



MAPPING OF SELF-DIRECTED SUPPORT IN EUROPE



Intellectual Output 5





Table of Contents

Introduction	2
Self-directed support in Europe	3
Austria	4
Belgium (Flanders)	6
Czech Republic	8
Denmark	10
Finland.....	12
Germany.....	14
Iceland	16
Ireland.....	18
Italy	20
Malta.....	22
Netherlands	24
Norway	26
Romania	28
Spain (Catalonia)	30
Sweden	32
United Kingdom (England).....	34
United Kingdom (Northern Ireland).....	36
United Kingdom (Scotland).....	38
United Kingdom (Wales).....	40
Main conclusions and recommendations	42

Self-directed Support systems in Europe



Introduction

Welcome to the mapping report of the SKILLS Project! We conducted an online survey and interviewed experts from different European countries to present to you this overview of self-directed support or similar systems in different countries.



Objective

In this report, we provide an overview of map existing legal and financial frameworks for self-directed support or similar system in different countries. For each country covered in this report, you will learn what target groups and services are covered by the existing systems and who controls the support delivered.



What do we mean by Self-directed Support?

Self-directed support (SDS) is a system to organise the help people need so the person has as much control as possible. It aims to improve the lives of people with social care needs by empowering them to be equal partners in decisions about their care and support. For example: SDS allows people to choose how their support is provided and gives them as much control as they want of their individual budget.



Methodology

Findings presented in this report are based on the data collected via an online survey of experts in the field of disability rights and services as well as desk research of relevant resources. EASPD carried out an online survey (in English) available at <https://goo.gl/forms/Zh8AC4bP7PAIhCdD3>. There were 47 eligible responses from 24 European countries.

About the project

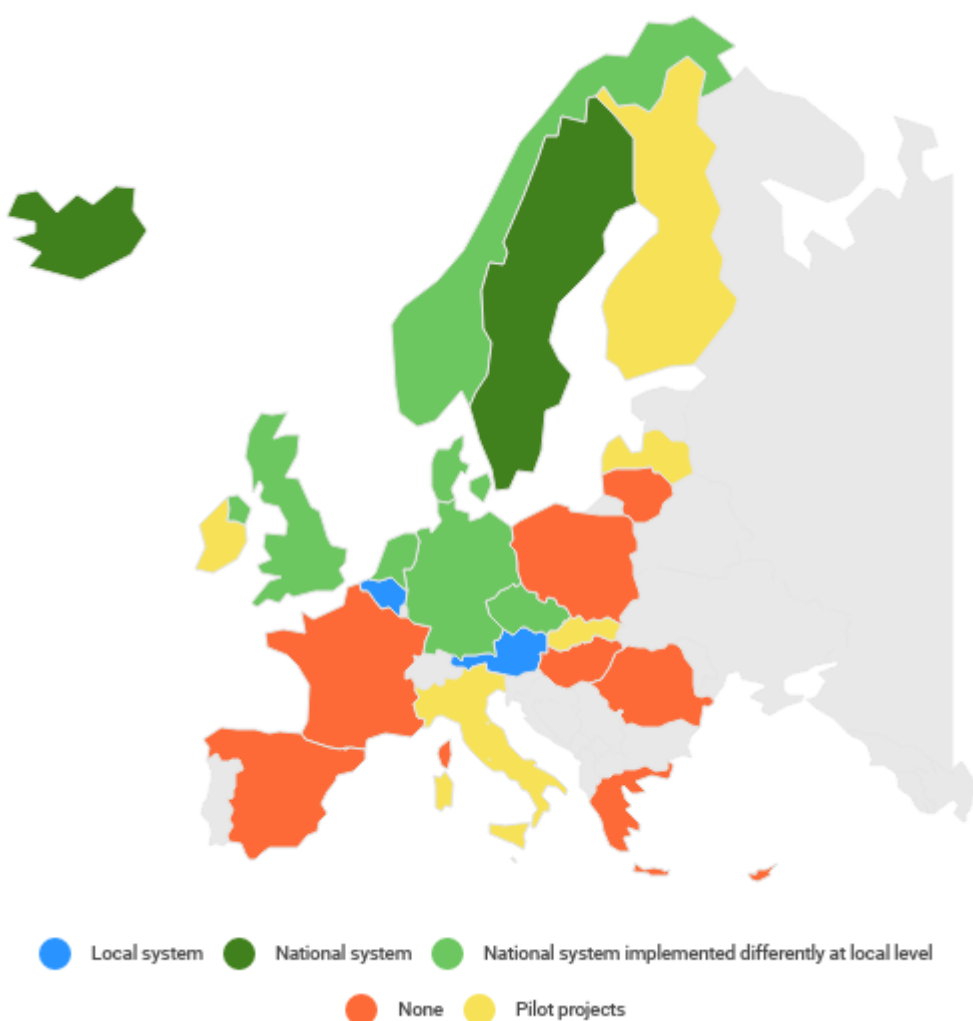


SKILLS is a 24-month Erasmus+ project that aims to enable the full citizenship of persons with disabilities by improving skills and competencies of different stakeholders in self-directed support. The project addresses the need to explore and define what systems of self-directed support are in place in different countries and how they can best support individuals with disabilities in exercising choice about their lives.

Self-directed support in Europe

Mapping of responses given to the following question:

“Is there any system in your country that to any extent allows people with disabilities to exercise control over their individual budgets or to choose, purchase or arrange their social care & support services?”



Austria



Legal & financial frameworks supporting self-directed support:

The federal law **Bundespflegegeldgesetz** (Federal Care Allowance Act, 1993) introduced the Care Allowance (**Pflegegeld**) aimed at supporting persons' long-term care needs (more than 65 hours per month), with seven levels of monthly care allowance, ranging from €157,30 for level 1 to €1.688,90 for level 7.

