UNIC

**TOWARDS USER-CENTRED
FUNDING MODELS
FOR LONG TERM CARE**

EUROPEAN ROADMAP
FOR USER-CENTRED FUNDING
FOR LONG-TERM CARE AND SUPPORT

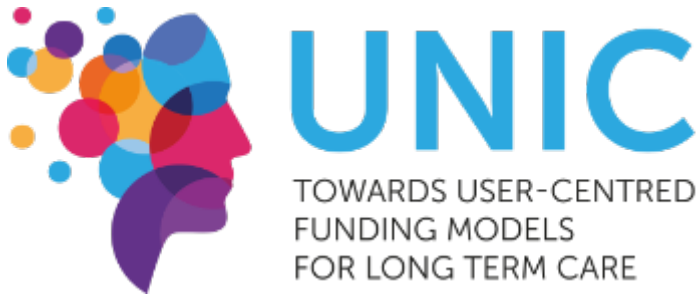## CHALLENGES-RESPONSIVE GUIDELINES

2021

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FOR USER-CENTRED FUNDING
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Challenges-responsive Guidelines

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Challenges-responsive Guidelines:
European roadmap for user-centred funding for Long-Term Care and Support

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Preface

This report was developed by the author with the support of the whole team at UNIC and with comments and suggestions by the independent Advisory Board. The report describes best practice in the emerging innovation of Personal Budgets and draws upon a wide variety of research and experience, particularly from outside the European Union. There is still much to learn and the report does not aim to define or dictate good practice. However we hope that this synthesis of the lessons from the implementation of Personal Budgets will provide a good road map for the future. Like all maps it cannot substitute for the thoughtful implementation of Personal Budgets in partnership with the people who need Long Term Care and Support. Local context, opportunities and needs will always be important. But we hope it offers a framework that will help public authorities make the most of the opportunity to genuinely respect human rights in the development of future reforms.

Dr Simon John Duffy

Executive Summary

The system for funding Long Term Care and Support (LTCS) needs to move from a service-centred model towards a user-centred model, and it is likely that Personal Budgets 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.

There are several reasons to move towards a user-centred funding model for LTCS:

- **Human rights** - The UN Convention on the Rights of Persons with Disabilities (UN CRPD) affirms that all people should be free, equal and full participants in their community. However, current funding models tend to limit freedom of choice and often promote the provision of services that are not in line with the principles of the UN CRPD.

- **Inclusive communities** - There is a still a powerful legacy of institutional services that leave too many people segregated from community life. In order to create inclusive communities, it is necessary to give people who need support the ability to develop community-based solutions that enable them to live independently and participate equally in the life of the community.

- **Coproduction** - Too often systems and services do not respect the experiences and aspirations of the people who use them, and people have too little power to bring about the changes they need at an individual or a community level. People who need support must be central partners in developing, managing and evaluating any LTCS system.

There are also good reasons to believe that systems like Personal Budgets can help public authorities tackle the four policy challenges for LTCS:

1. **Access and affordability** - Many people who need LTCS are not getting the support they need or are forced to bear an unfair level of the cost; too often LTCS is means-tested or rationed by waiting lists. Personal Budgets can be a tool for creating a fairer and better-funded system, with stronger public support.

2. **Sustainability** - States are uncertain how to make investment in LTCS efficient and effective, and this weakens the legitimacy and sustainability of LTCS. Personal Budgets can help public authorities create a better balance between investing in professional, community and family support, and help move resources directly to where they have the most benefit.

3. **Workforce** - There is a growing challenge to recruit staff into the field of LTCS and to provide them with good incomes, training and opportunities for development and professional growth. Personal Budgets can support the creation of new roles and better forms of support with increased job satisfaction.

4. **Quality** - There are continuing problems of abuse, institutionalisation and poor standards, and people who need support often lack the power to challenge poor practices or develop new support options. Personal Budgets are a tool for increasing accountability to the people who need support; Personal Budgets can reduce the risk of poor practice, raise standards and increase the level of innovation across the LTCS system.

The use of Personal Budgets is not a fundamentally new approach. The movement towards user-centred funding began over 50 years ago, led by the Independent Living Movement. Over time this approach has been

extended to include older people, people with intellectual disabilities, people with mental health problems and is increasingly welcomed by professional groups wanting to work in partnership with people with disabilities. However, progress has been slow and patchy. The majority of funding for LTCS continues to be service-centred, not user-centred. Some people are allowed some control over their own support, but many others do not benefit from a suitable system. Moreover, even when systems appear to offer people some control, it is often the case that the actual implementation of the system severely limits the degree of control actually available. An institutional and paternalistic culture can undermine the purpose of the system and holds back the advance of citizenship and Inclusion.

It is time to increase the pace of reform, to increase the scope of user-centred funding and to create a culture where people who need support are valued, in control of their own lives and included in community as full and equal citizens. Personal Budgets are an important tool for the

development of a more coherent and universal approach to reform, where everyone who needs support has a clear entitlement to a budget and where decisions about it are made as close to the person as possible.

As it stands each state has a different starting point. Many states have developed systems of personal assistance to support Independent Living for people with physical disabilities. However, many other groups would benefit from user-centred funding systems like Personal Budgets, for example:

- 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 others

States will need to assess their own stage of development. The process of implementing Personal Budgets takes time, and there is a natural logic to the development of good practice, in line with the diffusion of innovation:

1. **Initial experimentation** - Make it possible for people to test Personal Budgets with pilots and new permissions;

2. **Policy direction** - Encourage the use of Personal Budgets with guidance, training, research and information;

3. **Increase uptake** - Ensure the Personal Budget system is easy to use and that it is adapted to enable more people to take advantage of it;

4. **Complete transformation** - Define a suitable strategy to manage the transition and replace the old system with the new Personal Budgets system.

Extending the scope of Personal Budgets and growing the level of implementation is not merely an administrative or technical task. It is a social process that must be coproduced with the people and groups who use the system. Only they can provide the leadership necessary to bring about the necessary changes.

At the heart of the change must be people who need LTCS, and their allies, particularly families. It is important that public authorities identify and support a community of people with real lived experience of disability and support who will work with them to help reshape policy and practice. In addition, there are support providers who are innovating and working in partnership with people who need support to advance Inclusion. There is also a critical role for public authorities, administrators, social workers and others who play a role in funding and coordinating resources. Working together, using the synergy between these groups, it is possible to create the new models of practice and systems that will inform wider changes.

A system of Personal Budgets also requires reform at three different levels:

- **Micro-level** - Decisions by the person who needs support, informed by the immediate opportunities, supports and constraints created by the funding system;

- **Meso-level** - The system of local services, supports, collective organisation and coordination that shapes the context for people and communities;

- **Macro-level** - The laws, policy, financial systems and advocacy structures that provide the over-arching structure for communities and citizens.

Personal Budgets require appropriate systems at every one of these three levels, and we can distinguish twelve essential components for any Personal Budget system, distributed across these three levels. Although there are many open debates on matters of details the available research reinforces the importance of all these components to any Personal Budgets system:

1. **Clear entitlements** - An appropriate assessment of needs should identify a Personal Budget that is sufficient to enable a person to live a life of citizenship in accordance with the principles of human rights and Independent Living. Budgets, and any rules about defining or changing them, should be clear and fair.

2. **Budgetary control** - In order to exercise control over the Personal Budget and put it to good use the person must have the necessary authority and support to be able to make informed choices, try different options and change their mind. In practice this requires that the principles of Supported Decision-Making be followed to establish a decision-making process in partnership with the person. Many

different kinds of support may be necessary to enable someone to plan and organise their support.

3. **Flexible support** - There needs to be a full range of management and support options available so that everyone can manage their budget in the way that works best for them, whatever their support needs or available networks. Together, with any necessary support, the person is in the best position to identify the best support solution, change their support as necessary and combine formal and informal support.

4. **Focus on Inclusion** - The purpose of the system should be to enable people to live meaningful lives, as active and connected citizens, whatever their impairment, illness or disability. Budgets, Support Plans and support will need to be reviewed in the light of the real outcomes people are achieving.

5. **Personalised support** - People seek support that fits around their lives and relationships. Many people will want to select their own Personal Assistant, and some may choose to also employ their own

workers. Others will choose support from support organisations that are linked to their community or who offer the most appropriate skills and opportunities. Communities will want to nurture support options that keep resources and knowledge as local as possible.

6. **Peer support** - People and families grow in self-confidence, raise their expectations and find a powerful source of practical and emotional support when they come together with their peers. Peer support does not just provide value to peers; often peers become active in improving their communities, supporting those who are at risk of exclusion and encouraging self-advocacy. Peer support should be treated as an essential component of community life.

7. **Community-based support** - Families and communities provide much of the support people need. When resources can be used flexibly, they can strengthen family support, enable investment in community solutions. Personal Budgets are leading to new community businesses, micro-enterprises and new cooperative support solutions.

8. **Local coordination** - Inclusive communities also need to be organised to ensure that everyone is connected, safe from harm and supported to be an active member of the community. This takes strategic action and coordination, both to identify people who need support and to

promote community connections and neighbourhood power.

9. **Workforce development** - The introduction of Personal Budgets involves the use of a range of new skills for people, families and professionals. However, more fundamentally, it is also an opportunity to create a culture for LTCS based on human rights, Inclusion and respect for diversity.

10. **Delivery system for Personal Budgets** - A user-centred funding model will ensure that the person who needs support, their allies and the local community maintain the necessary authority for key decisions. However, an over-arching system architecture for delivering Personal Budgets is also necessary. There should be no need for unduly complex local systems for Assessment, Resource Allocation or the delivery of funding; ideally the system should be as simple and efficient with as wide a coverage as possible.

