUT THE ASSESSMENT AND PLANNING PROCESS?

ITEM	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE OR DISAGREE	AGREE	STRONGLY AGREE	DON'T KNOW
People are encouraged to connect with others with experience of LTCS.						
People can easily access independent support with planning and advocacy.						
People are encouraged to develop their own creative support solutions and plan for themselves.						
It is easy for people to change their minds and try new things.						

Do you have any ideas for how the freedom of people who use LTCS could be increased?	

Inclusion

People who use LTCS are entitled to live their lives as equal citizens, able to fully participate in the life of the community. These questions are designed to explore whether the system supports or obstructs inclusion.

SOCIAL VALUES: DO YOU AGREE WITH THE FOLLOWING STATEMENTS?						
ITEM	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE OR DISAGREE	AGREE	STRONGLY AGREE	DON'T KNOW
People who need LTCS are seen as equal and valued citizens.						
People who need LTCS can easily find work and join in recreational activities.						
People who need LTCS are expected to play an active role in the life of the community.						
Society sees spending on LTCS as an investment in citizenship and community.						

INCLUSION AND LTCS: DO YOU AGREE WITH THE FOLLOWING STATEMENTS?						
ITEM	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE OR DISAGREE	AGREE	STRONGLY AGREE	DON'T KNOW
It is easy to get support to help people stay in their own homes.						
Support services are flexible and focus on helping people live at home.						
Family and friends are well supported and their role is respected and valued.						
It is easy to adapt homes and make them safe and accessible.						

COMMUNITY: DO YOU AGREE WITH THE FOLLOWING STATEMENTS?

ITEM	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE OR DISAGREE	AGREE	STRONGLY AGREE	DON'T KNOW
Neighbours are encouraged to support each other.						
People know what to do if someone seems at risk of abuse.						
It is clear how to get professional support in each community.						
Local transport is available and accessible for people who need LTCS.						

Do you have any ideas for how the LTCS system could better support inclusion?	

Rights

The LTCS support system should create a strong framework of rights for people and families in order that people can live their own life as an equal within the community. These questions help evaluate the effectiveness of the legal and administrative system at making those human rights real.

RESPECT FOR HUMAN RIGHTS: DO YOU AGREE WITH THE FOLLOWING STATEMENTS?

ITEM	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE OR DISAGREE	AGREE	STRONGLY AGREE	DON'T KNOW
There are good laws that establish people's right to LTCS.						
Human rights and specifically the UN Convention on the Rights of Persons with Disabilities (UNCRPD) are widely recognised.						
There are independent organisations that help people achieve their rights.						
The complaints process is trusted and effective at resolving problems.						

ACCOUNTABILITY AND LTCS: DO YOU AGREE WITH THE FOLLOWING STATEMENTS?

ITEM	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE OR DISAGREE	AGREE	STRONGLY AGREE	DON'T KNOW
It is clear who is responsible for funding and organising LTCS.						
People can get LTCS before any crisis or family breakdown.						
There is a solid administrative framework underpinning people's right to LTCS.						
People know how to challenge assessments and decisions.						

MEANINGFUL ENTITLEMENTS: DO YOU AGREE WITH THE FOLLOWING STATEMENTS?

ITEM	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE OR DISAGREE	AGREE	STRONGLY AGREE	DON'T KNOW
Personal Budgets provide enough so people can live as active citizens. [sufficiency]						
People are clear how much money is in their Personal Budget. [clarity]						
It is clear how long the entitlement lasts and when any re-assessment will take place. [duration]						
Restrictions on how the Personal Budgets can be used are clear and fair. [rules]						
People are offered different options for managing their Personal Budget. [control]						
People are not expected to share private information unnecessarily. [privacy]						
People are free to live their life like any other citizen. [freedom]						

MEANINGFUL ENTITLEMENTS: DO YOU AGREE WITH THE FOLLOWING STATEMENTS?						
ITEM	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE OR DISAGREE	AGREE	STRONGLY AGREE	DON'T KNOW
People can get help to explore the best way to use their Personal Budget. [support]						
If people move they can take their Personal Budget with them. [portability]						

Do you have any ideas for how best to strengthen the right to LTCS?	

Workforce

The effectiveness of LTCS is based on the skills, values and mutual support provided to all the people who work in it: paid staff, and also people and families. Everybody matters. These questions explore how the LTCS works for all the people who provide support.

WORKING CONDITIONS: DO YOU AGREE WITH THE FOLLOWING STATEMENTS?						
ITEM	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE OR DISAGREE	AGREE	STRONGLY AGREE	DON'T KNOW
Support staff have good and secure incomes.						
It is easy for staff to join trade unions or other collective bodies.						
It is easy for people to recruit their own support staff or personal assistants.						
Families who provide support can maintain a good income.						