Different federal states in Austria have regulations on personal budgets (**Persönliches Budget**), e.g. Styria, Tyrol.



Targets groups covered:

- Persons with physical & sensory disabilities – fully covered
- Persons with intellectual disabilities – not covered
- Persons with mental health – not covered
- Elderly people – not covered
- Persons with nursing or therapy needs – not covered
- Families of children with disabilities – not covered
- Homeless persons – not covered
- Persons with drugs and alcohol abuse problems – not covered
- Women or children in extreme need – not covered



Data:

Not known, there is no national reporting. Only a minority uses individualized funding for personal assistance in relation to block funded services.



Types of services covered:

- Personal assistance – fully covered
- Daytime activities – not covered
- Residential accommodation – not covered
- Home modification or purchase – not covered
- Physiotherapy – not covered
- Nursing care – not covered
- Other medical services – not covered

- Help for families – not covered
- Childcare – not covered
- Schooling – not covered
- College education 18+ – not covered
- Training – not covered
- Support with work – fully covered
- Holidays or respite – not covered
- Support with leisure – not covered
- Transport – not covered
- Community action – not covered



Who can control the budget for the individual?

	YES	NO
The individual herself/himself	✓	
The individual's family or friends		✗
An independent professional	✓	
A service provider		✗
A government or local authority employee		✗



Opinion:

The Care Allowance (**Pflegegeld**) size was set in 1993 and has not been adjusted since.

A general lack of data on persons with disabilities prevents possible recommendations and is itself an obstacle to positive change. Personal support systems are regional and there is great variance.

Belgium (Flanders)



Legal & financial frameworks supporting self-directed support:

Diensten ondersteuningsplan (DOP), or A Service Support Plan, assists persons with disabilities to find adequate support. It is free of charge for one year.

In Flanders, the personal budget (**persoonsvolgend budget – PVB**) allows purchasing care and support within one's own network, with volunteers, individual counselors, professional healthcare providers and with healthcare providers licensed by the Flemish Agency for Persons with Disabilities. (in Dutch: Vlaams Agentschap voor Personen met een Handicap (VAPH)) Its stated goal is "to promote participation, integration and equal opportunities for people with a disability in all areas of social life." The VAPH provides personal budgets to people with disabilities and also uses its authority to license, accredit subsidize, etc., Flemish service providers.



Targets groups covered:

- Persons with physical & sensory disabilities – fully covered
- Persons with intellectual disabilities – fully covered
- Persons with mental health – partially covered
- Elderly people – not covered
- Persons with nursing or therapy needs – fully covered
- Families of children with disabilities – not covered
- Homeless persons – not covered
- Persons with drugs and alcohol abuse problems – not covered
- Women or children in extreme need – not covered



Data:

There is no data available.



Types of services covered:

- Personal assistance – fully covered
- Daytime activities – fully covered
- Residential accommodation – fully covered
- Home modification or purchase – not covered
- Physiotherapy – not covered

- Nursing care – not covered
- Other medical services – not covered
- Help for families – not covered
- Childcare – not covered
- Schooling – not covered
- College education 18+ – not covered
- Training – not covered
- Support with work – fully covered
- Holidays or respite – fully covered
- Support with leisure – fully covered
- Transport – not covered
- Community action – not covered



Who can control the budget for the individual?

	YES	NO
The individual herself/himself	✓	
The individual's family or friends	✓	
An independent professional	✓	
A service provider	unclear	unclear
A government or local authority employee	unclear	unclear



Opinion:

There is good legislation in place but not enough funding to provide adequate assistance to everybody.

Czech Republic



Legal & financial frameworks supporting self-directed support:

The Social Services Act No. 108/2006 Coll. regulates the care allowance (**Příspěvek na péči**), which is provided to persons dependent on another person's assistance for the purposes of arranging for necessary assistance. The amount of the allowance depends on the degree of "dependency" (there are four degrees of 'dependence' assessed by municipalities) and on the age (below or above 18).



Targets groups covered:

- Persons with physical & sensory disabilities – fully covered
- Persons with intellectual disabilities – fully covered
- Persons with mental health – partially covered
- Elderly people – not covered
- Persons with nursing or therapy needs – fully covered
- Families of children with disabilities – fully covered
- Homeless persons – not covered
- Persons with drugs and alcohol abuse problems – not covered
- Women or children in extreme need – not covered



Data:

345 961 persons have received the care allowance by the end of 2016.



Types of services covered:

- Personal assistance – partially covered
- Daytime activities – partially covered
- Residential accommodation – partially covered
- Home modification or purchase – not covered
- Physiotherapy – unclear
- Nursing care – partially covered
- Other medical services – not covered
- Help for families – unclear

- Childcare – unclear
- Schooling – not covered
- College education 18+ – unclear
- Training – unclear
- Support with work – unclear
- Holidays or respite – partially covered
- Support with leisure – partially covered
- Transport – unclear
- Community action – partially covered



Who can control the budget for the individual?

	YES	NO
The individual herself/himself	unclear	unclear
The individual's family or friends	unclear	unclear
An independent professional	unclear	unclear
A service provider	unclear	unclear
A government or local authority employee	unclear	unclear



Opinion:

The assessment of the degree of dependency can be subjective and not correspond to the real needs of the person. The system is underfunded, which leads to limited support in various areas. It is inflexible and insufficient for guaranteeing persons with disabilities a normal life. Very often, those people are also in a state of poverty.

