FUNDING OF DISABILITY SERVICES IN EUROPE: A STATE OF PLAY

ACKNOWLEDGEMENTS

This is a report of the European Association of Service providers for Persons with Disabilities (EASPD) subcontracted to Policy Impact Lab.

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Layout and graphs: www.beelzepub.com

Brussels, March 2020

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This publication has been produced with the financial support from the European Union Programme for Employment and Social Innovation "EaSI" (2014-2020). This publication reflects the view only of the author and the Commission cannot be held responsible for any use which may be made of the information contained therein.

Contents

How to read this report 3

Country selection 3

Sectors of focus 4

Methodology 5

Challenges and limitations 5

Context 7

Funding Models and Strands 9

Introduction 9

Findings 9

- Reserved Markets 11
- Public Procurement 14
- Personal Budgets 17
- Other funding models 18

Providers 23

Sub-sector specific information 25

- Day care 25
- Independent/Supported living 26
- Long-term institutional care 27
- Respite care 29

Impact 30
Sustainability of providers 30
Quality 31
Access 32
Working Conditions 33
Trends 34
Current and future trends on funding 34
Summary and Conclusions 36
References 42

How to read this report

This report presents a comparative analysis of financing of disability care services in 13 European countries: Finland, France, Germany, Greece, Hungary, Ireland, Italy, Moldova, Portugal, Romania, Slovakia, Spain and Serbia. This comparative analysis draws on country-specific factsheets, available as standalone reports on the EASPD website. While this report delves into trends relating to financing of disability care services across the countries covered, the country-level reports provide a detailed overview in each.

Finland
Ireland
Germany
Slovakia
Moldova
France
Hungary
Romania
Portugal
Serbia
Spain
Italy
Greece

Country selection

The selected countries represent diverse social welfare models and in turn different approaches to governance, financing and coverage of social care provision for persons with disabilities. The countries covered in the factsheets cover the main five welfare models[1]:

- ★ **Continental/Bismarkian systems** (e.g. France, Germany) organise social security as an insurance system where the right to social transfers is based on contributions;
- ★ **Anglo-Saxon/Beveridge systems** (e.g. Ireland) propose occupational/fiscal welfare for middle classes and means-tested benefits for the poor;
- ★ **Nordic/Scandinavian welfare system** (e.g. Finland) combines free-market economy and welfare state with equality and social rights for all;
- ★ **Mediterranean model** (e.g. Italy, Spain, Portugal): welfare state has a major role, but a substantial burden of social wellbeing is put on the family;
- ★ **CEE & Balkan countries** (Hungary, Moldova, Slovakia, Serbia). sharing a post-Soviet past are united by the withdrawal of the state from the welfare sectors, and the introduction of an institutionally pluralized welfare system.[2]

1 Urbé, R. (ed.) (2012) *The Future of the Welfare State: A comparative study in EU-countries*, Caritas Europa, Available: https://www.caritas.eu/wordpress/wp-content/uploads/2018/09/130101-PU-The-future-of-the-welfare-state-a-comparative-study-in-eu-countries.pdf; EASPD (n.d.) *Social welfare systems across Europe*, Available: easpd.eu/sites/default/files/sites/default/files/SensAge/d4-social_welfare_systems_across_europe.pdf; Begg et al. (2015) *The Welfare State in Europe: Visions for Reform*, Chatham House, the Royal Institute of International Affairs, Available: https://www.chathamhouse.org/publication/welfare-state-europe-visions-reform#

2 Bartlett, W. (2012) 'The Political Economy of Welfare Reform in the Western Balkans' in: Laderchi, C. and Savastano, S. (eds.) *Poverty and Exclusion in the Western Balkans: New Dimensions for Measuring Poverty*, Berlin: Springer.

Furthermore, the mix includes Europe's richer and economically less well-off countries, and, relatedly, countries that joined the EU at different junctures, including Serbia, a candidate country, and Moldova, with which the EU has an association agreement. The selection also includes countries that are governed and managed centrally, meaning services are organised in the same manner throughout the country (e.g. France), and others, where management and financing of services differs considerably from one region to another (e.g. Italy, Spain, Moldova).

The countries differ also in progress towards independent living and deinstitutionalisation (DI) - this has implications on funding of and priority given to residential and community support services. While for example Finland is advanced in the DI process and abolishment of institutionalised housing, Romania and France have seen increases in numbers of persons with disabilities living in institutions in recent years,[3] and DI has been slow in Greece and Slovakia. After progress in de-institutionalisation between 2009-2012, Italy has seen no decline in this respect since 2015. The countries also differ in terms of the percentage of persons with disabilities living in households with difficulty making ends meet[4] – Greece, Romania, Hungary, Ireland, Italy and Spain, for example, have more PwDs living in household poverty than the EU average (29.6%), while Finland, Germany and France have fewer.

Sectors of focus

This report analyses financing of disability services in the following sectors: day care, supported / independent living, long-term institutional care and respite care, with a focus on adults with disabilities. The term disability includes physical, sensorial, intellectual, psychosocial and Autism Spectrum Disorders.

TABLE 1 | Sectors of disability services covered in the study

Sector	Description
Day care	Day care centres for PwDs, where adults with disabilities who are past school age but not actively employed, spend the day and, with the support of staff, engage in small income-generating activities / leisure activities / learning life and social skills.
Supported living	All services that support PwDs in their daily living. This includes: ★ daily activity support / personal assistance (e.g. in personal care, daily living activities or homemaking); ★ home care services (e.g. telecare); ★ residential services in community settings (e.g. apartments of one / small number of PwDs with the support of staff for limited periods of time / on a 24-hour basis).
Long-term institutional care	Long-term institutional care for people with disabilities in institutions or a residence where a large number of PwDs are taken care of by carers.
Respite care	Residential services where people with disabilities who usually live at home with their families / carers, spend short periods of time to give respite to their families / carers.

3 ANED. 2019. *The right to live independently and to be included in the community in the European States: ANED synthesis report.* Available at: https://www.disability-europe.net/theme/independent-living

4 Eurostat. 2019. *People with disability: housing and finance.* Available at: https://ec.europa.eu/eurostat/web/products-eurostat-news/-/DDN-20191024-2

Methodology

The aim of this study is to produce country factsheets on the funding of disability care and support services in Europe and provide a comparative analysis. It addresses three key objectives:

- Assess the **state of play of initiatives and public policies taken by public authorities** from national to local level in the countries covered, looking into:
  - Funding – sources, amounts, funding models;
  - Governance – institutions involved, division of governance, management and financing functions;
  - Upcoming trends, initiatives, reforms which could impact the near future.
- Assess the **impact of these policy developments on the disability services** in terms of:

service quality and innovation including the ability to implement the UN Convention on the Rights of Persons with Disabilities (UNCRPD);

- accessibility for users, including availability of specific services needed;
- workforce-related developments including staffing levels, wages, training, recruitment and retention, etc;
- investment needs;
- sustainability of providers.

- Produce a **cross-European analysis of the factsheets, highlighting main trends** and developments for European stakeholders.

This study is developed using a qualitative research design. As a first step in the research, country experts on disability services in each of the eight countries prepared qualitative factsheets on the funding of the social care and support services sector for persons with disabilities with a focus on adult care services: day care, supported living, long-term institutional care and respite care. The data collection methods employed in preparing the factsheets include:

- **desk research** of national regulations and policies, academic and applied studies and assessments of policies and practice, country-level information in comparative EU reports. Given the focus on funding of services in four care sectors from day care to supported living, long-term institutional care and respite care – a specific emphasis was placed on exploring nationally available data on funding amounts and mechanisms.
- **Interviews** with 1-2 regulators, 3-4 service providers, at least one service user or representative of users, at least one service provider staff or representative and an expert with relevant contextual knowledge.

The resulting country-level factsheets were developed triangulating the collected data and reporting on those findings that are confirmed by multiple of the sources employed.

As a second and final step, the authors of this report conducted a comparative analysis of the key research questions and data gathered on specific indicators they imply.

Challenges and limitations

As in any research study, the present one is delineated by some challenges and limitations:

- **No agreed upon definition of funding models exists**. While the EASPD 2019 report[5] outlines four distinct funding models[6] used across Europe, in practice, some funding models overlap, while others are rather strands of funding models rather than funding models per se. Furthermore, the majority of stakeholders interviewed are not familiar with this classification and do not use the respective terminology to describe funding mechanisms at play, rendering it harder to identify which funding practices fall under which funding model.
- **Gauging the impact of funding models on such aspects as quality of service, working conditions and service users**: the emerging findings demonstrate obstacles to accessibility of services and working conditions, however the larger part of the factsheets do not make the link with the funding models employed in the country. This is due to various reasons including

5 EASPD.2019. *How to Fund Quality Care and Support Services: 7 key elements. EASPD Conference Report 2019.* Available: https://www.easpd.eu/en/content/new-easpd-report-how-fund-quality-care-and-support-services-7-key-elements

6 Reserved markets, public procurement, personal budgets and private investment.

lack of existing information (either from desk research or from the interviewed stakeholders); as well as the fact that such aspects (e.g. accessibility of care services) might not necessarily be linked to funding models (e.g. inaccessibility of day care services might be due to lack of transport or urban/rural differences). Many countries also experienced profound reforms in their social and care policies over the past few years. For these countries, it is too soon to assess the effects of the funding model on the quality of services, user access and working conditions.

- ★ **Coverage of countries with centralised and decentralised governance, management and financing of services posed a challenge.** For Spain, Italy, Germany and to some extent Romania, the factsheet authors presented the governance structure and insights on the research questions based on examples in specific regions, as equal representation of the situation in each administrative region was not possible within the scope of this study, and in most cases data across local authorities is not aggregated. This poses a challenge and limitations on comparison with other countries.
- ★ **Obtaining budget amounts for each care / support sector.** Most countries do not provide aggregated (or updated) data for budgets of care services for PwDs, much less for each care sector, thus obtaining budget amounts (especially at local level) is challenging to impossible depending on specific country. For example in Moldova spending data on disability care is not public.
- ★ Relatedly, **obtaining information on trends** (e.g. increasing budget for care services) while at times available, does not necessarily portray an accurate picture, in the sense that even if the budget is increasing, it is difficult to obtain information on whether such amounts are increasing in a parallel manner to increasing demand, or are sufficient to cover enough (quality) services for all PwDs.
- ★ **Gauging the effect of the COVID-19 crisis**: while emerging as a substantial factor in affecting funding of care services in some countries, this did not emerge as an impacting factor across the board. Desk research on this is still in its infancy and interviewed stakeholders could not always confirm how / whether the pandemic is / will change funding of care services for PwDs.
- ★ **Comparing budget figures** included in country-level reports: until further integration in the EU of definitions of disability care and what kind of services fall under which sector and a centralisation of data available at country level any meaningful comparison is elusive.
- ★ Comparing share of public versus private provision of care services is also complicated by availability of comparable data – in some cases the research draws on share of providers based on absolute numbers, in others on the number of users served, or budget spent on a specific type of service.

Context

Disability services in Europe currently are undergoing profound changes as they shift towards the human rights approach,[7] enabling their clients to integrate into society and fulfil their potential. Such rights are embedded in both regional and international human rights frameworks. The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)[8] – ratified by the EU in 2009 – enshrines, among other rights, the right to an adequate standard of living and social protection (Article 28) and the right for PwDs to live independently and be included in the community (Article 19). The EU in March 2021 launched the Union of Equality - Strategy for the Rights of Persons with Disabilities 2021-2030[9], which recognizes accessibility as an enabler of rights, the right of PwDs to decent quality of life and living independently and equal access among other rights. The Strategy gives a direction to service provision for persons with disabilities and links with the UNCRPD, foreseeing support to its implementation across the bloc. The previous strategy (2010-2020) led to the development of other initiatives such as the European Accessibility Act[10], a landmark agreement which was adopted by the EU in 2019. Rights for persons with disabilities are also enshrined in other frameworks such as the European Pillar of Social Rights (EPSR), proclaimed in 2017, and fortified with an Action Plan in 2021 to guide its implementation. While the EPSR does not target disability specifically (apart from Principle 17), it sees social development in Europe holistically and establishes such rights as the right to social protection and to home-care and community-based services.

Regulators and providers of disability care services have to adhere to the principles and values enshrined in the international frameworks while also facing pressure to be more efficient and adapt to the market logic. That is to say that international and national human rights and quality frameworks increasingly focus on the rights of the users but funding levels are not necessarily increased to make needed adjustments. As seen in the description of for example public procurement rules, price is often the main if not only criterion for regulators to select providers. Many countries in and around the EU still feel the impact of the economic crisis on social spending, with another one unfolding as a result of the COVID-19 crisis. According to Eurostat data on general government expenditure on social protection[11], social spending in EU countries varies. In 2018, countries such as Greece and Hungary struggled to recover to pre-crisis funding levels; while France, Italy and Germany increased their social spending quite significantly. **Amid increasing demands for quality and results, funding for disability-related services in many countries remains limited and increasingly uncertain.** Funding for disability services also varies due to different practices and arrangements in different welfare systems (described earlier).

There is a gap in knowledge of what funding models are used to finance disability care services across Europe and how the existing funding models and structures created in each welfare model impact the opportunities to deliver and outcomes of services for persons with disabilities.