PERSONALISING SUPPORT: DO YOU AGREE WITH THE FOLLOWING STATEMENTS?

ITEM	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE OR DISAGREE	AGREE	STRONGLY AGREE	DON'T KNOW
Support is focused on the goals of the person who needs LTCS.						
Help is available for people who want to employ their personal assistants.						
Support organisations typically design support in partnership with people.						
People, families and staff are well connected to others for mutual support.						

VALUING SUPPORT: DO YOU AGREE WITH THE FOLLOWING STATEMENTS?

ITEM	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE OR DISAGREE	AGREE	STRONGLY AGREE	DON'T KNOW
Working in LTCS is valued by wider society.						
Training on inclusion and human rights is widely available.						
People and families using LTCS are treated as experts and as trainers.						
There are effective programmes to recruit and support people in LTCS.						

Do you have any ideas for how to improve the system for support staff, people or families providing support?	

Finance

LTCS depends on a properly funded and well managed system of public finance which creates a strong framework for the realisation of human rights. These questions explore the strengths and weakness of funding for LTCS.

FUNDING FOR LTCS: DO YOU AGREE WITH THE FOLLOWING STATEMENTS?						
ITEM	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE OR DISAGREE	AGREE	STRONGLY AGREE	DON'T KNOW
The general public is aware of the importance of LTCS and committed to supporting it through taxation.						
Funding for LTCS is enough to make sure everyone who needs support gets some support.						
Funding for LTCS is enough to support people to be active and independent citizens.						
People who need LTCS do not face significant means-tests or extra costs in order to receive LTCS.						

FUNDING FOR PERSONAL BUDGETS: DO YOU AGREE WITH THE FOLLOWING STATEMENTS?						
ITEM	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE OR DISAGREE	AGREE	STRONGLY AGREE	DON'T KNOW
Personal budgets are an essential part of the LTCS system.						
All services are treated fairly by the current system.						
It is easy for new services and innovative approaches to emerge.						
People using LTCS are encouraged to innovate and create efficiencies.						

LONG-TERM STRATEGY: DO YOU AGREE WITH THE FOLLOWING STATEMENTS?						
ITEM	**STRONGLY DISAGREE**	**DISAGREE**	**NEITHER AGREE OR DISAGREE**	**AGREE**	**STRONGLY AGREE**	**DON'T KNOW**
There are good monitoring systems to improve how resources are used.						
There is good evidence available on future needs and costs.						
There is a solid long-term plan for funding LTCS.						
The coordination between LTCS and other public services is good.						

Do you have any ideas for how to improve the finances of the LTCS system?	

Policy

Improving LTCS depends on working with the people who use LTCS and the wider community. These questions explore the effectiveness of the current policy-making system.

ADVOCACY AT PRESENT	DOES NOT EXIST	WEAK OR FRAGMENTED	ORGANISED, BUT NOT INVOLVED IN LTCS POLICY	ORGANIZED, SOME INVOLVEMENT IN LTCS POLICY	ORGANISED, CRITICAL PARTNER IN POLICY-MAKING
Adults with physical disabilities					
Adults with sensory disabilities					
Adults with intellectual disabilities					
Older people who need support					
Adults with mental health problems or psychosocial disabilities					
Adults with long-term health conditions					
Children with disabilities or health problems and their families					
Adults with substance dependence					
Families with support needs					
Homeless people					

STRENGTHENING ADVOCACY: DO YOU AGREE WITH THE FOLLOWING STATEMENTS?

ITEM	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE OR DISAGREE	AGREE	STRONGLY AGREE	DON'T KNOW
It is easy to find self-advocacy groups for people using LTCS.						
Advocacy organisations free to express their views.						
There are effective systems of peer support for people and families.						
There is a fair and effective funding system for independent advocacy.						

POLICY DEVELOPMENT: DO YOU AGREE WITH THE FOLLOWING STATEMENTS?

ITEM	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE OR DISAGREE	AGREE	STRONGLY AGREE	DON'T KNOW
People with LTCS are involved in policy-making.						
Advocacy groups make a significant active contribution to policy.						
There is a commitment to ongoing research and innovation in LTCS.						
Policy-making is open and subject to challenge and debate.						

What could be done to improve decision-making about LTCS policy?	

System Change

In order to develop a strategy for improving LTCS policy you need to think about the forces that currently drive change and how LTCS needs to evolve in the future.