11. **Protection and advocacy** - As states design their user-centred funding model for LTCS they will need to ensure that this is defined in appropriate laws. Alongside these laws there must be systems of protection and advocacy that ensure that people can get support to advocate for and defend their rights.

12. **New funding settlement** - People who need LTCS have a right to that support and in general universal rights, backed by the community, are the most likely to achieve sustainable popular support. Funding should be sufficient to meet the individual's needs and to support their Inclusion and participation in the community and this will only be achieved with the necessary democratic support.

It is important to recognise that Personal Budgets go beyond the individualisation of funding. Personal Budgets combine individualised funding with a shift in power to the person and meaningful opportunities

for flexibility and the personalisation of support. However, reform is not only required at the individual level. It is the community that creates opportunities for Inclusion and citizenship. Some communities offer a welcoming and accessible place where people can take up valued roles and make a meaningful contribution to the life of the community; but many communities do not. Social isolation, prejudice and low expectations can also limit the person's ability to realise their potential and live a good life.

It is also important to recognise and respect the plurality and complexity of our communities. Neighbourhoods, towns, cities and regions all provide multiple resources of identity and opportunities for Inclusion. There will be no one single model or structure that can simply be replicated in every community. It is better to build on the unique strengths of communities and to establish solutions with deep local roots.

Beyond the local community it is also essential that there are educational, economic, legal and administrative structures to make a formal commitment to human rights a practical reality. Different states may devolve some of these relevant powers and responsibilities to sub-national structures, but ultimately these measures reflect universal human rights obligations and there must be a responsibility at the level of the nation state for their realisation in accordance with the principle of subsidiarity.

The additional challenge for policymakers is to maintain vision, integrity and momentum over the long-term as these new funding models and innovations are developed. There is an inevitable tension between rapid systemic change and meaningful embedded change in culture and understanding. Changes in legal or financial systems often do not lead to the desired change; instead, these changes need to be combined with changes in values, priorities and expectations:

- **Transparency and accountability** - Policymakers need to ensure that they continue to work in partnership with people who need support, sharing data, maintaining research and having open discussions on key policy matters.

- **Vision of Inclusion** - The purpose of user-centred funding is to respect human rights and create inclusive communities where everyone can live as an equal citizen. It is important to keep this goal in mind and to ensure that reforms are measured against this objective, rather than narrower or older standards.

- **Peer networks** - Personal budget systems have been evolving in Europe and globally and the pace of change seems to be increasing. There is much to be gained by networking across Europe to share lessons on good practice and innovation. Peer support for policymakers can increase confidence in making the necessary changes.

The UNIC Project is a good example of a pan-European project that aims to develop models that can be tested, shared and improved. The UNIC toolkit which builds on this guide will help public authorities evaluate their own approaches, set new goals and work to advance human rights and deinstitutionalisation. It is only if policymakers work in partnership with people with disabilities, families, professionals and the wider community that we will be able to face the serious LTCS challenges ahead of us. Working together, across all the communities of Europe, will create the necessary capacity to face these challenges with confidence.

Glossary

Even in one language the terminology used to describe elements of user-centred funding models can be complex and confusing. In the available literature the same term can be defined in conflicting ways. This glossary does not aim to capture every past usage; instead, it aims to offer a clear definition for future use.

Assessment - A system by which the state determines what people need in order to achieve Independent Living.

Centre for Independent Living (CIL) - An organisation, usually controlled by people with disabilities, organised to provide a range of advice and services to help people achieve Independent Living.

Commissioned Service - A service that public authorities fund on behalf of the person who needs support. Personal Budgets can be used for Commissioned Services.

Community-Based Support (CBS) - A support service that exists to support Independent Living and advance the person's citizenship in community.

Family Leadership - Support for families to learn about human rights and the principle of Independent Living and to practice skills in advocacy and mutual support to promote the best interests of their children and to act as strong allies with adult family members.

Funding Flexibility - The principle that the person, with support where necessary, is in the best position to determine how their Personal Budget should be used and so should be free to use it as they see fit.

Inclusion - The idea that communities should welcome and support all their members, respecting and valuing differences and working together to ensure everyone can make their own unique contribution.

Independent Living (IL) - The principle that people who need support should retain the right to live with freedom in the community, with the same rights as other citizens.

Individualised Funding (IF) - Funding for support that has been individualised and linked to a named individual. There is no implication that the funding is controlled by the person.

Individual Service Fund (ISF) - A Personal Budget managed by an intermediary person or organisation on behalf of the person.

Local Area Coordination (LAC) - A system where a person works within a neighbourhood to ensure that people at risk of isolation or harm are connected into the life of the community.

Long-Term Care and Support (LTCS) - Support that 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.

Microboard - A small organisation set up to manage support just for one person, but often organised into a network of Microboards.

Peer Support - Mutual help provided by people and families who also need assistance, use services or share common experiences.

Personal Assistance (Scheme) - A system set up to enable people who need support to recruit and manage Personal Assistants.

Personal Assistant (PA) - A person specifically chosen and employed by the person who needs support for Independent Living.

Personal Budget (PB) - Individualised Funding which is (a) transparent to the person (b) which can be managed directly or with assistance and (c) which can be used flexibly.

Personalised Support (PS) - Support that is organised to be flexible and under the control of the person.

Support Plan - A description of how the person chooses to organise their own support to ensure their own preferred lifestyle.

Resource Allocation System (RAS) - The rules which determine how to fairly determine the level and timing of any Personal Budget.

Self-Advocacy - The capacity to speak up for oneself, which can be enhanced with good support, particularly peer support.

Self-Directed Support (SDS) - A total system of funding, decision-making, advocacy and practical support designed to ensure all people who need support can direct that support.

Self-Managed Fund (SMF) - A Personal Budget controlled directly by the person.

Shared Management - A flexible partnership between a person and a community organisation to share responsibility in the management of support.

Supported Decision Making (SDM) - A system established to ensure that the people who need help making decisions can have access and enjoy support to take their own decisions and maximise their control over their lives.

Vouchers - A system where people are given tokens that they can use to request a variety of pre-defined support services.

Introduction

The UNIC Project aims to support public authorities to develop user-centred models of funding for Long Term Care and Support (LTCS). Long-Term Care and Support (LTCS) is a broad term that includes the many different forms of support that enable a person to live a good life, as a valued citizen. It is important to note that, for our purposes, the term includes children, adults and older people who need LTCS. It also includes people who need support for any number of different reasons and is not limited to people with particular disabilities, diagnoses, conditions, impairments or other factors. In this guidance we refer to people who need LTCS either as people who need support or, where there is no risk of ambiguity, just as people.

In particular, the project aims to help public authorities understand and visualise the potential advantages of using Personal Budgets. A Personal Budget is an entitlement to money that is clear, which the person can control (with support, if necessary) and which can be used flexibly to meet the person's needs. This approach is increasingly being used to help move LTCS away from a service-centred approach and towards a user-centred approach, where support fits around the person and where the person is enabled to live independently and maximise their participation in community life.

There are many potential benefits to using Personal Budgets, and many of these have been reinforced by the experience of the COVID-19 pandemic where people and families were able to cope much better when resources could be used flexibly and decisions could be made by the person, with their supporters and allies. It also seems likely that Personal Budgets could play an important part in helping public authorities tackle the four major challenges facing LTCS today:

1. **Access and affordability** - To enable more people to benefit from LTCS and to share the costs of support more fairly.

2. **Sustainability** - To create an efficient and effective system of LTCS that is widely valued and gets democratic support from public.

3. **Workforce** - To make work in LTCS more attractive and to ensure that there is a sufficient number of people willing to work in LTCS.

4.   **Quality** - To improve the standard of LTCS, minimise the risk of abuse and increase innovation and inclusion.

This guide is organised to offer public authorities a framework to design, develop, implement and evaluate Personal Budgets.

- Chapter 1 sets out the case for reform and explains the human rights basis of Personal Budgets.

- Chapter 2 helps public authorities to develop their own strategy for developing Personal Budgets by assessing their current starting point.

- Chapter 3 sets out the components of Personal Budgets at the level of the individual.

- Chapter 4 sets out what is necessary at the community level and

- Chapter 5 describes the over-arching structures necessary.

- Chapter 6 explores how public authorities can maintain and evaluate their own progress.

- Lastly, Chapter 7 shows how the adoption of Personal Budgets can play a critical role in facing the LTCS challenges ahead

- In addition, the report includes a glossary to key terms, which you may also find capitalised throughout the report.

This guidance is offered to all public authorities and will also inform the development of a series of tools that can be used for self-assessment and planning.

Why long-term care and support funding needs reform

Long-term care and support challenges

In the past services gave people no control over their own support and were designed to move people away from their families and communities. Although public authorities are making some progress towards deinstitutionalisation, the models for funding community-based support still rely largely but not exclusively on the old model of providing services. This is one of the reasons why the four challenges for LTCS are so hard to meet:

- **Access and affordability** - Funding models traditionally direct resources largely towards means-tested and institutional type of services. Often people only become eligible for support when family or community support is not available. This encourages crisis rather than prevention of need and tends to undermine family and community support. There is a variety of approaches to social protection for LTCS among Member States, and they differ in regard to the groups of people in need of LTCS that are covered, the types of services and the level of the financial protection that is offered. Access to LTCS can also be limited by a range of other factors (e.g. complex application procedures, non-accessible information on eligibility, strict eligibility criteria), as well as with a lack of awareness of the existence of these services. Research shows that people rely on informal care,

either by choice, or because there are no appropriate services available or because of the cost of using such services (European Commission, 2021).