7 EASPD position on the EU Multiannual Financial Framework regulations post 2020. 2018. Available at: https://www.easpd.eu/sites/default/files/sites/default/files/Policy/MFF/easpd_position_on_mff.pdf

8 https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html

9 https://ec.europa.eu/social/main.jsp?catId=738&langId=en&pubId=8376&furtherPubs=yes

10 https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=COM:2015:0615:FIN

11 Eurostat. 2020. *General government expenditure by function (COFOG)*. Available at: https://ec.europa.eu/eurostat/databrowser/view/GOV_10A_EXP__custom_121973/default/table?lang=en

Filling this gap gains increasing importance as the number of persons with disabilities in Europe, and the need to not only improve but increase service provision to this group, is growing. According to the EC, by 2020 approximately 120 MN Europeans were expected to have a disability.[12] Furthermore, together with other vulnerable groups, persons with disabilities stand to be more affected by the impending crisis as a result of COVID-19. Some 30% of people with a disability are at risk of poverty or social exclusion in the EU, compared to 21.5% of people without disabilities.[13]

In view of this, the findings emerging from the factsheets as well as the comparative analysis, a better understanding of the funding models (and policies which govern them) is obtained, providing a clearer picture of how service provision is affected and identifying gaps and priorities for the future. At the same time, concerted effort to gather, harmonize and make accessible data on spending on social care services, access to such services and monitoring of their quality across countries in Europe to facilitate comparative research on financing of care services and implications on access to and quality of services.

12 Chiara Scaratti et al. 2018. ‚Mapping European Welfare Models: State of the Art of Strategies for Professional Integration and Reintegration of Persons with Chronic Diseases', *International Journal of Environmental Research and Public Health* Apr; 15(4): 781. Available at: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5923823/

13 European Commission. 2017. *Progress Report on the implementation of the European Disability Strategy (2010 - 2020).* Available at: https://ec.europa.eu/social/BlobServlet?docId=16995&langId=en

Funding Models and Strands

Introduction

According to the EASPD 2019 report on funding models[14], European countries have laregly relied on four main models in the last decade:

- ★ **Reserved Markets** refers to a system in which authorities can reserve access to specific public markets for organisations having certain characteristics (e.g. not-for-profit organisations). In a broader understanding of reserved markets, any type of requirements for providers creates a reserved market in the sense that not all providers can enter the market. Thus, service vouchers as used in Finland are also considered a strand of the reserved market model in the framework of this study.
- ★ **Public Procurement** is understood as the way through which public authorities and state-owned enterprises purchase services, works and goods. Standard public procurement uses competition between providers in order to get the best value for money, albeit variations e.g. in Finland factor in quality in the award of contracts.
- ★ **Personal Budgets**: an amount of funding disbursed to an individual by a state body in order to enable the individual to make their own arrangements to meet specified support needs rather than having their needs met directly by the state.
- ★ **Private Investment**: the investment made by entities (which are not conventional public sector bodies) into social services. These investors require a financial return (or to break even) on their investment. Private investment can include capital/equity investment, public private partnerships, social impact bonds, etc. This funding model features least in this report as it is rarely used to fund day-to-day services particularly within the EU.

As the report confirms, overlaps between – as well as different strands within – each model exist. In addition to these four categories, the study found evidence of additional mechanisms through which service providers establish and/or sustain services, namely **public grants and subsidies** – direct public transfers to providers, and **user co-payments** – fees charged to users for the minimum level of service (i.e. not for additional services, as such are available for extra fees which are not considered for this study).

Findings

The data collection conducted for this research shows two of the above-listed funding models are most often used to finance private (non-profit and for-profit, where applicable) provision of care services for persons with disabilities in the countries under study, namely public procurement and reserved markets. (see Table 2) In some countries, public authorities and /or municipalities deliver most care and social services directly (Finland, Hungary, Moldova, Romania, Serbia). Personal budgets are used to a limited extent in the countries under study, and are in piloting mode where they are used. Germany, where personal budgets are used as a permanent funding model, relies on this mechanism for funding disability care services only to a limited extent. The study gathered some evidence of countries considering the introduction of personal budgets with the aim to expand user choice (e.g. Slovakia, Portugal). Private investment is also seen in several of the countries under study, but it should be noted that even if so, the share of services funded through private investment is marginal – in most cases private investment is used for infrastructure or to pilot new services.

Grants and subsidies, including from public and private sources, as well as EU funds, are used to fund disability services in some countries (Table 2). In addition, user co-payments play a role in sustaining service provision in some countries as Hungary and Slovakia (see Out of pocket payments).

14 EASPD. 2019. *How to Fund Quality Care and Support Services: 7 key elements. EASPD Conference Report 2019.* Available: https://www.easpd.eu/en/content/new-easpd-report-how-fund-quality-care-and-support-services-7-key-elements

TABLE 2 | Use of funding models **across countries studied**

Reserved markets	Public procurement[15]	Personal budget	Public grants and subsidies (incl. EU funds)	Private investment (marginal)
Finland, Germany, Greece, Hungary, Ireland, Italy, Moldova[16], Portugal, Romania, Serbia, Spain, Slovakia.	Finland, France, Greece, Ireland, Italy, Moldova, Portugal, Romania, Serbia, Spain.	Finland (piloting), Germany, Ireland (piloting).	Germany, Greece, Italy, Moldova, Portugal, Romania, Serbia, Slovakia, Spain.	Spain, Greece, Italy, Moldova, Slovakia, Portugal and Romania.

Table 2 does not indicate the extent of use of each funding model, this is addressed in the sections below, to the extent this is possible based on available data. Table 3 identifies the main funding model in each country under study.

TABLE 3 | Main funding models per country

Country	Main funding model[17]	Other existing funding models
Finland	Public procurement	Personal budget, reserved markets (service vouchers, grants & subsidies)
France	Reserved market (restricted public procurement)	None
Germany	Reserved market (service agreements)	Personal budget, reserved markets (grants & subsidies)
Greece	Public procurement	Reserved markets, private investment, European funds
Hungary	Reserved market	Grants and subsidies (e.g. through the Vatican Concordat for faith-based organisations)
Ireland	Reserved market (service agreements)	Personal budget, public procurement
Italy	Reserved market (service agreements)[18]	Reserved markets (service vouchers, grants & subsidies), public procurement, private investment
Moldova	Public procurement	Public grants, private grants (incl. individual donations), reserved markets (service agreements/public private partnership – regulated but scarcely used).
Romania	Subsidies and grants from the public sector	Sponsorships and donations, public procurement, user contributions, social economy activities, European funds
Serbia	Reserved market (restricted public procurement)	Reserved market (grants & subsidies)
Spain	Reserved markets (service agreements)	Private investment, public procurement, reserved market (grants & subsidies)
Slovakia	Reserved markets (service agreements)	Private investment and grants, European Funds
Portugal	Reserved markets (service agreements)	European Funds, Reserved market (restricted public procurement), private investment and subsidies

15 In France, Italy, Serbia, and Spain, access to public procurement is restricted to providers who have been accredited/licensed.

16 Little used though in principle regulated.

17 Co-payment and direct public delivery are excluded from this table.

18 According to stakeholder feedback out of pocket payments for informal care may in fact constitute the main ‚funding model' – the exact scale of such informal service provision is difficult to gauge but estimates are that it is sizeable.

An analysis of information in Table 2 and Table 3 shows that:

- ★ Reserved market is most used as a main model for financing disability care services across countries studied. Importantly, however, this funding model encompasses others, for example public procurement is often restricted to specific provider types.
- ★ Public procurement is sometimes used as the sole funding model for financing of disability care services (France), or not at all (Hungary).
- ★ Conversely, personal budget is always used in combination with other funding models. This is mainly due to the fact that several countries are still in the pilot phase of introducing personal budget as experiments (Ireland and Finland).
- ★ Private investment, while existing in many countries under study, is rarely used as a funding mechanism for care and social services for PwDs, this only being true for Moldova.
- ★ Public subsidies and grants are typically a mechanism that financially supports providers in addition to public budget allocations. In some countries and for some types of organisations, it can be the main funding model. For example in Hungary, faith-based organisations in addition to funding available to non-state actors through the reserved market mechanism also receive state-subsidies under an agreement with the Holy See. In Romania, grants and subsidies is the main funding model for non-profit providers.
- ★ Private financing plays an important role in sustenance of providers in Hungary, Moldova and Slovakia, including from private donations and sponsorships.

The level of funds channelled through each funding model is difficult to identify. However, in all countries that have personal budget, this funding mechanism represents a marginal portion of the overall budget allocated to care and social services for PwDs. Private investment also represents a marginal part of the overall budget.

The sections below detail each funding model and provide some comparison of the funding modalities for each country using the funding model under consideration.

Reserved Markets

This funding model is generally used to facilitate the involvement of private non-profit providers in the delivery of social and care services. It ensures a plurality of providers as well as a certain quality level via market restrictions. Possible strands include service agreements between funding institution and providers and/or provider associations, different forms of public procurement, subsidies and grants, and service vouchers.

Service agreements: For the purpose of this study, we call "service agreements" direct transfers from the public funding authority to the providers on the basis of a pre-established agreement between them.

Public procurement in reserved markets: Some countries restrict access to public procurement to only a few types of providers (e.g. licensed providers). This funding strand was included within the public procurement funding model section.

Service vouchers: Service vouchers are delivered by public authorities to users or directly to authorised providers based on provided services.

The table below details the use of each funding strand under reserved markets per country:

TABLE 4 | Reserved market strands per country

Service agreements[19]	Service vouchers	Restricted public procurement
Greece (only for sheltered workshops), Italy, Spain, Hungary, Ireland, Germany, Moldova, Slovakia, Portugal,	Finland, Greece, Italy	France, Greece, Moldova, Portugal, Spain, Serbia

19 The term service agreement is used for the purpose of comparison, countries each use a different term for this funding strand.

Service agreements

TABLE 5 | Service agreements framework per country

Country	Negotiation actors	Duration of agreement	Object of negotiation	Budget limit	Requirements for providers
Germany (Rahmen-vertrag)	Umbrella organisations and local authorities	Once a year of every two years depending on local rules	Price of each service	No specific budget limit	Standards requirements for providers as set in the law and implemented locally
Hungary	Providers and state	Three years (in some rare instances annual)	Number of users (flat rate)	Not known	Licensing
Ireland (Service agreements or grant aid arrangements)	Providers (only not for profit) and Community Healthcare Organisations (CHO) or Health Service Executive (HSE)	Yearly negotiation	Yearly budget for service providers.	Grant Aid arrangements < EUR 250,000 Service arrangements > EUR 250,000	Registered charities, public and employer liability, quality standards (set by Health Information and Quality Authority)
Italy (*accredita-mento*)	Providers and local authorities	Varies, can be up to five years.	Unit of service price	NA	Quality standards
Portugal	State and providers (mostly non-profit)	Two-year period, renewable after positive assessment, payment on a monthly basis	Typical service agreement: fixed payment per user/ service Atypical agreement: variable ans set in the agreement	NA	Norm compliance on facilities, functioning, staff/users ratios, monthly reporting, biennal assessment, ethical requirements
Slovakia	Municipalities or region and non-profit private providers Or: Ministry and non-profit private providers	Upon request and variable	Price per user per service type (the user fee depends on the sufficiency of the public contribution received)	NA	Registration in the Central register of social services providers (administered by the Government)
Spain (Social partnership agreement)	Providers and regional authorities	1 year (possibly to renew 1 year)[20]	Budget for the period and price of service	NA	Registration and standards compliance

20 Plans under way to extending agreement duration to four years to provide stability to providers and users.

For all the above listed countries, service agreements is the main funding strand, although not explicitly referred to as such in many of the countries. It is used in all four areas of care services under consideration. Moldova likewise uses service agreements but to a limited extent and this practice is not expressly regulated by law. Romania also has partnership agreements between local authorities and private providers. However, this system is very marginal and is not described here.

Generally, service agreements are used to guarantee some free choice of providers while maintaining a service that is locally or community based and adapted to the local needs. In some countries, it also has more practical advantages like in Italy where service agreements are meant to avoid the administrative burden of having repeated call for tenders. In Hungary, the reserved market system and tri-annual licensing agreements that include a fixed number of users ensures that the Hungarian state can control the budget allocated to services, but also gives opportunity to adjust services to local or regional specificities, such as certain demographic or economic characteristics of a region. Expert interviews in Hungary suggest, however, this opportunity is not always used to tailor approved services user numbers to local needs.

The paragraphs below provide insights on each country's specificities.

Actors of the service agreement:

In all countries, service agreements are signed between local/regional authorities and private non-profit (majority) and for-profit providers.

Local/regional authorities vary in each country. For federal countries (Spain and Germany), the contracting authority varies in each region. It may also vary depending on the sector of care (e.g. Germany). In Ireland, which is a unitary state, regional Health authorities (governed by the same national laws) are the contracting authorities. In Italy, which is a unitary state with elements of delocalization in some areas of service provision, contracting authorities for social services vary at sub-regional level.

Eligible providers are usually private non-profit and for-profit providers, although in some countries for-profits are financed through other mechanisms. In Ireland, providers signing service agreements are not for profit providers and for-profit providers are funded through public procurement. Slovakia has a similar scheme that prevents for-profit providers from accessing service agreements. For all countries, providers have to meet certain quality control requirements to be able to deliver social and care services to PwD. In Ireland, Slovakia and Spain, providers have to be registered while in Italy and Germany, they only need to meet the quality requirements. In Hungary, although for-profit providers can be funded through the reserved market mechanism, their number remains insignificant across social services for PWDs, mostly because they can only be funded up to a legally set 30% of the flat rates regulated annually in the Budget Act.