Denmark



Legal & financial frameworks supporting self-directed support:

The Social Services Act Sections 95 and 96 regulates personal assistance in Denmark. **Borgerstyret personlig assistance** (BPA), or Citizen-administered Personal Assistance, was introduced in 2009. The BPA is provided by municipalities as individual payments to organize personal assistance. Under this scheme, service users act as employers. There is a possibility to transfer the responsibility of employer to a family member, friend or an association or a private entity that can act as employers of the assistants in consultation with the person receiving services.



Targets groups covered:

- Persons with physical & sensory disabilities – fully covered
- Persons with intellectual disabilities – partially covered
- Persons with mental health – partially covered
- Elderly people – not covered
- Persons with nursing or therapy needs – partially covered
- Families of children with disabilities – unclear
- Homeless persons – not covered
- Persons with drugs and alcohol abuse problems – not covered
- Women or children in extreme need – not covered



Data:

2000 persons with different disabilities are using this system.



Types of services covered:

- Personal assistance – fully covered
- Daytime activities – fully covered
- Residential accommodation – unclear
- Home modification or purchase – unclear
- Physiotherapy – unclear
- Nursing care – fully covered
- Other medical services – unclear
- Help for families – partially covered

- Childcare – partially covered
- Schooling – not covered
- College education 18+ – partially covered
- Training – fully covered
- Support with work – fully covered
- Holidays or respite – unclear
- Support with leisure – fully covered
- Transport – fully covered
- Community action – fully covered



Who can control the budget for the individual?

	YES	NO
The individual herself/himself	✓	
The individual's family or friends	unclear	unclear
An independent professional	unclear	unclear
A service provider	unclear	unclear
A government or local authority employee		✗



Opinion:

Some people with disabilities are concerned that they are not equipped or trained to take on the role of managing their own budget and handling the responsibility of an employer role. This lack of training can influence their opportunity to take control in their lives.

Finland



Legal & financial frameworks supporting self-directed support:

Regions have started 7 pilots already based on current legislation, with more pilots starting after 1.7.2018. based on new coming legislation.

The Finnish government is currently running a three-year (1.6.2016 - 31.5.2019) project to develop and pilot the Personal Budgeting ('**Henkilökohtainen budjetointi**') operating model in co-operation with cities, polytechnics, businesses and communities. The project develops a new type of operational model for organizing support that is based on the client's choice through Personal Budgeting. The goal is to support users in their life path and to empower their participation and social citizenship. The target groups are families with children service, clients of adult social work, and clients of disability services, clients of informal care support and clients of child welfare aftercare. At the beginning of 2020, a legal framework is expected to be put in place.



Targets groups covered:

- Persons with physical & sensory disabilities – fully covered
- Persons with intellectual disabilities – fully covered
- Persons with mental health – not covered
- Elderly people – fully covered
- Persons with nursing or therapy needs – unclear
- Families of children with disabilities – partially covered
- Homeless persons – not covered
- Persons with drugs and alcohol abuse problems – not covered
- Women or children in extreme need – not covered



Data:

There is no data available.



Types of services covered:

- Personal assistance – fully covered
- Daytime activities – fully covered
- Residential accommodation – fully covered
- Home modification or purchase – partially covered

- Physiotherapy – partially covered
- Nursing care – not covered
- Other medical services – not covered
- Help for families – partially covered
- Childcare – not covered
- Schooling – not covered
- College education 18+ – partially covered
- Training – fully covered
- Support with work – fully covered
- Holidays or respite – fully covered
- Support with leisure – fully covered
- Transport – fully covered
- Community action – fully covered



Who can control the budget for the individual?

	YES	NO
The individual herself/himself	✓	
The individual's family or friends	✓	
An independent professional	unclear	unclear
A service provider	unclear	unclear
A government or local authority employee	✓	



Opinion:
N/A

Germany



Legal & financial frameworks supporting self-directed support:

Book IX of the Social Code (***SGB IX Rehabilitation und Teilhabe von Menschen mit Behinderungen***) of 1 July 2001 introduced the concept of Personal budgets (**Persönliches Budget**). The law allows recipients of benefits from rehabilitation funds to choose a personal budget in place of participation-oriented services or benefits in kind. Persons with disabilities receiving personal budgets are responsible for 'buying' the assistance they need. The law was modified in 2008 and 2018.

SGB XI Soziale Pflegeversicherung regulates the social long-term care insurance that provides social security for the risk of long-term care. Under this law, persons in need of care may choose between facilities and services of different providers. Their wishes for the organization of the assistance should, as far as they are appropriate, be met within the framework of the right to benefits. Support can be chosen from three options; in cash, in kind, or a combination of both.



Targets groups covered:

- Persons with physical & sensory disabilities – fully covered
- Persons with intellectual disabilities – fully covered
- Persons with mental health – partially covered
- Elderly people – partially covered
- Persons with nursing or therapy needs – fully covered
- Families of children with disabilities – partially covered
- Homeless persons – partially covered
- Persons with drugs and alcohol abuse problems – partially covered
- Women or children in extreme need – partially covered



Data:

14 193 personal budgets were granted in 2010, according to one study.



Types of services covered:

- Personal assistance – fully covered
- Daytime activities – fully covered

- Residential accommodation – partially covered
- Home modification or purchase – unclear
- Physiotherapy – unclear
- Nursing care – partially covered
- Other medical services – unclear
- Help for families – partially covered
- Childcare – partially covered
- Schooling – unclear
- College education 18+ – unclear
- Training – unclear
- Support with work – fully covered
- Holidays or respite – fully covered
- Support with leisure – fully covered
- Transport – partially covered
- Community action – fully covered



Who can control the budget for the individual?

	YES	NO
The individual herself/himself	✓	
The individual's family or friends	✓	
An independent professional	✓	
A service provider	unclear	unclear
A government or local authority employee		✗



Opinion:

Different regions have different systems – sometimes more than one – and the situation is complex.