- **Sustainability** – Traditional funding models are largely targeted towards institutional services and hierarchical systems of power and control, not towards people, families or communities where support is best organised. Although funding models for LTCS vary across Member States that funding is still largely locked into historical commitments to services and systems, even when people might use those resources differently if they could.

- **Workforce** – There is enormous potential for job-creation in LTCS sector. By 2030 there will be the need for an additional 3.2 million jobs for health associate professionals and 3.8 million for personal care workers. (European Commission, 2021) However these jobs are often associated with difficult working conditions and inadequate pay. Without significant reform there will be increased staff shortages and greater reliance on informal care. One of the key elements, further exacerbating staff shortages is the unattractiveness of the sector as a career choice. Support work is often organised around the priorities of the service system and power is often concentrated in hierarchical systems of management. Old service delivery models do not provide the same level of freedom, flexibility and the opportunity to create strong relationships between people who need support and paid staff. There is a close connection between how society values people who need support and how society values people who provide support.

- **Quality** - Quality standards are set by professionals and standardisation, rather than being driven by innovation and the expectation of people who need support. People themselves have little power to challenge or change their own support or define the

priorities of support itself. Still today, most funding for LTCS is not shaped according to the wishes of the people who need support. Additionally, comprehensive and facilitating legal frameworks, adequate funding, and an adequate and well-trained workforce are preconditions for quality, and Member States struggle on most of these fronts.

However, these service-centred funding systems are beginning to change, particularly as people with disabilities and others challenge the old system and work with public authorities to design new systems. The process of developing user-centred funding models began in about 1965 and has now been in progress for over 50 years (Shapiro, 1993). The movement began with the Independent Living movement, led by people with physical disabilities (O'Brien & Duffy, 2009). It was further extended by the inclusion movement, which developed the concept of Self-Directed Support and extended user-centred funding to other groups, particularly people with intellectual disabilities (Duffy, 2018).

Human rights

User-centred funding has also evolved in tandem with a growing awareness of the need to respect the human rights of disabled people. Service-centred funding models face difficulties in offering a flexible enough approach of support, meeting the needs and respecting the wishes and preferences of individuals. The European Union plays a key role in leading the way towards human rights-based approaches. Equality and non-discrimination have been first established through the Treaty on the Functioning of the European Union and the Charter of Fundamental Rights of the European Union, together with the UN Convention on the Rights of Persons with Disabilities, the UN Principles for Older Persons, the UN Convention on the Rights of the Child, the Universal Declaration of Human Rights, the European Convention on Human Rights and the European

Social Charter.

The European Pillar of Social Rights reaffirms under Principle 17, that "People with disabilities have the right to income support that ensures living in dignity, services that enable them to participate in the labour market and in society, and a work environment adapted to their needs." And, under Principle 18, that "Everyone has the right to affordable long-term care services of good quality, in particular home-care and community-based services."

The Strategy for the Rights of Persons with Disabilities 2021-2030 advocates for a Union of Equality, where barriers will be eliminated and people with disabilities will participate in the society on an equality basis with others.

In fact, the key challenge, which this guidance aims to help Member States meet, is to ensure that LTCS is provided in accordance with Principle 17 and 18 of the European Pillar of Social Rights. People with support needs should be supported to lead their life, as they see fit, participate equally in any aspect of community life and Member States shall support their right to citizenship by developing support systems that respect their human rights.

These rights include:

1.   The right to receive support

We all share a human right to all the different forms of support, education, resources, information etc. that make a good human life possible. Sometimes we need significant or regular extra assistance in order to live as a full and equal member of the community:

- Help to live safely at home;

- Help to speak out and express ourselves;

- Help to do the things that matter to us.

If people need a significant level support over an extended period, then they have an entitlement to LTCS, that must be respected by the community and supported by the state.

2.   The right to exercise freedom

We all share a human right to freedom and independence, and this right becomes all the more important when we also need help, because in providing assistance we can easily ignore matters of great importance to the other person. LTCS must be organised so that it respects our right to freedom, and this means creating a system of support which gives the person's control over their life and any necessary supports. For example:

•   To say what we want and express our opinion;

•   To set the direction of our life;

•   To make choices about lifestyle, culture, eating habits or any decisions that matter to us.

This right to freedom extends to people who need support with planning, decision-making or management of support. In accordance with Article 12 of the UNCRPD, all people, no matter any intellectual impairment, must be

recognised as full persons by the law, able to exercise their full legal rights and must therefore be entitled to appropriate support over decision-making itself. Additionally, Article 21 of the UN CRPD, demands that persons with disabilities can exercise their right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others.

3.   The right to contribute to community life

We all share the right to have responsibilities and to exercise our responsibilities as part of creating a better world together. For example:

•   To take care of ourselves and our families;

•   To help our neighbours and to join with others in improving our communities;

•   To vote, run for office, participate in democratic and civic duties.

LTCS must be organised to enable people to contribute, provide support to others and play a full part in the life of the community. People should be able to use their talents, exercise their abilities, follow their interests and build on their relationships to shape a fulfilling and connected life, at every stage of life, including at the end of life.

4.   The right to Independent Living and Inclusion

We all have a human right to inclusion in the life of the community and to be recognised and welcomed as an equal citizen. For example:

•   To be able to choose where to live and with whom;

•   To be able to receive adequate support to lead an independent life;

•   To be able to learn, work and join in community life on the same basis as others;

- To have friends, colleagues, a family and to find love like anyone else;

- To exercise full civic and political rights and to join in the democratic life of the community.

This means that public authorities have a responsibility to ensure that the community is itself accessible, in the fullest sense, to people with disabilities so that they can join and participate in it. The right to Independent Living and Inclusion [UNCRPD Article 19] is the recognition that disability or the need for LTCS does not in any way reduce our universal rights to support, freedom, participation, responsibility or accountability. Instead, the right to Independent Living exists to ensure that the duty to provide support does not provide any reason not to respect our other rights.

Accountability for human rights

We all have a right to live in a community where our rights are clear, where there are publicly acknowledged duties placed on citizens and public bodies to respect those rights and where there are checks and balances to ensure any problems are addressed. For example:

- Systems must exist to protect individual rights;

- Systems must exist to enable collective advocacy;

- Systems must be designed with people who need support as full partners.

This means that the system for LTCS also needs to be designed so that it is transparent and accountable to people who need support. Rights need to be meaningful, guaranteed by law, open systems of administration and protected by systems of advocacy. Ultimately people who need support must play an essential role in helping define, test and oversee any system.

How to begin the process of reform

Each state, region or municipality starts with a different context for introducing Personal Budgets depending on their own legacy and diverse capacities. Some have made progress by developing systems, such as personal assistance schemes to support independent living for people with disabilities. Others have systems of care allowances for people or families (although these are often too small to fund LTCS). Others have created systems of Personal Budgets or Individualised Funding for some groups, while excluding others.

The development of the system will depend upon other important elements, such as:

- Stable and facilitating legal frameworks;

- Sufficient and sustainable funding systems, including health, housing and income security;

- Supported decision-making, information, advocacy and self-advocacy systems;

- Support services based in the community, including personal assistance schemes;

- And an adequately trained support workforce

There will be different approaches in different communities and there is still much to learn. However, there are several key issues that each public authority will have to face in order to develop an appropriate system of user-centred funding for LTCS and Personal Budgets.

Scope of reform

The groups of people who need LTCS and who could benefit from Personal Budgets include:

- 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

Often it is useful for each Member State to begin their first reform efforts on groups who are already calling for reform, where leadership and partnerships are strong. While the goal may be to create one coherent system for all people in need of LTCS, in practice the scope of the reform efforts may need to reflect current priorities. It is possible to build outwards from already developed systems and make these available to other groups, but it will also be necessary to make sure the design of the system is sufficiently flexible that it can work for people with diverse needs.

Stages of reform

The process of introducing Personal Budgets tends to go through a series of stages, in line with the diffusion of innovations (Rogers, 1962). Public authorities may want to speed up the process of reform, but these stages still seem to be necessary to achieve a meaningful reform:

1. **Initial experimentation** - Public authorities need to make it possible for people to experiment with Personal Budgets. This process often generates ideas, practices, leadership communities and generates the data that supports further commitment.

2. **Policy direction** - Public authorities will need to establish Personal Budgets as a policy objective. The uptake of Personal Budgets will increase with guidance, training, research, raising awareness and information about the benefits of Personal Budgets.

3. **Increasing uptake** - Typically early systems of Personal Budgets need to evolve and become easier to manage for professionals and for people needing support as uptake of the system depends on how easily people can benefit from it. Early systems may be too bureaucratic, complex and may place unreasonable responsibilities on people who need support. Ongoing research and innovation is necessary to ensure transformation.

4. **Complete transformation** - Finally public authorities will need to plan suitable transition arrangements to replace service-centred funding system with the new Personal Budgets system.

Different strategies are necessary depending on the current stage of reform, as we will discuss in more detail in Chapter 6.

Levels of reform

The use of Personal Budgets also requires change at three different levels:

1. **Micro-level** - Decisions by the person who needs support, informed by the immediate opportunities, supports and constraints created by the funding system;

2. **Meso-level** - The system of local services, supports, collective organisation and coordination that shapes the context for people and communities;

3. **Macro-level** - The culture, laws, policy, financial systems and advocacy structures that provide the over-arching structures for communities and citizens.

The kinds of reform necessary at each level are explored in Chapters 3, 4 and 5, respectively.

Coproduction of reform

Critically, the process of reforming the LTCS must be carried out in partnership with the people with care and support needs, to define the central problems and to find better solutions together. This means states must:

• Ensure people, along with other key actors, are essential partners in the whole process of specifying outcomes, designing solutions, implementing change and evaluating progress.