In Germany, providers are represented by umbrella organisations that are in charge of negotiating with the contracting authority. The grouping of providers (in this case, usually private not for profit organisations) provides them with stronger negotiation power. As a result, there is little to no competition between service providers. Price negotiation ensures that prices do not spike due to the absence of competition. The fact that umbrella organisations are in charge of negotiating the price also plays a role in ensuring the prices are not cut. In Ireland, in 2019, the nine biggest disability service providers formed a Disability Action Coalition to lobby for the future of their services.

Object of negotiation:

In Germany and Italy, the price of each service is negotiated. In Germany, providers are free to provide the services to the extent of their capacity and the service they provide is then paid for by the local funding authority according to what was agreed. Providers receive payment only for the services they provide.

In Ireland, the yearly budget of providers is negotiated, partially based on the services delivered, partially on the amounts received in previous years. Stakeholder feedback suggests that criteria for funding are not clear and providers have difficulties planning their income. If providers need additional funding, they have to ask and justify what the funding is for. The HSE has the upper hand on negotiations and decide the number of services to be delivered and the price. In Spain, both the budget for the year and the price of services are negotiated.

In Hungary, the object of negotiation is the number of users for the three-year period (and in some rare cases annually), whereas prices are fixed by the state.

Duration of the agreement:

The duration of the agreement varies from country to country. In Ireland, budgets are renegotiated every year. In Germany, negotiation takes place every year or two depending on the region. In Hungary, it takes place tri-annualy. In Italy and Slovakia, the duration of agreements varies but are usually valid for several years.

In Spain, authorities at the time of this study in late 2020 were planning to extend the duration of the agreement to four years to increase stability and sustainability for both users and providers. This in turn reduces the administrative burden of agreement renewals. In Italy and Spain, the rational for introducing service agreement was to guarantee the continuity of social and care service delivery, as well as to provider stability for providers and users. Both countries have decided for a longer agreement duration.

The duration of the agreement is key: if the agreement is too short and the system appears unstable (with unclear requirements to obtain sufficient funding like in Ireland), this risks affecting the sustainability of providers. As a result, providers are wary to invest or innovate because they fear they might run out of funding or not obtain funding for the following year. Agreements for several years do address the sustainability issue in some cases. However, long lasting agreements might produce a negative impact on quality unless quality control is ensured throughout the duration of the agreement.

Service vouchers

In practice, service vouchers are direct payments from the funding authority to the provider or to the provider through the user (Greece). The PwD can claim services to the provider who gets paid the amount of the voucher. Vouchers are introduced in Finland and Italy to provide PwD with more freedom of choice. However, it is not certain that this is the case in practice. In Italy, the voucher monetary value depends on the income of the PwD and relatives. In Finland, the use of vouchers is not nation-wide and was introduced recently by some municipalities. This is a little used mechanism and the evidence gathered for this study does not present a clear picture how the use of vouchers affects service delivery and providers. An exception to this is Greece, where this mechanism is linked with issues for the providers. The process of the funding reaching beneficiaries and then getting transferred to the service provider results in delays and reportedly serious cashflow problems for the latter, further resulting in temporary cessation or delays in salary payments and hiring freezes.

Public Procurement

TABLE 6 | Public procurement framework per country

Country	Accreditation required	Contracting authority	Delivery	Rationale for use	Main funding model
Finland	Yes[21]	Municipalities	Local (municipalities)	For contract with value >EUR 400,000	No
France	Yes	Departmental councils and regional health agencies	Local level (departments)	Only funding model	Yes
Greece	Yes[22]	Central and local public authorities	Central or local	Reserved market to ensure coverage of needed services at local level	Yes
Italy	Yes	Municipal authorities or their groupings	Local (sub-regional)	Services not covered by the "accreditamento"	No

21 Two types of licensing applies. Private providers have to apply for a permission to practice from the National Supervisory Authority for Welfare and Health (Valvira). Professionals in social and health care must apply for the right to practice as licensed professionals from the same agency. They are registered in the national register and all employers (regardless of type of provider) are obligated to check that the persons they employ are registered.

22 Providers (public or private) need to have an operating license.

Country	Accreditation required	Contracting authority	Delivery	Rationale for use	Main funding model
Ireland	No[23]	HSE (Health Service Executive) – central authority	e-tendering system, central level	Used only when service arrangements are not enough to meet demand	No
Moldova	Yes	Local authorities	e-platform, local level	For contract values above 400,000 MDL (circa 23,000 EUR)	Yes
Romania	Yes	County and local authorities	Local level	To meet local needs	No
Spain	Yes	Regional authorities (autonomous communities)	Local level	NA	Depends on type of service provided and on provider
Serbia	Yes	Municipalities	Local level	Plurality of providers (not only public) and provide services that municipality is not able to offer directly	Yes
Portugal	Yes	Regional level	Through ESF funding and the National Institute for Rehabiliation	MAVI (Independent Living Support Scheme) programme piloted through ESF funding.	No

Public procurement is the main and effectively[24] the only funding model in France. In Finland use of public procurement is significant – it is the main funding model after direct provision and contracting of joint municipal authorities. Public procurement is also the main funding model in Serbia but only when municipalities do not provide the service directly. In Greece, public procurement is organised both as an open procedure and under reserved markets, for example to establish day care scentres for persons with disabilities (KDIF). In Serbia, there is a trend towards increased use of public procurement to increase the number of services and providers available. In Moldova, public procurement is also the main funding model for private providers, but even so used to a limited degree by public authorities. Particularly local authorities are not experienced with the use of this model and some do not even know they can apply it. Some public procurement calls end without selecting a winning provider due to limited interest in applying – this is linked by interviewed stakeholders to mistrust between public authorities and private providers. In some countries, public procurement can also be considered as a reserved market model when providers need to be registered to participate in public procurement.

In Spain, Romania, Ireland, Portugal and Italy, public procurement is not the main funding model. In Ireland, public procurement is only used when the needs exceed what was initially foreseen in the existing funding models and acts as an ad-hoc extra funding to provide the needed services. Romanian administrative units are reportedly also not using public procurement systematically.

In Portugal, public procurement-like funding model is only in use for the MAVI programme, an independing living support scheme funded partly ba the European Structural Funds and national co-payments. MAVI operates through a network of CAVI's (Independent Living Support Centres

23 Except for long-term institutional care services, where all providers have to be certified by the Health Information and Quality Authority (HIQA)

24 Stakeholder feedback suggests that in some but rare cases providers are paid from out of pocket fees entirely.

), managed by private non-profit organisations, who are considered, for the purpose of this programme, as the programme's beneficiaries. Funding is disbursed to these organisations who are responsible for selecting the personal assistance users (target group), for hiring and training the personal assistants, and managing all operational activities. These organisations were selected through a public-procurement-like competitive bidding procedure within a reserved market, launched at regional level, open only to non-profit organisations accredited.

Germany, Hungary and Slovakia are the only countries under review where public procurement is not used at all in the sectors under review.

Eligible providers:

Public procurement is used in all four sectors under review. Public procurement is used to outsource the provision of services and therefore providers funded through public procurement are rarely if ever public. In Ireland, public procurement is used only for private for-profit providers because other providers are already funded through othermodels.

Funding delivery:

The delivery of funding to providers also varies. In France, providers get reimbursed after the service was delivered. In Romania, private providers (usually NGOs) are also reimbursed after delivery of the services. The reimbursement is based on the minimum standards, which means that providers get a lump sum. Stakeholder feedback from Romania suggest that private providers prefer this funding model to for example grants, because fees per service user are regulated by applicable procurement law in the first case and in the latter case they are reimbursed on actual costs incurred.

Impact on service provision:

Public procurement is sometimes assessed as problematic in the countries under review. While not necessarily always the case, public procurement may create an incentive to decrease the costs of services at the expense of their quality. The quest for the best quality-price ratio may lead to a decrease in quality in comparison to other funding models.

In Finland, the initial introduction of public procurement in 2007 resulted in a focus primarily on price rather than quality. Reforms took place in 2016 to address this issue. In 2017, the Parliament examined an initiative to remove public procurement from the available funding model for social and care services for PwD. The appointed expert group produced guidance and it was decided that public procurement would continue according to this guidance emphasizing an increased focus on quality. Public procurement almost always implies the risk that price will be considered over quality requirements. This may therefore endanger the sustainability of small providers who cannot afford to cut down prices while big providers can.

In Serbia, similar problems have been observed with municipalities awarding tenders to new entrants in the market over experienced providers, mainly because of lower prices (stakeholder feedback). Monitoring of the quality is deemed insufficient and older/smaller providers also risk being put out of business because they do not cut service prices. Quality of services contracted through public procurement in Moldova was also reported as questionable because of the lowest price being the main award criteria.

On the other hand, public procurement is the preferred funding model for providers of PwD care services in Romania. According to public procurement regulation, providers are paid standard fees for services contracted this way as opposed to grants and subsidies, under which they are reimbursed in. lump sums rather than standard costs of providing services.

Personal Budgets

TABLE 7 | Personal budget framework per country

Country	Status of PB (pilot/ permanent)	Introduction date	Services available for PB	No users	Amount	Duration of PB (reassessment)
Germany	permanent	2001	Personal assistance	Less than 5% of PwD	Average between EUR 200-800 per month	Reassessed at least every two years – permanent mechanism
Ireland	Pilot phase	2019	Personal assistance	180 adults	NA	Pilot phase until 2021
Finland	Experimental phase	2016[25]	Personal assistance	NA	Total budget: EUR 2.9M	Pilot phase until 31 Dec 2021.

Only three of the countries under study were at the end of 2020 using personal budgets: Germany, Ireland, and Finland. The rationale to introduce this funding model is to provide autonomy to PwDs. Managing a personal budget means more free choice regarding the provider of the needed services and more tailored services to PwD needs.

Personal budgets in all three countries are used for personal assistance. Personal assistance includes care and social services that can take place in the home or outside the home. The way the PwD can use the personal budget depends on their needs assessment. The budget is not like a pension that the PwD can use as they want, it is meant to pay for needed services.

In Germany, PwD pay for the services themselves with the personal budget they receive and get a receipt from the provider. In Ireland, there are two additional ways to manage the personal budget. The HSE or disability service provider, or a broker can help PwD to manage their budget.

The extent of the use of personal budget is marginal in all three countries. Finland and Ireland have a purposefully limited use of personal budgets because this funding model is a pilot. In Germany, personal budgets exist since 2001 but use remains marginal. Stakeholder feedback on how personal budget works in Germany suggests that management of the budget is not easily accessible to all PwD and that the administrative burden is transferred from the funding authority to the PwD. The benefits of having more freedom of choice and tailored services are offset by increased paperwork and cumbersome budget management. This funding model therefore remains marginal in Germany's case as it requires some management skills.

Conditions to access the personal budget will be further defined after the pilot phases in Finland and Ireland. In Germany, any PwD who asks and meets the requirements is entitled to get a personal budget but less than 5% of PwD use this mechanism.

In Germany, the majority of personal budgets vary between EUR 200 and 800 per month. In Finland and Ireland, the amounts will be further defined after the end of the piloting phases. In Finland, EUR 2.9 million was earmarked for personal budget financing.

The introduction of personal budget is likely to have impact on the quality of services as it establishes a consumer relationship between the PwD and the provider. PB is only at the very early stage in Finland and Ireland so it is difficult to provide insights on the impact on the quality of service. In Germany, providers were somewhat reluctant

25 A three-year pilot project (1.6.2016–31.5.2019) developed and piloted the PB model as a part of practical work with clients in 20 municipalities in Finland in co-operation with three Universities of Applied Sciences, different companies and communities. This experiment was implemented in preparation of the Finnish act on freedom of choice (customer choice), which was to be a part of the large reform of regional government, health and social care services that however was cancelled in spring 2019 when Prime Minister Juha Sipilä's government resigned.

to the introduction of personal budgets. While service providers are regulated (even though quality control is not perfect), the PB allows to break the social triangle between the state (funder), the service provider (usually welfare organisation certified to provide service) and the PwD (beneficiary). With the personal budget, the PwD can decide to obtain services through providers who are not part of this triangle and therefore do not have to meet the same quality standards. Whether the worries of providers have materialised is unknown.

The commercial client-provider relationship created by PB is on the one hand challenging for providers as it forces them to change their offer of services, e.g. tailor their offer more to the needs of individual PwD rather than having (an already flexible) standard offer to all beneficiaries. On the other hand, it remains to be seen after PB is more widely used and impacts can be gauged whether the intention of expanding user choice also brings quality gains.

Other funding models

Public grants and subisidies (including EU funds)

In Finland, Germany, Greece, Hungary, Italy, Moldova, Romania, Serbia, Slovakia and Spain, providers can also receive grants and subsidies as direct public transfers to providers. However, these payments correspond to very different realities in each country.

In Finland, grants are transfers from the national government budget to the local budgets. The municipalities can then decide to outsource the service or to provide it directly with the funding of the grant. Additional subsidies can be received if conditions are more difficult in a specific municipality (e.g. remote). In 2020 the central grants covered 25,46 % of the total public service provision[26] in municipalities, with the rest financed from municipal budgets and direct tax collection.