In the German system, it is, in principle, always the persons who are entitled to services or grants. Support to families is regulated separately. There is a difference between using a personal budget and having control over it. Persons with disabilities and their families are more concerned about reliable assistance, than about a self-directed one.

Iceland



Legal & financial frameworks supporting self-directed support:

The Act on services for disabled people with long-term support needs (**Lög um þjónustu við fatlað fólk með langvarandi stuðningsþarfir**) was introduced by the Parliament on 9 May 2018. Article 11 of this Act regulates the User-managed Personal Assistance (**Notendastýrð Persónuleg Aðstoð**).

NPA's are implemented at municipal level. The user manages how the assistance is organized, what assistance is provided, when and where it takes place and who provides it. The user takes the responsibility over handling the task management.



Targets groups covered:

- Persons with physical & sensory disabilities – fully covered
- Persons with intellectual disabilities – unclear
- Persons with mental health – unclear
- Elderly people – not covered
- Persons with nursing or therapy needs – unclear
- Families of children with disabilities – unclear
- Homeless persons – not covered
- Persons with drugs and alcohol abuse problems – not covered
- Women or children in extreme need – not covered



Data:

There is no data available.



Types of services covered:

- Personal assistance – fully covered
- Daytime activities – fully covered
- Residential accommodation – unclear
- Home modification or purchase – unclear
- Physiotherapy – unclear
- Nursing care – fully covered
- Other medical services – unclear
- Help for families – unclear

- Childcare – unclear
- Schooling – not covered
- College education 18+ – not covered
- Training – unclear
- Support with work – fully covered
- Holidays or respite – fully covered
- Support with leisure – fully covered
- Transport – fully covered
- Community action – fully covered



Who can control the budget for the individual?

	YES	NO
The individual herself/himself	✓	
The individual's family or friends	unclear	unclear
An independent professional	✓	
A service provider	✓	
A government or local authority employee		✗



Opinion:

The trial stage has worked quite well and has given disabled people more independence.

Ireland



Legal & financial frameworks supporting self-directed support:

Personalised budgets: there is still not any relevant legal framework that regulates this system. This project is still in a pilot phase. It should be noted that different disabilities entitle people to different types of services.



Targets groups covered:

- Persons with physical & sensory disabilities – fully covered
- Persons with intellectual disabilities – unclear
- Persons with mental health – unclear
- Elderly people – not covered
- Persons with nursing or therapy needs – partially covered
- Families of children with disabilities – not covered
- Homeless persons – not covered
- Persons with drugs and alcohol abuse problems – not covered
- Women or children in extreme need – not covered



Data:

There is no data available.



Types of services covered:

- Personal assistance – fully covered
- Daytime activities – fully covered
- Residential accommodation – partially covered
- Home modification or purchase – not covered
- Physiotherapy – partially covered
- Nursing care – unclear
- Other medical services – unclear
- Help for families – not covered
- Childcare – not covered
- Schooling – not covered
- College education 18+ – unclear

- Training –partially covered
- Support with work – unclear
- Holidays or respite – unclear
- Support with leisure –partially covered
- Transport – partially covered
- Community action – unclear



Who can control the budget for the individual?

	YES	NO
The individual herself/himself	unclear	unclear
The individual's family or friends	unclear	unclear
An independent professional	unclear	unclear
A service provider	unclear	unclear
A government or local authority employee	unclear	unclear



Opinion:

Despite extensive process of engagement with stakeholders many of the suggestions were ignored and the model put forward for piloting is quite restrictive by design. However, it is a step in right direction. The implementation of the system has not commenced other than small community led pilots.

Italy



Legal & financial frameworks supporting self-directed support:

In 2017, the government launched the **Progetti Sperimentali per la Vita Indipendente** (Experimental Project of Independent Living). Projects involving self-directed support are in a pilot phase.



Targets groups covered:

- Persons with physical & sensory disabilities – fully covered
- Persons with intellectual disabilities – fully covered
- Persons with mental health – fully covered
- Elderly people – not covered
- Persons with nursing or therapy needs – fully covered
- Families of children with disabilities – not covered
- Homeless persons – not covered
- Persons with drugs and alcohol abuse problems – not covered
- Women or children in extreme need – not covered



Data:

Approximately 1500 persons on a national level are participating in such programs.



Types of services covered:

- Personal assistance – fully covered
- Daytime activities – fully covered
- Residential accommodation – partially covered
- Home modification or purchase – partially covered
- Physiotherapy – not covered
- Nursing care – fully covered
- Other medical services – not covered
- Help for families – partially covered
- Childcare – fully covered
- Schooling – not covered
- College education 18+ – not covered
- Training – not covered

- Support with work – not covered
- Holidays or respite – fully covered
- Support with leisure – partially covered
- Transport – fully covered
- Community action – not covered



Who can control the budget for the individual?

	YES	NO
The individual herself/himself	unclear	unclear
The individual's family or friends	✓	
An independent professional	unclear	unclear
A service provider	✓	
A government or local authority employee		✗



Opinion:

Article 14 of Law 328/2000 foresees a “global project of life” for persons with disabilities. However, this law does not include provisions for autonomy and choice, as seen in the self-directed support concept. The last two years have seen an increased acceptance of SDS methods.

Malta



Legal & financial frameworks supporting self-directed support:

Virtual Legal Clinic – Inspire Foundation – this is a pilot project still in its early stages. The project involves setting up a ‘virtual’ legal clinic. This web-based clinic will aim to support persons with disabilities and learning difficulties address areas related to Education, Employment, Estate Planning, Guardianship, Health Care, Leisure, Sports, Goods and Services, Abuse and Violence, Hate Crimes and Access to Justice.