• Break out of the silos; listen to the experience of people with care and support needs, families and professionals; create an open environment where people can explore future possibilities together.

- Keep an open mind; explore good practices from around the world and support local initiatives and practices in deinstitutionalisation, inclusion and human rights. Often there is relevant expertise, but it may not be close to policymakers, as innovators tend to be distant from the centre of decision-making.

People who need care and support are the primary actors in this work; it is they who have the primary entitlement to support and who make the decisions that determine the outcomes of the new way of working. They must be free to develop their own lives and must not be forced into relationships of undue dependence on their family or others.

However, families must also be respected. Families are the essential bedrock of support for all citizens. At their best, families provide support motivated by love and seek the wellbeing of their members. Often families provide an additional and important source of advocacy.

It is also important to note that different groups of people who need support may have different levels and types of Self-Advocacy or Family Leadership and in some areas, it may seem undeveloped. It may not be obvious who to include or where to begin to engage with people with care and support needs and families. However, the process of establishing a user-centred funding system is an ideal opportunity to identify new and emerging leaders and must be a priority for action. States must:

- Identify and support people who need support and families to meet together and to be active partners with genuine authority at every stage of the development process.

- Start by focusing on people and families who are eager for change or who are most dissatisfied with the current system as they will provide the most important learning in the early stages.

- Not ignore groups who may seem less eager for change. These groups will help guide work later, as states develop their systems; they will need to make them easier to use and accessible for all groups.

It is also important to remember that coproduction is an inclusive working practice between experts by experience (users), organisations providing support, public authorities and, if relevant, families and other stakeholders. (EASPD, 2016) Often resistance to change is a natural response by people who fear that old certainties are changing and that existing roles are under threat. So, it is important to support professionals and others who want to make the necessary changes and help them establish networks for sharing problems and solutions. This will require both raising awareness campaigns but also training and continuous support towards support workers that will help them with the uptake of their newly formed roles.

Reform at the individual level

Implementing Personal Budgets in practice starts with rethinking the relationship between public authorities and the people who need support. Instead of offering people support, pre-defined by professionals and commissioning processes, Personal Budgets give people the right to make real choices, control their own budget and direct their own support. To create this new system there are four key elements:

- Clear entitlements

- Budgetary control

- Flexible support

- Focus on Inclusion

We will outline each of these elements in more detail below.

Clear entitlements

Personal Budgets means more than just Individualised Funding. A Personal Budget creates a clear entitlement where all the following entitlements are clear:

- **Level** - the amount of funding

- **Regularity** - the frequency of payments

- **Duration** - how long the entitlement lasts and when re-assessment is required

- **Rules** - restrictions on how the money can be spent

- **Control** - options for controlling the budget

- **Support** - help to explore how to use the budget

- **Rights** - processes for assessment, appeal and challenge

Defining a fair Personal Budget depends upon making a suitable Assessment of need and applying some kind of Resource Allocation System (RAS) (Duffy, 2015). Both the Assessment and the RAS must be developed in accordance with the right to Independent Living and Inclusion. This means:

- There are clear rules about how the Assessment process works and accountability for how the rules are implemented.

- The purpose of the Assessment is to ensure that people have the means to achieve citizenship and is not artificially limited to a narrower purpose.

- The process of Assessment empowers the person to act with freedom. The purpose of the Assessment must be to empower the individual with knowledge about their entitlements, information about what is available and connections to others who can provide support and guidance.

- The Assessment must not limit freedom or artificially direct people to certain pre-defined solutions.

- The Assessment needs to be a continuous process and not a one-time event.

There is also some evidence to suggest Personal Budget works best if people are given information about their available budget at an early stage in the process of planning and organising support (Moseley et al. 2003;

Dalrymple & Etherington, 2015). This may be because:

• If budget setting is only done at the end of the planning process the planner will focus on services which they already know are being funded.

• Giving the person a budget to plan within stimulates innovation and allows the person to consider creative support options that build on their interests, relationship and opportunities within the wider community.

• Giving the budget as an entitlement signals greater trust in the person and enables them to actively commit to the process and seek ideas from their own networks.

• And, it allows people to explore different options for disability supports and put them in charge of the process of negotiation with service providers or community organisations.

However, given the nature of LTCS, there is a need to balance two competing considerations:

• It is possible to correlate most people's needs to a reasonably predictable set of budgetary levels that will increase in accordance with needs, and where the higher budget levels will apply to smaller numbers of people.

• Some people's needs are too complex for rapid correlation, and it may be difficult to confidently determine a fair cost for meeting those needs without detailed planning.

On these assumptions it may be useful to provide people with up-front information about an indicative budget level, which can be used to help people develop their own Support Plan. However, if during the planning

process this budget is found to be insufficient (or too large) then the budget can be adjusted (Duffy, 2013a). This may create a good balance between empowering people with helpful information, while reducing the risk that the budget level is inappropriate. However, there is still an open debate as to the best approach (Series, 2014; Duffy, 2015; Dalrymple & Etherington, 2015).

Budgetary control

In order to exercise control over the Personal Budget and put it to good use the person must have the necessary authority and support to be able to make informed choices, try different options and change their mind. It is particularly important that the Assessment process is consistent with the principles of Supported Decision Making (SDM) [UN CRPD Article 12], namely:

- Assume and ensure that the person has capacity to make their own decisions, even if there is good reason to believe they need support and that making their own decisions would put the person (or others) at a significantly increased risk of harm.

- Ensure that there is no general assumption of incapacity; so even if someone needs support in one specific area it does not mean that they need it in every area.

- If someone needs support to make decisions then the person should be able to select who will be their agent for that kind of decision, unless there are reasonable and substantial reasons to question that selection because there is strong evidence that the preferred agent would not act responsibly or a situation of undue influence can occur.

- If someone else must be selected to act as the person's agent, then they must be a suitable person who is able to fulfil the role effectively

and it should be finally approved by the person.

- The role of any agent is to support the person to make decisions. If due to the circumstances, it is not practicable to determine the will and preferences of the individual, then, the agent needs to follow the best interpretation of that person's will, wishes, preferences, values and priorities.

- People retain their right to be fully involved in all the stages of the decision-making process, even if they agree that someone else can support them making the final decision.

- These arrangements must be subject to a reasonable level of review and must not be artificially fixed, as both the capacity of the person or the suitability of the agent can change. This will require states to put in place practical systems to review any SDM agreements.

When people are organising their LTCS with a Personal Budget it is likely that the following kinds of resources will be useful to help people make the best decisions:

- **Support and encouragement** - People may need support to make decisions and providing them with options can be considered a good way to allow people to choose what may fit their needs and aspirations.

- **Information** - People should be provided with information about how they can use their budget, what control options and what community-based supports are available.

- **Peer support** - The best kind of support often comes from people who have shared experiences. People should be connected to other people who can share their experiences. Peer support should be an essential feature of the support architecture.

- **Advocacy and support** - Some people need help to think things through, explore different options and generate new community-based solutions. Skilled independent planners can provide useful support (e.g. some states have developed separate systems for independent planning or support brokerage (Leech, 2015)).

- **Community-Based Support** - People benefit from support provided by services established in the community close their place of living. Ensuring availability and accessibility of community-based services is essential.

- **Rules and processes** - It is essential that people are given clear information about how their budget will be agreed and how it can be challenged if necessary.

This approach to planning assumes that the state must develop a framework of support within which people and families can develop the best solution for their own needs. Training for both people, families and

professions in human rights and person-centred approaches, such as MAPS, PATH, Essential Lifestyle Planning and similar approaches will be very helpful (O'Brien & Mount, 2015; Smull & Harrison, 1996).

There is no reason to believe that one planning system, one professional input or service will be right for everyone. Instead, states should work from the assumption that the process of planning and organising support is subject to the same human rights constraints as the whole process. People should have a combination of rights and responsibilities and be free to develop their own individual approach to find the right solution (Duffy & Fulton, 2010).

It is also important to note that the state needs to ensure that it retains the capacity to organise appropriate support immediately, if a crisis situation emerges. Time for planning is important, but it should not be used to delay offering essential supports. However, any supports organised in emergency situations must be organised so that they can be quickly changed and adapted as the person's needs and goals become clear and evolve. The need to respond quickly in a crisis is no justification for providing institutional services and is more likely to create long-term problems and undue dependency. Crisis support also needs to be flexible and personalised.

Flexible support

The purpose of Personal Budgets is not to replicate the current service system. It is essential that the system gives the person the ability to use their budget flexibly and to use it in ways that are different to the current system. To begin with, people will need to decide how they want their Personal Budget to be managed and there are many possible options:

- **Self-Management** - People take direct control. This is often the model chosen by people with physical disabilities who wish to employ their

own Personal Assistants. However, it is important to remember that people may also use their budget to purchase services or to use their budget in other ways to advance inclusion.

- **Family-led support** - A family member controls the budget. This model is obviously critical for supporting children, but it can also be appropriate for adults where the family is the best agent for the person who needs support.

- **Shared Management** - The budget is managed cooperatively between the person and a support organisation (WAIS, 2012). This model allows people to balance responsibility with additional support.

- **Microboards** - The Personal Budget can be managed by a trust, company or small community group specifically designed to organise support and bring together a community of allies around the person needing support (Chenoweth & Clements, 2010).

- **Individual Service Fund** - The budget is managed by a support organisation, peer support organisation or other agency on behalf of the individual (Watson, 2020). Many people benefit from personalised support that they can direct, but prefer an organisation to employ staff.