In Germany, subsidies are available to providers in some municipalities to cover the so called ‘investment cost' (e.g. rent of facilities or purchase of a means of transport).

In Greece, EU Structural and Investment Funds – the European Social Fund through a Partnership Agreement for the Development Framework (ESPA, for the acronym in Greek) cover a significant portion of the cost of providing disability care services under some of the government-run programs like the Help at Home home-care programme.

In Hungary, faith-based organisations in addition to being financed through the reserved market mechanism described earlier can also receive subsidies under the Vatican Concordat[27]. The subsidies are annual, and have been extended to churches beyond the Catholic Church. In addition to what faith-based service providers receive through the reserved market system, they can get subsidies to to match the costs of services run by state-owned providers. Extra subsidies are further allocated to churches based on the total amount of money that *all state-owned and municipality-run services* spent in the previous year. (see Hungary factsheet for more information). The somewhat privileged financing of faith-based organisations compared to providers that are NGOs means the former have additional funding to improve their service quality, although feedback suggests this is not always the case. NGOs in Hungary can also apply for grants from the Hungarian state, but this funding cannot always be used for day-to-day running of services.

In Moldova, public grants work similarly to service agreements as implemented in other countries, whereby the state can use this model to competititely select and fund both non-profit and for-profit providers, particularly in the area of socio-medical services, and for PwDs specifically for social medical homecare services and only within the compulsory health insurance. Under this funding model, the state pays the cost of services provided by a private service provider, usually calculated per capita and according to the number of beneficiaries served. Providers wishing to receive public grants have to draft budgets for all planned expenses, which are then subject to approval by the National Medical Insurance Company – in some cases not all expenditures are approved and subsequently covered.

In Romania, private non-profit providers are partly funded through grants and subsidies. Subsidies are granted by the local authority for local providers and by the Ministry of

26 The state grant is targeted to these activities: basic education, early childhood education, foster care, family care, care of the elderly, support for informal care, homecare of children, public health, primary health care, special health care, social services, income support, meintanence support, child protection, services for people with intellectual disabilities, disability services, mental health care, alcohol and drug rehabilitation, libraries, art, etc.

27 Concordat between the Republic of Hungary and the Holy See – often called ‘the Vatican Concordat'. The Concordat sets out rules about the financing of services provided by churhces.

Labour and Social Protection for the providers present in more than two counties. Grants are provided on the basis of projects and subsidies for certain type of expenditures incurred while providing an existing social service.

In Serbia and Spain, providers have the possibility to receive grants from the funding authorities on an ad hoc basis. This funding model is marginal and corresponds to a very small proportion of providers' funding. In Spain, grants can be asked for opening new places in assisted living facilities if the demand exceeds what was initially planned for example. In Italy, it is also marginal and grants come from private actors such as foundations.

In Slovakia, grants received by providers from the Ministry for Labour, Social Affairs and Family (central government) are used for the purchase of sanitry/hygiene equipments (this was very demanded during the Covid-19) and also functioning expenses (e.g. could be for additional increase of salaries beyond the legal minimum).

In Portugal, non-profit service providers can apply for subsidies and grants within specific programmes. The funding channeled through this model is very small.

In several countries, including Germany, Moldova and Portugal, additional grants and subsidies were made available to providers so that they can face the Covid 19 crisis. The details were little known at the time of this study. In Moldova, support to disability care providers imn 2020 was made available by international donors including the EU, Embassy of the Czech Republic to Moldova, Romania. Governmental measures to support providers approved at the end of 2020 include an additional basic monthly salary for staff working in temporary placement centers (long-term institutional care) due to increased health risk.

Private investment

Information on private investment is very limited and it is not a significant funding model in most of the countries under review. It exists in Romania (social economy activities), Greece, Italy, Moldova, Portugal, Slovakia and Spain (private procurement). Private investment is explored as a way to deal with a lack of public funding for social and care services. In these countries, the trend is for private investment to grow in the coming years.

There is limited private investment for the provision of services for persons with disabilities in Greece.

In Portugal, private investment also take the form of social economy activities: the largest service providers who also host training and employment support activities rely partially on income generating activities to supplement funding for care services, e.g. income from the sale of products or services produced by PwD in sheltered employment or in other productive settings).

In Slovakia, private investment funds primarily non-profit providers. For-profit providers are not eligible for public funcing and rely on user contributions and sponsorhsifts, donations and private investments. The share of the funding is the overall figure remains very small.

European Funds

In Romania, private non-profit providers are also financed by European funds. The part of this funding is marginal.

In Slovakia, grants from the European Structural Investment Funds play an important role, especially in the area of community-based services. EU funds have been the main source of funding for the care-taker service to support independent living. Nevertheless, the amounts of EU grants remain small compared to overall funding in the social services sectors under study. However some services, such as the care-taker service under supported living is fully dependent on EU grants, these covered up to 50% of the private non-profit providers' expenses related to the care-taker service. According to stakeholders feedback, grants (both national and EU) are often used to cover additional expanses to improve working conditions and quality of services.

In Greece, the European Structural and Investment Fund also provides funding. Day-care and supported living centres are often co-funded by the national government and the EU. Many services are typically co-funded by the state (20%) and the European Structural and Investment Funds/European Social Funds (80%).

In Portugal, the European Structural Fund is funding the pilot project MAVI, the Independent Living Support Scheme through a funding model of public procurement in a reserved market.

Out of pocket payments

TABLE 8 | Co-payment framework per country

Country	Systematic use	Sector	Type	Extent of use
Finland	No	Not applicable in any sectors	n/a	Very marginal to non-existent for persons with intellectual disabilities
France	No – only when PwD wishes to obtain a level of service beyond that allocated	Independent living	Additional payment for service	relatively rare
Germany	No	All	Depending on income of PwD	Only when services are not covered by care systems
Greece	Yes	All	Depending on income and degree of disability	Systematic for all services
Hungary	Yes	All sectors	Depending on income	Systematic, in some sectors covering 35% costs of providing services
Ireland	Yes	Institutional care	Depending on income	Around EUR 140 per week
Italy	Yes, but largely unregulated	All, esp. independent living	Depending on income and municipality	Depending on income and municipality
Moldova	No	Long-term institutionalised care	Depending on agreement between beneficiary/legal representative and institution	Marginal by both public and private providers, albeit seen as a possibility for private providers to cover costs in the near future
Romania	No	Day care and residential care	User fee + income	Depends on provider
Serbia	No	All	On the basis of income	Depends on municipality
Spain	Yes	Independent living and long-term institutionalised care, respite care	On the basis of income	Depends on provider and type of service provided
Slovakia	Yes	All	User fee	Depends on provider and type of service provided
Portugal	Yes	All	On the basis of household income (means-tested)	User fees mandatory, even if marginal after means-testing for most needy; depends on type of service

In principle, services are free of charge in most countries. However, a user fee or a contribution can be asked from the PwD. We use the term co-payment when the services provided require out of pocket payments from PwD.

This section provides a brief overview of the various co-payment options in the countries under review. This section only covers cases where co-payment is required to get the minimum level of service. It is in principle always

possible to pay out of pocket to have more services and to bypass the public system described in this study but this is not the focus of the study.

It was not possible to obtain an estimate of the out-of-pocket payments because they do not enter in public statistics and vary greatly depending on the user's personal situation. In several countries, costs can also be paid for by public funds through social assistance mechanisms (e.g. Germany, Finland, France).

The bullet points below describe co-payment for each country. Because the framework varies greatly between countries, further cross-country analysis is not possible.

- ★ In Finland, it depends in which of the legal frameworks the service is provided. Different regulations apply depending on the type and intensity of the disability. In principle, services are free of charge but user fees exist for institutional and day-care services. In case the user is unable to pay for services, social services can cover for the additional costs.
- ★ In France, co-payment is relatively rare as the user fee asked from the user usually ends up being covered by support received from public funds.
- ★ In Germany, social assistance covers for the additional costs of some services not covered by the long-term care insurance of the integration assistance. The amount received depends on the income of the PwD. Before 2020, the income of the family was also considered to assess the level of financial assistance. This is no longer the case and the thresholds of income also became higher, meaning that there are less chances that the PwD will have to pay for services themselves. The income threshold is now around EUR 50,000 per year.
- ★ Greece us among the OECD countries with a very high out-of-pocket health spending as a percentage of the GDP, a fact that has directly impacted persons with disabilities, who already experienced structural disadvantage. Co-payments are particularly common in the long-term care of incapacitated elderly; the majority of such homes – approximately 240 care homes in 2017 – are run by private for-profit organisations, and are paid privately by the persons in care and their families (Ziomas et al., 2018).[28]
- ★ In Hungary, service fees contribute significantly to the income of service providers, however the share of service fees in the revenue of service providers varies across sub-sectors (up to around 35% of overall cost of services, in long-term care). However, user fees can only be charged when user income is above a certain threshold, and there is also a maximum threshold of service fee e.g. 80% of a client's income in long-term institutional care. Civil society organisations also often try to raise funds from private or corporate donations, however providers interviewed for this study said this would cover a maximum of 10% of all costs, and is an unreliable source of funding that complicates annual planning.
- ★ In Ireland, people placed in residential settings are expected to cover a part of their living there (usually food and utilities) by paying a 'Long-Stay Contribution'. The amount varies depending on the provider and the user's situation (personal income). Stakeholder feedback suggests that the amount charged is usually around EUR 140 per week.
- ★ In Italy, social care of PwD mostly relies on families and users' own expenditure. This is the case especially for the crucially important area of supported / independent living services for older PwDs (by far the largest demographic group among PwDs in Italy). Expenditure for much of this type of services is largely unaccounted for as services are often organized through the informal economy. In other areas, better regulated and accounted for, families and users' budgets still play a key role. For example, in institutional care, a large proportion is paid for by the families and public funds transfers only provide a marginal proportion of assistance to cover the costs.
- ★ In Moldova, user co-payments are sometimes used by all types of service providers, however to a limited extent. Given the large underfunding of private providers in the country, providers do consider user co-payments as a viable option to offset some of the costs of delivering services, however the use of this funding model will require drafting and approval of criteria for differentiating beneficiaries into different categories based on financial need/vulnerability level.

28 Care homes are mainly located in urban areas, with almost half of them situated in the Greater Athens Area. Besides private for-profit organisations, care homes can also be managed by the Church, charitable organisations, and local authorities. The non-profit care homes are partly subsidised by the state and partly funded by donations, and per diem fees paid by EOPYY (Ziomas et al. 2018).

- ★ In Romania, private providers of day-care may decide to impose user fees, depending on their sources of funding. Residential centres usually charge a user contribution. Persons with disabilities who receive care in residential centres must pay a monthly contribution which was set to RON 900 (EUR 191) in 2019. There is no obligation to pay the monthly contribution if the average net income per family member is under RON 1,450 (EUR 302) per month. Persons with severe mental and/or mental disabilities assisted in public residential centers for adults with disabilities and their legal supporters are exempted from paying the monthly maintenance contribution.
- ★ In Spain, user contributions depend on the type of service and the economic capacity of PwD.
- ★ In Serbia, disparities on the extent of out-of-pocket fees are reported across the country (in addition to quality of and acces to services). Percentage of co-payment overall decided on the basis of user income.
- ★ In Slovakia, the law stipulates that the average monthly price for a social service cannot exceed the difference between the provider's average monthly expenses spent on and average monthly benefits received from providing the given social service. This is meant to ensure that the public contribution results in a decrease of the out-of pocket fee fro users instead of an increase in profits by the providers. This only applies to providers financed through public contributions. Private for-profit providers are free to charge the price they want. Out-of-pocket fees varies from provider to provider. Even though the price of services is not high relative to the actual expense of service provision, the income of service users (usually disability pension) rarely covers the necessary care expenses.
- ★ In Portugal, user fees are calculated on the basis of the household's per capita income and fixed expenses. User fees cannot exceed the average effective cost per user. Service agreements foresee co-payment and these user fees can vary widely, depending on family income. Still, user fees tend to be low.

Providers

TABLE 9 | Information on providers by country[29]

Country	Main providers of PwD care services[30]	Share public (combined share of state and municipal)	Share non-profit	Share for-profit	Choice of SP
Finland	Municipalities	>50% (varies by sector)	>9% (varies by sector)	Not known	Municipality decides on delivery; PwD on SP
France	Non-profit	<20% (varies by sector)	>55% (varies by sector)	0-26% (varies by sector)	PwD approaches SP to obtain service
Germany	Non-profit	0%	Majority	Only in long-term care	In theory PwD
Greece	Public and non-profit[31]	Not known	Not known	Limited	PwD approaches SP to obtain service
Hungary	Municipalities	59%	41%[32]	Marginal	State authorities (Ministries) decide on SP
Ireland	Non-profit	<10%	Majority	Marginal	CHO (regional units) choose for PwD
Italy	Non-profit	7.4% of # providers, 11.2% of # staff	34% of # providers, 49.2% of staff	28.7% of # providers, 39.6% of staff	(When more than 1 available) PwD can choose from accredited SPs
Moldova	Municipalities	~80%	Not known, but <20%	Not known, but small share within the 20% on non-public providers	Local administrative units decide
Portugal	Non-profit	10%	61%	29%	Not known
Romania	Non-profit in # but public in % services provided	34%	66%	0%	Local administrative units or Ministry decide

29 Based on data available, the figures sometimes refer to the percentage of funding received by said types of organisations, other times to the share in the number of providers – as such this is a rough estimation of the share and not strictly comparable.