Aġenzija Support – originating in the 2000s, it provides persons with disabilities with money, with which they can employ carers. **Aġenzija Support** can also hire and manage care workers on behalf of the person with disabilities. Persons with disabilities who need special equipment can make use of the Empowerment Scheme, which provides funding and technical training.



Targets groups covered:

- Persons with physical & sensory disabilities – partially covered
- Persons with intellectual disabilities – fully covered
- Persons with mental health – partially covered
- Elderly people – unclear
- Persons with nursing or therapy needs – partially covered
- Families of children with disabilities – fully covered
- Homeless persons – unclear
- Persons with drugs and alcohol abuse problems – unclear
- Women or children in extreme need – unclear



Data:

There is no data available.



Types of services covered:

- Personal assistance – partially covered
- Daytime activities – fully covered
- Residential accommodation – partially covered
- Home modification or purchase – partially covered
- Physiotherapy – partially covered
- Nursing care – fully covered

- Other medical services – partially covered
- Help for families – partially covered
- Childcare – partially covered
- Schooling – fully covered
- College education 18+ – partially covered
- Training – unclear
- Support with work – partially covered
- Holidays or respite – partially covered
- Support with leisure – partially covered
- Transport – partially covered
- Community action – fully covered



Who can control the budget for the individual?

	YES	NO
The individual herself/himself	✓	
The individual's family or friends	✓	
An independent professional	✓	
A service provider	✓	
A government or local authority employee	Partially	Partially



Opinion:

Finances of persons with disabilities, especially persons with intellectual disabilities, are controlled by parents/guardians. The parents/guardians wouldn't necessarily have gone through the guardianship body but banks have started to ask for guardianship documentation to open an account for someone with a visible disability (mostly intellectual). Unfortunately, there is no system yet in place which supports individuals to make use of the governmental benefits. Unofficial guardians make the decision as to how these benefits are used, some of which are saved for the future of the individual, following the death of parents. Most individuals in Malta receive services from Government. The *Inspire Foundation* is currently looking at further developing its services which are based on a pay-per-use system to allow individuals to buy services they wish to buy for themselves.

Netherlands



Legal & financial frameworks supporting self-directed support:

The **Social Support Act 2015** regulates personal budgets (**Persoons Gebonden Budget**). The national law stipulates that municipalities are responsible for assisting people who are unable to independently arrange the care and support they need. Under certain conditions, the municipality may award a personal budget (PGB) which can be used to arrange and pay for the person's own support services. The money is not transferred to the person's account, but to the Social Insurance Bank (SVB), which manages the PGB and pays the care provider's bills. The person with disabilities is assessed by an independent third body ("indication office") that also determines the amount of support.



Targets groups covered:

- Persons with physical & sensory disabilities – fully covered
- Persons with intellectual disabilities – fully covered
- Persons with mental health – not covered
- Elderly people – fully covered
- Persons with nursing or therapy needs – fully covered
- Families of children with disabilities – fully covered
- Homeless persons – not covered
- Persons with drugs and alcohol abuse problems – unclear
- Women or children in extreme need – unclear



Data:

About 235.000 users per year (WLZ + WMO in 2017).



Types of services covered:

- Personal assistance – fully covered
- Daytime activities – partially covered
- Residential accommodation – not covered
- Home modification or purchase – not covered
- Physiotherapy – fully covered
- Nursing care – not covered
- Other medical services – partially covered

- Help for families – partially covered
- Childcare – fully covered
- Schooling – not covered
- College education 18+ – not covered
- Training – not covered
- Support with work – partially covered
- Holidays or respite – not covered
- Support with leisure – partially covered
- Transport – not covered
- Community action – not covered



Who can control the budget for the individual?

	YES	NO
The individual herself/himself	✓	
The individual's family or friends	✓	
An independent professional	✓	
A service provider		✗
A government or local authority employee	✓	



Opinion:

The system combines different types of personal budgets. Depending on the types of support needs, the personal budgets may be covered by municipalities, national budget or insurance companies. People get lost in this complexity.

The starting phase has seen corruption on the part of companies that managed the budget on behalf of vulnerable or incapable people. Now no money is transferred to the clients. Services selected by the clients are paid directly. What is crucial in the system is the identification of support needs, which is done by an independent 'Indication office'. Their assessment is crucial for the amount of support that will be received. There is some flexibility in how people can spend their money. However, this must be approved in advance.

Norway



Legal & financial frameworks supporting self-directed support:

The Patient and User Rights Act establishes the right to **user-controlled personal assistance (brukerstyrt personlig assistanse)** (§ 2-1 d). The right applies to persons under the age of 67 with long-lasting and substantial need for personal assistance (over 25 hours of support per week). The right does not include services that require more than one service provider present or night services, unless the user continuously needs such services.



Targets groups covered:

- Persons with physical & sensory disabilities – fully covered
- Persons with intellectual disabilities – fully covered
- Persons with mental health – fully covered
- Elderly people – fully covered
- Persons with nursing or therapy needs – unclear
- Families of children with disabilities – fully covered
- Homeless persons – not covered
- Persons with drugs and alcohol abuse problems – unclear
- Women or children in extreme need – unclear



Data:

There is no data available.



Types of services covered:

- Personal assistance – fully covered
- Daytime activities – fully covered
- Residential accommodation – fully covered
- Home modification or purchase – fully covered
- Physiotherapy – fully covered
- Nursing care – fully covered
- Other medical services – fully covered
- Help for families – fully covered
- Childcare – fully covered

- Schooling – fully covered
- College education 18+ – fully covered
- Training – fully covered
- Support with work – fully covered
- Holidays or respite – fully covered
- Support with leisure – fully covered
- Transport – fully covered
- Community action – fully covered



Who can control the budget for the individual?