- **Commissioned Service** - The Personal Budget is used by the funding agency or relevant public body to fund the services that they will provide to the person. Some people want to continue to access services that are already commissioned, although they may also choose to mix Commissioned Services with other forms of support.

- **Vouchers** - A system where people are given tokens that they can use to request a variety of pre-defined support services (Block et al. 2002). This is a useful way of giving choice over the provider of a very specific

kinds of support as defined by the voucher. Some states are also using pre-paid cards to offer choice within a managed system (Cole, Gilbertson & Reeve, 2016).

As long as the SDM principles are being followed there is no reason to artificially exclude any option for managing a Personal Budget and ensuring that all possible options are available is critical to designing a universal system that works for all people needing LTCS. Also, importantly, whichever system is used, it is necessary that whoever is managing the

Personal Budget should be able to use or navigate between the different options flexibly because they are in the best position to determine how it is used.

Focus on inclusion

Personal Budgets exist to advance the inclusion of people who need support, and they must be evaluated and revised in the light of that goal. This means there must be a framework of checks and balances that can be used to limit a range of different risks. In particular:

•   People need to be able to appeal against any judgements made about
       their needs or competence in the Assessment process or at a later
       stage.

•   Citizens and professionals must be able to alert the state if they are
       concerned that an individual is being abused or is putting themselves
       at undue risk.

•   The state must be able to review whether the public resources it is
       managing and using to generate entitlements or fund services are
       creating the best possible outcomes and advancing citizenship and
       inclusion.

When needs or circumstances change then states or public authorities
must retain the capacity to re-assess a person's needs in a balanced and fair
way and make any necessary changes to the organisation of support.

Personal Budgets are not usually treated as personal income. Their purpose
is to enable the community to fulfil its obligation to support the person to
be an included member of the community. Therefore, it is appropriate for
public authorities to monitor whether people are being successfully
supported and whether they are achieving Inclusion. In effect this is the
most important aspect of the process, and it should feedback into the
Assessment process and enable readjustment if there is a problem.

There is an open debate on how best monitoring should take place. Often
there is pressure to monitor spending, rather than outcomes, but it is not
clear that this is appropriate or effective. There are also concerns that
undue monitoring can breach people's right to privacy.

Reform at the community level

An effective user-centred funding model will provide people with the means to exercise their basic rights to support and freedom. However, people's ability to use those rights to build good lives as contributing citizens will depend on the ability of the whole community to support and work with the person. Change at the individual level alone will not be enough. Public authorities also have an additional responsibility to use their power and resources to help develop the best possible infrastructure so that people are equipped to use their rights effectively. In the following section we outline the key elements of an architecture for user-centred funding models and the need to establish suitable frameworks for:

• Personalised support

• Peer support

• Community support

• Local coordination

Together these elements can be combined to enable inclusion for people who need LTCS.

Personalised support

Many people with disabilities or families choose to employ Personal Assistants, who are individuals who are specifically recruited and employed to provide support to one person. The term Personal Assistance or Personal Assistance Scheme is also used in a much broader way to describe the

whole system of organising and funding the use of Personal Assistants (Mladenov et al. 2019). Sometimes Personal Assistants are also self-employed. This role can be rewarding, efficient and effective and there has been a considerable growth in the use of Personal Assistants.

However, it is important to support the development of Personal Assistance as an attractive and sustainable approach to support, employment and development. In particular it is important that states:

• Ensure people with disabilities, families and Personal Assistants are given helpful information about their rights and responsibilities;

• Encourage systems of peer support and cooperation for employers and employees, including the capacity for staff to receive the benefits of collective bargaining;

• Support skill development for everyone, Personal Assistants, disabled people families, community members and other professionals and ensuring the lived expertise of people with disabilities is central to ongoing learning;

• Ensure everyone has access to support for resolving conflicts and protecting their rights.

Some people will choose to use their Personal Budget to purchase a service from a support provider. This is an option for many people who may prefer to share the responsibility to manage or control their support with others. Support providers can also organise Personalised Support that is consistent with human rights principles and that can offer high quality, flexible and inclusive support (Fitzpatrick, 2010). In particular it is possible for support providers to:

• Recruit Personal Assistants to roles defined with and in partnership with the person;

- Work flexibly to person-centred Support Plans and policies set by the person;

- Support people to live in their own home, be included in the community and to exercise all their rights as citizens;

- Manage the Personal Budget together, using it flexibly and creatively with an Individual Service Fund.

However, because of the long-term history of institutional care, it may be necessary to encourage or support the development of Personalised Support (Duffy, 2013b). Market forces, on their own, do not seem sufficient to create the necessary momentum for positive change. So, states should consider:

- Nurturing the development of new forms of support with investment or support for emerging leaders and innovators;

- Encouraging learning communities and training to promote good practice across the sector;

- Ensuring existing regulations or assumptions do not obstruct innovation but facilitate it.

Peer support

A person's ability to speak up for themselves, to develop a positive image of the future and to strive to achieve it is closely linked to the person's sense of identity and courage. Many people with disabilities and their families have negative experiences, which make it harder to be self-advocates. For this reason, public authorities should seek to build confidence and capacity with these kinds of measures:

- Support Family Leadership and Peer Support for families with children with disabilities, including support to lead the design and control of appropriate family supports (Murray, 2010 & 2011; Mahmic & Janson, 2018);

- Support inclusive education and high expectations for all children with disabilities, including an expectation of paid work or other social contributions [UNCRPD Article 24] (Cowen, 2010);

- Support networks of self-advocates or peer supporters in every community, providing people with peers and allies who can share experiences and strengthen self-confidence (Duffy, 2012 & 2021);

- Guarantee clear opportunities for people and families to work together and with state and community actors to solve problems and create Inclusion in every community.

It is essential that people who are Self-Managing have access to effective systems of Peer Support, advocacy and other additional services that enable the person to make good use of their Personal Budgets. One effective model of support for people self-managing Personal Budgets is the Centre for Independent Living (CIL). A CIL will:

- Be controlled by disabled people;

- Provide peer support and share experience of good practice (ENIL, 2014a);

- Provide expert technical assistance with planning, recruitment and management;

- Support advocacy individually and collectively;

- Work in partnership with the state and community to promote change.

CILs may be able to efficiently replace, not duplicate, many management functions already provided elsewhere in the support system. Initial investment and long-term support may be necessary. However, if Personal Budgets are set at a reasonable level with enough to fund management costs, then some part of the CIL budget may also be funded by people paying for services from the CIL. How these costs are covered is a key issue in ensuring Personal Budget levels are fair and that there are no unfair incentives in place to stay with older forms of support.

Community-based support services

Some people may also choose to purchase other support services. However, in establishing the whole system of user-centred funding, the state also has a responsibility to ensure that:

- Services that are entirely inappropriate and where good evidence exists of their serious limitations or failures, like hospital-like long-stay institutions, are permanently closed down and rendered illegal.

- There are no direct or indirect subsidies for more institutional or congregate services. Such subsidies can be created accidentally, by creating a Resource Allocation System which does not treat all services equally (EEG, 2019).

- Services that are institutional or congregate are supported to change and improve. Many people working in inappropriate services are willing and able to work in a better way and to be accountable to people with disabilities (Duffy et al. 2019).

It is important that systems of regulation and commissioning are used dynamically to encourage progress towards a human rights approach for everyone and across all communities. We are also seeing other forms of community support develop where people are able to use their budgets flexibly. For instance:

- To pay for support at work

- To pool funds with other Personal Budget holders

- To pay for live-in support

- To create a business, social enterprise or co-operative

- To pay a neighbour or local community group

- To fund adaptations or the purchase of equipment

It is important that states do not try to limit how people use Personal Budgets. Instead, the focus should be on encouraging people to learn from each other, share good ideas and support innovation. The consistent finding of empirical research is that unnecessary restrictions on the use of Personal Budgets damage efficiency, effectiveness, satisfaction and innovation (Forder et al. 2012; Duffy, 2018; Fleming et al. 2019).

We are also seeing some communities start to rethink how community support is organised. Focusing on how small communities or neighbourhoods can increase the opportunities for mutual support that builds on the strengths of the community. These are just some examples of emerging models:

- **Micro-enterprises** - Local people are setting up small businesses to create new bespoke support arrangements connected to local neighbourhoods (Duffy & Catley, 2018)

- **Support brokerage** - Organisations are developed to help people find creative support solutions with their Personal Budgets (Leach, 2015)

- **Local Area Coordination** - A system where an individual living in a community is employed to ensure people can build capacities and solve problems locally (Broad, 2012 & 2015).

- **Self-Managing Teams** - Neighbourhood-based teams, pioneered by the Dutch organisation Buurtzorg, are now increasingly being used globally and seem highly compatible with Personal Budgets (Buurtzorg, 2021; Sheldon, 2017).

- **Asset Based Community Development** - This is an approach to neighbourhood development which focuses on building on local strengths, not deficits and can be used to create local systems of mutual support (Kretzmann & McKnight, 1993; Gillespie, 2011; Russell, 2020).

Local coordination

In addition to these forms of support it is also essential that there is a clear point of coordination for LTCS in each community to get help to:

- Access the support they are entitled to;

- Change or improve their support;

- Respond to an emergency;

- Intervene in a situation of conflict or abuse.

There are different ways of providing the necessary point of coordination and the role of the coordinator may change depending on how the process of Assessment is managed and where the budgetary responsibility for Personal Budgets lies (see Chapter 5).