30 Main providers are indicated in relation to the four sectors under study and cannot be generalised to the full extent of PwD services in a given country.

31 Share of public vs non-profit providers not known due to lack of available data in Greece

32 Includes faithbased organisations (30% funding), however some evidence in the factsheet suggests these organisations function more like for-profit providers rather than non-profit.

Country	Main providers of PwD care services[30]	Share public (combined share of state and municipal)	Share non-profit	Share for-profit	Choice of SP
Serbia	Public	>50% (varies by sector)	12-49% (varies by sector	0-8% (varies by sector)	Local administrative units[33]
Slovakia	Municipalities and Regions	63%	37% of non public providers	Very small share within the 37% of non-public providers	In theory PwD (amongst accredited providers)
Spain	Non-profit	Small	Majority	Small	Day care – Regional administration decides

General observations:

Descriptive statistics on the **number of service providers for the disability care sector** overall or the **average size of providers** have not been available across the countries studied with small exceptions.

★ The **number of providers** being elusive is sometimes linked to disability service categorisations that differ across countries (including differences e.g. between NGOs and non-profit organisations); lack of aggregated data from different regions and/or sectors; or inclusion of target groups like children with disabilities, who are beyond the scope of this study, and older persons without disabilities, in the case of for example long-term institutional care.

★ The interest in **considering size**, however, is to give an indication of whether large or small providers are more prevalent in a given country, size of providers potentially being important for sustainability and bargaining power among others. Most countries report the size varying greatly by region and sector. In Ireland, the disability care market is dominated by large providers - 33% disability spending went to five largest service providers in 2017. In several countries, service providers join forces in associations as in Spain or large welfare organisations as in Germany. In Ireland, In 2019, nine of the biggest disability service providers formed a Disability Action Coalition to address their immediate funding deficits and lobby for the future of their services.[34]

All countries rely to some extent on private provision of disability care services**; the bulk of services are delivered by non-profits.** Private for-profits are gaining in importance and public sector provision is shrinking in some but not all countries.

★ **Non-profit providers carry the weight of disability care service provision in many of the countries studied.** Public providers (state and municipality-run, depending on governance system) had a greater role in delivery of such services in Finland, Hungary, Moldova, Slovakia and Serbia. In the latter, however, the role of private providers is growing in importance considerably. While in 2015 private provision of disability care services was virtually non-existent, in 2018 private providers delivered 7% of services in this sector. In Romania, even though the share of non-profit providers is higher than that of public ones, the public providers provide a larger share of overall services, meaning they are bigger than the NGOs. In Finland, public provision is more prevalent than private in some sectors, namely housing and institutional care. In Slovakia, public providers (municipalities) are the prevalent providers of services and there is not indication that this trend is changing, although some types of services are primarily provided by non-profits. In Portugal, non-profit providers represent 61% of providers but manage 81% of care services.

★ **In most countries, non-profits face higher barriers to entry and sustainability than public providers (and church-based organisations)**, albeit municipalities sometimes face the same

33 Except long-term care, where either the national government or private providers deliver services.

34 The Disability Action Coalition, https://tdac.ie/about-us/, Date accessed: 2020 09 04

conditions as private providers. In Hungary, licensing for both private and municipal providers is provided tri-annually for a specific number of planned client numbers. The system gives full control to the state to control spending on social care, but is reported by providers as non-transparent and limiting to providers, who despite potentially higher demand than their license allows have to cap their services to the approved number. NGOs in the country report struggling to remain open despite high demand for services, and to ensure continuity of services sometimes opt for agreements to be overtaken by faith-based organisations, whose stability is ensured through multi-tier and multi-mechanism funding. This trend is reported as accelerating, also with a host of previously state- or municipality-run services being taken over by churches across the country, also true for long-term institutional care facilities.

- ★ **Private for-profit providers in general participate in disability care services in all countries except Romania.** What differs is how long for-profit providers have been eligible to participate in disability care services and their market share. In terms of the temporal dimension, while in Finland the state allowed private providers in disability care from back in the 1990s, in other countries private for-profit actors have been allowed to compete more recently. The extent of private sector role in delivery of disability care services differs from marginal in Finland, Hungary and Moldova and limited to just the long-term institutionalised care in Germany, to growing in importance in Spain and Serbia.
- ★ **Likewise, public sector role in delivery of PwD care services is decreasing**, but the study found some evidence where existing public providers may provide more services or employ a larger share of PwD care staff than their private peers. E.g. in Romania, where 66% of providers are private (non-profits) and 34% public, 55% of PwD care services are provided by the public ones. This is an indication that public providers are bigger and more institutionalised. Likewise, in Moldova, public providers, which constitute 80% of providers of social services, deliver 83% of all such services.

In some countries (Finland, Slovakia, Moldova), some services, for example long-term institutionalised care in Moldova, are provided directly by public entities and the service is not outsourced, while in Germany 100% of service provision is outsourced.

Sub-sector specific information

Day care

- ★ The importance of day care activities in the overall disability care budget differs. Day care constitutes 22% of the disability care budget in Ireland (2017), the biggest proportion (81%) of funding and 89% of social services users in Serbia (2018) and just 0.4% the disability care budget in Romania. In Hungary, day care services are the third most common service for PwDs based on client numbers, although available only in cities with over 50,000 inhabitants. Both the number of clients and the number of centres there have been rising since the 2000s.
- ★ Day care services are also little developed in Moldova – in 2019, there were just six day care centres for adult PwDs covering a total of 188 beneficiaries. In Serbia, the 'size' of this sector can partly be explained by the fact that day care is operationalised to include homecare services, which in other countries form part of independent living. In Romania and Moldova the bulk of the disability care budget goes to supported living, or more precisely to providing small support for family members to act as personal assistants, as an alternative to developing day care and institutionalised long-term care or respite care services.
- ★ **Waiting** lists are mentioned specifically in relation to Hungary (239 people in 2018), Greece, Spain (Valencia), Portugal and Germany, and assumed in Moldova where although no information on waiting lists was available, the scarce development of this sector would imply day care is not readily accessible to adult PwDs. In Greece, funding issues lead to operation problems. In many cases, lack of personnel and/or skilled personnel, together with inadequate funding, has led to the reduction of services provided or the number of beneficiaries that centres can accept, which is likely to further confound the supply and demand mismatch. In France, where PwDs have to organize their own transport to receive needed services, they may be deprived of day care if no providers available in their area unless they have access to transport. In Romania, where day care services are underdeveloped waiting lists were not mentioned but the unmet demand for such services was.
- ★ **Providers** are mostly non-profits across the board, as well as some faith-based organisations. A notable trend in Serbia is privatisation of day care services, where

public sector provision dropped from 74% in 2015 to only 58% in 2018. The drop was absorbed both by non-profit providers and private for-profit providers.

- Where day-care is financed through fixed payments per user to the providers (through public funding), as in the case in Hungary and Portugal, it can be problematic with regards to sustainability of providers, access to, quality and adequacy of the services offered. A lump sum per user may not allow to take into account complex needs and day-care activities can sometimes be costly to implement, e.g. promoting skill-development and autonomy of users. In Hungary, service providers charge service fees for day care, which contribute to around 20-30% of total cost of the services provided by NGOs. In 2018, around 54% users of day care services paid a service fee. Users with income below an established threshold are exempt from fees, meaning providers have to cross-subsidize provision to those in greater need, sometimes leading to reduced access to services for the most vulnerable groups. Overall, NGOs' analyses show that public funding allocated to NGO-run day services for PwDs constitutes less than 50% of costs of service-running (including all costs necessary for licensed services, like staff costs, taxes, rental fees, utility bills etc.).[35]

Independent/Supported living

- Definitions of supported living vary across countries, as is the case for most of the service types covered in this report. Supported housing, rather than living arrangements for a small number of people who receive social support independently from housing services, in Hungary is provided in houses and flats for up to twelve residents, but also in 'living centres' – units of residential institutions - for up to 50 people, and in most cases the same organisation is responsible for housing services and social support. Since its establishment of this type of service in Hungary in 2013, the number of clients in supported housing services has been rising, from 220 clients in 2014 to 1,626 clients in 2018, however still far below the demand and uptake of long-term institutional care.
- Personal assistant services to support independent living comprised 85% of disability care budget in Romania, are widespread in Moldova, Germany, Finland and Serbia. PA services are at the same time little developed in Spain, Valencia (only 13 companies accredited to provide the service), Hungary and Ireland; in the latter it constitutes 3% of disability care budget and stakeholders report the service is not readily available to those requiring it. In Slovakia, stakeholder feedback suggests there are few facilities offering independent/supported living and services are very scarce across the country.
- In Greece, there is no personal assistance scheme, leaving users to seek family members' assistance or procure unregulated paid care, financed out-of-pocket and beyond the financial strain this negatively affects the independence of persons with disabilities and contravenes to article 19 of the UNCRPD. At the same time, some government programmes like the 'Help at Home' home-care programme support independent living and keeping PwDs in their family and soial environment. This programme reaches about 75,000 citizens on a daily basis, provided by 273 municipalities and 3047 employees, and was further boosted with an extra 1,200 employees from municipal infrastructures shut due to confinement measures in spring of 2020. Supported living shelters (SYDs) for persons with disabilities in Greece provide supported living in the community, however are little developed still (reaching 389 people in 2018) and rely on a variety of additional resources beyond public funding (most of it from EU funds), including through social economy activities and international organisations like the World Bank and Council of Europe.
- In Portugal, personal assistance services are provided through a pilot programme MAVI (Independent Living Support Scheme) funded through the European Structural Funds and national co-funding. The Individualised personal assistance plan (PIAP) details the number of hours needed by each user, providing some dimension of personal budget. However, no direct payments are made to the users themselves. MAVI was created as a pilot programme, with limited duration (42 months at time of drafting this report), subject to a type of public procurement procedure, after which it will be evaluated with a view to adjusting the model and expanding it nationwide. Independent support living is a relatively new concept in Portugal.
- There is some degree of informality in this sector, particularly acute in Italy and Greece where recurring to informal caregivers is a widespread but not regulated practice, and to some degree also in Romania.
- Waiting lists have been mentioned in relation to France, Germany, Greece, Hungary, Portugal and

35 For instance MEOSZ, 2017; Céhálózat, 2016 etc.)

Moldova – where the number of PwDs with severe disabilities included in a waiting list outnumbers the number of personal assistants employed in the country twofold. In Romania an estimated 50% of the need for supported living services is not being met. The situation is particularly acute in rural areas of Romania, same holding true for Serbia and Moldova where PA services are better budgeted for in Chisinau. In Greece, there is an estimated 3 places available for every 200 PwD with a learning disability. Waiting lists there are reportedly very long for supported living services, which are even less accessible in rural areas; current demographic trends and little done to expand service provision in this area suggest the unmet demand for supported living services will grow.

- ★ In Finland no waiting lists mentioned but sometimes choice is limited and services cannot always be qualified as needs-based.
- ★ Types of providers – private or public, vary across the different types of services that fall under the umbrella of supported living. PA services are often provided by private persons, with the exception of Moldova, where they are hired by public interlocutors. PAs are typically family members rather than specially-trained professionals. This affects both working conditions in the light of underdeveloped respite care services, unregulated hours, and no annual leave, but also the quality of the services provided as training for PAs is reported as insufficient. In Greece, care by family members extends to all sectors of disability care given the number and quality of services are inadequate across the board.
- ★ In Spain telecare is a widespread option and completely free for users as opposed to day care that comes with some co-payment (but means tested).
- ★ In Moldova, in addition to public assistant services (2664 PAs employed in 2018), several other supported living options are available to PwDs, including mobile teams (700 beneficiaries in 2018), and home care by social workers, which can be provided by public providers (more common) or private non-profit ones. In 2019, 55,000 home care and 18,000 palliative care visits were performed in the country.
- ★ Interestingly in Ireland, this sector is very consolidated whereby a significant share of personal assistance services is provided by one (section 39) organisation – the Irish Wheelchair Association.
- ★ In Hungary, non-state providers are financed based on a flat rate which they report only covers around 35-40% of all annual costs related to running of a supported housing service; service fees account for around 35% of costs. Due to better funding, the share of state-funding is higher, and the share of service fees is lower (around 30%) at church-run services. The UNCRPD in its inquiry report 2019[36] criticized the supported housing sector in the country finding that the service remains institutional in its nature, under the control of service managers, restricts the private life of clients and fails to provide undividualised support.