	YES	NO
The individual herself/himself	✓	
The individual's family or friends	✓	
An independent professional	✓	
A service provider	✓	
A government or local authority employee		unclear



Opinion:

The welfare state services are strong in Norway. Even if the latter years policies have opened up more and more to private agencies, the main service providing to people with disabilities is given by the government. Norwegian laws regulate the service users' right of self-determination in their own lives and user-involvement in the organisation of health and social services. The county governor has a responsibility to ensure that this is taken care of in the municipalities. Norwegian surveys from the government show that there are big gaps between guidelines in the legislation and people's self-determination in practice. Several people with ID have lost (according to Norwegian law) opportunities to manage their own private money as well as social security contributions. Often there are people who lack knowledge of the person e.g. lawyers, which is appointed to manage the person's money.

Romania



Legal & financial frameworks supporting self-directed support:

Law 448/2006 regarding the protection of rights of persons with disabilities provides legal basis for personal assistance in Romania. However, persons with disabilities cannot act as employers of the assistants themselves. They have an option to choose between personal assistants or a monthly allowance equal to the net salary of the starting social worker. This allowance is paid by mayoralties.



Targets groups covered:

- Persons with physical & sensory disabilities – fully covered
- Persons with intellectual disabilities – fully covered
- Persons with mental health – fully covered
- Elderly people – partially covered
- Persons with nursing or therapy needs – fully covered
- Families of children with disabilities – fully covered
- Homeless persons – not covered
- Persons with drugs and alcohol abuse problems – not covered
- Women or children in extreme need – not covered



Data:

805.653 people with different types and degrees of disability (the total number of people with disabilities, according to National Authority for People with Disabilities).



Types of services covered:

- Personal assistance – fully covered
- Daytime activities – fully covered
- Residential accommodation – partially covered
- Home modification or purchase – partially covered
- Physiotherapy – fully covered
- Nursing care – fully covered
- Other medical services – fully covered
- Help for families – partially covered
- Childcare – fully covered

- Schooling – not covered
- College education 18+ – not covered
- Training – not covered
- Support with work – not covered
- Holidays or respite – fully covered
- Support with leisure – fully covered
- Transport – fully covered
- Community action – partially covered



Who can control the budget for the individual?

	YES	NO
The individual herself/himself	✓	
The individual's family or friends	unclear	unclear
An independent professional		✗
A service provider		✗
A government or local authority employee		✗



Opinion:

The **448 / 2006** law offers many rights and facilities to persons with disabilities, but its stipulations are not always implemented and respected by the public and private institutions. Also, allowances are not sufficient for people with disabilities to manage their needs and acquisitions (especially for people with mild and moderate disabilities). Poverty is an ever-present obstacle.

Spain (Catalonia)



Legal & financial frameworks supporting self-directed support:

A national system provides money ("**pensión no contributiva**") directly to persons with disabilities, or to their families if the persons are ineligible. This system has been running since 1991.



Targets groups covered:

- Persons with physical & sensory disabilities – fully covered
- Persons with intellectual disabilities – fully covered
- Persons with mental health – fully covered
- Elderly people – fully covered
- Persons with nursing or therapy needs – fully covered
- Families of children with disabilities – fully covered
- Homeless persons – fully covered
- Persons with drugs and alcohol abuse problems – fully covered
- Women or children in extreme need – fully covered



Data:

There is no data available.



Types of services covered:

- Personal assistance – unclear
- Daytime activities – unclear
- Residential accommodation – unclear
- Home modification or purchase – unclear
- Physiotherapy – unclear
- Nursing care – unclear
- Other medical services – unclear
- Help for families – unclear
- Childcare – unclear
- Schooling – unclear
- College education 18+ – unclear
- Training – unclear

- Support with work – unclear
- Holidays or respite – unclear
- Support with leisure – unclear
- Transport – unclear
- Community action – unclear



Who can control the budget for the individual?

	YES	NO
The individual herself/himself		✗
The individual's family or friends	✓	
An independent professional	✓	
A service provider	✓	
A government or local authority employee	✓	



Opinion:
N/A

Sweden



Legal & financial frameworks supporting self-directed support:

The Act concerning Support and Service for Persons with Certain Functional Impairments (**Lagen om stöd och service till vissa funktionshindrade, LSS, 1993: 387**) promotes equality in living conditions and full participation in community life for the persons with extensive and permanent functional impairment.



Targets groups covered:

- Persons with physical & sensory disabilities – partially covered
- Persons with intellectual disabilities – partially covered
- Persons with mental health – partially covered
- Elderly people – partially covered
- Persons with nursing or therapy needs – not covered
- Families of children with disabilities – partially covered
- Homeless persons – not covered
- Persons with drugs and alcohol abuse problems – not covered
- Women or children in extreme need – not covered



Data:

21 000 persons with disabilities are using the system.



Types of services covered:

- Personal assistance – fully covered
- Daytime activities – not covered
- Residential accommodation – fully covered
- Home modification or purchase – not covered
- Physiotherapy – not covered
- Nursing care – not covered
- Other medical services – not covered
- Help for families – not covered
- Childcare – not covered

- Schooling – not covered
- College education 18+ – not covered
- Training – not covered
- Support with work – not covered
- Holidays or respite – fully covered
- Support with leisure – not covered
- Transport – not covered
- Community action – not covered



Who can control the budget for the individual?