Local coordinators are also in a good position to help ensure that the community architecture for Personal Budgets is helping people find the best solution for their LTCS needs. While many people will identify better ways to organise their LTCS naturally, many others will need some support. Change is not natural and there are many factors that discourage creativity. For this reason, public authorities should establish strategies for promoting creativity and support people to change and improve their LTCS arrangements:

- Establish good communication and information sharing systems;

- Encourage Peer Support and Family Leadership communities to offer mutual support and coach service providers;

- Enable professionals to work creatively with people and families to develop the best support solutions;

- Enable independent planners, support brokers or community activists to help people develop person-centred solutions;

- Support agencies that support innovation, micro-enterprise and new forms of support;

- Enable support providers to develop and share innovation.

Ongoing innovation and community development will increase the value of Personal Budgets and make the whole system more effective (Inspiring Scotland, 2016).

Reform at the level of the state

Although the principle of subsidiarity implies that individuals should have a high degree of control and local communities should be able to shape their own solutions it remains critical that there is an over-arching structure to support the system of Personal Budgets. Several issues are most likely best resolved at the macro level, including:

- Workforce development

- Delivery system for Personal Budgets

- Protection and advocacy

- Funding settlement

In this chapter we will explore how these elements can be used to create the best possible framework for the promotion of Independent Living and Inclusion.

Workforce development

A commitment to human rights and to Personal Budgets implies wide-ranging changes to workforce development. A whole new strategic perspective on professional learning and development is necessary. As such, capacity-building programmes to upskill and reskill professional staff will be necessary:

- Putting human rights and the values of Inclusion and Independent Living at the heart of the education system;

- Respecting people and families as experts, and not only of their own experience, but also as potential teachers and trainers in many relevant subjects;

- Widening the definition of the workforce; recognising that people, families and other citizens may often be appropriate recipients of training;

- Increasing standards and accountability across professional services to ensure consistency with human rights principles and the end of institutional or inappropriate practices;

- Apply the principles of inclusive education and ensure people with

and without disabilities can learn together as equals;

- Enable people who use Personal Budgets to develop their own skills, to become a trainer of others and to help their supporters to develop the most relevant skills;

- Create hubs and points of leadership for sharing expert or specialist knowledge as widely as possible for those who need it.

Many skills and principles relevant to LTCS are of universal relevance and could be usefully developed as part of general education. Other skills may be more specialised, but will still need to be shared, not just by the professional workforce, but also by people, families or others. It may be

useful for states to connect the development of Personal Budgets with a strategy to reform professional training in LTCS and also to link this reform to wider changes to adult education and awareness raising in partnership with disability groups and other allies. Personal Budgets could feature in an awareness raising campaign to support Inclusion for all.

Governance for personal budget system

Systems for funding and delivering Personal Budgets will tend to be organised at the highest level possible, although functions of the system may be delegated to the local level. Key components include:

- **Financial systems** - The administrative and finance system for transferring Personal Budgets to people, their agents or support organisations needs to be coherent and as simple and efficient as possible. There is no obvious justification for multiple overlapping systems.

- **Assessment** - The principles of Assessment and Resource Allocation may best be centralised, even if the local administration took on the work. It will be important to regulate the system so that the overall geographic distribution is fair and properly reflects needs.

- **Portability** - National systems of Personal Budgets increase the possibility of portable systems that enable people who need care and support to enjoy the same freedom to travel and work where they decide. In the future transnational agreements or EU rules may also support the same freedom on a pan-European basis.

- **System compatibility** - As Personal Budgets develop, they will create opportunities to create coherence with systems of funding for income security, healthcare, and education.

More generally there needs to be some system for the overall governance at a system level to ensure that Personal Budget levels are fair and sustainable, that overall outcomes are positive and that communities are learning how to increasingly improve how they include people and how to effectively honour people's human rights. The system, rather than individuals, will require regulation to ensure that it is delivering the desired outcomes. There is clearly an important role for ongoing research and a role for academic partners.

Protection and advocacy

As Personal Budgets are established, the right to LTCS and the right to control that support will need to be established in law. It must be clear:

- What rights and freedoms people with care and support needs and families have;

- What are the corresponding duties and powers and to whom those duties are assigned;

- What democratic, judicial and administrative accountabilities exist to ensure the effectiveness of the law.

In some countries, such as Australia, a whole new institution has been created in order to manage responsibility for Personal Budgets (Commonwealth of Australia, 2013). In other countries, such as Scotland, new legislation has been introduced to amend the responsibility of local government for meeting people's right to LTCS (Scottish Parliament, 2013). In Italy important rights to Self-Directed Support exist, but are rarely realised (SKILLS, 2019).

The critical point seems to be that correct and facilitating legislative frameworks are helpful; however, on their own they are not sufficient. What

seems more important is the necessary strategic and policy leadership to indicate the direction of progress and to create the right environment to encourage the necessary major systemic changes. There needs to be clear leadership and democratic accountability for pursuing this policy.

The right to LTCS and user-centred funding must be underpinned by systems of legal protection and advocacy. These rights should be organised so as to achieve the most efficient resolution of problems at the lowest level possible. However, rights, protections, and funding to protect those rights is most likely to be effective if managed at a national or transnational level. Suitable systems of advocacy and protection, including the right to access legal support, should be universal public services and available to all citizens.

Funding settlement

People have a right to support and providing sufficient public funding for LTCS is an essential component of the state's responsibilities under the European Social Charter and Article 18 of the European Pillar of Social Rights. It should be noted:

- Only a minority of people are ever likely to be able to fund LTCS with private or insurance income; most people will not be able to afford LTCS from private funds.

- Means-testing LTCS is possible, but it is associated with significant disadvantages, both discouraging earning and saving while also undermining general public support and solidarity for LTCS.

- No adequate system for improving LTCS is going to be possible without the state's support and leadership and the best system will be universal and self-directed.

Ultimately it is the responsibility of member states to provide adequate funding for LTCS and to ensure that this funding does not place unfair burdens on people who need support and their families. In many states moving towards a new funding settlement which is both adequate and fair may seem extremely challenging.

However, reforms of LTCS are possible if there is democratic support from the public for the idea. LTCS is much more likely to obtain this support if it is seen as a universal and attractive public service that is relevant to any citizen, family or community. The Australian campaign Every Australian Counts is a leading example of a successful reform to LTCS which was based on making disability services relevant to all Australians by combining a policy of Personal Budgets with full, non-means-tested, funding (Galbally, 2016). The modest tax increase to pay for this service was actually popular with the general public. Similarly, reform and extra spending on services might get more support if it is treated as an investment in citizenship and community life (Feeley, 2021).

Organising for the long-term

The introduction of Personal Budgets presents a significant opportunity for positive reform, but the process of change is not merely technical, and it takes time to maintain vision, integrity, and momentum over the long-term. This is particularly important because the required changes are not merely technical, legal, or financial. The reform process is ultimately social, and all the technical changes need to be combined with changes in values, priorities, and expectations. As we discussed in Chapter 2 the process of implementation goes through four stages:

• Initial experimentation

• Policy direction

• Increasing uptake

• Complete transformation

Each stage requires a different strategy which we will approach below:

Initial experimentation

The early experimentation process is important to define what user-centred funding means and what changes it requires. It is important to stimulate this process by the following measures:

• Allow changes to be made where existing rules may appear to limit the possibility of change by creating exemptions or clarifying permissions;

- Identify and support people who are eager to use Personal Budgets and enable them to make changes quickly;

- Identify areas of crisis or poor practice where user-centred funding may provide the right methodology to solve problems in a better way;

- Identify and celebrate exiting examples of good practice that already offer models of practice close to the desired model;

- Support the development of leadership communities to organise, fund and promote new forms of good practice;

- Begin a policy dialogue with partners at all three levels: people, community and state.

The central policy direction at this first stage should be to ensure that the demand for user-centred funding is seen as legitimate and to begin a meaningful exploration of how to make further advances.

Policy direction

The second stage of the process is policy formation. Policy formation takes place as different groups enter into dialogue and a pattern for making significant change is identified. Change is likely to be incremental and different strategies will be needed to support different groups and different communities. Ideally policy formation will:

- Provide a clear and attractive narrative about why changes are necessary and what kind of changes are involved, connecting to human rights, independent living, Inclusion and the nature of citizenship;

- An incremental process for targeting areas where changes can be achieved most easily;

- Support for leadership communities to champion the change and lead the process of public and professional education;

- Any necessary legal or administrative changes to allow the process to proceed;

- An investment strategy that moves resources from the old towards the new system.

It is noticeable that often it seems to require new civil society groups or alliances to emerge in order to develop new ideas and ensure that these ideas are adopted by states. In states where progress has been made it is usually possible to identify distinct groups that lead policy development and advocacy (SDS Network, 2021). States may want to encourage this kind of policy advocacy as a means to open up debate and ensure the voices of people, families and advocates for change are amplified.

Increasing uptake

As the policy begins to make progress it becomes increasingly important to acknowledge and resolve any significant barriers to progress. These barriers are often created by undue complexities and vested interests who are threatened by the new way of working. If user-centred funding is treated as only one kind of option for managing LTCS, then older services will seek to retain older systems of funding. In order to make progress in moving to a universal system it will be necessary to:

- Make Personal Budgets a requirement for LTCS, not just an option;

- Create plans for existing services to move to Personal Budgets;

- Ensure people who do not want to Self-Manage Personal Budgets are offered easy to use alternatives, like Shared Management and Individual Services Funds (TLAP, 2015);

- Eliminate unnecessary complexity and confusion from national and local systems (Feeley, 2021).

It is important to note that special arrangements may be necessary for people who currently use LTCS. For people who currently receive LTCS there are further rights, responsibilities and constraints that apply to them and to any staff currently employed in providing LTCS. For this group, a modified approach to self-direction may be necessary to:

- Design specific implementation strategies for people in the old system (e.g., a day service could be redesigned on the principles of Self-Directed Support) (Edwards & Waters, 2009)

- Clearly distinguish the norms and principles of the new system from the rules of the old system that is being replaced.