Long-term institutional care

- ★ The type of services considered for this sub-sector of care includes congregated (institutional) and community-based (dispersed) care of persons with disabilities. In terms of how both are funded they are indistinguishable. It is also based on available evidence not possible to say to what extent funding models encourage or DI or not. Answering this question would require a look into how countries are financing re-housing (social housing for PwD moving out of congregated settings) as part of DI efforts.
- ★ Despite the normative agreement to move towards de-institutionalised care for PwD, long-term institutional care remains prevalent in many of the countries under study – in Ireland in 2017, long-term institutional care constituted 63% of disability expenditure, equivalent of 1 billion euros. A working group report on how to move away from congregated settings in Ireland among its recommendations suggest to retain all funding being spent on congregated settings, redeploying it to support community inclusion.[37] In Finland, which is most advanced in de-institutionalisation of the countries under study, in 2018 EUR 886 million went towards institutional and 24/7 housing for PwD. Long-term institutional care is likewise a strong sector in Hungary, where there are around 39,000 PwDs living in facilities including specifically for PwDs and mainstream ones for the elderly. (Halmos, 2019) In Slovakia the long-term institutional care sector receives the biggest share of disability care spending and this is forseen for the foreseeable future as well. The country where according to data available institutional care constitutes a small share (13.6%) of disability care services is Romania, where supported living with family

36 See https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=25799&LangID=E

37 https://www.hse.ie/eng/services/list/4/disability/congregatedsettings/time-to-move-on-from-congregated-settings-–-a-strategy-for-community-inclusion.pdf

members as personal assistants is more widespread as an ad hoc and alternative solution to developing services. While disability care budget figures are not available for Moldova, the long-term institutional care sector there is also reported as little developed – in 2019 serving a total of 5,900 adult PwDs. In Greece, the sector is decreasing both in terms of staff and user numbers – this is both explained by a (slow) expansion of community-based services but even more so due to austerity measures. The result has been increasing waiting lists.

★ In terms of numbers of users admissible in institutional care settings, these can be very high – for example in Romania there are several centres with over 200 beneficiaries and around 100 centres with over 50 users. While the centres with this large capacity remain operational at the time of this study, new long-term care establishments being set up must not exceed capacity of 50 users. In Serbia, this number is capped at 100. While the maximum number of users in such settings in Moldova is not known, there is feedback on them being overpopulated. Such congregated institutional care is not in line with the UN Convention for the Rights of Persons with Disabilities (UNCRPD).

★ In Hungary, conditions in state-run long-term institutional care facilities are reported by persons interviewed for this study as 'often miserable' and 'sometimes medieval', with institutions in a decayed state; likewise working conditions in these facilities were deplored by staff. Church-run facilities are reported as being better quality both for users and staff. A lack of a quality framework and likewise evaluation of quality is reported as an issue also in Greece. The majority of long-term care institutions are characterised by the absence of operating standards, issues with licensing, certification, control and supervision, staffing issues, shortcomings in care, social life and entertainment, participation and expression of opinion, and protection of privacy of persons with disabilities (ESAMEA, 2020). Among other reasons, the lack of monitoring and evaluation of service quality are linked with serious cases of abuse at some of these institutions, for example, the Lechaina centre.

★ Out of pocket user co-payment is typical for long-term institutional care services across the countries studied, though in more cases than not it is means tested. In Romania, users pay about EUR 191/month, the minimum user contribution in France is 270,81/month, in Finland EUR 90/month. In Italy, the extent of user co-payment is unaccounted for and largely depends on type of service, but may reach 3 or more times the amount paid by the state (EUR 520/month). In Slovakia, the user contributions for long-term institutional care are relatively low in terms of provider's expenses but high in terms of share of users' income. That can be explained by continuous public investment in such facilities. In Portugal, user co-payment is linked to the income per capita of the household and varies between 30% to 90% of this income. In Hungary, user co-payments contribute to around 35% of long-term institutional care provider income, more than the share covered through public funding.

★ In Moldova, co-payment for social care services across all sectors are means-tested. From the user perspective, care in the health sector is usually much cheaper than long-term institutional care, as co-payments in the health sector are fixed and relatively moderate.

★ Access to services is the most problematic in long-term care – the country reports provide evidence of considerable unmet need and waiting lists (e.g. 1,766 people in 2018 in Hungary)[38] or both. Interim solutions include reliance on the health sector. In Ireland, using respite care beds for long-term arrangements or placements in hospitals and nursing homes (1,200 such cases in 2018). In Moldova, the lack of service provision in the community care sector often makes prolonged hospital stays or hospitalization of PwDs in need of LTIC necessary, even though there is no acute care need that would require a hospital stay. Beyond the question of adequacy of services and rights of PwDs staying in hospitals in lieu of long-term care facilities, this also puts a strain on the health sector capacity, likely further complicated at the time of the Covid-19 pandemic. In a more extreme example, in Valencia, Spain some service users and their families reportedly have filed for civil incapacitation in order to receive institutional care services as in such cases the government is liable to provide the service. Albeit the facilities providing long-term care are among the most numerous in Slovakia, a trend that is contrary to the declared deinstitutionalisation process launched in 2011, accessibility is worsened by lack of vacant places, resulting in long waiting lists. In 2018, the total number of people dependent on another person waiting to be placed in a social service facility amounted to almost 10,000 from which more than half were facilities for elderly people. However, the waiting lists are commonly

38 Kovács-Angel, 2019

known for not being fully up to date and there might be duplication of entries. In Portugal, service providers also reported there are significant waiting lists for residential homes for PwD. In Moldova, PwD are admitted to a long-term institutional care facility only as a last resort, if they cannot be provided care in their own home or other services in the community, albeit the latter are little developed. At the same time, even when care at home is not an option, there are waiting lists for publicly financed long-term care services, and private provision is too expensive for users relying on disability pensions.

★ Long-term institutional care has been a sector with a significant role of private for-profit providers in some countries, but not at all in others (like Hungary). In Spain, where for-profit companies play an ever-increasing role in disability care services, their involvement was initially limited to long-term care, later extending to day care. In Finland, however, long-term care is contracted primarily (76,5%) from other public entities.

★ Moving forward, the unmet need for institutional care is expected to grow. This brings into question how countries should go about the transition from care in congregated settings to DI. On the one hand, institutional long-term care of persons with disabilities that segregates them from the community is not in line with the right to living independently and being included in the community enshrined in Article 19 of the UNCRPD[39]. On the other hand, developing community-based care is a long-term process and one that it is far from complete across European countries. In the interim, access to institutional long-term care as suggested by the information gathered for this report is limited, meaning that PwD plainly do not receive the care they need, without considering aspects of its quality. Indeed, situations when families have to give up their guardianship rights to ensure placement in such a care facility as reported for Valencia, Spain or placement of PwD in hospitals or nursing homes as reported in Ireland and Moldova are also in breach of the UNCRPD and the right to accessibility (Article 9) and protecting the integrity of the person (Article 17). Likewise, deplorable conditions in long-term care institutions, particularly state-run ones in Hungary, require immediate redress until community-based alternatives are developed.

Respite care

★ Of the sub-sectors under study, respite care services are least developed, with some countries like Romania and Serbia reporting user numbers in recent years being under 100, and in Moldova just at 160 beneficiaries per year, and total capacity of 265 beds and 226 service users reported in Hungary in 2018, according to the Central Statistical Office (2019). In Slovakia, repite care demand is low because this is not available as a standalone service and rather provided through e.g. day care. In the mean time, public actors are reluctant to invest in this sector because the demand is low, irregular and relatively unpredictable. Respite care may also be financially inaccessible to many carers of PwDs and there is no upper-fee limit for this type of service. In Portugal, there are no specific services for respite, even though the possibility of short-term institutionalisation in residential care facilities is an option. There is generally a lack of awareness and use of respite care in Portugal and information on the availability and take-up of this service is not available.

★ Respite care not being readily available results in carers of PwD not receiving the support they need. In countries like Romania, where the care system is built on family members acting as carers/personal assistants, the lack of respite care options results in subpar working conditions of the main providers of care. In Greece, it is estimated that about 34% of the population is an informal carer. Yet, there is a lack of structures for repite care. Not having respite care options in place is likely to further add to social exclusion of families with PwD as carers have no off time from their care duties.

★ In general, there is a lack of awareness around the availability of such services or entitlement of carers to receive them throughout the countries studied. Waiting lists are therefore insignificant – for example 42 people in Hungary in 2018.[40]

★ The study found no examples of respite care being provided by private providers, although this may exist particularly in the case of non-profits in some of the countries.

39 Article 19 of the UNCRPD, available at: https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-19-living-independently-and-being-included-in-the-community.html

40 Kovács-Angel, 2019

Impact

Overall, there has been little to no study of links between funding models and their bearing on access to, quality of services or working conditions of staff. As such, any insights into potential links are exploratory in nature and merit further study to confirm them.

At the same time, for providers, users and employees concerned, several issues have been noted across countries, whether making a link with funding models per se or not, and are documented in this section.

Sustainability of providers

Sustainability of providers is perhaps most closely linked to funding models and how they are applied. One key issue for providers, particularly private non-profit ones, is continuity of funding and being able to plan budgets for a period ahead – most of the funding models fall short of ensuring provider sustainability.

Service agreements, a common strand under reserved markets, in some countries are renegotiated annually, and where this is true the feedback from providers is that this gives them limited stability. This has been particularly problematic in Ireland, where providers run deficits and in most extreme cases have gone bankrupt over inability to secure stable funding. The main issue there according to providers interviewed is that they have little influence in negotiations on annual budgets – as a result, in 2019, nine of the largest disability service providers formed a Disability Action Coalition to lobby for the future of their services. In Slovakia, municipalities and regions often do not provide private non-profit providers with the contribution they are entitled to receive. This results in users having to pay a bigger fee or in providers having to terminate their activity.

Portugal provides an example of how service agreements can be problematic. Public funding is adjusted on a monthly basis, taking into account the number of users. However, it does not integrate the fixed cost that cannot change as fast as the number of users. This can be problematic for SPs.

In Hungary, reserved market funding through a type of lincesing agreement is the main channel for providers to receive public funding and the only one that covers day-to-day running of services. At the same time, in most sub-sectors, state funding for NGOs accounts for less than 50% of costs necessary for running licensed social services. Several interviewees noted – in line with NGO and DPO statements – that underfunding seriously jeopardises the sustainability and availability of NGO-run services, some of which are resorting to soliciting takeovers by the better-funded faith-based organisations in order to ensure continuity of services for users.

Social partnership agreements in Spain, however, led to greater stability to both the service providers and users; however, it coexists with other funding systems, including grants and private procurement – i.e. not all service providers enjoy this increased stability.

Service vouchers – a mechanism used in Greece whereby beneficiaries receive the required service costs from the National Organization for the Provision of Health Services (EOPYY for the Greek acronym) and they then need to transfer the service charge to the provider.[41] Delays in any of the stages of this process creates cash flow problems, which can result in temporary cessation of salary payments, delayed salary payments, and hiring freezes.

Public procurement has also been linked to issues with sustainability – in Finland, for example, smaller providers fear for sustainability of their activity as they do not have the margin of manoeuvre to cut costs to be competitive on price. In Greece and Moldova public procurement contributes to some degree of uncertainty for service providers because they do not know if there will be follow up call for tenders after their current agreement has expired and this complicates long-term planning. In Greece, the low level of resources made

41 This is not personalised budget, as it is not a separate form of financing but merely a payment method. People are assessed as neededing a service, EOPYY decides the costs, and people recieve the corresponding cash. They then need to pay it to the provider, that in turn needs to be registered with EOPYY.

available through public procurement (as well as reserved markets) leads providers to hire lower grade staff, under-hiring of professionals, and over-reliance on informal carers. The combined effect of inadequate staffing levels and hiring lower grade staff, often means that services cannot meet their nominal purpose which is to enhance independence, teach new skills, and promote social integration, and instead act as sitting services away from home. In Moldova, where public procurement will be the sole source of income for a given provider to establish services in a given municipality, if not renewed, the private service provider has to co-share costs of the services for PwD, and always search financial alternatives in order to ensure the sustainability of the services, and make them accessible at least to their existing beneficiaries that come to depend on the service.

Conversely, in Romania, public procurement is a preferred funding model for providers as prices meet certain standards. There, the issue threatening sustainability of providers is the unsystemic use of one funding model or another by local administrative units, as well as lacking capacity in some locales to properly budget for the need for care services in annual budgets; the latter issue has been mentioned in relation to France and Moldova as well. In Moldova, local authorities do not systematically use this mechanism as they both lack administrative capacity and understanding of the mechanism, there is a lack of public funds for employing it altogether. There, it is also reported as common that procurement calls have to get cancelled due to insufficient applicants. In Moldova, in general, there is a reported mutual mistrust between private non-profit organisations and public authorities.

Sustainability of pilot projects can also be problematic. In Portugal, the MAVI programme on independent living support cheme is funded by the European Structural Funds as a pilot. This raises concerns with its continuity and how it may affect users if the programme suddenly ceases. Issues regarding the financial implications for the organisations that manage these services were also mentioned. For instance, costs related to the termination of contracts with personal asssistants due to dismissal or when the programme ends are not elegible and must be supported by the organisations themselves. Considering the high number of labour contracts involved, this is an important cause of concern for organisations. Support to independent living is expected to continue, in some form or another, after the pilot programme, but there is high degree of uncertainty regarding when that will take place, what will happen to current MAVI service providers, users and personal assistants, and if and how the programme will be expanded to other regions and beneficiaries.

Likewise in Greece, newly-established supported living shelters (SYDs), funded from the the PA (Partnership Agreement for the Development Framework) 2014-2020 (in Greek refered to as ESPA), have no guarantee of the state overtaking funding after the initial period. This creates a high degree of uncertainty to institutions. Further, there have been reportedly serious issues related to the ESPA programme leading to significant disruptions in the smooth operation and financing of many such structures.

User fees play a role in sustainability of providers particularly in some of the countries under study. In Hungary, user fees in some sectors like long-term institutional care cover a higher share of service costs for non-profit providers than those covered by the reserved market mechanism.