	YES	NO
The individual herself/himself	✓	
The individual's family or friends	✓	
An independent professional	✓	
A service provider	✓	
A government or local authority employee	✓	



Opinion:

The system is for certain people with disabilities. The family or friends would help when there is a need of supported decision making and this is formalized. The system has worked but faces political challenges by some people who find it too expensive.

United Kingdom (England)



Legal & financial frameworks supporting self-directed support:

The **Care Act 2014** of the Parliament of the United Kingdom has received Royal Assent on 14 May 2014, after being introduced on 9 May 2013. The main purpose of the act was to overhaul the existing 60-year-old legislation regarding social care in England. It regulates a system that supports people in choosing their social services and controlling their individual budget, called **Direct Payments**.

Personal Health Budgets and **Integrated Personal Commissioning** (where a person has combined health and social care funding) are in place from a legislative perspective but still in pilot phase in many places. The **Children and Families Act (2014)**, which introduced personal budgets for education, is still being fully implemented, with target deadlines for conversion to Education Health and Care Plans being missed in many areas.



Targets groups covered:

- Persons with physical & sensory disabilities – fully covered
- Persons with intellectual disabilities – fully covered
- Persons with mental health – fully covered
- Elderly people – fully covered
- Persons with nursing or therapy needs – fully covered
- Families of children with disabilities – fully covered
- Homeless persons – partially covered
- Persons with drugs and alcohol abuse problems – partially covered
- Women or children in extreme need – partially covered



Data:

26% Direct Payments, or 98,735 people.



Types of services covered:

- Personal assistance – fully covered
- Daytime activities – fully covered
- Residential accommodation – not covered
- Home modification or purchase – partially covered

- Physiotherapy – fully covered
- Nursing care – not covered
- Other medical services – not covered
- Help for families – fully covered
- Childcare – not covered
- Schooling – partially covered
- College education 18+ – partially covered
- Training – fully covered
- Support with work – partially covered
- Holidays or respite – fully covered
- Support with leisure – fully covered
- Transport – fully covered
- Community action – partially covered



Who can control the budget for the individual?

	YES	NO
The individual herself/himself	✓	
The individual's family or friends	✓	
An independent professional	✓	
A service provider	✓	
A government or local authority employee	✓	



Opinion:

There is great regional variance in how SDS is implemented in England.

Direct Payments are tied to what is in the Care Plan, so to some extent the social worker decides what the money can be spent on. Flexibility very much depends on the social worker who is to be contacted if the user wishes to spend the budget on something not in the care plan. The answer to this is usually 'No' as it would restrict the chances of "clawback" when the budget is audited by financial services. This policy is attributed to the cutbacks in the funds received by local authorities from government.

United Kingdom (Northern Ireland)



Legal & financial frameworks supporting self-directed support:

Self-Directed Support schemes are being rolled out in Northern Ireland HSC Trusts on a phased approach. Self-Directed Support enables individuals to choose how their support is provided and gives them as much control as they want over their **Personal Budget**. The personal budget can be:

- Taken as a Direct Payment,
- A Managed Budget (where the Trust holds the budget, but the individual is in control of how it is spent),
- The Trust can arrange a service, or
- You can choose a mixture of these options

The **Carers and Direct Payments Act (Northern Ireland) 2002**, among others, aims to provide for the making of direct payments to persons in lieu of the provision of personal social services or carers' services.



Targets groups covered:

- Persons with physical & sensory disabilities – fully covered
- Persons with intellectual disabilities – fully covered
- Persons with mental health – fully covered
- Elderly people – fully covered
- Persons with nursing or therapy needs – unclear
- Families of children with disabilities – fully covered
- Homeless persons – unclear
- Persons with drugs and alcohol abuse problems – partially covered
- Women or children in extreme need – unclear



Data:

Estimated at 12,500 people approx. 60% of total support packages.



Types of services covered:

- Personal assistance – fully covered
- Daytime activities – fully covered
- Residential accommodation – not covered
- Home modification or purchase – partially covered
- Physiotherapy – partially covered
- Nursing care – not covered
- Other medical services – not covered
- Help for families – fully covered
- Childcare – fully covered
- Schooling – fully covered
- College education 18+ – fully covered
- Training – fully covered
- Support with work – fully covered
- Holidays or respite – partially covered
- Support with leisure – fully covered
- Transport – partially covered
- Community action – fully covered



Who can control the budget for the individual?

	YES	NO
The individual herself/himself	✓	
The individual's family or friends	✓	
An independent professional	unclear	unclear
A service provider	unclear	unclear
A government or local authority employee	✓	



Opinion:

The system is still in its infancy. The main issue is service users are concerned about spending the money and front-line staff/management are struggling to let go of the power to do so. Many topics concerning SDS, including legislation and the market environment, need to adapt to the new system.

United Kingdom (Scotland)



Legal & financial frameworks supporting self-directed support:

Social Care (Self-directed Support) (Scotland) Act 2013 - The Bill for this Act of the Scottish Parliament was passed by the Parliament on 28 November 2012, received Royal Assent on 10 January 2013 and came into force on 1 April 2014. Audit Scotland review of implementation (published Autumn 2017) said as top lines: 'Many examples of positive progress in implementing self-directed support BUT no evidence of the transformation required' and 'examples of people supported in new and effective ways BUT not everyone is getting the choice, control and flexibility envisaged in the strategy.'



Targets groups covered:

- Persons with physical & sensory disabilities – fully covered
- Persons with intellectual disabilities – fully covered
- Persons with mental health – fully covered
- Elderly people – fully covered
- Persons with nursing or therapy needs – partially covered
- Families of children with disabilities – fully covered
- Homeless persons – fully covered
- Persons with drugs and alcohol abuse problems – fully covered
- Women or children in extreme need – partially covered



Data:

Self-directed support is seen as the way all social care is delivered in Scotland, but so far about 30%-40% of people accessing support have made a choice about how they are directing their own support.