- Define when and how the new system of user-centred funding in LTCS will apply to everyone.

Complete transformation

The final stage of the process requires close attention to services and systems that may still be in use, but which are no longer necessary or appropriate. In particular, that is likely to include:

- Institutional services which may have not chosen to change or adapt;

- Systems that were set up with a temporary purpose and which are no longer relevant;

- Funding streams that were designed to develop or protect services no longer needed;

- Older roles for professionals that are no longer required and need to be redefined.

At this stage, Personal Budgets will have been normalised and may even be combined, extended or merged into other systems. For example, there is good reason to believe that some increased personalisation of services has benefits in health and education (Alakeson & Duffy, 2011; Cowen et al. 2011). In addition, it may be possible to connect Personal Budgets to the social security system (Elder-Woodward & Duffy, 2018).

Maintaining momentum and integrity

Given the complexity and length of time required to move towards user-centred funding models the central challenge is to maintain momentum and integrity over time. Key strategies that public authorities might consider include:

- **Transparency and accountability** - Policymakers need to ensure that they continue to work in partnership with people who need support, sharing data, maintaining research and having open discussions on key policy matters.

- **Vision of Inclusion** - The purpose of user-centred funding is to respect human rights and create inclusive communities where everyone can live a life of citizenship. It is important to keep this goal in mind and to ensure that reforms are measured against this objective, rather than narrower or older standards. Seeing user-centred funding as an essential component of the process of deinstitutionalisation and respect for human rights can help the reform process stay on track.

- **Peer networks** - Personal Budget systems have been evolving in Europe and globally and the pace of change seems to be increasing. There is much to be gained by networking across Europe to share lessons on good practice and innovation. Peer support for policymakers can increase confidence in making the necessary changes and help public authorities avoid unnecessary errors.

Facing the long-term care and support challenges

The process of implementing a system for Personal Budgets takes time and integrity. It does not provide an immediate solution to the four LTCS challenges identified above (Chapter 1), but these challenges can help guide the process of reform. If public authorities use human rights to guide their approach to the funding of LTCS then this can help them respond to the four challenges for LTCS using Personal Budgets.

It is also critical to build a response for the four key challenges into the design of the reform process, as well as developing the community architecture for Personal Budgets. The major policy challenges of LTCS can all be faced more effectively if combined with a system of Personal Budgets:

Access and affordability

Key challenge: Are Personal Budgets being made available to more groups and are people able to exercise increased levels of meaningful control?

Everyone who needs support should be entitled to an appropriate Personal Budget. This would be part of a universal and attractive system of entitlements, accessible to all, and more likely to gain wide public support. The goal must be to shift resources away from institutional practices and towards people and families who are excluded or under-supported. For example, Personal Budgets can be a useful tool in helping people transition

from institutional care to living independently in the community while receiving adequate to their needs and wishes support (Brown & Dalrymple, 2018). They have also been used successfully to help families under risk of separation to work together and to avoid their children going into alternative forms of care (Keilty, 2020). Targeting Personal Budgets in the right areas can grow support and release resources to reinvest in widening access (Block et al. 2002).

Personal Budgets provide a powerful tool for integrating support and reducing the undue separation of different services and funding systems. Support can be organised around the needs, resources and priorities of the person and funding can be directed where it is really needed. Currently most spending on LTCS is effectively an investment outside the life of the community. Instead Personal Budgets create an opportunity to invest in the person's inclusion in the community and to thereby strengthen the local economy. The public commitment necessary to support adequate funding for LTCS increases when the system is made more attractive and universal. Personal Budgets create the basis of a system which will work across the whole community, for people with varying needs, and which enables people to exercise choice and maximise their inclusion in family and community life.

Sustainability

Key challenge: Are increasing levels of LTCS funding being invested in community life and being used to support Inclusion and Independent Living?

Personal Budgets are defined by need and maximise people's ability to stay connected to family and friends and maintain and build a positive and contributing life within the community. Instead of moving resources out of the community and into segregated services Personal Budgets function as

an investment in the life within the community and further support the local economy.

Sometimes it is useful to create new funding streams for Personal Budgets, however it is important to bear in mind the need for the strategy to transform the use of existing resources. Adding resources without changing how other resources are used can create a false appearance of inefficiency (White, 2011). Showing that existing resources can be used more efficiently is very helpful for growing support for Personal Budgets (Glendinning et al. 2008).

Personal Budgets encourage people to take more responsibility for choosing, managing or shaping their own support. This builds on personal or wider social capital and can be a good opportunity to grow networks. It is important however that the Resource Allocation System does not take natural support and personal self-management for granted and unduly reduce the Personal Budget level for people who have more natural support available. The budget setting process should encourage people to self-manage and to build on their natural supports, while also allowing people to purchase additional support when they need it.

The ability to use resources flexibly and to direct funding towards community-based solutions is also critical to increasing efficiency. When people build on their natural talents, interests and connections and use their Personal Budget to increase their participation then resources are likely to be used in a highly efficient way. The development of a coherent Personal Budget system also creates opportunities to reduce waste and complexity and creates opportunities to invest in the people, communities and the services that people really value.

Workforce

Key challenge: Does the workforce value Personal Budgets as a means for partnership with and accountability to people and families?

Personal Budgets enable personalised support, focused on promoting inclusion. This work is more attractive for support workers and creates more opportunities for meaning, spontaneity and building relationships, the basis of job satisfaction (IFF Research, 2008). This system should also ensure adequately paid support workers, less administrative burden for the staff and more direct support work. Identifying social workers, community activists or community organisations who are keen to work in new ways is an essential ingredient of the reform process. It is important that people

working in the system can champion the changes and demonstrate the value in terms of values and job satisfaction (Ellis et al. 2014).

This should go together with raising awareness strategies and training the workforce on how to deliver services in a user-centred way, responding to the needs of individuals, while respecting their wishes and preferences. Personal Budgets shift the point of decision-making closer to the person who needs support and to those who support them. It is a system which encourages a sense of personal responsibility, in planning, managing and providing support, and it is based on relationships of trust which make this kind of person-centred work more rewarding. Personalised support is relationship-based and as support moves closer to the person it is increasingly better connected to the local community and local people. This creates work, job opportunities and economic value within the community and enables both the person who needs support and the supporter to be better connected to local community activities and opportunities. Increased public support for LTCS is also the basis for increasing the value of the work of support work and the chance to improve salaries.

However, the new forms of work and increased personalisation of support do require new forms of collective bargaining to protect the rights of

workers. Moreover overall level of funding available for LTCS needs to be sufficient in order to ensure that there will be enough staff available for the different kinds of work necessary.

Quality

Key challenge: Are people who need LTCS increasingly present and valued in community life and able to make their own unique contributions?

Personal Budgets should radically change the focus of quality management. Instead of standardisation and inspection the focus should shift to user-control, innovation, peer support, community contribution

and result-oriented quality monitoring approaches, focusing on the impact of support services on the quality of life of individuals. It is important to work with people who need support, not only to track progress in improving quality, but also to define the measure of success.

The shift to Personal Budgets is also a shift in thinking and perspective. When people define what is important to them, they often focus on aspects of citizenship and Independent Living rather than service standards (Murray, 2010). Personal Budgets put the authority to choose and terminate support in the hands of those who have the greatest stake in making the right decision. There is no reason to delay responding to problems or continue with an unsatisfactory arrangement. New opportunities can be seized as soon as they are identified. The system is responsive and focused on the immediate needs and desires of the person and those who know them best.

The best guarantee of quality in support is active local presence. Local people are both more likely to create opportunities for inclusion and meaningful activities and also to pay attention to ensure that people are safe from abuse, isolation or neglect. A new system allows for a reorientation of the purpose of the LTCS system. Wider public understanding of the purpose of LTCS as a means to support Inclusion for all, for people over every age or ability, will benefit the whole community and its commitment to treating everyone with respect.

None of this means existing systems of quality control and regulation should be abandoned. However states need to recognise that there will need to be a transition towards forms of regulation which support empowerment, innovation and local accountability. Older systems of regulation that are suitable for monitoring forms of institutional care will not be suitable for ensuring quality in inclusive communities or where people are enjoying Independent Living.

Looking to the future

The UNIC Project is a pan-European project which aims to develop models that can be tested, shared and improved. This guide is offered to all public authorities interested in the development of user-centred funding models and Personal Budgets in particular. In addition, the UNIC Project will provide a toolkit which builds on this guide, and which will help public authorities evaluate their own approaches, set new goals and work to advance human rights and deinstitutionalisation. This set of tools will provide public authorities with the opportunity to design, implement and evaluate a personal budgets system. And they include:

• A tool to monitor the quality of services provided in the framework of a personal budgets system;

• A tool to help service providers design and deliver user-centred services in the framework of personal budgets, following a co-production approach and focused on the development of homecare and community-based services;

• A tool to help public authorities in the promotion engagement and enforcement of a personal budgets system, including the development of community-based services (vboth the transformation of current services and the creation of new ones).

The guide and the tools will be tested by VAPH, an Agency of the Flemish regional government in Belgium, responsible for funding LTCS for adults with disabilities. These resources will be further improved and made available to the public.

References

Alakeson V & Duffy S (2011) Health Efficiencies: The possible impact of personalisation in healthcare. Sheffield: Centre for Welfare Reform.

Animate (2014) Individual Service Funds. Sheffield: Centre for Welfare Reform.