Quality

Quality is broadly understood in this study as ‘adequacy’ of available services, qualification of those providing it and when possible, user feedback.

Quality of services provided is difficult to gauge reliably across the countries studied and any insights on this aspect derive from regulator, provider, user and staff interviews. Countries which stand out in terms of ensuring high quality services include Ireland and Finland. In Ireland, despite wide agreement that disability care services are underfunded, quality has been reportedly high and maintained courtesy of the Health Information and Quality Authority (HIQA), which certifies residential and some respite services, not exclusively to persons with disabilities.

A factor in quality according to feedback gathered is location – particularly in Romania, Greece, Spain, Italy and Serbia vast regional differences have been mentioned. In Serbia, quality of services tends to be better in larger urban areas and more training opportunities for staff exist. Similarly, in rural areas in Romania services involving community recovery or rehabilitation and personal assistants/carers tend to lack qualified staff and thus face staff shortages, this has been reported also in relation to Moldova. In Spain, some regions have penalized companies for not meeting commitments to ratios and quality of services. In Italy, the differences due to local-level funding is most marked between high and low-income regions, especially when paid from local taxation; service quality in cities is reported as better as well. Interestingly in Germany, as suggested by

stakeholder feedback, quality control has been reported as uneven. This has been linked to cases when personal budgets are used for services. Providers do not need to be recognised and have to provide a tailored service rather than a generic (regulated/standardised) one, rendering quality control difficult. In Greece, the majority of care services provided in large urban areas; in many rural areas, care services for persons with disabilities are extremely limited and often of lower quality.

In Greece, there is a lack of clear policy framework on the delivery of social services and multiple ministries and local institutions involved in the provision of social care and services. This creates fragmentation of the services, a general lack of coordination and duplication of some activities, which in turn degrades the quality of services available. More concerningly, in certain cases, long-term institutional care can reportedly be a site of abuse, maltreatment, and social exclusion, whereby the rights of persons with disabilities are not met. Limited monitoring mechanisms contribute to this.

Capacity of residential care centres is linked to quality, which was reported as particularly problematic in this respect in Moldova, Serbia and Romania, the latter having some centres with 200+ users and many (100) with 50+ users. In Spain, underdevelopment of residential care services and years long waiting lists result in people either not receiving the needed services or receiving unsuitable ones – there is some evidence suggesting that young people may be placed in elderly residences as an interim solution to lack of places in suitable care facilities. Likewise in France, young adults overstay with service providers for children, resulting in unsuitable care. In Ireland, respite beds or nursing homes and hospitals are used to fill the gap in unmet demand for long-term care services resulting in unsuitable quality of care. The same is true for Moldova, where relying on hospital care is an alternative that is both more accessible and cheaper for users, leading to inadequate services for persons needing long-term care.

Public procurement in Finland had resulted in a focus on the price of services rather than quality, leading to multiple system reforms to address such issues. In such a context, large companies may have more capacity for lowering the price, gaining an advantage on smaller SPs which might cut staffing costs in order to be able to compete.

In Portugal, where funding comes from service agreements based on a flat rate per user, the diversity of users' profile is often not taken into account, which may result in a variable quality of services depending on the needs. Funding for services for users with complex needs tends to be insufficient. Flat rates are also applied in Hungary, and quality assurance as such does not feature in any of the funding mechanisms, as auditing and monitoring focuses on administrative issues. Due to differences in funding of different types of organisations providing the same types of services (state vs municipal vs faith-based vs NGOs), quality differs considerably too, and due to a lack of quality monitoring system sometimes is not ensured even with the better-funded service providers.

In Italy, the funding strand of Accreditation (service agreements) for pre-selection of SPs has strict quality requirements and guarantees continuity of services. Public procurement/on-off tenders are reported as less conducive to both quality and access.

Qualification of staff has come up as a major issue in Moldova and Romania, where the majority of PwD care services are essentially organised by paying family members as personal assistants without measures in parallel to ensure quality and working conditions. In France, the qualification of staff, previously problematic, is reported as improving. In Slovakia, the lack of funding covering wages above minimum wage prevents provider to hire university graduates in the field of social care and work. Employees usually have accreditation certificates in social work. The necessary expenses in requalification or staff training can be covered by European and national grants, though it is not always the case. Qualification of staff is also an issue in Greece where funding is reducing, preventing service providers to hire highly qualified staff (e.g. occupational therapists, physiologists, etc.) the funding uncertainty also does not foster long-term contracts.

Access

Demand for care services exceeding supply **poses a key challenge to accessibility** of support and care services. This research found evidence of waiting lists for care services for PwDs in France, Greece, Ireland, Moldova, Slovakia, Spain and Portugal and an underdeveloped offer of services in Italy and Romania. Once again, **regional (including urban/rural) differences** emerge as a significant factor: in Ireland, Greece, Moldova, Romania and Serbia, for example, not all services are available or well developed in each region/area; while in France, the lack of capacities of service providers in

some areas, waiting lists can be up to two years. Such issues **affect PWDs with severe disabilities more than others in France**. On the other hand, in **Romania, persons with severe disabilities are often the only ones being taken into account** (leaving out other PwDs) in communes' annual action plans, due to lack of specialised personnel.

Furthermore, in **Greece, Hungary, Moldova and Romania, social services for adults with disabilities are generally financed according to the available budget**, and not according to PwDs' needs. Local level funding – where some areas have smaller budgets than others – is not always conducive to the development of services such as day and home care ones. In Moldova, this is also linked to limited awareness about the possibility for local authorities to procure services, or administrative capacity to do so, as well as limited supply of private providers in some locales leading to cancelled procurement procedures. Similarly, in **France, the autonomy of local authorities in the allocation of social care funding might result in underfunded services for PwDs** where the councils place less emphasis on this type of care: the current funding mechanism through publishing tender calls is built on the presumption that the relevant authority understands the current needs in the department or region. In Greece, high service demand has led to long waiting lists, particularly in the case of independent living structures. Beneficiaries and their families that can afford private services often opt for that solution.

In Slovakia, the lack of funding result in a lack of staff that directly impacts the availability of the social services. There have been already cases where not all eligible users could be provided a social service due to the lack of staff caused from a large part by inadequate salaries. Many services are unavailable to PwD either due to the lack of facilities, staff or insufficient personal finances.

In Hungary, Lack of funding is a strong barrier to the availability of services. Only a fraction of PWDs access community-based services and existing services often do not respond to their real needs.

In Moldova, as private providers are mostly NGOs relying on donors and development partners for financing, it is quite difficult to develop services, especially high-cost ones as long-term institutional care for PwD and to ensure their sustainability or increase capacity to meet demand. Public funding for NGOs is non-systematic, and regardless of funding model imply insecurity for providers and users alike.

Working Conditions

Working conditions according to feedback gathered depend on a variety of factors, including:

- the policies of individual service providers (Germany, Slovakia).
- 'proximity' to status as statutory staff – conditions in public sector employment have been mentioned as superior to those in the private sector, particularly in Spain, Ireland and Romania. In Ireland, there are two main types of non-profit organisations providing the same type of disability care services, the staff of one, so-called Section 38 providers, being statutory employees and enjoying restoration of salaries after pay cuts, pensions entitlements and greater job security. In Romania, public sector PwD care staff gain 45-50% more than their private sector counterparts; while wages in the private sector are negotiable there, those in the public sector are regulated by law and are non-negotiable and supplemented by bonuses for certain working conditions. Private sector staff are also less well off in terms of hours worked and job security. The differences in working conditions of statutory vs non-statutory staff is linked with the type of provider of care services and in turn the funding model. For example, in Romania, when the state is the provider, it is financed differently from the mechanisms used to fund private non-profit providers. At the same time, in Hungary, there is evidence of staff in state-run institutions being worse off than their counterparts in the non-profit sector, simply because of the poor state of some of the state-run facilities, particularly in the long-term institutional care sector.
- Collective agreements in place can be a determining factor on wage levels (irrespective of funding model) – this has been mentioned for Spain, where wages are set according to the collective agreement of each sector. In Portugal, there is also a collective contract for workers of the social and solidarity sector, which is below payment for equivalent functions in the public sector.
- Types of contracts used to hire staff – in countries with widespread use of temporary contracts, e.g. in France, working conditions for those under such contracts are lower; less qualified professionals in PwD care services are hired under such contracts.
- Location – working conditions for disability care service staff are reportedly better in in urban areas, not least also for training opportunities.

- ★ Working conditions for personal assistants, regarding of funding model applied, have been reported as problematic in particularly in Moldova, Romania but also in Italy and Spain. This is because PAs are often family members, not specifically trained, and not privy to annual leave, respite care (as underdeveloped in almost all countries under study), and overtime.
- ★ Working conditions in the social care sector in general are poor in most countries under study, as evidenced by lower than average wages and difficult working conditions. In Moldova, social care sector staff remain in the sector an average two years, meaning the qualifications and experience of staff providers have to rely on is diminishing, and there are acute staff shortages. In Hungary, despite some improvements in the last decade following trade union lobbying efforts and an inquiry report in 2012 by the Ombudsman about the bad working conditions and low salaries in the social care sector, many social services continue to face staff shortages due to still bad working conditions and uncompetitive wages. Some service providers, mostly churches and some municipalities, are seen to be able to provide better working conditions including better wages for staff – for example, some church-run services provide benefits such as living allowance, contribution to housing costs of staff etc.
- ★ Funding – one link to funding source as a factor in working conditions has resulted in Germany, where the latest reform of the long-term care insurance introduced better working conditions for people in the long-term care insurance service providers. This materialised through the number of support staff and salary increases. In Spain, conditions for care workers have been improving in the sense that since 2006, there has been an increase in the number of staff employed with social security. In Slovakia, funding allocated to providers to cover functioning costs and services is linked to the minimum wage. Thus, any increase in wages above the :minimum wage requires other sources of funding. Working conditions for social workers in Slovakia are generally inadequate and with below average salaries. Due to the financial restrictions, facilities can employ only a limited number of care and social workers.

Trends

Current and future trends on funding

- ★ Germany - Reform of care services with Federal Participation Act & long-term care reform; increase in funding.
- ★ Ireland - Drop in governmental funding after financial crisis until 2016; increase from 2018 to 2019. Potentially – a drop after COVID-19 pandemic. As for private financing (fundraising, charity) even before the pandemic the willingness to donate fell, partially due to loss of trust in charitable organizations. Furthermore, COVID-19 had a significant impact on charitable activities: various organizations were forced to close their shops or cancel their planned fundraising events.
- ★ Italy – Accredited private services are expected to keep growing as replacement for direct public delivery; coordination in planning for disability services is likely to continue its slow improvement, thanks to the strengthening of dedicated central authorities. Uncertainties however remain in the face of a booming population of older PWDs, with the care system rapidly moving from a situation of chronical shortages to one of acute crisis. Central and local social expenditure is growing, but (assuming this trend is not reversed due the COVID-19 economic crisis), it is not doing so fast enough to address present and future unmet needs. Some experts point to the growth of private insurances and private donations as a potential source of funding to offset, at least partially, the shortcomings in public funding, but are sceptical about the possibility of this relatively new funding model to solve the problem.
- ★ Finland - SOTE reform of social health care to be implemented in 2023.
- ★ France - Reform of disability services funding launched in 2014 expected to be rolled out in near future; COVID impact on economy might lead to social security budget deficit.
- ★ In Greece, the Ministry of Labour at the time of drafting this report is preparing the National Strategy for Deinstitutionalisation but no details are known yet. The decrease in social benefits for PwD, as well as the reduction in services and personnel, are due to the fourteen austerity packages passed by the Greek government during the period 2010-2017. During the

period 2009-2017, as a result of the economic crisis that Greece was facing, the country cut down 25% of social spending. Continuing the trend of reduction in social spending, social benefits for persons with disabilities were reduced by 173 million euros, from 913 million euros in 2019 to 740 million euros in 2020 (AMEA-CARE, 2020). Regarding future policies and plans, a policy paper for the review of disability benefits was being finalised in 2021, and a pilot project was expected to be launched in March 2021 in three regions of the country (European Commission, 2020); however, due to the pandemic, the project was postponed to November 2021. A policy paper for the review of disability benefits is currently being finalised, and a pilot project is expected to be launched in November 2021. Due to the impact of the pandemic, it is expected that public funding will continue the decreasing trend seen since the economic crisis, while private funding / donations will decrease.

- ★ Hungary – No major reforms in progress at the time of study. Qualitative feedback suggests stakeholders do not expect positive or indeed negative trends in social care policies or funding in Hungary. EU funds continue to be spent on innovation projects or sometimes on infratstructural investments but interviewees think these hardly make an impact on the general state of the social care sector for PwDs. Despite a recent UNCPRD Inquiry report[42] pointing out several chronic problems of the social care system, it has had no impact to date and a general sense of fatigue is evident among social service providers.
- ★ Moldova – No major reforms in progress at time of study. There are plans to develop methodologies on cost calculations for social services for PwDs, at this time absent in most sub-sectors of disability care.
- ★ Portugal - Over the past decades (1998-2018), care services for persons with disabilities have doubled in size (+116%), presenting the greatest increase in all care service sectors. This reinforcement of coverage was largely anchored on service agreements. DPOs there push towards introducing personal budgets and a transition towards more flexible and person-centered funding and governance model, however this model is yet to be introduced in practice.
- ★ Romania - Reform of care sector expected with Strategy 2021-2027.
- ★ Serbia - Reform of care sector with Act on Social Care in near future.
- ★ Slovakia - Reform of the entire social services sector is planned to be done within the current governemnt mandate (2020-2024). More specifically, (and in relation to the funding) the reform should change the current funding system which is oriented more on social services providers and put more emphasis in terms of funding on social service users. No specific steps have been officially done towards this reform and it is not yet clear what the changes would be in reality. So far only the intention to reform the system has been proclaime in the current government's program (2020-2024).
- ★ Spain - Significant cuts due to financial crisis.