FORCES FOR CHANGE: SELECT THE 5 FACTORS THAT SEEM MOST POWERFUL TO YOU FROM THIS LIST:	
	European guidance on best practice
	Responding to institutional abuse scandals
	Independent Living as a goal
	Community inclusion as a goal
	Compliance with UN Convention on Rights of Persons with Disabilities (UNCRPD)
	Deinstitutionalisation strategies
	Terms and conditions for professional staff
	Policy responses to COVID-19, or other post-disaster reconstruction efforts
	Organisations representing service providers
	Disability advocacy organisations
	Family advocacy organisations
	Personal interest of politicians
	Private financial interests
	Pressure to increase access to LTCS
	Desire to reduce burden cost of LTCS on people and families
	Desire to reduce cost of LTCS to taxpayers
	Pressure to improve the quality of LTCS
	Responding to crises in the community
	Increasing the supply of LTCS staff
	Reducing waiting lists for LTCS
	Momentum of current policies already being pursued

References

General

Duffy, S. (2020). Challenges-responsive Guidelines: European roadmap for user-centred funding for Long-Term Care and Support. UNIC-towards user-centred funding models for long-term care. Consulted on 23 November 2021 from https://www.unicproject.eu/wp-content/uploads/2021/09/2.2-Challenges-responsive-guidelines.pdf

Quality Monitoring Tool

EASPD (2021) Innovative Frameworks measuring the quality of services for persons with Disabilities. Available here

Ferraina Sabrina. The United Nations Convention on the Rights of Persons with Disabilities and the European legal context. Available at https://dlot.eu/

Gómez L., Asunción Monsalve A., Morán L., Alcedo A., Lombardi M., Schalock R. (2020) Measurable Indicators of CRPD for People with Intellectual and Developmental Disabilities within the Quality of Life Framework. International Journal of Environmental Research and Public Health.

Houseworth J., Roger J. Stancliffe R., Renáta Tichá R. (2019) Examining the National Core Indicators' Potential to Monitor Rights of People With Intellectual and Developmental Disabilities According to the CRPD. International Association for the Scientific Study of Intellectual and Developmental Disabilities and Wiley Periodicals, Inc.

Lombardi, M.; Vandenbussche, H.; Claes, C.; Schalock, R.L.; De Maeyer, J.; Vandevelde, S. (2019) The concept of quality of life as framework for implementing the UNCRPD. J. Policy Pract. Intellect. Disabil.

McEwen Jade, Bigby Christine, Douglas Jacinta (2020) Moving on from Quality Assurance: Exploring Systems that Measure both Process and Personal Outcomes in Disability Services. International Association for the Scientific Study of Intellectual and Developmental Disabilities and Wiley Periodicals, Inc.

National Disability Authority (2012). The Transition to Personal Budgets for People with Disabilities: A Review of Practice in Specified Jurisdictions: A National Disability Authority Working Paper. Available here

National Core Indicators: https://www.nationalcoreindicators.org/

Schalock, R. L., Brown, I., Brown, R., Cummins, R. A., Felce, D., Matikka, L., Keith, K. D. & Parmenter, T. (2002). Conceptualization, Measurement, and Application of Quality of Life for Persons with Intellectual Disabilities: Report of an International Panel of Experts. Mental Retardation, 40(6): 457–470. DOI: 10.1352/0047-6765(2002)040<0457: CMAAOQ>2.0.CO;2

Schalock, R., Keith, K., Verdugo, M., & Gómez, L. (2011). Quality of Life Model Development and Use in the Field of Intellectual Disability. In Ralph Kober (Ed.) Enhancing the Quality of Life of People with Intellectual Disabilities (pp.17-32). Springer. DOI:10.1007/978-90-481-9650-0_2

Shogren KA, Luckasson R, Schalock RL. (2020) Using a Multidimensional Model to Analyze Context and Enhance Personal Outcomes. Intellect Dev Disabil. 58(2):95-110. doi: 10.1352/1934-9556-58.2.95. PMID: 32240045.

United Nations. Convention for Rights of Persons with Disabilities. Available here

Vedugo M., Gomez L., Martinez B., Dominguez M., Herrero D., Cuadrado J. (2013) INICO-FEAPS Scale, Comprehensive Quality of Life Assessment of people with Intellectual or Developmental Disabilities. The University Institute on Community Integration. Available here

Vedugo M., Gomez L., Reinders H. (2015) Moving Us Toward a Theory of Individual Quality of Life on the American Journal on Intellectual and Developmental Disabilities.

Verdugo, M.A.; Navas, P.; Gómez, L.E.; Schalock, R.L. (2012) The concept of quality of Life and its role in enhancing human rights in the field of intellectual disability. J. Intellect. Disabil. Res.

Service Delivery Tool

Compliance Assurance Tool

Common European Guidelines produced by European Expert Group on the Transition from Institutional to Community-based Care (2012).

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.

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UNIC Toolbox

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