Basterfield S & Fulton K (2019) Rethinking Organisations. Perth: Western Australia individualised Services

Block S, Rosenberg S, Gunther-Kellar Y, Rees D & Hodges N (2002) Improving Human Services for Children with Disabilities and Their Families: The Use of Vouchers as an Alternative to Traditional Service Contracts. Administration in Social Work, Volume 26(1) 23-36 doi: 10.1300/J147v26n01_02

Breedlove L (2020) Self-Direction Worldwide: contrasting beliefs and their impact on practice. Sheffield: Centre for Welfare Reform.

Broad R (2012) Local Area Coordination. Sheffield: Centre for Welfare Reform.

Broad R (2015) People, Place, Possibilities. Sheffield: Centre for Welfare Reform.

Brown F & Dalrymple J (2018) A New Way Home: A personalised approach to leaving institutions. Sheffield: Centre for Welfare Reform.

Buurtzorg (2021) https://www.buurtzorg.com/news/ accessed 30th April 2021

Chenoweth L & Clements N (2010) Evaluation of Self-directed leadership: Parents creating participatory lives with adults with disability. Sydney: Interaction.

Chetty K, Dalrymple J & Simmons H (2012) Personalisation and Human Rights. Sheffield: Centre for Welfare Reform.

Cole I, Gilbertson J & Reeve K (2016). Evaluation of the Prepaid Card Live Test. London: DWP

Commonwealth of Australia (2013) National Disability Insurance Scheme Act 2013

Cowen A (2010) Personalised Transition - Innovations in health, education and support. Sheffield: Centre for Welfare Reform.

Cowen A, Murray P & Duffy S (2011) Personalised Transition: A Collaborative Approach to Funding Individual Budgets for Young Disabled People with Complex Needs Leaving School. Journal of Integrated Care, Vol. 19 Iss: 2, pp. 30-36 doi: 10.5042/jic.2011.0158

Dalrymple J, Macaskill D & Simmons H (2017) Self-Directed Support: Your Choice, Your Right. Sheffield: Centre for Welfare Reform.

Dalrymple J & Etherington K (2015) Upfront. Glasgow: In Control Scotland.

Duffy S (2012) Peer Power. Sheffield: Centre for Welfare Reform.

Duffy S (2013a) Travelling Hopefully: best practice in self-directed support. Sheffield: Centre for Welfare Reform.

Duffy S (2013b) Returning Home: piloting personalised support. Sheffield: Centre for Welfare Reform.

Duffy S (2015) "Commentary – what is a resource allocation system?", Tizard Learning Disability Review, Vol. 20 Iss: 4, pp.207 - 212

Duffy S (2018) Self-Directed Support: If it's so good then why is it so hard. Sheffield: Centre for Welfare Reform.

Duffy S (2019) Lobbying for Self-Directed Support. Sheffield: Centre for Welfare Reform.

Duffy S (2021) Growing Peer Support. Peer-led crisis support in mental health. Sheffield: Centre for Welfare Reform.

Duffy S & Catley A (2018) Beyond Direct payments: Making the case for micro-enterprise, Individual Service Funds and new forms of commissioning in health and social care. London: TLAP

Duffy S & Etherington K (2012) A Fair Budget. Sheffield: Centre for Welfare Reform.

Duffy S & Fulton K (2010) Architecture for Personalisation. Sheffield: Centre for Welfare Reform.

Duffy S, Dalrymple J & Crosby, N (2019) Self-Directed Support for Service Providers. Brussels: EASPD

Edwards T & Waters J (2009) It's Your Life - Take Control: The implementation of self-directed support in Hertfordshire. London: In Control.

Elder-Woodward J & Duffy S (2018) An Emancipatory Welfare State: How basic income might underpin the development of human potential. Sheffield: Centre for Welfare Reform.

Ellis R, Sines D & Hogard E (2014) Better Lives. Sheffield: Centre for Welfare Reform.

ENIL (2014a) Peer Support for Independent Living: A Training Manual. Dublin: European Network on Independent Living.

ENIL (2014b) Myth Buster on independent Living. Dublin: European Network on Independent Living.

Eurofound (2020), Long-term care workforce: Employment and working conditions, Publications Office of the European Union, Luxembourg

European Expert Group on the transition from institutional to community-based care (EEG) (2019) Checklist to ensure EU-funded measures contribute to independent living by developing and ensuring access to family-based and community-based services. Salisbury: Hope and Homes for Children.

Feeley D (2021) Independent Review of Adult Social Care in Scotland. Edinburgh: Scottish Government.

Fitzpatrick J (2010) Personalised Support: How to provide high quality support to people with complex and challenging needs - learning form Partners for Inclusion. Sheffield: Centre for Welfare Reform.

Fleming P, McGilloway S, Hernon M, Furlong M, O'Doherty S (RIP), Keogh F, Stainton S. (2019) Individualised funding interventions to improve health and social care outcomes for people with a disability: a mixed-methods systematic review. Campbell Systematic Reviews 2019:3 (DOI: 10.4073/csr.2019.3)

Forder J, Jones K, Glendinning C, Caiels J, Welch E, Baxter K, Davidson J, Windle K, Irvine A, King D & Dolan P (2012) Evaluation of the Personal Health Budget Pilot Programme. Department of Health.

Galbally R (2016) Working for Lives of Common Dignity. Sheffield: Centre for Welfare Reform.

Gillespie J (2011) Positively Local. Sheffield: Centre for Welfare Reform.

Glendinning C, Challis, D, Fernandez J, Jacobs S, Jones K, Knapp M, Manthorpe J, Moran N, Netten A, Stevens M & Wilberforce M (2008) Evaluation of the Individual Budgets Pilot Programme: Final Report. York, Social Policy Research Unit.

Hay M & Waters J (2009) Steering My Own Course. In Control Publications, London.

IFF Research (2008) Employment Aspects and Workforce Implications of Direct Payments. Leeds: Skills for Care.

Inspiring Scotland (2016) Self-Directed Support Innovation Fund: Year 1 Progress Report May 2016. Edinburgh: Inspiring Scotland.

Keilty T (2020) Adventurous Social Work? Using resources differently with Look After Children and their families - some early lessons from the Scottish pilot sites. Glasgow: In Control Scotland.

Kretzmann J & McKnight J (1993) Building Communities From the Inside Out: a path toward finding and mobilizing a community's assets (3rd ed.). Chicago, IL: ACTA Publications.

Leach L (2015) Re-imagining Brokerage. Sheffield: Centre for Welfare Reform.

Mahmic S & Janson A (2018) Now and Next: an innovative leadership pipeline for families with young people with disability or delay. Sheffield: Centre for Welfare Reform.

Mladenov T, Pokern Y & Cojocariu IB (2019) PA Checklist: a tool for assessing Personal Assistance schemes. Brussels: European Network on Independent Living.

Moseley C E, Gettings R M & Cooper R (2003) Having It Your Way: Understanding State Individual Budgeting Strategies. Alexandria, NASDDDS.

Murray P (2010) A Fair Start. Sheffield: Centre for Welfare Reform.

Murray P (2011) Developing Family Leadership. Sheffield: Centre for Welfare Reform.

O'Brien J (2001) Paying Customers are Not Enough: The Dynamics of Individualized Funding. Lithonia, RSA

O'Brien J and Duffy S (2009) Self-directed support as a framework for partnership working in Glasby J and Dickinson H, International Perspectives on Health and Social Care. Chichester, Blackwell Publishing.

O'Brien J & Mount B (2015) Pathfinders: people with developmental disabilities and the allies building communities that work work better for everyone. Toronto, Inclusion Press.

Rodrigues, R. (2020), 'Caring relationships and their role in users' choices: A study of users of direct payments in England', Ageing & Society, Vol. 40, No. 7, pp. 1469–1489.

Rogers E M (1962) Diffusion of Innovations. New York: The Free Press of Glencoe

Russell C (2020) Rekindling Democracy, A Professional's Guide To Working In Citizen Space. Cascade Books.

Scottish Parliament (2013) Social Care (Self-directed Support) (Scotland) Act 2013

SDS Network (2021) https://www.selfdirectedsupport.eu accessed 30th April 2021

Series L (2014) Resource allocation systems: complex and counterproductive? in Needham C and Glasby J Debates in Personalisation. Policy Press, Bristol. pp. 37-43

Shapiro J P (1993) No Pity: People with Disabilities Forging a New Civil Rights Movement. New York: Times Books.

Sheldon T (2017) Buurtzorg: the district nurses who want to be superfluous BMJ 2017; 358 doi: https://doi.org/10.1136/bmj.j3140

SKILLS (2019) Migliorare le competenze e le capacità nell'ambito del sostegno auto-gestito. Helsinki: Citizen Network.

Social Protection Committee (2010). A Voluntary Quality Framework for Social Services, Brussels.

Social Protection Committee and European Commission (2014). Adequate social protection for long-term care needs, Brussels

Social Protection Committee and European Commission (2021). Long-Term Care Report. Trends, challenges and opportunities in an ageing

Smull M & Harrison S B (1996) Essential Lifestyle Planning. Annapolis, Maryland: Allan Shea Associates.

TLAP (2015) Individual Service Funds (ISFs) and Contracting for Flexible Support. London: TLAP.

United Nations (1989) Convention on the Rights of the Child (UNCRC)

United Nations (2006) Convention on the Rights of Persons with Disabilities (UNCRPD)

WAIS (2012) Shared Management. Perth: WAIS.

Watson (2020) A Commissioners' Guide to Individual Service Funds. Sheffield: Centre for Welfare Reform.

White C (2011) The Personal Touch: The Dutch Experience of Health Budgets. London: The Health Foundation.

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