As can be expected, the **2008 financial crisis led to a decrease in funding for care services, as was the case in Spain, Greece and Ireland.** In the latter, there was a 7% drop in funding between 2009 and 2016; while in Spain, it leads to waiting lists for services and an increase in co-payments (service user contributions). The current **pandemic crisis brought about by COVID-19 is now expected to bring about a social security budget deficit due to its impact on the economy in France.**

In Ireland, however, the trend changed between 2018 and 2019, when there was an increase of 2.7%. This is a similar situation to that in **Germany, where an increase in the funding of care services is taking place with the reforms** brought about by the Federal Participation Act (to be implemented until 2023) and long-term care reform in 2017.

Reforms in care and / or disability services are also taking place / are planned in Finland, France, Romania and Serbia. Finland plans a reform in 2023, moving the responsibilities for social and health care to the regional level. France, meanwhile, launched a reform of disability services funding in 2014 to facilitate access for PwDs by allocating funds on the basis of the real costs of care, where funding would be allocated to SPs based on type of activity support provided. This scheme is expected to be rolled out in coming years. In Serbia, improvements are also expected with the Act on Social Care to be reformed in the coming years; while in Romania, limited access to care services will be addressed by a strategy covering the period from 2021 to 2027. In Portugal and Slovakia, the possibility to implement personal budgets in the future is under discussion. However, it is unclear whether/when reform in that sense will happen. In Portugal, the extension of the MAVI programme to the national level mentioned above is also under discussion.

42 See https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=25799&LangID=E

Summary and Conclusions

This study sheds light into **how care services for adults with disabilities are financed** in thirteen European countries: Finland, France, Germany, Greece, Hungary, Ireland, Italy, Moldova, Portugal, Romania, Serbia, Slovakia and Spain. The countries finance care services for adults with disabilities with a mix of direct provision, reserved markets, public procurement and personal budgets. Out of pocket payments by users may be considered as a funding model as well. Each is described briefly below, as well as the rationale behind using this model and its impact on providers, their staff and users based on interview feedback.

TABLE 10 | Direct provision of care services by national/local state agencies

Description	**Direct provision of care services by public authorities whether at the central or local level can be considered a funding model** in its own right, with its own implications on for example quality of services or working conditions of staff (the study found differences in working conditions of statutory and non-statutory employees in several countries most notably Romania and Ireland). Direct provision of care for adults with disabilities is dominant in Finland, Slovakia, Romania and Serbia and also exists in Spain.
Rationale	Direct provision of care services was the status quo prior to reforms towards quasi market systems that opened service provision up to private non-profit and more recently forprofit providers. The rationale why in some countries the state is the main provider of care services may be linked to path dependency and/or a quest to have more control over the quality of services.
Impact	Concerning impact, direct provision of some care services and outsourcing of others results in differences in **working conditions** for statutory and non-statutory staff providing the same type of service. Stakeholder feedback in several countries (Romania, Ireland, Spain, Serbia) suggests that statutory staff enjoy more secure contracts, higher wages, better working hours and pensions entitlements. This suggests room for standardising conditions for providers and staff.

TABLE 11 | Reserved markets

Description	★ The most widely used model to fund disability care services across the countries studied is **reserved market**, whereby authorities reserve access to specific public markets for organisations with certain characteristics (non-profits, for-profits, organisations holding specific licences etc). ★ Reserved market funding models in the countries studied are implemented through **two main strands**: **service agreements** and **public procurement**. Other strands include **service vouchers** as well as **subsidies and grants**. › **Service agreements** are direct transfers from the public funding authority to providers of services on the basis of a pre-established agreement. Such agreements are most often signed for one year, but for example Spain is considering extending the duration to four years, and the duration of such agreements varies in Italy where they can be signed for up to a fiveyear period. These are used in Germany (Rahmenvertrag), Italy (accreditamento), Spain (concierto social), Ireland (service agreement/grant aid arrangements) and Slovakia. › **Public procurement** can be considered both as a strand of reserved markets (in Spain, Serbia, Portugal and France) and a funding model in its own right (see point below). › **Service vouchers** – used in Finland and Italy, service vouchers are direct payments from the funding authority to the provider based on user choice. Service vouchers are not the main funding model in any of the countries under study. › **Subsidies and grants** are used in Romania, Germany, Italy, Serbia, Finland, Slovakia and Spain but the terms refer to different mechanisms. They are not the main funding model in any of the countries under study.
Rationale	**Service agreements** (as well as service vouchers) are used to partner with usually non-profit providers meeting demand that direct provision cannot address and providing some free choice of providers while maintaining a service that is locally or community based and adapted to the local needs. In some countries, it also has more practical advantages like in Italy where service agreements are meant to avoid the administrative burden of having repeated calls for tenders. In Spain, they developed as an alternative to public procurement in order to strengthen social partnership between the contracting authority and providers and afford them more stability. **Subsidies and grants** are used more as an ad hoc measure to contract specific care services.
Impact	Service agreements as the main strand under reserved markets are a prevalent funding model in Germany, Spain, Italy and Ireland, and imply diverse impacts on access to and quality of services. POSITIVE IMPACTS: ★ Greater stability (compared to public procurement) for both service providers and users, especially when signed for longer periods (more than a year). ★ Quality can be assured in the reserved market system by restricting access to those complying with national quality standards (e.g. Health Information and Quality Authority – HIQA in Ireland). MIXED IMPACTS: ★ Stability of providers depends on the ***duration* of the agreement** – annual renegotiations are linked to negative impact on sustainability of providers. Longer duration agreements by regulators in some countries are feared to have adverse effects on quality. ★ **Parties in negotiation** - when negotiated one-on-one between the contracting authority and providers (ES, IT, IE, SK) as opposed to umbrella organisations (DE) bargaining power is not equally distributed. ★ **Object of negotiation** varies across countries covered from the price per type of service (DE, IT, SK) to yearly budget and service price (ES) or just yearly budget (IE). There is room, from the point of view of providers, for more transparency of the price setting mechanism – e.g. in Ireland several providers report difficulties planning their income. ★ **Working conditions** for provider staff under this and other models used as an alternative to direct provision are less favorable for non-statutory staff.

TABLE 12 | Public procurement

Description	In addition to being used as a strand of reserved markets in Spain, Serbia and France, public procurement is used as a funding model in Finland, Italy, Ireland and Romania. Of countries studied, only Germany and Slovakia do not use this funding model to finance PwD care services. Public procurement is the main funding model for contracting care providers in Serbia and France, in the latter it is the only funding model.
Rationale	Public procurement is meant to address a demand for services and engage different types of private providers – non-profit and for profit (IE). In Serbia, where it is the main funding model when local authorities cannot provide the services themselves, it is increasingly used to have more services and providers available to users. In some countries – Ireland and Romania, public procurement is used ad hoc to meet unforeseen need for service provision.
Impact	POSITIVE IMPACTS ★ In Romania, where service agreements are not yet common, public procurement is the funding model of choice for providers. **Contracts under this funding model activate application of legislation regulating fees per type of service**, meaning that providers get standard rates as opposed to for example being reimbursed for fees incurred for providing services as under grants and subsidies. MIXED IMPACTS ★ **Quality** is difficult to control under public procurement. This funding model almost always implies the risk that price will be considered over quality requirements. In Serbia, stakeholder feedback suggests municipalities award tenders to new entrants in the market over experienced providers due to lower prices. Use of this model requires monitoring of quality. ★ **Working conditions** for provider staff under this and other models used as an alternative to direct provision are less favorable for non-statutory staff. ★ Public procurement through the focus on price may threaten **sustainability of providers** particularly for smaller providers with no economies of scale.

TABLE 13 | Personal budgets

Description	**Personal budgets** are little developed across the countries studied – this funding model is operational but little used in Germany and being piloted in Ireland and Finland with a limited number of participants. In all cases, personal budgets are only used to finance personal assistance services.
Rationale	The rationale to introduce this funding model is to provide choice to PwDs, with the expectation that when providers have to compete for users, there is an incentive to maintain quality.
Impact	Given the limited extent to which personal budgets are applied across the countries under study, however, it is difficult to gauge its impact. Based on limited stakeholder feedback in Germany, PB is difficult to manage as the administrative burden is transferred from the funding authority to the PwD. The benefits of having more freedom of choice and tailored servicesis offset by increased paperwork and cumbersome budget management hence its limited use in Germany for the time being.

TABLE 14 | Out of pocket payments

Description	While in principle PwD care services are available free of charge to users in most countries, some degree of co-payment is required from users for in long-term institutional care (IE, RO, ES), day care (RO), independent living (ES), respite care (ES) or across all sectors under study (DE, IT). Countries where user co-payment for PwD care services is used systematically (IE, IT, ES, SK) apply means testing to such contributions, meaning that PwD and families with lower income are charged less to be able to afford the services.
Rationale	Financing the services they receive is always an alternative for users to either top-up the minimum level of service or bypass the public system. The focus on co-payment in this study is however on those cases when users *have* to make a contribution for the publicly provided services. The rationale for user co-payment may be to share the financing of the services.
Impact	Gauging the impact of co-payment on the users would require separate consultations as the bulk of interviewees for this study were providers. At the same time, stakeholder feedback suggests that in Italy the extent of co-payment needed to access long-term institutional care services carries an excessive burden for families and threatens accessibility to needed services. The average facility there is estimated to cost EUR 1,500-3,000 while public transfers amount to around EUR 520, plus a varying amount depending on what (and whether) individual municipalities can afford it, leaving families to absorb the rest.

Access to services

A key finding in this study is that access to services is problematic in many countries. It has not been possible to determine whether specific funding models somehow impact on access. Rather, it has been treated as a horizontal research question throughout the countries.

Demand for care services exceeding supply **poses a key challenge to accessibility** of support and care services. This research found evidence of waiting lists for care services for PWDs in Spain, Ireland, France and to a lesser extent Germany, and underdeveloped offer of services in Italy and Romania. In the latter, care services for adult PWDs are financed according to available budget rather than actual need.

Access to services is particularly problematic in long-term care – the country reports provide evidence of considerable unmet need and waiting lists or both. Interim solutions include, e.g. in Ireland, using respite care beds for long-term arrangements or placements in hospitals and nursing homes (1,200 such cases in 2018). In a more extreme example, in Valencia, Spain some service users and their families have filed for civil incapacitation in order to receive institutional care services as in such cases the government is liable to provide the service.

Waiting lists are also common to access day care services across different PWD age groups – indeed the size of this sector in budgetary terms ranges from under 1% of the disability care budget in Romania to 81% in Serbia.

Supported living services are also developed to a different degree across countries – in Romania financing family members to act as carers are essentially an alternative to developing services for PwD – 85% of the PwD care budget is concentrated in this sector, and still an estimated 50% of the need for supported living services is not being met. Personal assistant services are widespread in Germany, Greece, Finland, Ireland and Italy, but little developed in Valencia, Spain. Waiting lists for supported living services have been mentioned in Germany, France and Serbia. In Italy informal workers carry the weight of personal assistant services, financed by users through a mix of disability allowances and out of pocket fees. In Greece, family members act as personal assistants without either training or financial benefits. Instead, family carers use disability pensions and benefits provided for the persons with disabilities in order to help them in their caring activities.

Also problematic is access to respite care services which are largely underdeveloped in the countries under study – this leads to poor working conditions of family members (Greece, Italy, Moldova, Romania) who act as carers.

TABLE 15 | Main messages on providers and sub-sectors

Country	Main funding model	Main providers of PwD care services	Share public (state and municipal combined)
Finland	Public procurement	Public	>50% (varies by sector)
France	Reserved market (restricted public procurement)	Non-profit	<20% (varies by sector)
Germany	Reserved market (service agreements)	Non-profit	0%
Greece	Public procurement	Not known	Not known
Hungary	Reserved market (licensing and the approval of client numbers)	Public	59%
Ireland	Reserved market (service agreements)	Non-profit	<10%
Italy	Reserved market (service agreements)	Non-profit	7.4% of # providers, 11.2% of # staff
Moldova	Public procurement	Public	80%
Portugal	Reserved markets	Non-profit organisations (publicly funded)	71%
Romania	Subsidies and grants from the public sector	Non-profit in # but public in % services provided	34%
Serbia	Reserved market (restricted public procurement)	Public	>50% (varies by sector)
Slovakia	Reserved market (direct provisions from local budgets and service agreements)	Public	63%
Spain	Reserved markets (service agreements)	Non-profit	0%

★ Non-profit providers carry the weight of disability care service provision across the countries studied.

★ Private for-profit providers in general participate in disability care services in all countries except Romania.

★ Likewise, the public sector role in delivery of PWD care services is decreasing, and the use and development of funding models to finance care services provided by other types of organisations increasing.

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