Types of services covered:

- Personal assistance – fully covered
- Daytime activities – fully covered
- Residential accommodation – partially covered
- Home modification or purchase – unclear
- Physiotherapy – partially covered
- Nursing care – not covered
- Other medical services – not covered

- Help for families – partially covered
- Childcare – unclear
- Schooling – not covered
- College education 18+ – unclear
- Training – partially covered
- Support with work – partially covered
- Holidays or respite – fully covered
- Support with leisure – partially covered
- Transport – partially covered
- Community action – partially covered



Who can control the budget for the individual?

	YES	NO
The individual herself/himself	✓	
The individual's family or friends	✓	
An independent professional	✓	
A service provider	✓	
A government or local authority employee	✓	



Opinion:

Good national legal and policy framework for self-directed support but local implementation does vary by local authority as does the assessment of eligibility for support and the approval of flexibility of use of a budget to meet outcomes – the local councils decide very differently to one another. SDS in rural areas is a challenge due to lack of staff. The system may get too complicated for some people, or the eligibility threshold may be too high.

United Kingdom (Wales)



Legal & financial frameworks supporting self-directed support:

The **Social Services and Well-being (Wales) Act 2014** has come into force in April 2016 and includes significant changes for carers including new rights and new duties on local councils. Direct payments are monetary amounts made available by local authorities to individuals to enable them to meet their care and support needs. Direct payments replace care and support provided directly, or commissioned by, a local authority.



Targets groups covered:

- Persons with physical & sensory disabilities – partially covered
- Persons with intellectual disabilities – partially covered
- Persons with mental health – partially covered
- Elderly people – partially covered
- Persons with nursing or therapy needs – not covered
- Families of children with disabilities – partially covered
- Homeless persons – not covered
- Persons with drugs and alcohol abuse problems – not covered
- Women or children in extreme need – not covered



Data:

120 persons in Ceredigion.



Types of services covered:

- Personal assistance – partially covered
- Daytime activities – partially covered
- Residential accommodation – partially covered
- Home modification or purchase – partially covered
- Physiotherapy – not covered
- Nursing care – partially covered
- Other medical services – not covered
- Help for families – partially covered

- Childcare – not covered
- Schooling – not covered
- College education 18+ – partially covered
- Training – not covered
- Support with work – partially covered
- Holidays or respite – not covered
- Support with leisure – partially covered
- Transport – not covered
- Community action – not covered



Who can control the budget for the individual?

	YES	NO
The individual herself/himself		✗
The individual's family or friends		✗
An independent professional	unclear	unclear
A service provider	unclear	unclear
A government or local authority employee	unclear	unclear



Opinion:

Great variance depending on location.

Main conclusions and recommendations

Progress towards self-directed support as well as deinstitutionalisation remains challenging throughout Europe. Several countries with systems like self-directed support were identified in this mapping exercise, however, all of them indicate a room for improvement, to a lesser or greater degree.

The report shows that many countries have some system of disability benefits and the boundary between disability benefits and personal budgets is not clear. Clear data is generally hard to find and often terms do not map consistently from one country or language to another.

Many European countries have systems of **personal assistance**, but these tend to focus on disabled people of **working** age (e.g. Iceland) and groups who need more support, children and the elderly can be excluded.

Wider system change (self-directed support) is not at a mature stage of development with different levels of take-up (e.g. Finland has just begun implementation, Scotland began in 2013, Germany has model since 2001, Catalonia has had a system running since 1991).

Some countries have systems that can be used in principle, but they are not made very **accessible** (e.g. Italy) or have **no clear system** (e.g. Ireland). In countries like the Netherlands, **independent** bodies are used to assess level of need.

The degree of flexibility in which resources are used can be different in theory and in practice. Such is the case in England, for example.

There are also different approaches to **brokerage** and **planning**, with some countries supporting independent planning (e.g. Flanders region of Belgium).

Lack of funding, low levels of funding, high eligibility and means-testing remain critical issues in many places. Available resources are not always sufficient for purchasing the needed support.

While it is important to ensure adequate funding, there is also a need to make services available and accessible for persons with disabilities.

There is also a difference between the needs of different groups that can benefit from self-directed support. People with **physical disabilities** may need much less help around decision-making and may want to employ their own personal assistants. Hence Self-Directed Support or independent living often focuses on employment of your own staff team. Whereas people with **intellectual disabilities** may need more help with decision-making and this has led to a greater focus on advocacy or brokerage systems. **Older people** may be much less likely to employ staff and may be more willing to purchase services from existing community organisations. People with **mental health problems** may be focused on solutions that include counselling and peer support to provide support while making decisions.

Recommendations:

To develop self-directed support systems that truly support full citizenship and inclusion of individuals, it is important to ensure that the following principles are taken into account.

- **Independent living** - people have the right to be a citizen with full access to ordinary lives – they have a right to live their lives in a way that makes sense to them.
- **Entitlement** – everyone is entitled to enough support to achieve citizenship. People have a right to enough support and also the right not to be over-supported.
- **Freedom** - people should be in control of their own lives. They have a right to make decisions about how they live their life.
- **Openness** - Any rules or systems should be clear and understandable by all parties. It should be possible to have a clear overview of the entitlements, available services, rules, rights and responsibilities.
- **Flexibility** – individuals should be free to use their entitlements as we see fit. They should be able to chose the support they need and change it when their needs and wishes change.
- **Learning** – learning from the experiences of other and knowledge exchange is essential for developing self-directed support systems in your countries.
- **Contribution** - we have a responsibility to contribute and to build stronger communities.

